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Understanding the Experience of Chronic Illness in the Age of Globalization

by

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Cronico Mal

Sin tregua encrespa y marca

Dolor bien largo

Olor de sueños

Animo rancio y débil

La vida es tenue

Zenon Nieves (2011)

Chronic Malaise

Without truce

relentlessly crashed and label

long lasting pain

aroma of dreams

rancid mood and weakness

Life is weak

Zenon Nieves (2011)

Abstract

Chronic disease is the largest cause of death in the world. Yet little is known about how globalization forces affect the body and the experience of someone who is chronically ill. The need for specialized knowledge of subjective data is significant as it will assist us to improve our understanding and develop stronger nursing practices for people who are chronically ill. The purpose of this research is to understand the effect that globalization forces have on the personal experience of people living with chronic illnesses. People living with chronic illness from Canada and Colombia are participants in the study. The following research questions guided the study "What is it like to live with a chronic illness in the context of contemporary globalization forces? How do these political, economical and social forces affect the body of the chronically ill? Are experienced difficulties similar or different in a middle-income country as compared to a high-income country? The methodology for the study follows an interpretive inquiry approach using a critical hermeneutic phenomenological method. Hermeneutic phenomenology explores the various dimensions of human experience in human situations such as embodiment, spatiality, relationality and temporality. Critical pedagogy as a theoretical perspective invoking the work of Paulo Freire and Enrique Dussel is used to examine emerging findings in the context of globalization and resulting global inequities. This dissertation presents the experience of people who are chronically ill including access to health care, respect, compassion, social, political and legal exclusion, and calls for understanding and action on the part of health care professionals, policy makers and society. The findings urge us to move from merely acknowledging the difficulties people living with chronic illness endure in an age of globalization to action to bring about health care, social, and political reform through a process of conscientization and mutual transformation.

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Table of Contents

Understanding the Experience of Chronic Illness in the Age of Globalization

Globalization is a highly charged term with multiple meanings. It describes how nations, businesses and people are becoming more interconnected and interdependent on one another. This phenomenon transcends national borders affecting technological, cultural, economic, institutional, social and natural environments. It is a process of greater integration within the world economy through complicated transnational economic and political processes that have restructured alignments of nations and regions which lead progressively to economic decisions being influenced by global conditions (Cushon, Muhajarine & Labonte, 2010; Finn, Nybell & Shook, 2010; Mohindra & Labonte, 2010). Supporters of economic globalization claim that the economic growth of any given nation depends exclusively on the level of its integration into the world market (Canales Kriljenko, Jacome, Alichi & Olivera Lima, 2010). Detractors of globalization claim that for developing nations increased participation in international trade forces a focus on exporting raw material and other basic commodities as the only products they can produce competitively on the global market thereby keeping these nations impoverished and unable to develop healthy and diversified economies (Oxfam International, 2010). The growth of globalization is a process based on competence and those who cannot compete are forced to the periphery.

The situation of chronic illness worldwide is not an easy one. In health research it is widely acknowledge that the health of people and populations is strongly influenced by the social determinants of health (Raphael, 2006, 2009; Reutter & Kushner, 2010). It is less common for health researchers to recognize that the quality of these social determinants of health is greatly determined by the organization of societies and how these societies distribute equally material resources among their members. And yet it is even less common for health researchers to explore the impact of political, social, and economic forces that influence the organizational and distributional practices of societies in specific groups such as people chronically ill. This, research, however, is limited. There is little knowledge about the meaning of living with chronic illness under the pressure of neoliberal ideologies. And, also, we know little about the effects that economic, politics, social forces produced by globalization have on the experience of living with chronic illness. This situation evokes the necessity for health professionals to understand the experience of living with chronic illness in the age of globalization and how the political, cultural, social and economic forces affect the body of someone who is chronically ill. With my research I wanted to examine the experience of living with chronic illness in the age of globalization, using a hermeneutic phenomenology method applied to the chronically ill's own stories. Also, I wanted to critically explore the effects of social, cultural, economic, political, and gender forces on the body of people with chronic illness.

In this critical hermeneutic phenomenological study, conversations were conducted with five participants in Colombia from the Chronic Patients Care Support Group associated with the Faculty of Nursing at the Universidad Nacional de Colombia, and in Canada three participants were recruited from the Canadian Kidney Foundation Alberta and Northern Territories Branch. Findings showed how the chronically ill in Colombia and Canada live through the effects and pressures of globalization and corporate agendas. Participants perceived the care offered by health care professionals as being dismissive. They see themselves as mere spectators without treatment choices with few political, legal, and advocacy groups to represent their interests and urgent needs in society. In Colombia, participants talked about their experience of abandonment with little access to care in the home despite their frail health status. Participants in Canada described their experience with the health care system as positive. Yet they experience severe discrimination from financial institution and insurance companies due to their chronic condition. Participants in both Colombia and Canada faced their experience with resilience and optimism. They strongly believe that chronic illness never defines who, as people they are.

The results of this research enhance in a number of ways nursing practices with people who are chronically ill in Colombia and Canada. First, these findings assist us to develop and strengthen sensitive clinical practices for the chronically ill. Secondly, through this study we encourage nurses to advocate and take action to address people's perception of alienation and abandonment within the health care system. And third, the results of this study will be disseminated through a knowledge exchange day with researchers, nursing professors, health care professionals, people chronically ill and their caregivers. This encounter will provide a venue to articulate the moral and ethical urgency for policy and program development necessary for legitimate reform to reduce health disparities and promote equity for chronically ill people in Colombia and Canada.

Chapter I Entering into the World of Chronic Illness: Posing the Question

To ask a question means to bring it into the open. The openness of what is in question consists in the fact that the answer is not settled. It must still be undetermined, awaiting a decisive answer (Gadamer, 2006, p. 357)

Developing an understanding of the experience of living with chronic illness in the age of globalization has been a challenging but, also, rewarding journey for me. It has meant my recognizing the many challenges people living with chronic illnesses face in a world that is not prepared for chronicity. Questions about being chronically ill, that is, living with a chronic condition in our present global context geared towards the healthy, came up repeatedly during the study. I entered into the world of chronic illness with a humility (due to my healthy body) and an openness (due to really wanting to know) that let me explore the complexities of the daily life of a chronic situation. Through this process I wanted to explore how chronically ill people deal with external forces imposed upon them globally. And, yet, as I entered into the world of chronic illness, I developed a consciousness or, to use Paulo Freire's word, *conscientization*. He holds that we cannot maintain a neutral position in the world. In nursing, advocacy is the result of our moral commitment with our patients. But, it is through this kind of research that we become aware of what is happening in the world of our patients. When we enter into the world of the chronically ill, we are letting nursing be a part of that world. As nurses, we become aware of what is entailed in the reality of lived disparities and inequalities in the world of chronic illness today. This study gives us a chance to create strategies to fulfill our roles as caregivers and advocates. This chapter is the beginning of my journey to understand what it is like to live with chronic illness today when social, political and economic forces have such a profound effect upon the vulnerable.

Below I first engage in Gadamerian philosophy (2006) to understand the process of questioning. Questioning is an important process that requires detailed attention. Gadamer pursues questioning in hermeneutics as an elaborate process of reflection and continued questioning about our experiences in the world. When we question our curiosity is fed and our sense of the world increases. When Gadamer explores the hermeneutic priority of the question, he digs into the nature of dialogue and the importance of bringing into the open what is already present. This way of being foresees and reveals without expectations what is not known and, thereby, creates “the space for truth, or what is, to manifest” (Vandermause, 2008 p. 70). The process of questioning positions our experiences in a particular perspective. According to Gadamer (2006), the structure of the question is implicit in all experiences.

The second section begins with a presentation of the meaning of health. To define what sickness, disease and illness are, first we need to define health. Ironically, we are most acutely aware of health when we are ill. I explain later the complex and abstract concept of health. The following section briefly presents the meaning of sickness, disease and illness. The Spanish word for disease is *enfermedad* which means unhealthy condition of the body or mind, society or institutions (Diccionario Real Academia Española, 2001). In Spanish, we do not have the other English definitions of illness or sickness. There are several synonyms of *enfermedad* in Spanish such as afección, achaque, sufrimiento, perturbación, dolor, padecimiento, mal, peste, malestar, trastorno and indisposición to name a few. In my attempt to understand these three concepts of sickness, disease and illness, I have decided to use forms of literature such as poetry and story as sources to enrich with meaningful insights the experience of living with sickness, disease and illness. To use van Manen’s (1997) words, “Phenomenological sources allow us to see our limits and to transcend the limits of our interpretive sensibilities” (p. 76); this artistic way of understanding serves as a source of experiences to which the researcher may turn to increase practical insights. Thus, literature or art enlightens our path to comprehend certain aspects of the human condition. Consulting literature has enabled me to reflect more deeply on the lived experience of these three concepts.

In the final section, I go back to my past to explore the roots of my passion and interest to understand the experience of chronic illness in the age of globalization. My personal, professional and academic lives come together to feed my passion for this broad area of study. I believe that chronic illness has reinforced my passion for nursing, a passion that was first rooted in my personal experience. As Gadamer (2006) points out, “An experience is no longer just something that flows past quickly in the stream of conscious life; it is meant as a unity and thus attains a mode of being one” (p. 58). Thus, our past experiences flow back and forth in our personal life, and in my case chronic illness is my anchor to the past. Through the images created in our relationships, we see who we were, who we are, and who we can be. Through time I have learned how professional encounters with people living with chronic illness have led me to a particular interest in their broad health-illness circumstances. I have not specialized in caring for people with any particular medical condition, but, rather, what has interested me is the phenomenon of day to day living with an illness. Finally at the end of this chapter I present my question of chronic illness in the age of globalization followed by a short section where I describe the structure of this dissertation.

Beginning to Question

In our practice of nursing, all of our encounters with our patients start with a question. When we question in our practice we want to know what distinguishes that person from another one. For example, in nursing, the patient's identity covers more than an easy description of a health problem that includes her or his name. It is complete information about someone else. Although these types of questions are sometimes impersonal at the same time they show us a proper identity of our patients. It is a question which addresses our knowledge toward that person. It is not just a simple recognition of the other with a name. As nurses, once we know a name, the story behind that face becomes more apparent and unique. Whether I am interested or not, these questions open the door to share with someone else; the recognition of the other implies that you are part of the other, share in the other's world, with the possibility to know more about the universe of that human being, and in that way start a relationship of mutual interchange of experiences and interactions in specific situations. Thus, in our everyday practice, questioning often becomes a dialogical interaction in which questions and responses are interpretable (Vandermause, 2008).

Gadamer (2006) constantly reminds us of the importance of questioning to obtain knowledge. Through his work, he speaks about the complexity of questioning, and the philosophical commitments of questioning that frequently go unnoticed in the current context of nursing (Fleming, Gaidys & Robb, 2003). His work shows both the advantages and the disadvantages or dangers that can occur when questions are posed. To question implies an interactive and dialogical exchange among human beings. To use Bergum's (1989) words, "Questioning indicates the existence of an unsettled issue, a difficult matter, an uncertainty, a matter of discussion" (p. 45). Questioning is an open process in which the answer to one question leads to another question. The process of questioning leads us continually to re-evaluate our previous knowledge, thoughts and understandings. The process of questioning is not static. It is a meaningful process on the pathway to understanding.

Questioning is not a simple task. It requires true and deep examination "from the heart of our existence, from the center of our being" (van Manen, 1997 p. 43). The question "breaks open the being of the object" (Gadamer, 2006, p. 262). When we want to break open the object we are willing to admit that we do not know all about the object. When we ask a question, the expression of wanting means first that we desire to know and second that we do not know something. To inquire in this way is an admission of incompleteness that requires humility (Gadamer, 2006). But also, "The significance of questioning consists in revealing the questionability of what is questioned.... The sense of every question is realized in passing through this state of indeterminacy, in which it becomes an open question" (Gadamer p.364). Then the question presents itself with finitude. When we question, we are emphasising the possibility that an object may be otherwise (Bergum, 1989; Bingman, 2005).

According to Gadamer, the question leads us toward a field of possible experiences. Bingman (2005) calls this "spectrum of experience" in which creating questions is not simply a reminder that an object of questioning may cease to exist as we know it and it is not just a statement about the limits of our experience. Questioning opens up a world of possibilities but at the same time it suggests the limits of those possibilities (Bingman, 2005; Vandermause, 2008). A question positions and opens up an inroad with regard to the object. Thus, the spectrum of experience started by the questioning entails both a limit and a field of possibilities. The question evokes the limits of its answers at the same time that it invites possible responses. Gadamer writes that posing a question is not an easy task. But "it is possible to question in such a way that the question itself, while sowing the seeds of its own answer, drives right for that spot where the answer is truly unknown to both the questioner and the respondent" (Bingman, 2005 p. 555). The questioning process is an interactive exchange, but there are multiple ways to think about questioning.

There are complex problems in healthcare and specifically in the area of chronic illness that require multiple avenues of inquiry and attention. As a nurse and human being, I recognize there are many things about the experience of chronic illness that I do not know and that I want to know. Through this dissertation the process of continuing to question has evoked new knowledge and understandings about the experience of living with chronic illness in the age of globalization. And new questions have emerged to enrich and challenge my experience and understanding. But before I dig deep into the experience of chronic illness and globalization, I need first to understand concepts that approach the experience from different perspectives such as social, biological and personal or subjective. Thus, to question about the experience of chronic illness, first we need to define what the meaning of disease, sickness and illness are.

Understanding the Path of Sickness, Disease and Illness in Nursing

One day my body broke down, forcing me to ask, in fear and frustration, what's happening to me? Becoming ill is asking that question. The problem is that as soon as the body forces the question upon the mind, the medical profession answers by naming a disease (Frank, 1991 p. 8).

Frank's story is lived everyday and everywhere by many people. Perhaps it is because when we are ill it is impossible to know what to do. As human beings, when we are ill our minds constantly spin around the same question: what is happening to me? Sometimes we do not know the answer to that question and it is for others to name our problem as disease or sickness. But what does it mean to be labelled as sick, diseased or ill? The meaning of those designations can be viewed from three different perspectives: sickness as the social mode of being sick, disease as the objective and pathological approach, and illness as the subjective and personal meaning of being ill (Boyd, 2000; Brody, 2003; Susser, 1990). It seems that these three dimensions–the social, the pathological and the personal–must be considered while on the road to a cure. But what is it like to live in each one of them? Exploring those experiences gives rise to many questions. As Frank says above, once we are ill, the medical profession responds by naming the disease. Other questions follow for me, are the naming and the medical response to the pathology sufficient? Is this naming a characteristic of nursing? And more important, which one of these perspectives fits within nursing? Why is it necessary to understand that person's specific situation of life? Why should we address illness as experience?

In 1986, the Ottawa charter of health promotion defined health "as a resource for everyday life, not the objective of living… a positive concept emphasizing social and personal resources, as well as physical capacities" (p.3). In 2005, the Bangkok charter of health promotion added to the concept of health the responsibility and commitment that governments must have with their citizens. Then, in this new trend, "…health is a major determinant of socioeconomic and political development. Local, regional and national governments must: give priority to investments in health, within and outside the health sector [and] provide sustainable financing for health promotion. To ensure this, all levels of government should make the health consequences of policies and legislation explicit, using tools such as equity-focused health impact assessment" (WHO, 2007 p.13). It seems that health is a normative concept derived from categorizing what is or is not healthy, while avoiding the moral point of view, the local and global inequities point of view. Categorization determines what normal or abnormal is (Canguilhem, 1991; Pörn, 1984). However, being normal and being healthy are not altogether equivalent. For example, the pathological is a kind of normal because pathological means that the relationship between organism and environment has changed through a change of the organism, and that thereby many things which had been adequate for the normal organism are no longer adequate for the modified organism (Canguilhem, 1991). On the other hand today in 2011 the changing environment is rapidly increasing the morbidity of some acute and chronic diseases.

In reality, health and normal are abstract concepts that depend on the individual's perception. Perhaps there is no boundary between health and not health. As Gadamer (1996) points out, "Health does not actually present itself to us" (p. 107). Historically, Greek physicians recognized that the body cannot be treated alone without taking into account the treatment of the soul. And yet this seems not enough, mainly because to treat the body it is necessary first to possess knowledge about the being as a whole. In fact, it is through a disruption of the whole that a genuine awareness of the problem and a genuine concentration of thought can come up. Illness then makes us insistently conscious of our bodily nature by creating disruptions in something that normally is out of our focus of attention (Gadamer, 1996). To understand health, first we need to position it in space. Health obtains its position from illness because health almost completely escapes our attention. Health does not have a concrete presence. According to Gadamer presence refers to something that fully occupies a space. We cannot perceive health but we describe when we are ill what used to be healthy, giving illness a concrete space. Health is a remarkable, protected state that allows us to fulfill our desire to be active and to flourish in life. Indeed, as Gadamer says, health is a real mystery, a fact that dwells inside of each one of us, that we are not aware of until the moment that we do not have it anymore. At that moment we could describe what health is or was for each one of us. Hence, the concept of health cannot be standardized. The meaning of health is ambiguous and specific to the individual; the imposition of standards can cause the labelling of healthy people as ill. If health is an ambiguous concept, a state of relative well-being, then what is it like to live with sickness, disease and illness? In the next section I explore the understanding of these concepts.

What is it like to live with sickness?

Sickness is the social construction of an episode of illness. In other words, sickness is the way illness is handled as a social, cultural entity and the way it is dealt with within a given society (Fabrega, 1997). Sickness is also known as a social role and public mode of being sick. Sickness is a negotiated position in the world between the person called sick and society in charge to recognize and sustain that human being. The role of sickness depends on a number of factors not least of which is the presence of the disease. In fact, sickness based on illness alone presents itself as an uncertainty status. But having a disease does not guarantee equity in sickness. Consequently, people with chronic diseases are much less secure to receive equal treatment in society than those who have acute diseases (Brody, 2003; Susser, 1990).

Sickness involves the cultural pre-understandings that provide meaning and organize actions with respect to an illness as well as the ideology associated with the political economy of society and its medical traditions. It also takes into consideration ideas and efforts associated with healing (Fabrega, 1997). The recognized Colombian writer Gabriel Garcia Marquez (2006) describes in *One Hundred Years of Solitude* what happens when epidemics of insomnia and amnesia invade the town of Macondo. Rebeca is an orphan the family adopts and raises as their own. She is the first one to present symptoms of the epidemic of insomnia and memory loss. When Visitacion, indigenous woman in the family, shares her knowledge about this disease with the family they do not believe her. But, one by one, they start to suffer the effect of the epidemic.

> *One night about the time that Rebeca was cured of the vice of eating earth and was brought to sleep in the other children's room, the Indian woman, who slept with them, awoke by chance and heard a strange intermittent sound in the corner. She got up in alarm, thinking that an animal had come into the room, and then she saw Rebeca in the rocker, sucking her finger and with her eyes lighted up in the darkness like those of a cat. Terrified, exhausted by her fate, Visitacion recognized in those eyes the symptoms of the sickness whose threat had obliged her and her brother to exile themselves forever from an age-old kingdom where they had been prince and princess. It was the insomnia plague.*
>
> *Cataure, the Indian, was gone from the house by morning. His sister stayed because her fatalistic heart told her that the lethal sickness would follow her, no matter what, to the farthest corner of the earth. No one understood Visitacion's alarm. "If we don't ever sleep again, so much the better," Jose Arcadio Buendia said in good humour. "That way we can get more out of life." But the Indian woman explained that the most fearsome part of the sickness of insomnia was not the impossibility of sleeping, for the body did not feel any fatigue at all, but its inexorable evolution toward a more critical manifestation: a loss of memory. She meant that when the sick person became used to his state of vigil, the recollection of his childhood began to be erased from his memory, then the name and notion of things, and finally the identity of people and even the awareness of his own being, until he sank into a kind of idiocy that had no past. Jose Arcadio Buendia, dying with laugher, thought that it was just a question of one of the many illnesses invented by the Indians' superstitions. But Ursula, just to be safe, took the precaution of isolating Rebeca from the other children. After several weeks, when Visitacion's terror seemed to have died down, Jose Arcadio Buendia found himself rolling over in bed, unable to fall asleep. Ursula, who had also awakened, asked him what was wrong, and he answered: "I'm thinking about Prudencio Aguilar again." They did not sleep a minute, but the following day they felt so rested that they forgot about the bad night (Garcia Marquez, 2006 p. 47, 48).*

Later on when inhabitants of Macondo realized they were all sick, measures to prevent the spreading of the outbreak of insomnia outside of the village were taken.

> *When Jose Arcadio Buendia realized that the plague had invaded the town, he gathered together the heads of families to explain to them what he knew about the sickness of insomnia, and they agreed on methods to prevent the scourge from spreading to other towns in the swamp. That*

> *was why they took the bells off the goats, bells that the Arabs had swapped them for macaws, and put them at the entrance to town at the disposal of those who would not listen to the advice and entreaties of the sentinels and insisted on visiting the town. All strangers who passed through the streets of Macondo at that time had to ring their bells so that the sick people would know that they were healthy. They were not allowed to eat or drink anything during their stay, for there was no doubt but that the illness was transmitted by mouth, and all food and drink had been contaminated by insomnia. In that way they kept the plague restricted to the perimeter of the town. So effective was the quarantine that the day came when the emergency situation was accepted as a natural thing and life was organized in such a way that work picked up its rhythm again and no one worried any more about the useless habit of sleeping (p. 50).*

Crazed by the lack of sleep and forgetting elementary words the Macondians decided to write the names of things and attached them to the relevant objects. But then they went into a new state of insanity: due to the lack of sleep they forget how to read. Being sick means that something has changed in that person as a social human being. As van den Berg (1987) points out that at first the sick person will be missed at work and in society. But then, "While during the first few days or weeks it seemed that his absence would create problems, now these problems are no longer apparent. No one seems to worry about them. Things are going pretty well without him, he is not needed anymore" (p.235). Definitely, life goes on. Being sick means to have something wrong with oneself compared with others; it means that the human being as a whole is divided as an object according to parameters of health imposed by society at large.

> *It was Aureliano who conceived the formula that was to protect them against loss of memory for several months. He discovered it by chance. An expert insomniac, having been one of the first, he had learned the art of silverwork to perfection. One day he was looking for the small anvil that he used for laminating metals and he could not remember its name. His father told him: "Stake." Aureliano wrote the name on a piece of paper that he pasted to the base of the small anvil: stake. In that way he was sure of not forgetting it in the future. It did not occur to him that this was the first manifestation of a memory loss, because the object had a difficult name to remember. But a few days later he discovered he had trouble remembering almost every object in the laboratory. Then he marked them with their respective names so that all he had to do was read the inscription in order to identify them. When his father told him about his alarm at having forgotten even the most impressive happenings of his childhood, Aureliano explained his method to him, and Jose Arcadio Buendia put it into practice all through the house and later on imposed it on the whole village. With an inked brush he marked everything with its name: table, chair, clock, door, wall, bed, pan. He went to the corral and*

> *marked the animals and plants: cow, goat, pig, hen, cassava, caladium, banana. Little by little, studying the infinite possibilities of a loss memory, he realized that the day might come when things would be recognized by their inscription but that no one would remember their use. Then he was more explicit. The sign that he hung on the neck of the cow was an exemplary proof of the way in which the inhabitants of Macondo were prepared to fight against loss of memory: 'This is the cow. She must be milked every morning so that she will produce milk, and the milk must be boiled in order to be mixed with coffee to make coffee and milk'* (p 50,51).

Sickness as a social phenomenon portrays a set of rights and duties in need to be fulfilled socially. Ontologically, sickness is an event located in society and defined by participation in the social system. Epistemically, sickness is determined by levels of performance with reference to expected social activities when these levels fail to meet social standard in a given society (Mature, 2007). For Hofmann (2002) sickness is a negative bodily event as determined by society and/or its institutions. For the patient it is to act out our social roles and relationships in ways that will be influenced by cultural belief systems. Sickness is a population norm, not an individual one. This means that individuals can be sick, but not populations (Brody, 2003). Being sick depends on social roles and relationships. In other words, life is planned by society, and whoever does not observe its rules is left behind. Being sick means changing the plans of our life, determining what, if anything, is the same. Brody writes, "if the experience of sickness involves a much altered sense of time or space, we might imagine difficulties in the sick person's engaging in such reflection" (p 91) and in the ability to interact with other people and society. It is a radical change that alters time and space as Leonard Cohen the Canadian poet, novelist and singer-songwriter describes in his poem *On the Sickness of My Love*. Sickness is an alteration that produces a lack of perception in the flow in life where everything outside changes while we perceive that inside everything continues the same.

> *On the Sickness of My Love by Leonard Cohen, 1973*
>
> *Poems! break out!*
> *break my head!*
> *What good's a skull?*
> *Help! help!*
> *I need you!*
>
> *She is getting old.*
> *Her body tells her everything.*
> *She has put aside cosmetics.*
> *She is a prison of truth.*

Make her get up!
dance the seven veils!
Poems! silence her body!
Make her friend of mirrors!

Do I have to put on my cape?
wander like the moon
over skies & skies of flesh
to depart again in the morning?

Can't I pretend
she grows prettier?
be a convict?
Can't my power fool me?
Can't I live in poems?

Hurry up! poems! lies!
Damn your weak music!
You've let arthritis in!
You're no poem
you're a visa.

A visa meaning travel to some other place, for his love it is to go to pain, to further incapacities. Cohen rages against this. His poems have not protected him from sickness entering his world.

Often ill people may feel treated differently by others and even behave differently. The sick role involves cultural, social and interpersonal expectations regarding the ill and disabled people’s behaviour. These social expectations not only include reciprocal expectations the patient has of others such as family, friends, physicians, nurses, and therapists but also the right to receive attention and services from other people in society to solve, assist or control the health issue when it is needed. More broadly, the sick role encompasses the social consequences of being labelled as ill or disabled. The sick role becomes validated in society when ill people share concerns about their health with others and receive social support, exemption from social expectations, and the direction toward health care resources. Thus, becoming sick is a social process in which perceptions and responses to impaired well-being are shaped by the behaviour of family, friends, colleagues and employers (Winkelman, 2009).

Sickness is the way others interpret the condition of a person (Maturo, 2007). Then, sickness entails the perception of a meritocratic society in which the capacity to move and produce is highly appreciated. Sickness makes the world more difficult to overcome. It is like pulling the rug out from under daily life, plans, and expectations. Everything changes. In fact, sickness can disrupt daily productivity, often in deep ways. Productivity is defined as the process of engaging in activities with personal and social value (de Almeida Filho, 2001; Maturo, 2007; Wikman, Marklund & Alexanderson, 2005). For those who can continue working through illness they become models of how illness should be confronted, this enormous responsibility to bear the illness and work. If their illness is visible to the casual onlooker, their actions reinforce and foster moral ideals of productivity that is applauded by family members, friends, colleagues and society. Even when illness is not visible people can maintain moral worth by not letting their condition slow their lives. These efforts are socially acknowledged and encouraged. But for other people who live with illness so incapacitating, whether it is visible or invisible, to fulfill the ideal of productivity despite illness is almost an impossible task (Hay, 2010). Sick people are not responsible for their failures and consequently, they are excused from performing role responsibilities. The sick role carries with it the assumption that the sick cannot be happy with their situations. The sick look for help from physicians, nurses and others as socially defined as a part of the desire to get well (Brody, 2003). Perhaps the social role of being sick enables the ability to conform one's life to the rules and protocols of society or, as Wendell (1996) points out, conform "to subtle cultural factors that determine standards of normality and exclude those who do not meet them from full participation in their societies" (p. 36). Why? It could be possible that we spend our lives living under labels of normal and abnormal by judging the other's situation. It seems that society builds concepts such as disabilities or sickness into constructs of stereotyping and stigmatization that feed fears (Wendell, 1996).

What is it like to live with disease?

> *Suddenly I woke up and had that strange feeling that something was missing. Then I realized that my leg was not there in the place that it was supposed to be. Nobody said a word. In that moment I was only the diabetic woman without her leg. I just was there alone and without my leg* (Camargo Plazas, 2005, p.128).

This woman is no longer viewed as a whole human being with feelings, thoughts and opinions. It is the moment when 'she' becomes 'it' or 'who' transforms to 'what'. Etymologically the word disease comes from old French *desaise* that means want of ease (Skeat, 1963). Disease is an objective biological phenomenon (Boyd, 2000; Hay, 2010). It is a negative bodily event as considered by the health care professions (Hofmann, 2002). Disease has been defined as an organic phenomenon independent of subjective experience and social conventions. Epistemically, disease can be measured by lab reports, sight, touch and smell (Mature, 2007). This definition of disease encompasses the idea that in most cases the specific condition has a known biomedical cause and often has known treatments and cures (Boyd, 2000). Living with disease as in the following poem is to battle everyday with the unknown. Disease alters the flow of life.

> *The Disease* by Anonymous (2008)
>
> *So how do I make*
> *my peace with this?*
> *This invader*
> *This thief*
> *This jailor*
> *This stranger in*
> *my body.*
> *There should be a dance for this.*
> *A song*
> *A story*
> *Some marking of the change.*
> *Not this slow invasion into*
> *every part of me.*
> *Each day I number casualities.*
> *Some battles lost, some battles won.*
> *Some remain the same.*
> *As the man I was*
> *And that man that I am,*
> *Change places.*

Disease is often seen as other when we believe we have been attacked as in the poem above. This invader now somehow directs the course of my life. Why should it have this power? I did not consent to it. How hard it is to understand this thief, this jailor, this otherness as something I now carry with me. The poem shows us this part of the lived life of someone with disease. There is no ease in this life with the invader.

In *Maria,* Jorge Isaacs (1890), another Colombian writer, recounts the love story of Efrain and Maria. When Efrain returns from school in Bogota to his house in the Cauca valley he meets Maria, the daughter of a friend of his father, whose parents have died. Efrain and Maria fall in love at first sight and embark on a platonic romance, but Maria suffers from epilepsy, the same disease that caused her mother’s death. Their love story is overshadowed by the presence of disease. So that Efrain may avoid suffering, his parents send him to London to finish his medical studies. While Efrain is away, Maria dies of epilepsy. Through the story of love, disease, and death Isaacs explores the depths of human emotion and tragedy. At the time Maria suffers from epilepsy, there were no known cures for the disease. So her only possibility is to live with it and expect the unavoidable death.

> *One afternoon, as I came down from the mountain, I observed signs of excitement on the faces of the servants whom I met in the corridors. My sister told me that Maria had suffered a nervous shock, and was still unconscious. She then tried to dispel my loving anxiety.*
>
> *Forgetting everything, I went straight to the room where Maria was, and could scarcely control the mad impulse to press her to my heart and restore her to full life. My father was seated at the foot of her bed. He fixed upon me one of his intense looks, and then, turning towards Maria, seemed to be accusing me as he pointed to her. My mother was there: but she did not look at me. She knew of my love, and like a good mother, knew how to pity me.*
>
> *I stood motionless, gazing at Maria, without daring to ask the cause of her sickness. Her face, half hidden by her dishevelled hair, wore a deadly pallor. In her hair were the flowers I had given her in the morning, now all crushed. Her contracted forehead spoke of unbearable pain, and a slight moisture was on her temples. Her eyes were closed; but tears had tried to force their way out, and lay glistening under the lashes.*
>
> *My father understood my anguish. He rose to go out, but before opening the door, he went to the bed and felt Maria’s pulse.*
>
> *“She’s getting better,” he said. “Poor child! It’s the same disease her mother had.”*
>
> *Her breathing was growing less convulsive. I stood at the head of the bed, and as soon as my father was gone, unmindful of Emma and my mother, I took the hand which lay upon the pillow and bathed it in the tears I could no longer keep back. I understood the full force of the calamity; it was the same disease her mother had. Her mother had died very young of an incurable form of epilepsy. This was the thought that was mastering and almost destroying me (Isaacs, 1890 p 33, 34).*

As in Isaacs story, disease calls for actions by the health care professions to identify, treat and care for its occurrence in the individual. As Engelhardt (1974) states, “The concept of disease is an attempt to correlate constellations of signs and symptoms for the purpose of explanation, prediction and control” (p. 135). Disease has been understood as biological abnormalities in the body’s structures, chemistry or functions. In other specialities within medicine, such as psychiatry, the employment of psychological, behavioural, and social models are common to understand mental illness. Yet, biology is the dominant model used in psychiatric medicine worldwide. Most diagnostic models in mental health have described mental health problems as the result of abnormalities in biology, particularly neurotransmitter levels, for which medications are prescribed (Winkelman, 2009). But in practice there are several limitations to this idea. First, a number of medical diagnoses are based on subjective information given by the patient. Second, a number of diagnoses are based on syndromes and complex interrelations between different organ systems making them not always specific (Boyd, 2000). Also, this perspective of disease as a pathological condition is so deeply engrained in the thinking of most health professionals that they consider the biomedical views as the only one valid perspective, disregarding the person or social environment as important component of the process of disease (de Almeida Filho, 2001; Winkelman, 2009). Disease prevention, health promotion, health advice is not given, the biomedical model remains supreme (Duncan & Reutter 2006).

I Wanted to Be a Doctor by Leonard Cohen, 1973

The famous doctor held up Grandma's stomach.
Cancer! Cancer! he cried out.
The theatre was brought low.
None of the interns thought about ambition.

Cancer! They all looked the other way.
They thought Cancer would leap out
and get them. They hated to be near.
This happened in Vilna in the Medical School.

Nobody could sit still.
They might be sitting beside Cancer.
Cancer was present.
Cancer had been let out of its bottle.

I was looking in the skylight.
I wanted to be a doctor.
All the interns ran outside.
The famous doctor held on to the stomach.

He was alone with Cancer.
Cancer! Cancer! Cancer!
He didn't care who heard or didn't hear.
It was his 87th Cancer.

Here Leonard Cohen shows in *I wanted to be a Doctor,* the biological perspective oriented in health care professions results in the neglect of other factors responsible for patients' diseases and concerns. Then, biomedicine tends to isolate health problems from the social contexts that affect a patient's condition. For instance, social and emotional factors may be recognized as complicating some disease by increasing stress or encouraging non-adaptive behaviours such as poor diet. By definition, disease only pays attention to the lab results, neglecting what the patient experiences. Mostly, the patients' experience is denied when diseases are defined as universal with identical and specific features, symptoms, causes and processes across the globe (Winkelman, 2009). Disease is not only the result of infectious agents, but, rather, occurs in interaction with contributory psycho-physiological and socio-cultural aspects that bear on the body's response to the agent. Then, social, economic and environmental conditions can undermine the person's well-being. What is it then in light of the above, to live with chronic illness?

What is it like to live with illness?

Chronic Illness by: JoAnn Kranik (2009)
Chronic illness sometimes is unseen
by others. Others cannot feel what they cannot see.
So if sometimes I look well, but I tell you I am in pain
please do not judge me, I wish I "was" well again.

Illness is not my choice it's what life dealt to me.
For you to disbelieve me or doubt me,
breaks my heart.
For you are my Family, Doctor or even a Good Friend.
Must I earn your "trust" all over again?

Chronic means on and off but always there
Today I may be able to do something, tomorrow maybe I can't
I have to try hard to work within my limit.
Or the next day I may wind up at the clinic.

Funny how when you have a chronic illness and you finally adjust
you find that it has led to another and you must handle that too.
Sometimes you have two or even more,
oh my what a chore.

Some even tell you, you can't walk anymore.
All of these illnesses robs me of my life.
I can never be normal like you
again.
It is hard for me to accept what I am going through.
I don't need the extra stress trying to convince you.
At times, I have mood swings,
I may snap at you.

If I do I am sorry, please understand,
I am angry at "me."
I try to do what I've done before
perhaps even a simple chore.
But then I find that my muscles don't seem to work anymore.
I want to be that parent, grandmother or friend
the one I "lost" when this illness came upon me.
The one I tried to be when I was there for you.
The one I "was" when I was able to do.
Every time I say no to you, don't be angry at me.
Every no I have to say reminds me
I am "not" normal anymore.
So please, don't doubt me, just try to understand.
It was not my choice! It is just God's Plan.

As in this *Chronic Illness* poem written by JoAnn Kranik (2009), illness is a subjectively interpreted, undesirable state of health. It is comprised of subjective feelings and states such as pain, weakness and weariness. With illness there is a personal evaluation and perception of bodily function and/or feelings of competence (Hofmann, 2002). Illness is often grounded on self-reported mental or physical symptoms. For some, this means minor or temporary health problems, whereas for other people self-reported illness might include difficult and long-lasting health problems or acute suffering.

In *My Left Foot,* Christy Brown (1990) recalls his story as an Irish boy born with cerebral palsy. Christy could control only his left foot. He grew up in a poor working class family and became a writer and a painter. His mother is the only one who recognizes Christy's intelligence and sensibility. Physicians disregard his humanity. Eventually, Christy matures into a writer who uses his left foot to communicate what he feels and thinks. His left foot becomes the instrument to communicate with the external world.

> *It was mother who first saw that there was something wrong with me. I was about four months old at the time. She noticed that my head had a habit of falling backwards whenever she tried to feed me. She attempted to correct this by placing her hand on the back of my neck to keep it steady. But when she took it away back it would drop again. That was the first warning sign. Then she became aware of other defects as I got older. She saw that my hands were clenched nearly all of the time and were inclined to twine behind my back; my mouth couldn't grasp the teat of the bottle because even at that early age my jaws would either lock together tightly, so that it was impossible for her to open them, or they would suddenly become limp and fall loose, dragging my whole mouth to one side. At six months I could not sit up without having a mountain of pillows around me; at twelve months it was the same.*

> *Very worried by this, mother told my father her fears, and they decided to seek medical advice without any further delay. I was a little over a year old when they began to take me to hospitals and clinics, convinced that there was something definitely wrong with me, something which they could not understand or name, but which was very real and disturbing.*
>
> *Almost every doctor who saw and examined me, labelled me a very interesting but also a hopeless case. Many told mother very gently that I was mentally defective and would remain so. That was a hard blow to a young mother who had already reared five healthy children. The doctors were so very sure of themselves that mother's faith in me seemed almost an impertinence. They assured her that nothing could be done for me.*
>
> *She refused to accept this truth, the inevitable truth—as it then seemed—that I was beyond cure, beyond saving, even beyond hope. She could not and would not believe that I was an imbecile, as the doctors told her. She had nothing in the world to go by, not a scrap of evidence to support her conviction that, though my body was crippled, my mind was not. In spite of all the doctors and specialists told her, she would not agree. I don't believe she knew why—she just knew without feeling the smallest shade of doubt (Christy Brown, 1990 p 9-11).*

As in Christy's story, illness or chronic conditions limit people's leading a normal life. Illness is seen as a rather wide concept (Boyd, 2000). Ontologically, illness, then, is the subjective state of the individual often referred to as symptoms. Epistemically, this can only be perceived directly and observed by the subject and indirectly assessed by tests (Mature, 2007). Illness calls for actions of the individual, making the person aware to communicate the negative occurrence to others (Hofmann, 2002). In illness the person assumes a sense of ownership, ownership that falls into the appreciation of control (Marcel, 1964) wherein body and self work together as a whole. Overall, illness encompasses an individual's psychosocial and subjective response to being unwell or feeling unhealthy. The experience of illness includes the effects of conditions such as limitations on abilities to engage in daily life activities. And also illness influences and shapes the interaction with others and how they respond to one's condition. Cultural beliefs are closely linked to the experience of being ill (Winkelman, 2009). How lucky Christy was to have his mother who believed in his life as being here for a reason. She could not be dissuaded.

Christy's describes of what it is like to live with cerebral palsy:

> *I could now no longer run away from myself, I had grown too big for that. In a thousand ways, large and small, as each day went by, as the family grew up one by one and became—to me—strange self-supporting adults, I saw and felt the limitations, the boredom, the terrible narrowness of my*

> *own existence. All around me were signs of activity, effort, growth. Everyone had something to do, something to occupy them and keep their minds and their hands active. They had interests, activities and aims to make their energies a natural outlet and a natural medium of expression. I had only my left foot.*
>
> *My life seemed just like a dark, stuffy little corner in which I was thrust with my face turned toward the wall, hearing all the sound and motion of the big world outside, and yet unable to move, unable to go out and take my place in it like my brothers and sisters and everyone else that I knew. I felt as if I was merely moving along a groove, thinking the same things, feeling the same things, dreading the same things. I was left with nothing but frustrated tryings and little narrow thoughts (p 78).*

The paradigm case in health care is the situation in which a person feels ill, the medical profession is able to detect disease, and society assigns to this person the status of sick (Hofmann, 2002). Illness and disease do not stand in a one-to-one relationship (Eisenberg, 1977). When disease is extreme such as in terminal stages of cancer or when there is pain, its pervasiveness becomes inevitable. Illness makes understandable the situation to the person who lives with it, disease allows medical attention, and sickness frees the person from ordinary duties of work and gives the right to economic assistance such as for renal failure and stroke.

What it is by Erich Fried (1983)

What it is

It is nonsense
says Reason

It is what it is
says Love
It is misfortune
says Calculation
it is nothing but pain
says Fear
It is hopeless
says Insight
It is what it is
says Love

It is ridiculous
says Pride
It is frivolous
says Prudence
It is impossible
says Experience
It is what it is
says Love

Yet, there are conditions where certain signs or markers are recognized by the medical profession before the patient experiences any illness, and where society gives the person treatment and economic support. Also, there are cases of disease and illness, but not sickness as with tooth decay or seasickness. Furthermore, there are examples of illness and sickness, but not disease. Fibromyalgia and chronic fatigue syndrome are examples of situations where the person feels ill and society entitles the person to assume the role of sick, but where the medical profession cannot correlate with any negative bodily event. These examples must suffice to illustrate the variability of the experience of illness in the presence of ascertainable disease of comparable severity. And yet, sometimes for a disease to be accepted as real by the patient, it needs to be lived or felt in the body first. The other side of the coin is the problem of illness in the absence of noticeable or measurable organ pathology, for which psychosomatic syndrome provides a convenient paradigm (Boyd, 2000; Hofmann, 2002). There is discrepancy between disease as it is conceptualized by the physician and illness as it is experienced by the patient. Therefore, illness, as with other things in life, is unique. As Marcel points out, “Speaking of my body is, in a certain sense, a way of speaking of myself; it places me at a point where either I have not yet reached the instrumental relationship or I have passed beyond it” (p.123). Even though a disease *per se* could be presented with the same pathological signs, one’s perception of illness and how to deal with it is unique, because each human being is different. The meaning and uniqueness of the moment of being ill is based on the person as subject.

For this study, understanding sickness, disease or illness leads us to question how these designations described above apply to the chronically ill. Can we use the same constructs to define the changing and long lasting situation of people with chronic illnesses? Do these designations even work in the face of globalization forces that encroach on the bodies of the chronically ill and become visible through an examination of their social determinants of health? Through time I have learned how professional encounters with people living with chronic illness have led me to a particular interest in their broad health-illness circumstances. As the dissertation develops, the reader will see how each one of these terms presents itself according to how the experience of chronicity is lived by the participants. My attempt with this study is to follow the path of illness. I have not specialized in caring for people with any particular medical condition, but, rather, what has interested me is the phenomenon of day to day living with an illness. And I have understood throughout this work how Bergum's (1994) work was seminal in escaping these categorizations, fixed ideas of illness, sickness and disease. Her Living I, how the person lives what she or he has in terms of illness, from the inside, how the objective I is only the measurement things, and how the Personal I is symptoms felt by the personal I not the health care professionals. Understanding the context and the voices of people who live with chronic illness will illuminate the practice of nursing in different ways: first, it will assist nursing to critically question the health system. Second, it will explore the causes of iniquities within the health care system. And third, these descriptions will assist us with planning and implementing equality in health system delivery and policy development for people chronically ill.

My First Attempt to Question Chronic Illness

My interest in the area of chronic illness and disability is deeply rooted in my personal experience. I am the youngest of four children. My older brother, Mauricio, was my playmate and my best friend. Despite our age difference he was always eager and happy to play with me. At first I did not notice, but, later, when I was growing up, I noticed there were some differences between him and my other siblings. He was not going to regular school; he was attending a special school in Bogota. My parents were closely involved with his school. Even I noticed how my mother and father were special with him. My father proudly told us many times the story of how he taught him how to read and write. When I saw my parents writing a book about him, I had to know more. So one day I approached my mother and asked her, "Why does Mauricio not go to the regular school like Zulma and Alejandro? Why is he so different?" My mother answered me in simple words, "Mauricio is special. He needs all our attention, love and understanding. He needs us as a family and he will always." My father later explained to me how my brother's brain was injured with the forceps during birth. He showed me with a coin the size of his lesion. Mauricio has always been able to do many things on his own. He speaks sometimes in the third person and has some difficulties with recent memory and speech but overall my brother is the healthiest in my family. However, when my father told me his story, for one week I kept doing most of the things for Mauricio.

When I was eight years old, my grandmother suffered her first heart attack. I went to the hospital to visit her but before we got there my mother explained to us what to expect in the hospital. My grandmother took medication for her heart, but, when I was 12 years old, on Christmas Eve, she had her first stroke. Today, I still have the image of her in what was my bedroom that we adapted as a hospital room with a hospital bed, oxygen tank, IV lines and bedpans for her. However, the image that struck me the most was my mother taking care of her, organizing shifts for the whole family to take care of my grandmother day and night. That December, through the hand of my mother, I had my first experience of nursing when my mother taught me how to care for my ill grandmother. My duties at night included helping my mother change my grandmother's position every two hours, massaging her, and when she awoke from her coma, frightened and disoriented, encouraging me to speak to her. In the mornings my mother and I bathed her. We did this every other night during the month of December. I also still remember that the person who woke up from the coma one month later was a different one. The strong woman whom I knew was not there anymore even though she did not have any apparent physical impairment. She was so vulnerable and sensitive, almost powerless, in her new life. She spent just two years of her life with me after her stroke, but in that brief time without my knowing it she marked my life forever in a meaningful way.

I ended up being a nurse like my mother and working in the same place my grandmother was hospitalised and died. As a nurse, I had the opportunity to interact with many chronically ill people. My encounters with them and my personal experience led me to begin my master's degree in nursing with emphasis in chronic illness, but I did not know that until one of my supervisors in one of our meetings about my thesis asked me, "Have you ever thought about how our choices of work in our professional life are strongly tied to and influenced by our personal life?" She continued, "In my case, the fact of living with my sister who suffered and passed away from chronic renal failure was essential to address my work as a nurse toward chronically ill people and especially people with chronic renal failure." She then said, "You should think why chronic illness is such an important deal for you in nursing." Until then I had never thought about it.

Looking back on my life, I realized that chronicity has been present in my family for my whole life. First, my brother and, later, my grandmother with her chronic heart problems marked me forever, although I did not recognize the impact until many years later. Thus, after that meeting, I dug into my memories and began to realize that, as my teacher said, my decisions concerning my professional life have been influenced by my personal life. Through time I have learned how professional encounters with people living with chronic illness have led me to a particular interest in their broad health-illness circumstances.

In my Master's work on chronic illness (Camargo Plazas 2000, 2005) in an endeavour to understand it better, I investigated the individual's experience of living with and caring for chronic illness. The major finding of this study was that chronically ill people perceived their condition as part of their being. There were positive and negative perceptions of chronic illness but they kept going with the support and love given by family and friends. The lack of medication was replaced with the use and practice of traditional medicine. Spirituality was an important part of the experience of being chronically ill. To achieve comfort they relied on their spirituality, traditional medicine and interaction with family and friends.

While the findings of this study did give me insight into the patients' experience arena, I recognized I had fallen short. I did not connect what I was seeing in my practice with what I was experiencing with my participants in the data collection. As a nurse, I saw many times how for some of my patients access to treatments was denied by their insurance companies. For instance, it was common to see patients fighting through legal means with their insurance companies to obtain their authorization for angioplasty and stents after myocardial infarction. To access those stents each patient had to wait one month in the hospital until a judge cleared their situation, while for others the access was unlimited. There were inequities. As a nurse, it was difficult to see how the lives of some of my patients were at stake. Despite my considering this situation to be unfair, I never asked myself what forces were behind the lack of access to health care for my patients. In Canada, my teachers and my supervisor, Dr. Brenda Cameron, instilled on me a passion to learn about globalization and its effects on nursing. So I began to wonder how the social, political, economic forces of globalization affect the experience of someone who is chronically ill.

Understanding the experience of chronic illness in the age of globalization, then, has become the guiding endeavour and overall concern of this research study. The content of this dissertation attempts to situate myself within the daily life of chronically ill people in Colombia and Canada. This dissertation is guided by two objectives: first, to describe and understand the personal experience of individuals living with a chronic illness; and, second, to critically examine how the social determinants of health shape their personal and collective health situations. The first objective is framed to understand the unique experience of chronic illness; the second flows out of the first and it also examines from a critical perspective how globalization as a force shapes personal and collective health situations for chronically ill people. So, today, when the world pushes for economical profit and competence on one hand and for moral commitment to care, respect and advocate for all human beings on the other, the care for the chronically ill represents a challenge for health professionals. This challenge is especially significant because harm and benefit, justice and injustice, respect and disrespect are separated by a fine line that is easy to transgress.

The Question of Chronic Illness

It is not until I have identified my interest in the nature of a selected human experience that a true phenomenological questioning is possible. To do phenomenological research is to question something phenomenologically and, also, to be addressed by the question of what something is "really" like (van Manen, 1997 p.42).

As I began to reflect on what the lived meaning of chronic illness might be for people in Colombia and Canada, I realized that although I could cite historical precedence and quote what health care professionals and scholars had to say about the impact of chronic illness, I could not articulate what it is that distinguishes the experience of living with chronic illness under social, economic and political pressures forced by global processes, or what it means in the lives of those with chronic illness. It is from this position of not knowing that my questioning began to emerge: "In order to be able to question, one must want to know, and that means recognize that one does not know" (Gadamer, 2006 p. 357). Living the questions involved, above all, a continuing questioning throughout the whole experience. Questioning is at the heart of our understanding of the world. We live in a changing world, a world in which, to achieve social justice, it is necessary to keep questioning the system. As Cameron (2004) states:

> In seeking for an understanding of ethical practices in health care situations, our challenge is always both to recognize and respond to the call of this moment while much vies for our attention elsewhere.... In attuning ourselves to this claim an ethical moment arises (p 54).

As I explain in the next chapter, the situation of chronic illness worldwide is not an easy one. In health research it is widely acknowledged that the health of people and populations is strongly influenced by the social determinants of health (Raphael, 2006, 2009; Reutter & Kushner, 2010). It is less common for health researchers to recognize that the quality of these social determinants of health is greatly determined by the organization of societies and how these societies distribute equally material resources among their members. And yet it is even less common for health researchers to explore the impact of political, social, and economic forces that influence the organizational and distributional practices of societies in specific groups such as people chronically ill. Thus, research, however, is limited. There is little knowledge about the meaning of living with chronic illness under the pressure of neoliberal ideologies. And, also, we know little about the effects that economic, politics, social forces produced by globalization have on the experience of living with chronic illness. This situation evokes the necessity for health professionals to understand the experience of living with chronic illness in the age of globalization and how the political, cultural, social and economic forces affect the body of someone who is chronically ill. With my research I wanted to examine the experience of living with chronic illness in the age of globalization, using a hermeneutic phenomenology method applied to the chronically ill's own stories. Also, I wanted to critically explore the effects of social, cultural, economic, political, and gender forces on the bodies of people with chronic illness. Therefore my research questions are:

1. What is it like to live with a chronic illness in the context of contemporary globalization forces?
2. How do these political, economical and social forces affect the body of the chronically ill?
3. Are experienced difficulties similar or different in a middle-income country as compared to a high-income country?

Structure of the Dissertation

In the following chapters, I delineate the research questions. In Chapter II, I engage with the existing literature on chronic illness in both the South and the North as a way to see how these texts describe the experience of chronic illness in the world today. To do so, I explore globalization and neoliberal policies and their connection with health. Following that, I look at the social determinants of health and how those forces affect the processes of health and illness and health outcomes for people around the world. Then, I continue by describing the Colombian and the Canadian health care systems. Following this, I engage with chronic illness in the global context. In the next section, I explore the research text of chronic illness in the South and the North. From both worlds, important perspectives and strategies have emerged; however, little is known about the experience of living with chronic illness under the pressures of global forces. That paucity of knowledge calls us to reconsider our approaches to understanding the experiences of chronically ill people.

In Chapter III, I examine the philosophical and methodological approaches of this study. To understand the experience of chronic illness in the age of globalization I focus on the human science tradition and interpretive inquiry. But the complexity of globalization and neoliberalism require a critical approach to understand the impact on the life experiences of these people. To do so, I return to my Latino roots. Through Enrique Dussel's philosophy of liberation and Paulo Freire's critical pedagogy, I explore how the social, politic, and economic forces shape the experience of living with chronic illness. Also, in this chapter, I present methodological elements of this study, highlighting the ones that were fundamental to develop my understanding of the experience of chronic illness. In this chapter, I present my participants and my interaction with them. Finally, I describe some ethical considerations for the study.

In Chapter IV, I bring the experience of chronic illness in Canada into our midst. The context is different and the experience of these three participants is filled with their positive outlooks toward their conditions. But, despite that place, language and culture are different, Canadian participants perceive and identify the stigmas and the discrimination that society imposes on them.

Chapter V presents the experience of living with chronic illness in Colombia. Following the four existentials--lived, body, lived others, lived space, and lived time--through in-depth descriptions, I seek to understand the daily life of these people with chronic illness in Colombia. Their stories portray the drama that chronic illness brings into their lives. Difficulties, struggles and resilience are part of their daily life when facing uncontrolled periods of their disease. But not every illness is perceived as negative; sometimes illness brings the opportunity to make radical changes in their lives or a moment to strengthen the bonds with family and friends. Yet, the social, political and financial contexts play a key role in the way these people perceive their experiences. Without the support of their health care system or the state or advocates, the lives of these people fall into the cracks. The experience becomes perceived as negative. For some, fighting back is the way to resist, but for others, despite that their health and well-being are threatened, they acquiesce to the *status quo*.

In Chapter VI, I continue with the experience of chronic illness in Colombia. Adhering to the underpinnings of Freire's critical pedagogy, I describe my encounter with my participants in a group activity. We engaged in a dialogue on chronic illness in Colombia; my idea was to uncover some solutions to the issues raised during the individual conversations in a process that required mutual growing and understanding. The outcomes of this encounter were beyond my expectations.

In the final chapter, I return to the various threads of this study. Here, I offer a process of a critical primary understanding of this inquiry. This understanding not only invites us to revisit our manner of relating to the chronically ill both locally and globally, but also to understand the effects and impact of policies imposed by international organizations on the lives of these people. It is a call for health care professionals, politicians and the state to redefine and reshape health care practices and health care systems that encumber the chronically ill. These chronically ill people relentlessly strive to thrive even in the face of rigid structures imposed by global forces.

Challenges of the Study

Several challenges of this study should be noted. First, this study attempted to understand eight people's experiences of living with chronic illness in the context of contemporary globalization forces in Colombia and in Canada. For some, this number of participants may be considered too small to generalize in the traditional sense. However, the tendency to generalize may keep us away from the uniqueness of the lifeworld (van Manen, 1997). The imposition of standards can cause labelling of people as healthy, normal or ill which only brings exclusion for those who cannot fit into these definitions.

Second, initially I planned to have the study in two settings. In what follows you will see that there were two wings to the study, one in Colombia and one in Canada. It was not that I wanted so much to do a comparative study with the two settings as much as to describe through phenomenological work what it is like to live with chronic illness in a middle-income country and a high-income country. In Canada, due to participants' work, travel and life limitations we could not engage in a group activity as I did with the Colombian wing of the study.

Third, I found it difficult to address direct questions about the financial impact of chronic illness. In both countries it is culturally inappropriate to ask people about financial matters. I did ask the question but participants were not comfortable answering. So I decided to follow the flow of the conversation and during most of our encounters they shared with me some of the financial constrains and expenses they were exposed to due to their conditions. The cost of transportations to visit doctors, specialist, picking up medications and other expenses were addressed by participants. In Canada, participants told me how difficult it was for them to live with a long-term disability.

Chapter II Engaging with the Writing on Chronic Illness in the Age of Globalization

There are times when I fear that someone reading this, even if not yet totally converted to neoliberal pragmatism but perhaps somewhat contaminated by it, may think that there is no more place among us for the dreamer and the believer in utopia (Freire, 1998, p. 41)

To keep up with the flow of the study, I needed to engage with the existing literature on chronic illness as a way to see how these texts tap into the experience of chronic illness in the world today. I am acceding to a world where researchers, health care professionals and the chronically ill and their families engage to describe their experiences and mutual interactions. Yet, to really understand the world of chronic illness we need to get in touch with all of the dimensions of the experience in the South and the North. To use Smith's (1994) words, "the idea is to get people in touch with precisely those parts of their experience which lie beyond, behind, underneath, and above the superficial pleasures of merely getting by" (p.148); thus, my idea in this chapter is to get in touch with all aspects and dimensions of the experience of being chronically ill in the South and in the North as a way to understand what the position of chronic illness is globally.

In Spanish, we use the world *adentrar* to mean that we want to go deep into something. In this chapter I want to *adentrame* or to go deep into the world of chronic illness. To do so, I need to first explore what globalization and neoliberal policies are and their connection with health. Following that, I look at the social determinants of health and how those forces affect the processes of health and illness and health outcomes for people around the globe. I then present a brief description of the Colombian and Canadian health care systems. I continue with the global dimension of chronic illness and present what world agencies, banks and researchers have to say about chronic illness and how globalization and neoliberal policies have increased the number of people affected by chronic conditions. The next section looks at how chronic illness is described in the South and the North. The South-North division is not a geographical one; it is derived from the positions those nations have gained through the United Nations Human Development Index (2010). When I refer to the South, I am presenting literature from low- and middle-income countries; the North includes literature of the high-income countries. The South literature includes studies from Estonia, Georgia, Colombia, Iran, Russia or South Africa. I have included literature from Australia and Japan that belong geographically to the South but economically to the North or Western countries. Together, all the sections support the urgency to address the experiences of the chronically ill in the context of contemporary globalization forces and how these political, economic and social forces physically affect the chronically ill.

As a PhD student, I have read and heard many times about "The North-South Dialogue." While it seems to be a widely accepted way to reach understandings between both sides, it seems to me to be a way of domination in which the North speaks first and imposes its knowledge onto the South. Following my South heritage and culture in this dissertation, I have decided to let the South speak first. When the South speaks, sometimes its voice is stronger and more secure with innovative ways to present the world of chronic illness to the North. The text of the South presents the struggles, challenges, effects and solutions in the quest to deal with chronic illness. Other times the South accedes to the knowledge development of the North and brings to its context North's approaches to understanding chronic illness. I am not implying that the approaches of the North are bad, because some of these strategies have been proven to be effective in the North; however, the context in which they emerge and are proven is different from the context and culture in the South. To be effective those strategies must be adapted to the South context, but most studies do not consider if these strategies were adapted or not.

Globalization and Neoliberal Policies

Globalization is a complex and disputed concept. Globalization is understood as a more or less economic process characterized by increased deregulated trade, economic communication, and capital mobility. Yet, globalization is increasingly perceived as a more comprehensive phenomenon that is shaped by a multitude of factors and events, and that is reshaping our society rapidly; it encompasses not only economic, political and technological forces, but also social, cultural and environmental aspects (Martens, Akin, Maud & Mohsin, 2010). It is a process of greater integration within the world economy through complicated transnational economic and political processes that have restructured alignments of nations and regions which lead progressively to economic decisions being influenced by global conditions (Cushon, Muhajarine &

Labonte, 2010; Finn, Nybell & Shook, 2010; Mohindra & Labonte, 2010). Supporters of economic globalization claim that the economic growth of any given nation depends exclusively on the level of its integration into the world market (Canales Kriljenko, Jacome, Alichi, & de Olivera Lima, 2010). Then, when markets function without any restrictions, they will efficiently utilize all economic resources and automatically produce full employment and economic growth (World Bank 2009). According to this statement, poverty, unemployment and periodic economic crisis in the world today are the result of constraints implemented by unions, the state, and a host of social practices rooted in culture and history (Soleymani, 2010). Proponents of globalization argue that the only way to eradicate poverty is through economic growth and that economic growth will occur only when all nations participate in international trade to the greatest possible extent (Canales Kriljenko et al., 2010). Also, they argue that the benefits of economic globalization outweigh the risks; thus, nations become integrated into globalization hoping their economies will grow (Soleymani, 2010). Detractors of globalization claim that for developing nations increased participation in international trade forces a focus on exporting raw material and other basic commodities as the only products they can produce competitively on the global market thereby keeping these nations impoverished and unable to develop healthy and diversified economies (Oxfam International, 2010). Others frame globalization in terms of acceleration of social and environmental degradation and the main cause of the rising rates of poverty, unemployment, inequality and violence on a global scale (Finn et al., 2010; Holland, Malvey & Fottler, 2009; Soleymani, 2010). As well, within this current global context, an increasing number of people are becoming marginalized at an alarming rate due to global changes that lead to harmful effects on their health and social status (Hall, 1999).

To understand globalization and the processes through which global forces infiltrate local contexts, a number of scholars have focused on neoliberalism as the driving ideology and political strategy of economic globalization (Harvey, 2005; Navarro, 2009; Smith 2010, Bourdieu, 2007). The central tenet of neoliberalism is that human well-being is best advanced when individuals are free to apply their entrepreneurial skills and freedoms in a market economy (Harvey, 2005). This philosophy holds that the social good will be maximized by maximizing the reach and frequency of market transactions and so seeks to extend the market into all arenas of social life (Finn et al., 2010). Harvey (2005) argues that neoliberalism is a political project aimed to establish the necessary conditions for capital accumulation and to restore power among economic elites. Neoliberalism has brought devastating consequences, including the widening social disparities and the concentration of income and wealth among a few (Navarro, 2009). Harvey carefully distinguishes between neoliberalism in theory and in practice. In theory, neoliberalism places human dignity and individual freedoms as core political ideals. Individual freedoms, such as business and corporations which legally are considered individuals, should be guaranteed via private property rights, the rule of law and institutions enabling unfettered markets and free trade. These freedoms should eventually trickle down from the better off to the poor. In practice, the concept of freedom has been debased to advocacy of free enterprise–at any price—to the benefit of those who are already better off (Mohindra & Labonte, 2010). Also, neoliberalism is centred on the belief that private enterprise and individual initiative are the keys to the creation of wealth, the elimination of poverty, and the improvement in human welfare. Competition among individuals, communities, businesses, cities or nations, is seen as a primary virtue under neoliberalism. Therefore, under neoliberalism social insurance, welfare, public education, and social services are viewed as economically and socially expensive obstacles to maximizing economic performance and productivity (Ferguson, Lavalette & Whitmore, 2005). The responsibility of deficiency, or deviance, is argued to be located in the individual (Harvey 2005).

To date the opportunities resulting from globalization are asymmetrical due to the imposition of the neoliberal model. Inequalities have risen significantly since the early 1990s as the result of increasing concentration of income, resources and wealth both between and within nations. As well, economic changes have slowed health improvements, particularly in low income countries, due to growing health care inequalities. The gap between the poorest and the richest groups is growing in all nations. Wealthier groups are increasingly healthier and living longer whereas poorer groups have higher rates of illness and are dying at a younger age. Globalization has affected health in several ways; one of the ways is through the impact on the structure and functioning of health care systems and its effects on access to health care (Chapman, 2009; Semin & Guldal, 2008). The core of a healthy and egalitarian society is an effective health system. According to the World Health Organization Commission on Social Determinants of Health (2007), in order to achieve national and international goals—including the Millennium Development Goals (MDGs)—it is necessary to invest in health services and systems. Throughout the world, nations are looking for ways of doing more with existing resources. Governments are seeking innovative ways to create innovative health systems with the help of communities, non-governmental organizations (NGOs) and the private sector. However, there is no guarantee the poor will benefit from reforms unless they are carefully designed with this end in mind (Navarro, 2009). Yet, neoliberalism perceives health care systems as commodities where productivity and economic growth are the sources of potential revenue. In neoliberalism, health systems cannot be seen as public and social goods. Institutions like the World Bank promote health care systems with a market-oriented concept in which reductions in public sectors, the introduction of user fees and other costs reduce the access to health care for the poor. Therefore, globalization has been associated with the weakening of the health systems in middle- and low-income countries (Chapman 2009). According to the WHO (2007a), health systems in too many countries are on the point of collapse, or are accessible only to particular groups in the population.

Translation of neoliberal ideologies into the health arena has brought a new policy environment that emphasizes the need: first, to reduce public responsibility for the health of populations; second, to increase choice and markets; third, to transform national health services into insurance-based health care systems; fourth, to privatize health care; fifth, to create a discourse in which patients are referred to as clients and planning is replaced by markets; sixth, for each individual to be responsible for her or his own health improvements; seventh, to see an understanding of health promotion as behavioural change; and eighth, for people to increase their personal responsibility by adding social capital to their endowment (Navarro, 2009). In this economic and social order, states lose their power and are replaced by a new, world-wide market-centred economy based on multinational corporations which are presumed to be the main units of activity in the world today (Holland et al., 2009; Mohindra et al., 2010; Navarro, 2009). These changes have systematically benefited some groups at the expense and detriment of others (Finn et al., 2010; Soleymani, 2010). For example, the World Trade Organization's (WTO) Agreement on Trade-Related Aspects of Intellectual Property Rights (TRIPS) demands that all members introduce patent protection on medication, thereby not allowing generic competition and tending to drive up the prices of medications (Chapman 2009; Semin et al., 2008). Thus, public interventions have benefited some classes at the expense of other classes, some races at the expense of others, one gender at the expense of the other, and some countries at the expense of other countries. Lately, worldwide, we have witnessed an increase of class as well as gender, race, and national tensions among groups as a result of heightening inequalities.

Neoliberalism is the ideology of dominant classes in the North and in the South. Health reforms and privatization are class polices, because they benefit only high-income groups at the expense of middle- and low-income classes (Chapman 2009; Navarro, 2009; Semin et al., 2008). However, class analysis has been dismissed from the political and scientific discourses. But classes do exist. According to Navarro (2009), there is no such division of the world into the rich North and the poor South; this division ignores the existence of classes within the countries of the North and within the countries of the South. For example, 20 percent of the largest fortunes in the world come from wealthy groups of the so-called poor countries. In fact, "The wealthiest classes in Brazil, for example, are as wealthy as the wealthiest classes in France. The poor in Brazil are much poorer than the poor in France, but there is not much difference among the rich" (Navarro, 2009, p 428). What the world has witnessed in the last 30 years is an alliance between the wealthiest people of the North and the wealthiest people of the South to support neoliberal policies that benefit only them and exclude and oppress the poorest people in both North and South (Navarro, 2009).

The Social Determinants of Health in the Current Global Context

Currently, we witness how good health and life expectancy continue to grow in parts of the world while in other nations it fails to improve (CSDH, 2008). There are dramatic differences in health between and within countries that are closely linked with degrees of social disadvantage. These avoidable inequalities in health arise because of where people live, work and age, and because of the systems put in place to deal with illness (Dahlgren & Whitehead, 2006). The conditions in which people live and die are shaped by social, political and economic forces (Labonte & Schrecker, 2007). For example, today a newborn girl can expect to live more than 80 years only if she is born in certain countries and within certain financial circumstances, but less than 45 years if she is born in other countries and with less favoured financial circumstances (WHO, 2008a). Globalization is considered to influence health status and the determinants of health in important ways (Cushon, Muhajarine & Labonte, 2010; Mohindra et al., 2010). Global processes influence the determinants of health. Thus globalization has brought about diverse changes in both health determinants and related health outcomes. As a result the importance of health issues is increasing. Changes in the drivers of disease are brought about not only by economic changes, but also by changes in the social, political, and environmental domains at local, regional, and global levels. Health is embedded in the process of globalization (Martens, Akin, Maud & Mohsin, 2010). In fact, economic and social policies have a deciding impact on whether individuals grow and develop to their full potential and live flourishing lives or whether their lives will not be prosperous (Baum, 2008; Dahlgren et al., 2006).

Worldwide the poorest of the poor have high levels of illness and premature mortality. And yet poor health is not limited to those worse off; at all levels of income health and illness follow a social gradient: the lower the socioeconomic position, the worse the health. The huge gap in health between and within countries is a matter of social justice. Social injustice is killing people on a grand scale. The health of the poor, the social gradient in health within countries, and the marked health inequalities between countries lead to unequal distribution of power, goods, income and services, locally, nationally and globally. As a result, injustice in the immediate, visible circumstances of people's lives, adversely affects their access to health services and education, their conditions of work and leisure, their home, communities, cities or towns and their chances to live a flourishing life (Navarro, 2009). This unequal distribution of health care is not a natural phenomenon; instead, it is the result of social policies and programmes, unfair economic arrangements, and politics. Together, the structural determinants and conditions of daily life constitute the social determinants of health which are responsible for most of the health inequalities between and within nations (CSDH, 2008; WHO, 2008a).

Throughout the 1980s and 1990s, a package of neoliberal economic reforms, called the Washington Consensus, began to challenge the global development consensus achieved in the aftermath of the Second World War, enforcing a radical form of market fundamentalism on middle- and low-income nations (Fox & Meier, 2009). Reforms organized by the International Monetary Fund (IMF), the World Bank, or trade agreements in exchange for loan-based debt assistance obliged most nations to implement economic reform strategies that included marketization, liberalization, privatization, and decentralization with the aim to free these nations from excessive state intervention. The commitment to health equity is not new. In 1978, an overarching consensus among a number of nations created the Alma Ata Declaration on Primary Health Care; this declaration recognized the necessity of equitable socioeconomic development in order to build sustainable, comprehensive primary health care systems in middle- and low-income countries. Yet, today, despite progress toward that goal, millions of people die or become disabled from causes that are easily preventable or treatable (Labonte et al., 2007). However, parallel to neoliberalism was the beginning of selective primary health care, known as the GOBI (Growth-monitoring, Oral-rehydratation, Breast-feeding, and Immunization) approach to global health. Consequently, the broad horizontal vision of primary health care was interchanged by a contemporary GOBI approach to health which emphasized narrow and vertical intervention that fails to create the underlying conditions necessary to bring about sustained improvements in public health outcomes (Fox et al., 2009). The Alma Ata Declaration included primary health care as a pathway to expand health services worldwide; however, under this declaration health inequities and social determinants of health were not considered (Martin & Peterson, 2008). In 2005, the Montevideo Declaration made the problems associated with primary health care a priority in order to understand the local determinants of health, local health care needs and the local health inequities outcomes (Iqbal & Chambers, 2009). However, progress toward health for all has continued to be uneven (Sanders, Baum, Benos & Legge*,* 2009). To improve health and social conditions for *all* populations, it is necessary to recognize that health policies and health promotion efforts will not be equally effective across all contexts and cultures (Richmond & Ross*,* 2008). The complexity to reduce health disparities requires the involvement of different actors in government and civil society (Reutter et al., 2010). An awareness of and sensitivity to social conditions are crucial to understanding the health status of populations (Dahlgren et al., 2006).

Health must be considered as a matter of social justice because health and the social determinants are issues of human rights; consequently, equitable distribution of resources is thought to be the best approach for good health care (Kelly, Bonnefoy, Morgan & Florenzano, 2006; WHO, 2008b). To deal with unfairness and injustice it is necessary to attend to the underlying societal causes of disparities (WHO, 2008a). The aim of governments is not to eliminate all health differences, but rather to decrease to the lowest level possible or eliminate those which result from factors avoidable and unfair (CSDH, 2008; Dahlgren et al., 2006; WHO, 2008a, 2008). In theory, this aim is a good one; however, in reality, minorities have to face restrictions and the governments are controlled by external forces that make it impossible to control the widening gap. Thus, instead of well-being for all, market competence becomes the priority for governments and, coupled with globalization, has direct and indirect effects on health. The direct effects of globalization on health are related to the impact on health systems, health policies and the exposure to hazards such as tobacco marketing. The indirect effects are related to trade liberalization and the availability of resources for public expenditure on health with its resulting effects on living conditions and household income (Labonte et al., 2007; Navarro, 2009). Meanwhile, minorities continue to expose themselves to risky behaviours and struggle with a lack of continuing treatments, lack of money to pay for care and, as a consequence, live with uncontrolled illnesses and functional limitations. States need to look for quality of attention toward human beings, need to change the concept in capitalism of the creation of wealth as equivalent to eliminating inequality and to understand that health inequities always have moral and ethical dimensions (Kawachi et al., 2002; Whitehead, 1992). Hence, international and national responses toward social determinants of health must be rooted in ethical values and principles to avoid exploitation and marginalization of vulnerable people.

Health care system in Colombia

In Colombia, Law 100 set the legal framework for a national health insurance system projected to increase insurance coverage from 20% to 100% by

2001 and guarantee the right to a basic package of services through a *Mandatory Health Plan* (POS) for all Colombians (Homedes & Ugalde, 2005). The health system was changed as a part of wider state reforms and also as a consequence of external neoliberal pressures; its programs and interventions address external priorities at the expense of integrated approaches that incorporate internal realities such as the social determinants of health (Homedes et al., 2005). The main goal of this reform aims to integrate the social security and public sectors in order to create universal access, and at the same time to generate market-competence with the objective of improving effectiveness and responsiveness (Yepes, Ramirez, Cano & Bustamante*,* 2008). This health reform is based on nine key principles: equity, universality, solidarity, efficiency, quality, and responsibility, respect for cultural and ethnic diversity, community participation and effective integration—all of them considered important to pursue well-being (Castaño & Zambrano*,* 2006). Despite its decentralized structure, the health system is directed, regulated, supervised, monitored and controlled by the national government and the Ministry of Social Protection, which dictates the government policies and plans, programs and priorities that serve as the foundation for territorial plans (Castaño et al., 2006; Yepes et al., 2008). According to Law 100, the Municipal budget must be distributed with 25% for health, 30% for education, 20% for potable water, 5% for physical education, recreation, culture, and sports, and the remaining 20% left to the discretion of the mayor or the community. In 2007, the Colombian government, through the Ministry of Social Protection, created the National Public Health Plan which deals with health promotion, disease prevention, rehabilitation and recovery from disease, surveillance of health, and the management of the development of the National Public Health Plan. The National Public Health Plan has been organized to complement and give direction to Law 100. This plan is focused on population, social determinants of health, and social management and development. The priorities of the National Public Health Plan are childhood health programs, sexual and reproductive health, oral health, mental health, communicable diseases and zoonosis, non-communicable diseases, nutrition and food safety, environment and sanitation programs, occupational health and management of the development of the National Public Health Plan (Ministerio de Proteccion Social, 2011). Colombia's current health care system covers only

89% of the population. Yet, the expansion of coverage has raised some questions of equity as Colombians employed in the formal sector have access to more benefits than low-income Colombians do (Tsai, 2010). Health care, then, becomes in capitalism a business like many others, except that with health care the merchandise is human beings. This commercialization changes the scale of human values; compassion, respect, and equality are low priorities because they do not produce economic reward (Smith, 2000). Thus, despite the ethical issues, health care is a victim of global disparities and economical progress.

Colombia's health reform has been widely criticized because the goal of universal coverage by the year 2001 was not achieved. Indeed, the financial sustainability of Colombia's health system was threatened by the economic recession of 1998 (Alvarez, 2005; PAHO, 2005). High rates of unemployment, underemployment and the informal job sector frustrated the projections of universal coverage made in 1993 (Homedes et al., 2005; PAHO, 2005; Restrepo & Valencia, 2002). Competence among the public and private sectors was another point of criticism of the new reform (Yepes, et al., 2008). Under the health reform, old public hospitals become State Social Enterprises or Empresas Sociales del Estado (ESE) with decentralized resources and autonomy adjusted to compete with private hospitals in order to guarantee their survival in the market (Homedes et al., 2005; McPake, Yepes, Lake & Sanchez, 2003; PAHO, 2005). However, old infrastructure and technology, lack of resources and administrative preparation to face the competition of private hospitals forced some of them into bankruptcy (Castaño et al., 2006; Homedes et al., 2005; PAHO, 2005; Restrepo et al., 2002).

Finally, financing catastrophic or high-cost conditions such as organ transplants and chronic conditions have also threatened the financial stability of Colombia's health system (PAHO, 2005). To this end, the health system for the chronically ill presents itself as unequal and discriminative, far away from the principles of equity, efficiency and universality that it promotes. Also, the health system lacks preparation for the social reality of Colombia, which is experiencing typical changes of transitional societies such as aging population, decreasing fertility, rapid urbanization, and the persistence of infectious diseases with concomitant increasing of chronic conditions (PAHO, 2005; Rodríguez-Monguió & Infante, 2004). For the chronically ill, this health reform is a mirror of how as human beings we reduce one another to numbers and physical conditions for the sake of economic profit. The Colombian health system promotes universality and access to health care; under these health care principles, citizens are supposed to be provided with preventive and curative care. However, in reality, the Colombian chronically ill face restrictions and sometimes lack in their access to health care. Minorities struggle and expose themselves through risky behaviours, lack of continuing treatments, and lack of money to pay and, as a consequence, uncontrolled presence of illness and in some cases functional limitation.

Health care system in Canada

Canada's health system, known as Medicare, is administered by ten provincial and three territorial health insurance plans. It is mainly funded through federal and provincial taxes, administered mostly publicly, and delivered in some provinces or territories privately (Health Canada, 2005). However, the federal funding for Medicare is only provided if the provincial and territorial health insurance plans meet the five criteria put forth by the federal government in the Canada Health Act, the federal legislation for publicly funded health care insurance. The Act sets out the primary objective of Canadian health care policy, which is "to protect, promote and restore the physical and mental well-being of residents of Canada and to facilitate reasonable access to health services without financial or other barriers" (Health Canada, 2007, p. 1). The five criteria are universality, accessibility, comprehensiveness, portability and public administration. Under these guidelines Canada's government aims to ensure that all residents of Canada have access to health services on a prepaid basis, avoiding charges at the point of service (Health Canada, 2007). The system works with three health care services—primary service, secondary service and additional services. Primary service provides the first contact with health services and it also ensures continuity of care through referrals to specialized services, easing the movement across the health care system. Secondary service is used when a person is referred for specialized care at a hospital, a long-term care facility or a service in the community. Most of the hospitals in Canada work with the help of community boards of trustees, voluntary organizations or municipalities. Consequently, hospitals are funded by annual and global budgets negotiated with ministries of health or regional boards (Health Canada, 2005). In community settings, health care services are provided by short-term institutions and long-term facilities for chronic care. Most of these services are not covered by the Canada Health Act; however, all the provinces and territories fund certain kinds of home services, and long-term services are covered by provincial and territorial governments. In 2006, these public services accounted for 70% of health spending (CIHI, 2007). Additional services such as medications, dental care, vision care, as well as medical equipment and appliances are not covered by the public health care system. People who require additional services must pay personally or through private health insurance plans that usually are covered at least in part by employers. In 2006, in Canada, this private system accounted for 30% of health expenditures (CIHI, 2007).

However, despite Canada's health system organization, in which there are no direct costs for medical and hospital services, the presence of barriers in the health system makes it difficult for many individuals to access health care professionals, thus developing vulnerabilities within minority populations (Reutter et al., 2010). These disparities are produced mainly by a lack of communication skills in the official languages, lack of culturally sensitive care, longer waiting time periods and, for a variety of other reasons, limited access to health care service (Reutter et al., 2005). In Canada, to reduce social and health inequities, many programs and services have been organized, but, despite these efforts, certain trends for vulnerable communities continue to raise concerns (Butler-Jones, 2008; Raphael, 2009). Canada ranks fourth on the Human Development Index, (UN, 2009); however, rural Aboriginal reserves in Canada rank 68th and Aboriginals residing elsewhere in Canada rank 36th (Webster, 2006). In Canada, disparities in the health status of Aboriginal communities in relation to non-Aboriginal Canadians have been well documented (Buxton et al., 2007; Gracey & King, 2009; Reading & Wien, 2009).

Another barrier to accessing health care in Canada is geography: remote areas, especially aboriginal communities, have poor or ineffective primary care (Shah, 2003). In rural and remote areas of Canada, residents have access to only a small range of services thus leading to poor health conditions (Raphael, 2006, 2009). Such barriers are responsible for the presence of disparities and inequalities among Canadians. In fact, the presence of disparities in Canada for Aboriginal groups, women and, most recently, the homeless has been censured by the United Nations (Raphael, 2009; Raphael, Curry-Stevens & Bryant, 2008).

In 2005, 2.8 million Canadians 15 years of age or older visited a medical specialist and from among them, 19% reported difficulties accessing care. Similarly, 1.6 million Canadians used the surgery service and among them 13% reported difficulties accessing care. As well, 2.2 million Canadians 15 years of age or older required diagnostic tests and among them 13% reported difficulties accessing the service. Among those who experienced difficulties accessing a specialist, 68% indicated waiting time as the main problem followed by 32% who reported difficulties getting an appointment (Statistics Canada, 2006). Most of the time people who reported difficulties receiving health care when it was needed were more likely to have lower income, lower education and suffer from chronic conditions (Kasman & Badley, 2004). Thus, issues related to access to health care, geography, gender and race create disparities and build barriers for vulnerable people and expose them to risk factors and unhealthy life styles. For the federal government, access to health care is considered a top priority. In 2004, First Ministers agreed to develop a ten year plan to improve access and reduce waiting times in areas such as cancer, heart disease diagnosis, imaging, joint replacement and sight restoration. Indeed, the Canadian government committed to spend $4.5 billion over the next six years, beginning in 2004-2005, in the waiting times reduction fund. Little is known about the effects of waiting times on the health and well-being of users (CIHI, 2007; Health Canada, 2007; Statistics Canada, 2005). If health systems and its services are considered to be key to impact on the predisposition of individuals, families, societies and countries to illness, as well as the way all of them experience and recover from illness, and if policy fails to address this fact, then governments are ignoring one of the social determinants of health and they are exposing their citizens to exclusion, insecurity and deprivation. Thus, in Canada's publicly funded health service, inaccessibility to health care leads to social exclusion and marginalization for minorities; it means that the government at federal, provincial and territorial levels must improve access to and control quality of health services instead of assuming that accessibility and universal services provided by law are equitable in practice.

Understanding the Global Dimension of Being Chronically Ill

Until recently, infectious diseases were the main cause of death worldwide. Due to new medical discoveries and the evolution of public health, life expectancy and the ability to survive acute threats improved, thus changing the course of diseases from acute to chronic (Atkin, Stapley & Easton, 2010), Globally, chronic diseases are a major problem and they are a barrier to development and to alleviating poverty (Daar et al., 2007; WHO, 2005a). In low- and middle-income countries, chronic diseases are the major cause of premature death and reduced quality of life. In these countries the epidemic of chronic diseases is such that in some cases it is overtaking the epidemic from infectious diseases. The epidemic of chronic disease threatens not only economic and social development of nations but also the lives and health of millions of people worldwide (PAHO, 2009; Strong, Mathers, Epping-Jordan & Beaglehole, 2006; WHO, 2005b, 2008b). Chronic diseases, including cardiovascular diseases (CVDs), diabetes, obesity, certain kinds of cancer and chronic respiratory diseases, account for 60% of the 58 million deaths annually. This corresponds to 35 million deaths worldwide in 2005 from these diseases. Of those deaths caused by chronic diseases 80% will occur in low- and middle-income countries. In 2005, regional data estimations indicate that chronic diseases accounted for nearly 78% of all deaths in the Americas; 86% in the European Region; 78% in the Western Pacific Region; 54% in the South-East Asian Region; 52% in the Eastern Mediterranean Region; and 23% of the African Region (WHO, 2008b). In 2005, in Colombia, chronic disease accounted for 62.6% of the total of all deaths. The leading cause of death among chronic diseases was cardiovascular with 46.9%, followed by cancer at 22.9%. Chronic respiratory diseases were responsible for 10.7% of those deaths, and diabetes for 6.3% (Ministerio de Proteccion Social, 2008). This data reinforces the fact that the burden of chronic disease is highly prevalent worldwide regardless of a nation's overall economic status (WHO, 2008b).

This threat has been described extensively by the World Health Organization (WHO), Pan-American Health Organization (PAHO) and other agencies; however, heads of state from high-income countries, private foundations, IMF, the World Bank, and regional banks, and NGOs have mobilized resources and attention towards only infectious diseases in low- and middle-income countries while ignoring chronic illness (Colagiuri, Colagiuri, Yach & Pramming, 2006; Yach, Kellogg & Voute, 2005). How is poverty going to be eradicated from the world if chronic disease is the first cause of morbidity and mortality worldwide does not have a place on the health development agenda? Is this limitation in place because, for example, we think more people die from malaria as a separate entity than from diabetes, COPD, or cardiovascular disease worldwide? Comparing the proportion and the distribution of malaria and cardiovascular diseases or diabetes alone, shows clearly how the politics of health have not been focused on realities. In 2005, cardiovascular disease (CVD) accounted for 17. 5 million deaths as the leading cause of death globally (WHO, 2005a). By contrast, among the infectious diseases, 2.8 million deaths were from HIV/AIDS, 1.6 million from tuberculosis, and 0.8 million from malaria; these three diseases combined account for 3.3 times fewer deaths than those from cardiovascular disease (Fuster, 2006). In fact, despite chronic diseases being the greatest contemporary health challenge in the world, policies to deal with them are not strong enough to fight their magnitude worldwide (Quam, Smith & Yach, 2006). In the Millennium Development Goals (MDGs), health is related specifically to three issues: reducing child mortality, improving maternal health, and combating HIV/AIDS, malaria and other diseases (WHO, 2005b). There is no pertinent representation of chronic diseases in the UN's MDGs. Chronic diseases are being ignored by policy makers and development agencies, and limited funds mean limited action to address prevention and control. The MDGs were developed to reduce poverty and promote health in low and middle income countries, and should be reached by the year 2015 (Boyle, 2006; Fuster, 2006; Magnusson, 2007).

Despite the recognition of a linkage between health and economic development, it is worrisome that these health goals are so narrowly defined and fail to include preventive strategies to control chronic diseases (Boyle, 2006; Quam et al., 2006). Several myths have probably led to the neglect of chronic diseases. Many people still believe chronic diseases are the result of self inflicted unhealthy lifestyles. But in fact, chronic illness is a bigger problem in low-income populations because they do not have the resources to pursue healthy choices. Another myth is that little can be done about chronic disease; however, deaths from heart disease have decreased by up to 70% in the past three decades in Canada, Australia, Japan, United Kingdom, and United States. Fifty percent of deaths by chronic diseases are attributable to modifiable risks, including tobacco use, unhealthy diet, and raised blood pressure (WHO, 2005a). According to

Quam et al (2006), “the current Millennium Development Goals are appropriate for the poorest billion people in the world, but action is needed to better manage chronic disease for the 4 billion people living in… low-to-middle income countries” (p. 1221). Low and middle income countries are the global engines of growth. Thus, an epidemic of chronic diseases in these emerging economies not only threats their productivity and financial stability but also affects households. Worldwide, the expectation is that the same international founders of action against infectious diseases would start supporting a broader range of health issues like chronic diseases. Yet, realistically it is unlikely that those funders will provide full support for programs on chronic disease when the pressure for investment is focused on the needs of the poorest nations (Boyle, 2006; Fuster, 2006; Yach et al., 2005). There is some sort of support for specific areas like tobacco-control programs, but different approaches are needed to find new sources of investment. Prevention seems to be the major strategy to combat chronic diseases (Colagiuri et al., 2006). Inexpensive and cost-effective interventions can prevent 80% of cardiovascular diseases, type 2 diabetes and 40% of cancers (WHO, 2005b).

The main risk factors contributing to the increasing number of deaths from chronic diseases are unhealthy diet, physical inactivity, and tobacco use. Unfortunately, in chronic disease the ability to prevent, control, and treat does vary according to the ability to pay (Strong et al., 2006). Those who do not have the economic resources to pursue healthy choices suffer more. In low- and middle-income countries the cost of chronic diseases is high and often patients’ assuming those costs contributes directly to family poverty. Why? Perhaps the answer dwells in the fact that globalization has changed many features of modern life, including diets. Worldwide trade changes diets, and although food becomes more secure, the reliance on imported food, and the influence of food marketing drive up consumerism and drive down nutrient density (Boyle, 2006; Quam et al., 2006; Yach & Beaglehole*,* 2004). Globally, 11% of global trade is in food, an activity which has lead toward a profound relationship between income and fat consumption. The tobacco industry is another example of the dark advance of global trade markets in the developing world. It took decades to make people aware of the catastrophic consequences of smoking, but when it did, American tobacco companies moved overseas. Then, tobacco companies in countries such as China saw the potential as well and, hence, smoking rates, like rates of obesity, have been increasing in China and in other countries such as Indonesia, Botswana and Uruguay. By 2015 the number of smokers is expected to increase by 45% and by 2030 the estimated number of deaths attributed to smoking will increase from 4 to 10 million. The epidemic simply has migrated from one side of the world to another (Brownell & Yach, 2006). Thus, the burden of chronic diseases is the result of past and cumulative risks. The major risk factors for chronic diseases are more complex than those of infectious diseases; as well, they are well known and they account for almost all such events (Boyle, 2006; Magnusson, 2007; Yach et al., 2005).

Globalization directly affects the worldwide health status and lifestyles of citizens through advances in communication and the widespread use of the internet (Parker & Thorson, 2009). On the positive side, these technologies can be used as a way to disseminate health promotion. However, the greatest effects on health are mostly negative, i.e. it is already widely acknowledged and probated that several behavioural factors such as unhealthy diet, smoking, physical inactivity, alcohol misuse and illicit drug use are due to the influence of the media. In the current era, obesity is a global issue which cuts through all economic, cultural, social and political barriers. It affects both developed and developing countries. In 2004, in Canada, the economic burden of physical inactivity was $5.3 billion ($1.6 billion in direct costs and $3.7 billion in indirect costs) while the cost associated with obesity was $4.3 billion ($1.6 billion of direct costs and $2.7 billion of indirect costs). The total economic cost of physical inactivity and obesity represented 2.6% and 2.2%, respectively, of the total health care costs in Canada (Katzmarzyk & Janssen, 2004). In Bogota, the capital of Colombia, low consumption of fruits and vegetables, tobacco use, and physical inactivity are public health concerns. Women in Bogota are less physically active, 61.9% compared to men at 56.2%; however, 38.6% of men smoke compared to 19.1% of women (Lucumí, Sarmiento, Forero, Gomez & Espinosa, 2006). Regardless of this data, there are no reports on the economic burden for physical inactivity in Bogota; however, the estimated loss is 2.5% of Bogota's total budget (Secretaria de Salud de Bogota cited by Lucumi et al., 2006).

Through the rules of economic globalization and the World Trade Organization (WTO), trade can be regulated and also can improve population health status by increasing national incomes. But in reality, the poorest nations and people have not experienced this benefit. Global rules and power imbalances constrain nations to respond adequately to the health needs of their peoples. Although states can modify international trade rules, their influence has been restrained due to the lack of resources, expertise and technical support (Magnusson, 2007; Yach et al., 2005). According to Yach et al (2004), globalization has affected the development of chronic diseases directly and indirectly. The indirect effects of globalization are the result of national economic performance and act through changes in household income, the exchange rate, price, and government expenditure. Among them, national income is particularly significant because of its effects on public sector resources available for health and on household health-related behaviours—in particular in low-income families. The direct adverse health effects are related to the increasing globalised production and marketing of tobacco, alcohol, and unhealthy diets. Protection of domestic producers by many high-income nations and their regional organizations, impacts on chronic diseases. For instance, the European Union (EU) and the United States agricultural subsidies limit competition from primary producers of fresh produce in low- and middle-income nations and seriously reduce these nations' national incomes (Magnusson, 2007; Yach et al., 2005).

Chronic diseases have a negative economic impact. In the next 10 years, China, India and the United Kingdom are projected to lose $558 billion, $237 billion, and $33 billion, respectively, in national income as a result of reduced economic productivity due to chronic diseases. Longer lifespan, tobacco use, obesity, decreasing physical activity, and consumption of unhealthy food are in great part responsible for the increasing burden of chronic disease worldwide (Daar et al., 2007). Once chronic illness develops within a society, it becomes a trigger for disparities and inequalities. At the same time, poverty and exclusion increase the risk of developing a chronic illness (WHO, 2005a). And behind all of this, economic policies feed rather than interrupt the circle of illness, poverty and disparity. For example, the World Bank, in loans for health to developing world, provides only 2.5% of the budged for chronic illness (Quam et al., 2006; Yach et al., 2004). A healthy population is not an automatic by-product of economic development, but it can drive economic growth. Good health is an important determinant of economic productivity, and declining mortality from chronic diseases is associated with very high levels of social and economic development (Brownell & Yach, 2006; WHO, 2008b). For countries, the cost of chronic diseases and their risk factors range from 0.02% to 6.77% of countries' GDP. In high-income countries the total cost of cardiovascular disease (CVD) varies between 1% and 3% of GDP (Suhrcke, Nugent, Stuckler & Rocco, 2006). For example, in 2005, in Canada, the estimated loss in national income from heart disease, stroke and diabetes was $80 billion per year (Chronic Disease Prevention Alliance of Canada, 2006). Economically, Canada lost $500 million in national income from premature deaths due to chronic diseases such as heart disease, stroke and diabetes. These losses are projected to increase through time to approximately $9 billion over the next 10 years (WHO, 2005b). Furthermore, we can expect costs to rise since chronic conditions such as heart disease, cancer and diabetes--those typically associated with heavy utilization of health resources--are progressive in terms of monitoring of the situation (Daar et al., 2007).

On the other hand, in 2004, the cost of renal failure in Colombia was equivalent to the 2.49% of the budget for health of the nation for a population equivalent to 0.034%. In December 2004, the average cost of one session of haemodialysis was $218, 000 Colombian pesos, approximately US $91. Monthly, the cost was $2,842,000 Colombian pesos or US $ 1,184 per patient. In the same year there were 13,347 patients with renal failure with a reported annual cost of US $188,222,976 and 467 renal transplants were made at a cost of US $5,642,761. The annual cost of post-transplant follow-up was US$ 3,509,596 for 2,184 patients. The total cost of chronic renal failure for that year in Colombia was US $197,375,333, money that would have helped to restructure 10 hospitals in Colombia (Gomez Velez, 2006). Thus, despite the alarming socio-economic situation of chronic illness throughout the world, it has not had the necessary attention to prevent or control it.

Chronic diseases have many economic and social consequences for people who are affected by them. In fact, frequent medical visits, medications, symptom management, the risk of acute and major events, expensive procedures such as revascularization, hemodialysis or angiographies, and lost productivity due to chronic illness and related risk factors may impose a substantial economic burden on household economies (Sasser et al., 2005; Suhrcke et al., 2006;

Trogdon, Finkelstein, Nwaise, Tangka & Orenstein, 2007). According to the WHO (2005b) the poor are more vulnerable to chronic diseases because of material deprivation, stress and unhealthy life styles resulting from lack of knowledge or lack of resources. Once chronic disease strikes the poor, they are more likely to suffer adverse consequences. Sometimes they are forced to sell all their possessions in order to attend to their health care. In the short-term it helps to cover the emergency, but what happens later? Such people through time end up without any resources and are driven into complete poverty. If policy fails to address poverty, it not only ignores the most important determinant of health, it also ignores the most important social justice issues facing the world today (Raphael, 2009; Reutter et al., 2010).

Chronic conditions are situations that swing back and forth between control and uncontrolled periods of illness, and most of the time, due to the lack of resources, chronic diseases are attended to when it is too late. In other cases, the fact that an adult family member has a chronic disease can also have direct consequences for children, especially when they have to drop out of school because they need to get a job in order to improve the family's economy (WHO, 2008b). Then, chronic diseases also affect labour productivity and labour supply. As Suhrcke et al (2006) say, "The theoretical underpinning of these effects stems from the concept that healthier individuals can produce more output per hour worked… because healthy people have better physical and mental capacity" (p.24). People with chronic illnesses are more likely to face unemployment due to their productivity limitations, cost of their disabilities and stigma (Suhrcke et al., 2006). As an example, in Colombia, disability decreased male rural earnings by 32% and female earnings by 13% and for urban areas it decreased the earnings of males by 28% and by 14% for females, (Ribero & Nuñez, 1999; Suhrcke et al., 2006). To address chronic diseases it is necessary to develop a multilevel-multisectoral public health approach. A multisectoral approach should include not only states, non-governmental organizations (NGOs) and private sectors, but also civil society, and academic and research institutions. Actions must start at all levels from health promotion to primary, secondary, and tertiary care (Barcelo, 2006). Thus, chronic conditions affect production, investment and consumption patterns. However, chronic conditions are prevalent and solutions cannot wait. Everyone affected or at risk should turn their attention towards prevention and control. Creating a consciousness within a population makes it possible to prevent these diseases from advancing.

Understanding the text of chronic illness in the South

Writing about chronic illness in the South. The text of the South is eloquent and rich in describing the experience of being chronically ill in those nations. With a huge range of cultural, historical, social, political and economic diversity, the South portrays the experience of being chronically ill as a unique experience with all the beliefs, thoughts, values, social support and other characteristics of each human being (Guerra Guerrero, Díaz Mujica &Vidal Albornoz, 2010; Schneider, Manabile & Tikly, 2008). Studies from low- and middle-income countries document chronic illness as a significant experience that needs to be explored more in the healthcare area so that health care professionals can provide the necessary support and offer adequate nursing care to their patients (Soares Sarlo, Ribeiro Barreto & Moreira Domingues, 2008). Worldwide, chronic illnesses demand new and different approaches from those currently offered, since these illnesses hinder the economical and social development of all nations. In that regard, the plethora of studies from low- and middle-income nations offers a unique perspective on chronic illness, and also it provides a venue to engage high-income nations in this global issue and mobilize efforts toward this area of great need. In this section, I present a number of studies from low- and middle-income countries oriented toward the experience of chronic illness in those nations.

Araujo Sadala and Groppo (2008) explore through a phenomenological study what the heart transplantation experience is according to patients' descriptions in Sao Paulo, Brazil. Heart transplantation represents a possibility to survive and improve the quality of life for many people with heart failure. Studies to date have shown how quality of life is related to patients' increasing awareness and participation in the work of the health care team in the post-transplant period. Lower adherence to the postoperative regimen is the result of deficient relationships and interaction between health care providers and patients. Three categories emerge from data: first, the time lived by the heart recipient, a category that addresses the time lived by patients in the final phase of heart failure; second, donors, family and caregivers; and third, reflections on the experience lived. Overall, life after a heart transplant means living in a complex situation that involves lifelong immunosuppressive therapy associated with many side effects. Some participants feel healthy whereas others report persistence of complications as well as the onset of other pathologies. In general, all participants were happy for the improvement in their quality of life. The support of health care providers, family and friends was essential to overcome their disease and, later, their transplant. However, participants realize that life after heart transplantation is a continuing process demanding support and structured follow-up for the rest of their lives. Thus, each individual has unique experiences of the heart transplant process. They have to adapt and accept changes to go on living.

Pinto, Vieira and Nations (2008) present an anthropological study on the experience of living with chronic obstructive disease (COPD) for low-income individuals in the city of Fortaleza, Brazil. Findings of this study suggest COPD provokes subjective sensations, signs, and meanings. Breathlessness creates hardships and limitations in the daily life of these participants. Strategies to confront acute shortness of breath and low self-esteem include avoiding direct contact with the patient’s phlegm, quitting or reducing smoking, treating symptoms with popular body therapies or traditional medicines, remaining calm during the moments of crisis, rejecting imposed therapies, and relying on spirituality. According to this study, the experience and knowledge cannot be excluded from the objective perspective or the pathology when health care professionals work with COPD patients.

Bassanesi, Azambuja and Achutti (2008) investigate the relationship between early mortality by cardiovascular disease and socioeconomic conditions in the city of Port Alegre, Brazil through a cross-section ecological study. Findings of this study suggest that almost half of the mortality by cardiovascular disease before 65 years of age can be attributed to poverty. In fact, 62% of early deaths by cardiovascular disease could have been avoided if the respective population living in the low stratum had had the same socioeconomic conditions as population from the high stratum. The average number of years of education of the household head—an indicator of the exposure to risk--explained 61% of the distribution of mortality by cardiovascular disease among the different districts of the city. The presence of disease contributes to poverty and reduces competitiveness of the country. Thus, it becomes necessary to take action and develop strategies to reduce poverty with investments that end up in national economic development and improvement of the social conditions of the population.

Person et al (2008) present findings from qualitative research with women who have lymphedema, a mosquito-transmitted disease caused by a parasite, which often results in physically disfiguring and debilitating lymphedema of the leg. This study aimed to investigate how women with lymphedema experience stigma and its consequences in Ghana and Dominican Republic. A stigma framework was developed from literature and emerging themes from the data. This framework included enacted stigma, perceived stigma, and internalized stigma. In the enacted stigma, women of both countries reported being teased, shunned, marginalized, gossiped about, and discriminated against due to their condition. This inevitably led to labelling, public rejection, forced exclusion from social situations, and deferential treatment in educational and health care settings. Perceived stigma included expectations of discrimination, along with fear of and uncertainty about being marginalized and is mostly associated with other people's experiences of enacted stigma. The internalized stigma happened with increased visibility of leg disfigurement as the disease progressed. In this stage, women expressed devaluation of self and suffered from the absence of social interactions. The coping strategies are challenged when there is poverty, lack of access to health services, limited social support and limited education. Thus, this study suggests that lymphedema-related stigma is a social, cultural and moral process that needs to be explored further.

Chronic illness and family life in the South. These studies show how challenging life is for family members of someone who is chronically ill. Chronic illness is not a static or stable state. However, it cannot always be generalized as a bad state because chronicity can change family values, beliefs and goals for the better (Goulart, Garcia de & Andressa, 2009). There is a process of transformation in the family life. For family members, chronic illness transcends bodily experience or physical events of the one affected and it can cause the creation of bonds that keep a family together (Nascimento, Rocha, Hayes & Lima, 2005). The family is tied to the other, trying to figure out how to deal as a family with the whole situation. With chronic illness, family life loses its independence and experiences emotional despair for both the chronically ill and their family. Also, some of the literature deals with the development of nursing care models that are family and caregiver oriented (Barrera-Ortiz, Pinto-Afanador & Sanchez-Herrera, 2005; Barrera, Pinto & Sánchez, 2007; Fráguas, Soares & Silva, 2008). In this section, I present a number of studies from low- and middle-income countries that describe the worlds of families and caregivers of people who are chronically ill.

Robles Silva (2008) explores the caregiver trajectory among poor and chronically ill people in Guadalajara, Mexico. This ethnographic study develops a conceptual framework to understand caregiving changes over time. Caring for the elderly, the chronically ill or the disabled is not a static phenomenon, but a process that is gradual and ongoing. This study followed the trajectory framework of Corbin and Strauss which allowed the researcher to move away from a description of changes to focus on the dynamics of the transformation of caregiving over time, providing an insight into how the phases differ in timing, content, and transition. The trajectory of chronic illness has a beginning and an end, but also moves through three phases: semi-care, care and dying. Results of this study present an important contribution to the understanding of the process of providing care to the chronically ill. Being a caregiver has been depicted as an excess workload and explained by an ascending linear process that grows over time; however, though it is true that caregiving increases through time, the most intensive stage is not in the dying phase, but, rather, in the prior one. The identification of the phases in the trajectory of illness allowed the researcher to see that the workload was not a uniform process over time; it increased and fell depending on the phase and it is not continuous (Robles Silva). The phases of caregiving differ by the type and timing of actions developed, and the degree to which the caregiver takes over physical functions and social roles of the ill person.

Kendall-Taylor (2009) through an ethnographic approach explores how family members of children with seizure disorder decide to manage this disorder in Kilifi, Kenya. This study provides a unique opportunity to examine treatment seeking in the context of a chronic paediatric condition. Seizure symptoms are difficult to manage when they are recurrent in children who lack access to medical care. In children, seizure disorders require ongoing treatment and monitoring even when there are not symptoms. For these reasons, families of children with seizure disorder are forced to often re-consider their decisions to pursue or abandon treatments or search new options. This study emphasized cultural influences on the process of decision-making for families of children with seizure disorder. Also, family members' initial perceptions of effectiveness were based on their beliefs about the causes of the child's symptoms. However, after initial treatment was sought, the results of previous treatments became the primary consideration in evaluating treatment effectiveness. These results suggest that in chronic illness, choice was not determined by a single dominant factor. Additionally, family members used different standards to assess biomedical and traditional treatment options. For instance, symptom persistence after biomedical treatment was seen as a sign of treatment ineffectiveness; however, family members were hesitant to deem traditional treatments as ineffective. Results of this study suggest that the basis of making treatment decisions changed over the course of the child's illness as families gained more experience with treatment provided and the outcomes. A model was presented to summarize the decision making process. The model accounted for treatment seeking in families of children with seizure disorders in coastal Kenya but may also help explain how families manage other chronic conditions.

Montalvo Prieto and Florez Torres (2008) carried out a cross-sectional study to determine the characteristics of family members in charge of caring for their chronically ill relatives in Cartagena, Colombia. To determine the characteristics of the caregivers, researchers used the Characterization of Caregivers Inventory developed by Chronic Patients Care Support Group associated with the Faculty of Nursing at the Universidad Nacional de Colombia. Findings of this study suggest a higher proportion of female caregivers, something that is not unusual in the Colombian context. The average age of caregivers was 35 years. Most of these caregivers spent more than 18 months at 12 hours per day taking care of their chronically ill relative. Most caregivers had a lower, elementary school level of education. The socioeconomic status of these caregivers was lower, information that supports the findings in other studies. Most caregivers described caring for a chronically ill relative as a challenging, overwhelming and disruptive task. These feelings emerged from the lack of knowledge about the condition, depletion or lack of economic resources to provide adequate care, social stigmatization, discrimination and lack of support from other family members. For nursing, this study provides the opportunity to understand the context in which care is provided in Cartagena, Colombia.

Barrera Ortiz et al. (2006) present results from an ongoing study on the ability to care for chronically ill family members in Colombia, Argentina and Guatemala. This study emerged while working on an international project in nursing when similar difficulties in health care of chronically ill people were identified. Quantitative, descriptive and transversal studies were done and the Caring Ability Inventory developed by Ngozi Nkhongo was used to describe, analyze and compare how the caring ability presents itself when caring for chronically ill relatives. Similar findings were seen in the three countries. There were challenges and low ability in general in each of the components of the inventory. The proportion of women caring for chronically ill relatives was higher than the proportion of men. Most of the caregivers belong to the intermediate generation, The majority of caregivers were older in relation to the chronically ill, a factor which leads to developing strategies of health promotion for these people because they are the next generation in need of care. Also, most have been caregivers for a long period of time. The extent of the commitment and dedication of the caregivers was seen when comparing the ability to function of the chronically ill relatives. This study highlights the necessity to support and care for the caregivers of the chronically ill. Providing this support will help them to strengthen their knowledge and improve their ability to care.

Nursing care for the chronically ill in the South. This group of studies identify the most important care needs for chronically ill people. However, caring for the chronically ill literature has been focused on the evaluation of the nurses' role, follow-ups of nurses' interventions, implementation of self-management programs and shared decision making (SDM) programs that help the chronically ill deal with risky behaviours. Also, nursing research has centred its efforts on understanding the experience of patients with acute exacerbations of chronic situations such as COPD or cardiovascular disease, the attitude towards patient's expertise, the end-of-life planning and the nursing intervention to avoid the effects of social isolation as an important part of the care (Gutierrez Vilaplana, Samsó Piñol, Cosi Ponsa, Ibars Moncasi & Craver, 2007; Pulido Agüero, Arribas Cobo & Fernández Fuentes, 2008). These studies have addressed only specific aspects of the nursing practice, but despite that they are oriented toward specific areas, the findings are valuable to the development of nursing knowledge in the South.

Cardoso and Faleiros Sousa (2009) present results from four studies aimed at identifying and validating Brazilian pain descriptors. Specific tools to assess chronic pain are necessary because of cultural differences in the verbal expression of pain and the psychological problems that pain creates. Several assessment tools have been developed and used to assess pain in diverse cultural contexts. However, in the translation of those tools to other languages, many issues emerged. The main difficulty is that the pain descriptors have semantic connotations specific to a particular socio-cultural context and, during the translation from one language to another, all the semantic nuances of the original descriptors cannot be expressed. For those four studies, indirect and direct psychophysical methods were used: category estimation, magnitude estimation and line-length. Findings showed which ones are the best descriptors of chronic pain that best suit the Brazilian culture. This study demonstrated that the psychophysical scale of judgment of pain descriptors is valid, consistent and stable. Results reinforced the statement that translations of word descriptors and research tools may be inappropriate due to cultural differences in perception and communication, but also due to the inadequacy of exact translations to reflect the intended meaning.

Gau et al (2010) present results from a cross-sectional survey aiming to examine the clinical applicability of the World Health Organization Quality of Life Scale brief version (WHOQOL-BREF) to mothers of children with asthma and to compare the results of this questionnaire with the 2001 National Health Interview Survey (NHIS) data in Taiwan. Asthma is a prevalent and costly chronic childhood health condition in Taiwan. Due to social, economic, and medical development over the last few years, health improvements have been seen in Taiwan. However, instead of focusing on mortality or morbidity rates, the effectiveness of treatment is now evaluated by measuring health-related quality of life (QOL) as well as survival rates. To measure quality of life, the World Health Organization created the World Health Organization Quality of Life Scale brief version (WHOQOL-BREF) tool to be used in all contexts. Results suggest the WHOQOL-BREF showed acceptable psychometric properties to measure quality of life perceived by mothers of asthmatic children in Taiwan. Mothers’ quality of life was significantly affected by the burden of asthma care practices and stressors associated with their children's health problem. Thus, physical and psychological health aspects are the two domains impacting on quality of life of these participants who need more support and attention from health care professionals. Researchers suggest the necessity to do more research to compare quality of life measured by the WHOQOL-BREF in mothers of children with other chronic conditions.

Chaves, Carvalho, Terra and Souza (2010) identify and validate the defining characteristics of the nursing diagnosis of impaired spirituality using the methodological framework proposed by Fehring for the clinical validation of nursing diagnoses. The chronically ill constantly face complex situations that go beyond clinical aspects of their disease. They deal with the suffering provoked by difficult moments, and deal with rejection, guilt and other emotional struggles in the daily attempt to live in harmony with their health condition. Living with a long-lasting condition creates existential conflicts that can lead to spiritual anguish, which in turn aggravates the physical and emotional symptoms and the ability to cope with their condition. This study was carried out in a dialysis clinic. The research found that only 27.5% of patients had the nursing diagnosis of impaired spirituality showing that there was an important conflict in the spiritual dimension which could commitment their ability to deal with their renal disease. In the clinical context, 15 defining characteristics were validated, of which four were classified as primary and eleven as secondary characteristics of the nursing diagnosis of impaired spirituality. The application of nursing diagnosis in clinical practice requires nursing skills to investigate its defining characteristics. Further research on this nursing diagnosis is required in other populations.

Chronic illness is an overwhelming problem worldwide and is in need of new approaches. Soleimani, Rafii and Seyedfatemi (2010) explored the concept and nature of patient participation from the perspective of nurses, chronically ill patients and their families in Iran. This study used grounded theory as the methodology with the intention to explain the phenomenon from within the social situation and to identify the inherent process operating therein. It was intended that patient participation utilize the patient's capabilities in order to work as part of a team. However, patient participation changed over time depending on factors related to the caring agents, status of illness and nature of the relationship between nurse, patient and family. Participation occurred when nurses, patient and family worked together. The beginning of participation depended on the caring agents knowing and appraising each other. Patients and family members appraised the skills and behaviours of the nurses and the nurses assessed the patients' and family members' dedication and capabilities. To participate, it is necessary to trust; therefore, in this study, patients and family members were more likely to be open to participate with a nurse that they knew and trusted. This study suggested that nurses' positive attitudes toward patients' capabilities and their friendly relationship encouraged patient participation. Iranian patients with symptomatic chronic diseases were concerned about making mistakes in their care, so they preferred to take careful note of the nurses' advice and follow their recommendations. Hence, patient participation in the Iranian context is a dynamic process when patients, nurses, and family work together toward a common goal. The factors related to the caring agents and caregiving context could predict the level of participation.

Pellison et al (2007) apply nursing diagnoses and interventions based on the North American Nursing Diagnosis Association (NANDA) Taxonomy of Nursing Diagnoses and the Nursing Interventions Classification (NIC) on an adolescent with diabetes mellitus secondary to cystic fibrosis and her caregiver in order to provide guidelines for nursing care. The nursing interventions were based on the diagnoses of ineffective confrontation and stress syndrome due to alterations. The initial difficulty in using the NANDA, NIC decreased by the continued use of clinical reasoning; this led to support and promotion of a nursing plan aimed at addressing the real needs of this adolescent, resulting in the improvement of her health conditions. According to Pellison *et al.*, nursing diagnoses help nurses to develop effective nursing interventions that provide a framework for individualized care, in addition to promoting a standardized nursing language.

Accessing health care in the South. These studies show the number and quality of health services available for people who are chronically ill. Researchers have widely described the main barriers to accessing health care, the cost of chronic conditions, the difficulties to access medications, and the link between poverty and chronic illness in low- and middle-income countries. Results from these studies have shown important inequities in health related matters, reinforcing the need for policies to expand access to health care for lower-income populations in low- and middle-income nations. According to the WHO (2010), in order to achieve national and international goals—including the Millennium Development Goals (MDGs)—it is necessary to invest in health services and systems. Yet there is no guarantee the poor will benefit from reforms unless they are carefully designed with this end in mind (WHO, 2010). The following set of studies present some of the issues people with chronic illness face in low- and middle-income countries.

Põlluste, Kalda and Lember (2009) analyse the self-reported use of health services among the older Estonian population to explain the predictors of health care utilisation and determine how access to health services for this population compares with other population groups. In Estonia, the elderly group is considered to be a particular group that needs and uses more health services than the rest of the population due to their health status. Sometimes they are considered to be a more disadvantaged group to receive appropriate and prompt health care. In this study, older people rated their health status lower than younger populations. Also, older people were more likely to report chronic conditions than the rest of population. Compared with other groups of the population, elderly respondents were more likely to agree that access to health services was good. Comparison of waiting times to see specialists confirmed that elderly people have more of an advantage than people with chronic illness. As well, findings of this study report geographical barriers as a common issue for rural communities to access the health care system. Thus, as the number of older people is gradually increasing, the health services should respond to their health care needs.

Attesting to the reality that health systems around the world are not organized to meet the needs of the chronically ill; Goudge, Gilson, Russell, Gumede and Mills (2009) through a qualitative longitudinal research study explore the affordability, availability and acceptability barriers to health care for chronically ill people in South Africa. This research describes the experience of low-income families attempting to access chronic care in rural area of South Africa. According to researchers there is an increasing burden of chronic illness in low- and middle-income countries. Also, people's perspective on the difficulties of accessing care needs to be better understood, particularly in poorly resourced settings. Findings of this study suggest that health care is not being sought for a substantial proportion of chronic diseases, with many of those who sought care not obtaining it. Participants of this study faced several problems to accessing health care, such as: insufficient clinical services at the clinical level necessitating referral, interrupted medicine supplies, referrals not done due to lack of ambulances, and weaknesses in administrative processes. Another factor that prevents participants from accessing health care is the inability to pay. Chronic conditions can be costly for low-income families. Financial stability was threatened for participants from previous setbacks of their illnesses and deaths. There are limited social networks to provide financial assistance, thus preventing consultation for highly vulnerable households. However, families with income, strong social networks, social grants, or exemptions from public hospital fees were more likely to seek care regularly, incurring much lower cost burdens for their families. Despite having sought care, over a third of the participants with chronic conditions did not have an allopathic diagnosis that they were able to report to fieldworkers. This situation may be the result of a lack of clinical staff to make a diagnosis, no explanation given to the patient or the explanation was given but insufficient effort was made to ensure that the patient had understood the information given. This lack of information leads these people to inappropriate treatment actions, healer shopping, and at times to giving up on the public system. Hence, strengthening the public sector must include not only improving treatment supply, ambulance services, referral systems, clinical capacity at public settings, and the financial constrains faced by low-income families, but also thinking through how providers can engage with patients in a way that strengthens the therapeutic alliance between patient and health care professionals.

Fan and Habibov (2007) examine the determinants of accessibility and affordability of healthcare in post-socialist Tajikistan, the poorest country among the former Soviet republics. After independence was achieved, severe economic crisis and prolonged civil war were the main issues of this nation. Today, there is a growing concern about the levels of accessibility and affordability of health services in low-income post-socialist nations of Central Asia and the Caucasus. To explore determinants of healthcare utilization in Tajikistan, researchers used the modified Andersen Behavioural Model. According to this model, some individuals have greater propensity to use more health services than others. This propensity depends upon one's personal, familial, institutional, social, and economic characteristics. The model classifies these characteristics in three broad groups: predisposing, enabling and need. Findings of this study suggest that as the process of economic transition progresses, the poverty level of out-of-pocket payments relates directly to health care utilization. Also, results of this study showed how poverty, chronic illnesses and disability appear to be the most important determinants of health care utilization. Having a poor household increased the probability of not seeking or delaying health care or even not being able to use it at all. As the number of chronically ill or disabled people increased in a household the propensity not to use health services increased as well. Also, in this study other determinants were identified such as gender, level of education of the household head, and availability of health care professionals. These results suggest an urgent need for health care reform in order to ensure equal access to health care for the entire population in Tajikistan.

Rodrigues et al (2009) carried out a cross-sectional study to assess the use of health care services by elderly people with chronic illness in 41 municipalities of the South and Northeast regions of Brazil. The health care system in Brazil that was created by the 1988 Constitution guarantees to all Brazilians egalitarian access to health services. Since 1994, the health system has adopted the Family Health Program as the strategy to reorganize primary health care aiming to improve assistance and prevention of diseases at the community level. In 1999, the National Policy for the Elderly's Health was created, but it was not until 2006 by means of the Health Pact that the Brazilian health system began to consider the elderly population as a priority. However, the use of health services is the result of an interaction process among factors related to the individual, the health care system and the context where this occurs. Results suggest that the prevalence of medical visits was 45% in the South region and 46% in the Northeast region. There was a greater prevalence to participate in educational groups in the Northeast region than in the South region. Yet, in both regions the use of primary health services was higher for people under the age of 80 with low level of education and living in catchment areas of primary care units. In the South region elderly with functional disability had higher prevalence of medical visits. However, the prevalence of medical visits and participation on educational activities were lower compared with previous studies. These findings indicate that even though Family Health Programs promote greater use of services at primary health care units by elderly people with chronic diseases, it is necessary to enlarge the scope of those programs to better include those aged over 80 and with functional disabilities.

Lucumí et al (2008) describe the experience of proposing a local plan to prevent chronic diseases in Pasto, Colombia following a planning model developed by the World Health Organization (WHO). The aim of this proposal is to reduce main risk factors for chronic diseases in the next decade through a local plan of prevention that addresses actions in public policy, context of daily life and access to health services. Chronic diseases are a major problem in the world. In Colombia, chronic conditions are the major cause of morbidity and mortality. Bearing this in mind, several organizations have recommended planning and conducting actions to prevent chronic diseases; however, few initiatives have been developed to address this reality known worldwide as the neglected epidemic of chronic diseases. To deal with the rising number of chronic diseases it is necessary to develop strategies on health promotion and disease prevention in the community as well as strengthen disease management within health care services. This group of researchers used the Chronic Care Model Initiative Framework to promote primary health care concepts: intersectoral partnerships, community participation and seamless population-based care. The use of these initiative models have demonstrated reduction in health care costs, lower use of health care services, and improved health status. However, writing this proposal was not an easy task mainly because prevention and promotion of chronic diseases must always compete with other priorities in public health. It becomes difficult to promote chronic diseases as a health concern when they do not have a clear position in Colombia's health agenda. In planning and developing strategies, therefore, it becomes necessary to include different actors from the health and political arenas. This experience suggested how significant and feasible the processes to develop proposals at the local level are. But, also, it identified how challenging the coordination with the national level is when proposing these initiatives of prevention and promotion of chronic diseases.

The cost of chronic illness in the South. Dror, van Putten-Rademaker and Koren (2008) present results from a household survey aimed at determining the cost of chronic illness in India. Health services in India are largely provided by private entities and funded by out-of-pocket spendings (OOPS). This situation has been recognized as unfair and a serious threat to accessing health care. Results suggest that informal cost accounted for only 3.2% of total cost which meant that there was low utilization of indigenous systems of medicine in India. This study highlights that about two-thirds of total healthcare expenses was due to direct costs that include consultations, prescribed treatments, tests and hospitalizations, and less than one third was due to indirect costs that include transportation and income loss of the ill and the caregiver. In fact, the cost of an illness episode was influenced by the individual characteristics of the patients and the pathology and the location where the family lives. In terms of indirect cost there was a lower allocation of resources for women. This difference was significant in all age groups due to intra-familiar decisions to allocate resources for illness-related travel and care giving of males. In terms of age, young groups were most exposed to acute illness, whereas adults were more prone to chronic diseases; and the cost associated with these illness types were markedly different. Thus, acute illnesses, represented by 61% of total illnesses, accounted for only 37.4% of total costs, while chronic illnesses, representing 17.7% of illnesses, accounted for 32% of the costs. Hospitalization was considered the most costly component on average. As well, illnesses that required hospitalizations were also associated with higher costs for other services such as tests, medications and procedures. Medications were the second most expensive item. As the number of chronically ill people grows the cost per illness episode will inevitable increase in the next decade in India. This study showed that the main financial burden of illness among the surveyed poor population was due to the combined cost of drugs and primary care, more so than due to the cost of hospitalizations. However, when they occur, hospitalizations can have a devastating financial impact.

In summary, studies from the South portray chronic illness as a life-long situation that affects not only individuals and families but also communities and nations. In terms of the experience of chronic illness, researchers from the South have oriented their efforts toward the identification of needs, the experience of living with diverse symptoms, the perception of stigma, the adherence to treatments and the coping of chronically ill people with their situations. Studies about the cost of chronic illness in the South are scarce. There is a growing need to know more about the economic impact of chronic illness for individuals and families in low-and-middle-income nations. Studies show the importance of support for the chronically ill, the effects of depletion of economic resources in family life, the experience of care-giving for an ill relative, and the bonds and commitment caregivers have with the chronically ill person (Nascimento, Rocha, Hayes & Lima, 2005). This group of studies, in which nursing considers care according to the uniqueness of each human being, has demonstrated that nursing in the South is building specific knowledge about the individual, cultural and regional needs of families with people who are chronically ill. There are areas of chronic illness that have not been studied yet, but this is being addressed by their own people. Regarding the chronically ill, there is little knowledge about the meaning of living under the pressures of globalization with such parameters as productivity, competitiveness, individualism, consumerism and commercialization. And, also, we know little about the effects that economic, social and political forces that are produced by globalization have on the body of chronically ill people in low- and middle-income nations.

Understanding the Text of Chronic Illness in the North

The experiential text of chronic illness in the North. The panorama of chronic illness in the literature of the North has focused on the perception of chronic illness as a shadow, an alien or intruder (Andenaes, Kalfoss & Wahl, 2006). It is like an uncontrollable enemy that attacks the person's life, perhaps as the punishment for wrong, older life styles (Wallberg, 2003). In general, chronic illness is something unexpected that disrupts the normal life. For example, in childhood, life should be an open world full of unlimited and challenging opportunities and promises.

However, the world of children with chronic illness is not open; it is restricted and limited because every step forward is made with great difficulty (Lindsay Waters, 2008). A life that should be open is full of obstacles; the vitality trapped and restrained inside of the body. It is a life in which independence is exchanged for dependence and control for uncontrolled. Being chronically ill changes drastically every aspect of life (Andenaes et al., 2006; Kralik, 2005). Such changes are for most of the time a major obstacle due to the person's inability to maintain usual daily activities and quality of life (Jorgensen, 2006). Chronically ill people do not regard these limitations as isolated phenomena, but they are concerned about the consequences they have for themselves and the people close to them (Chodosh, 2005). Thus, quality of life is an important piece in the puzzle of chronic illness, something necessary to address in an individual way. The person who lives with chronic illness at some point learns how to understand, control and handle the needs of day-to-day life (Downe-Wamboldt, Butler & Coulter, 2006; Guler & Akal, 2009). As with the South, the text from the North speaks in a unique manner. Below, I present an overview of studies done by and researched in high-income nations.

Badlan (2006) draws upon a qualitative study based on young people's experiences with cystic fibrosis. Through a set of individual and group interviews Badlan provides an insight into the life-world of people living with cystic fibrosis. This research addresses the needs of young people to successfully integrate their disease into their lifestyle and their aspirations so as to be considered normal and not different. It also considers the psychological and practical issues and effects of their disease in their health care management. Children born with cystic fibrosis attend regular school and have aspirations and hopes in keeping with their healthy peer group. Dealing with this disease is a complex task and there are many aspects to consider when coming to term with this time consuming disease. Findings of this study show how complex it is to handle a life with a demanding chronic illness like cystic fibrosis. Overall, participants of this study desire to be integrated into society and to be perceived as normal, an aspiration in conflict with their recommended ongoing treatment. Compliance to treatments is a difficult task for participants in this study, especially when they want to fit into the canons of normality imposed by society. According to Badlan, health care professionals need to understand not just the pathology in delivering care but they also need to develop an insight into the individual experience of living with this disease. Finally, health care professionals should not only rely on compliance of treatments but rather to support the making of informed decisions about lifestyles and healthy behaviours.

Sutton and Treolar (2007) explore the experiences of people with hepatitis C within two models of chronic illness—illness trajectory and shifting perspectives. The idea is to analyze the effects of clinical markers of disease in relation to perceived health. The illness trajectory model suggests a process of adjusting to life with a chronic condition from when it begins to when the person starts to accept and adapt to it. The model of shifting perspectives states that attitudes of people with chronic illness may change over time, mostly focusing on either health or illness (Sutton et al., 2007). Findings of this research suggest how these two models can complement and inter-relate with one another. Living with hepatitis C has social consequences such as the potential for social limitation and isolation. The consequences were more significant and had greater effect than clinical markers of disease progress, an outcome which should be emphasized in understanding transformation experiences in chronic illness.

Collins and Reynolds (2008) describe how adults with cystic fibrosis cope with the diagnosis of diabetes as a second chronic illness. Diabetes is a common complication for people with cystic fibrosis. Both diseases are complex situations that require daily treatment schedules as a part of their management. In this study, four themes were identified: emotional response to diagnosis of diabetes, looking for understanding, learning to live with diabetes, and limiting the impact of the diagnosis. For participants of this study, having diabetes is a challenge mainly because of the diet restrictions. Findings of this research suggest that health care professionals need to increase their awareness about the effects of the diagnosis of diabetes in people with cystic fibrosis to provide adequate support and structured evidence-based education throughout the course of their illness, particularly in relation to dietary restrictions. Yet, patients' knowledge about regular daily routines and problem-solving attitudes play a key role in limiting the impact of diabetes.

Costantini et al (2008) explore the self-management experience of people with mild to moderate chronic kidney disease to evoke participants' perceptions of health, kidney disease, and supports needed for self-management. Early identification and treatment for people with chronic kidney disease is acquiring increased attention because one of the main goals of nephrology is the preservation of renal function and prevention of progressive to end stage renal disease. By means of semi-structured interviews, participants discussed such topics as perceptions of health, kidney disease, illness management, and support needed for self-management. According to this study there are unmet needs for people with chronic kidney disease. The development of collaborative care models to support self-management care in early chronic kidney disease is threatened by the lack of research in this area. For participants of this study there is an ongoing process of renegotiating life which encompasses the process of being aware of and learning to live with kidney disease. The study identified a number of themes, including searching for evidence, realizing that kidney disease is lifelong, managing the illness, taking care of the self, and the need for disease specific information. Participants of this study wanted to self-manage their disease in collaboration with health care professionals. The asymptomatic nature of the early stage of kidney disease was considered by participants to be a barrier to self-management since they could not differentiate between the need for medical attention and feeling well. Thus, more support and education from health care professionals will help them to easily recognize implications of the diagnosis and the need for compliance with ongoing treatment.

Goodridge, Hutchinson, Wilson and Ross (2010) explore the impact of living with advanced chronic respiratory illness in rural areas. Using an interpretive descriptive approach, this research describes the experience of seven people living with chronic respiratory illness in a rural area of Western Canada. Rural health care is essentially different from urban health care, potentially creating a different set of challenges for those living with chronic conditions. Four major themes emerged from this study: distance as a barrier to accessing health care, positive relationships with primary health care providers, supportive local community, and lack of respiratory education and peer support. Overall, participants of this study were positive about where they lived. They seemed to be compensated by the benefits of being known and supported within their own communities. Belonging to a place was more important than distance from health care when choosing to remain in rural settings. However, challenges were presented by excessive travel, unpredictable physician availability and lack of local respiratory-related education and support. Finally, despite that living with advanced respiratory illness in rural areas posed some challenges, participants did not feel that their health was commitmentd by their rural residency, and they identified positive advantages of rural areas in helping them to live with their illness.

The Jeon et al (2010) study which took place in Australia aimed to understand the experience of patients and family caregivers affected by chronic illness in order to propose policy and health system interventions that are patient centred. Researchers conducted face to face, semi-structured in-depth interviews with each participant. Questions were developed from the Explanatory Model of Illness designated to assist researchers to understand the experience of chronic illness from participants' points of view. Balancing life and illness was a key element of the experience of people with chronic illness, highlighting the generally held view that people with chronic illness have to continuously adjust their lives. Participants of this study struggle in the process to balance their lives with the increasing demands and intrusion of chronic illness. However, their attempts to achieve balance were threatened by fragmented services, complexity in navigating health services, relationships with health care professionals and others, and co-morbidity. Thus, this research draws attention toward the importance to promote patient centered approaches within the Australian health system.

Davis (2010) explores the meaning, experiences and perceptions of care by Native Hawaiian *kupuna* who live with chronic illnesses. The objective of this study is to understand the caring needs of Native Hawaiian *kupuna* in order to inform nursing practice and education on the importance of culturally sensitive care for vulnerable populations. In the United States, providing culturally sensitive care to an increasingly older population who live with chronic illnesses is a priority. Native Hawaiians experience significant disparities in health outcomes when compared with other ethnic groups in Hawaii. They have the lowest life expectancy and the poorest health indicators. The theoretical framework of this study comes from Leininger's theory of Culture Care Diversity and Universality. This theoretical approach was selected to orient the design and analysis of the study because it provides a holistic understanding of cultural values, meanings, patterns, and expressions of care in different cultures. Four major themes emerged from this study: knowing and respecting the Hawaiian culture, living in two worlds, speaking from the heart, and learning from each other. Findings of this research showed how Native Hawaiian *kupuna's* perceptions of care of those with a chronic illness are embedded with cultural meanings of life itself. Living with a chronic illness was drawn as a relation journey within the context of Hawaiian cultural values and beliefs. Results showed the importance of understanding the experience of chronic illness within the context of Hawaiian history and cultural values and health practices. Thus, by recognizing cultural beliefs as strengths and integrating Hawaiian cultural values into care, the health and well-being of Native Hawaiian *kupuna* with chronic illnesses may be improved.

Taieb et al (2010) explore the beliefs about the causes of systemic lupus erythematosus (SLE) in France. Any illness tends to raise questions about the causes and the meaning of the illness. Questions like "Why me?", "Why here?" and, "Why now?" often occur for people who live with chronic conditions. Most participants who were interviewed cited several causes such as autoimmune, psychological, transmission, hereditary, contagion and infection, magical-religious, guilt and punishment, and a latent disease that might explain their illnesses. Some of these causes are congruent with biomedical models and others belong to the cultural beliefs held by participants. For health care professionals, this study brings an understanding of the beliefs held by people with SLE, an understanding that will help to provide optimum care. Understanding the narratives of people with chronic illness will facilitate a long-term partnership between patient and health care professionals.

Gullick and Stainton (2008) in their phenomenological study describe the experiences of patients and their families living with chronic obstructive pulmonary disease (COPD) who chose palliative surgical procedures presented to them as either experimental or of potential risk. Merleau-Ponty's and Heidegger's philosophical approaches help to understand how the Lung Volume Reduction Surgery and Endo-Bronchial Valve have expanded the therapeutic choices for people with COPD. For participants of this study, having COPD meant living with a terminal illness whose symptoms and consequences through time could be worse. For them, to take a chance on surgery becomes the essence of their lived experience. Narratives suggest that palliative surgery is presented as yet another way to handle their disease. Even though the procedure was presented as either risk-laden or experimental, taking a chance on an invasive procedure was worth it because life with severe breathlessness was not an alternative for them. They took the risk to improve their quality of life. Results of this study showed that outcomes of the surgery are not always tied to visible, objectively measurable improvements determined by outsiders, but may be relevant to some extent to a regaining of self. Different from health care professionals, patients and families living with COPD were more likely to accept the risk of morbidity and mortality to improve in some way their quality of life. Regardless of the outcome, participants did not regret their decisions. Therefore, an understanding of the effects of illness on the person's world requires not only an understanding of the experience as *doing*, but also as *being*. This highlights the importance to include both psychological measures and the achieving of meaningful activities and self-concept when determining the outcomes of new interventions.

Shearer, Fleury, Reed, Ueno and Kamibeppu (2009) report findings from a qualitative study about the rhythm of health in older women with chronic illness. Using Rogers's conceptual system helped researchers to frame their perspective of human beings and health but did not prescribe what themes would come out from the data. Three themes emerged: realizing the potential for purpose, listening to meaning of low energy, and purposefully participating in health-related decisions. Participants of this study expressed a rhythm of changing meanings and practices that were a key element to enhancing personal strengths central to managing the challenges, as well as acknowledging the losses and changes associated with their conditions. Findings of this research capture the dialectic and rhythmic process in women's personal perception of health brought on by their experiences with chronic conditions and the challenges of aging. Results of this research support prior theoretical conceptualizations of health, and validate the knowledge of health.

Ueno and Kamibeppu (2008) undertook a modified grounded theory approach to describe the experience of mothers with chronic mental illness in Japan, their feelings toward their children and their parenting practices in relation to their children. Researchers identified four categories that impacted on the parenting practices of mothers with mental illness: feeling of affection for the child, feeling sorry for the child, getting frustrated with poor parenting and feeling the child's compassion. Findings of this research suggest how, besides the challenges of parenting, mothers have to deal with their self-care as well. Sometimes the needs of mothers with mental illness might conflict with the needs of their children. This study showed that mothers with mental illness might be advised by health care professionals about performing self-care without recognizing the mothers' parenting context. One suggestion of this research is to establish a system that records whether adults with mental illness have children.

In addition, health care professionals when advising about self-care practices must include the context of parenting by discussing parenting issues with mothers who have mental illness. Thus, parenting practices are not only influenced by the feelings mothers with chronic mental illness have toward their children but also by their subjective perception of their children's feelings toward them or their illness. These perceptions contributed to their well-being and their parenting practices.

Measuring chronic illness.

Sato, Yamazaki, Sakita and Bryce (2008) describe the nature of benefit-finding, examine its predictive social factors and evaluate its impact on mental health for individuals with rheumatoid arthritis in Japan. Benefit-finding is the ability of people with chronic illness to find positive aspects of the illness experience. It includes the positive changes in self-perception, changes in life priorities, an improved appreciation of life, positive effects on interpersonal relations, and positive behavioural changes. A web-based questionnaire was used to evaluate the responses of 364 participants with rheumatoid arthritis. Findings of this research suggest that most of the participants engage in some kind of benefit-finding. Participants reported larger emotional support networks and those practicing self-care activities reported higher levels of benefit-finding. Developing compassion toward others and appreciating things not previously important were the most usual benefit-findings described by participants. Benefit-finding was also reported as an important predictor of mental health for participants. These results have extended the knowledge based regarding living with rheumatoid arthritis and represent a rational for the promotion of well-being.

Schoen, Osborn, How, Doty and Peugh (2009) present the results of a 2008 survey of chronically ill adults in Australia, Canada, France, Germany, the Netherlands, New Zealand, the United Kingdom, and the United States. Advances in medicine and improved living standards have saved lives and contributed to longer life expectancy in developed nations and yet these countries now face the growing challenge of caring for chronically ill people. Health systems initially developed to attend to acute illnesses now have to respond to the increasing number of people with ongoing conditions, where the goals include preventing complications or deterioration rather than finding cures. Findings of this survey suggest different variations in care experiences regarding access, safety, coordination and efficiency, all of which indicate that countries' polices and health systems make a difference for patients coping with chronic diseases. The chronically ill in the US appear at particularly high risk due to gaps in coverage and lack of organized care. In countries with strong primary health care infrastructures, chronically ill people tend to do better. Yet, lack of transitional care when patients leave the hospital, lack of coordination among multiple clinicians in charge of the care of the patients, and weak efforts to engage or support patients to manage their condition happens in all eight countries. According to this survey, the US ranks high for negative patient experiences, ranking last or low for access, care coordination and efficiency, and patient reported safety concerns. The Netherlands rank highest for positive access experiences and low rates of patient-reported errors, duplication, perception or wasteful care. The United Kingdom ranked high with the exception of waiting times for specialists and some aspects of patient engagement. In Canada, on the other hand, there is some restraint in both primary health care and access to specialists. The results of this survey highlight the necessity to introduce innovations into the health system to improve outcomes for people with chronic conditions.

Whittemore and Dixon (2008) explore how adults with chronic illness integrate the illness experience into their life context in Connecticut, US. People with chronic conditions are challenged to learn self-management strategies to prevent complications as the way to improve their quality of life. A mixed-method descriptive design was employed to understand the process of integration for people with chronic illness. The process of integrations of chronic illness into the lives of participants was complex and challenging. Participants had to make a considerable daily effort to manage not only their illnesses but also to overcome unpredictable physical or emotional challenges associated with the particular illness. Consequently, psychosocial difficulties were common among participants. Yet, despite difficulties, adults with chronic illness were remarkably resourceful in developing attitudes and strategies to assist them in integrating the illness into their life context. The process of integration requires ongoing self-management, as well as psychosocial, vocational and existential support especially for individuals with multiple and/or progressive chronic illnesses and limited resources.

Else et al (2008) examine the effects of active untreated chronic lymphocytic leukaemia (CLL) on health-related quality of life (HRQoL), measured by the European Organization for Research and Treatment of Cancer quality of life questionnaire (EORTC QLQ-C30). Findings of this baseline study suggest that participants with CLL had impaired health-related quality of life compared with population norms. The most common symptoms that decreased the quality of life were fatigue with 81%, sleep disturbance with 56%, and dyspnoea with 49% of the participants. There was no correlation between liver, spleen or lymph node enlargement or lymphocytosis and any health-related quality of life domain. Older participants reported poorer physical functioning but fewer financial difficulties. Thus, to improve health-related quality of life it is necessary to begin treatment when patients experience symptomatic disease.

Chronic illness and family life in the North. This group of studies describes families battling against challenges with chronic illness and the emergence of natural bonds in order to enhance their situations (Hopia, Paavilainen & Astedt-Kurki, 2005; Ray, 2006). The panorama of chronic illnesses in the literature is a dark one because it is full of intimidation, frustration, disruption, powerlessness, hopelessness and exhaustion for family members. Caring for a person with a chronic illness is a process which requires strength and willpower; it is an enduring battle against the characteristics of that particular situation (Adamson & Donovan, 2005; Chesla, 2005; Eriksson & Svedlund, 2006). Chronic illness is like a stranger that has the power to control the lives of family members; they have to live under its shadow, coexisting with it and learn from it. Through time, the family becomes resourceful and gains knowledge, living and learning one day at a time (Gallant Spitze & Grove, 2010). Chronic illness cannot always be generalized as bad because chronicity can change family values, beliefs and goals for the better (Chesla, 2005; Hopia et al., 2005).

Family caregiving for children can begin from birth and last indefinitely, especially if the illness or disability prolongs their dependency. Still, with chronic illness each member of the family learns about the situation and how to deal with it. Even when the person dies from a chronic illness, he or she continues living in the memories of the family, teaching about the uncertainty of life (George, Vickers, Wilkes & Barton, 2008; Feigin, Barnetz & Davidson-Arad, 2008). For family members, chronic illness transcends bodily experience or physical events of the one affected and it can cause the creation of bonds that keep a family together. The family is tied to the other, trying to figure out how the chronically ill relative feels. There is a sense of solidarity, and perhaps more important, a feeling of filial love growing out of the family's need to be there with that person. The following group of studies looks deep into the world of chronic illness and family life.

Yogarson et al (2010) examine illness perceptions and coping activities as they relate to illness management and relationship resilience in older couples. Spouses are the first to provide care for ill partners. Following the family stress framework this study explores couple-based perceptions of multiple-chronic diseases, as well as coping activities developed to handle those diseases. For participants, coping strategies included efforts to receive medical attention when needed, exercise and management of their diets, adjustment to daily activities and routines, and the seeking of education. Those with a proactive approach to coping used a healthy management of their illness approach in which coping activities were described as either individual, shared, or a mix of individual and shared efforts. Couples who might not have managed their health also spoke of activities they wanted to do or knew they should be doing, but there was no evidence that they were doing them. For some couples the management of multiple chronic illnesses was considered as stressful. Reports of fear, uncertainty and frustration must be linked to ambiguity on what the future holds for these participants and their illnesses. For other participants their current situations were described as lifelong lessons. Findings of this study suggest a mix of negative and positive illness perceptions. Most couples in this study have learned to accept and deal with health problems while keeping a positive outlook on life.

Kim and Spillers (2010) characterize the multidimensional aspects of the quality of life survey for cancer caregivers (QOL) at two years after the diagnosis in the United States. The American Cancer Society's Quality of Life Survey for Caregivers was designed to assess the impact of cancer on the QOL of family members and friends in charge of caring for cancer survivors. Findings from this study suggest that family members and friends were at normal levels of QOL after two years post-diagnosis; however, these participants were more likely to experience increased awareness of spirituality than individuals who personally experience a chronic illness. Also, caregivers' ages and care-recipients' poor mental and physical functioning were predictors of their QOL at two year post-diagnosis. In conclusion, younger and relatively low-income caregivers who provide care to relatives with poor mental and physical functioning may benefit from interventions to help in their spirituality and psychological and physical adjustments two years after the initial cancer diagnosis. Also, older low-income caregivers may benefit from programs to reduce the physical burden of care-giving for cancer survivors.

Andrews et al (2009) explore age-related patterns of association between parent-reported illness intrusiveness and parent distress in parents of youth with rheumatic diseases. Researchers used the Brief Symptom Inventory to assess global parent psychological adjustment. It also used the Illness Intrusiveness Scale—Parent (IIS—P) to assess the degree to which parents perceive their child's illness as interfering with their own ability to engage in activities across diverse life domains, such as work, recreation, and relationships. The Juvenile Arthritis Functional Assessment Report—Parent (JAFAR—P) assess parents' subjective estimates of their child's ability to perform tasks related to daily life such as dressing and walking. Also, the Children's Depression Inventory (CDI) is a scale to measure youths' depressive symptoms. Findings of this study suggest that greater parents' perception of illness as intruder was related to greater distress across age groups. Increased perception of illness intrusiveness was related to poorer parent adjustment among parents of older youth, but not a finding among parents of younger children. Thus, adjustment to chronic illness is determined by a combination of individual, family, and illness development factors. The complexity of chronic illness requires family flexibility and introduces unique challenges for family members as they negotiate normative development stages. Compared with other studies, this study's results are consistent with family life cycle development models of adjustments to childhood chronic illness.

Hasnain and Rana (2010) unveiled Muslim voices when exploring how aging parents with disabilities live and what the role of their adult children and family caregivers is in the United States. In the United States it is becoming important to provide culturally competent care as the population grows older. The Muslim community in the United States is growing older and, as more people live longer, more will risk chronic health conditions such as diabetes, cardiovascular disease, rheumatoid arthritis and cognitive or mental illnesses, posing new challenges and demands for the families. Home care of an ill parent is emphasised in Islam. Muslim families do not consider the American concept of institutional caregiving as an option for aging parents or relatives with chronic conditions. To care for one or both parents at home is considered an honour or blessing and an opportunity to grow spiritually. This is reciprocity, a cultural norm nurtured over a lifetime. Thus, most Muslim families see institutional care for elders as a form of neglect and abandonment. However, despite the desire to care for a parent, doing so becomes difficult for caregivers who must also juggle the needs of their own family and work. When family members decide to institutionalize a parent, the Muslim community usually reacts negatively and provide limited or no support for the families affected. For Muslim families it has been difficult to find institutional care that is culturally sensitive to the needs of their aging relatives. Thus, as the Muslim community expands, it is important to take into account the needs, values and practices of their members, and the role of their adult children and community. Access to social services may be limited by ethnical differences and also by different perceptions of what disability or illness is.

Nursing care for chronically ill people in the North. Currently available studies in nursing indicate how chronic illness has been increasingly recognized as a widespread, debilitating and costly burden (Fitzsimons et al., 2007). Literature in nursing for the chronically ill has been focused on the evaluation of the nurse role, organization of strategies to improve quality of life, efficacy of specific medical treatments, validation and implementation of tools to assess nursing strategies, follow ups of nurses' interventions, implementation of self-management programs and shared decision making programs to assist a decrease in debilitating behaviours (Boldy & Silfo, 2006; Chodosh, 2005; Macdonald, Rogers, Blakeman & Bower, 2008). In general, quality of care is the vision of the group of studies. For nurses, acknowledging the circumstances of people's lives and monitoring the impact of nurses' actions are important because the impact of distress produced by lack of participation may thereby be reduced (Elder, 2007; Hellstrom, 2004). The following studies are some examples of these actions.

Goodridge, Duggleby, Gjevre and Rennie (2008) present results from a qualitative study in Canada aimed at describing the experiences of critical care nurses and respiratory therapists providing end of life care to patients with COPD dying in ICU. Managing difficult symptoms, questioning the appropriateness of life-sustaining care, and establishing care priorities were described as important challenges to consider when providing high quality of end of life care to people with COPD in ICU. While nurses experience these challenges during more routine admissions for acute exacerbations, each of the themes acquired an additional urgency and poignancy when caring for a patient with COPD who was dying. Nurses struggled to harmonize their desire to facilitate a peaceful death with the realities of the ICU. Among the symptoms associated with patients dying of COPD, dyspnea and anxiety were the most associated with death by health care professionals. This study highlights how ethical considerations were central to the discussion of end of life care for people with COPD in the ICU. Participants of this study often felt hampered in their ability to provide care to patients dying with COPD by their own questions about the futility of treatment and whether the aggressive treatment in the ICU was adjusted to their patients' own wishes. Often critical care clinicians face the necessity to prioritize care to the most unstable ICU patients with COPD while other stable patients did not always receive the attention that practitioner felt they should have. In summary, critical care practitioners need organizational support to effectively deal with these issues.

Shigaki, Moore, Wakefield, Campbell and Lemaster (2010) explore how patients with multiple chronic diseases perceive the role of nurses who work in a care management role in a primary care setting in the United States. In this primary health care setting and as part of its chronic disease care initiative Wagner's chronic care model was followed. This model emphasizes the role of nurses in charge of monitoring chronic conditions and treatments, and in providing support to patients and family through self-management practices. These nurses are called nurse partners. Three themes emerged from this study: first, an overwhelming positive regard for the nurse partner, both as a person and a professional; second, appreciation for the availability of the nurse partner; and third, a perceived partnership with healthcare providers. Findings of this study place nurses as key providers of chronic illness care. These nurses have facilitated productive interactions and minimized gaps in care through healthcare support and care coordination services and have the flexibility to provide intensive services when patients need it. Participants with chronic illnesses perceive nurse partners as accessible and collaborative. They are confident that there is a caring, responsive, and competent human being available to help when needed. Nurse partners with emphasis in chronic conditions are flexible and respectful in providing care wherever patients may be on the continuum of self-management skill.

Park and Han (2010) describe Korean daycare nurses' perceptions of key daycare services and their working experiences with stroke patients and their families. This study followed, first, a cross-sectional survey to determine how nurses working at adult daycare perceive key services. And, second, focus group interviews of nurses were conducted to determine the working experience of daycare nurses from their perspective. According to the descriptive survey, daycare nurses fully recognize the importance of direct nursing services as key elements to rehabilitate older adults with stroke. In contrast the focus group data revealed significant gaps between the identified areas of key services and the challenging realities daycare nurses have to face. These nurses pointed out several barriers to providing adequate healthcare originating from the ambiguity of role definition, the neglected care from the families involved, and the lack of a monitoring system. Other challenges such as the lack of qualified daycare nurses were identified. Thus, despite full awareness about the key daycare services essential to adequate recovery and rehabilitating of people with strokes, Korean nurses experience several challenges in real working situations.

Ingadottir and Jonsdottir (2010) present results from a retrospective and prospective pre-test—post-test intervention study about partnership-based nursing practice for people with chronic obstructive pulmonary disease (COPD) and their families. COPD is a progressive chronic disease that needs relentless attentiveness not only toward the people who have the disease but also toward the families involved. This study is based on the theoretical framework oriented toward partnership as practice. In this framework the overarching component is dialogue. There must be open, caring, mutually responsive and non-directive dialogue in which meaning of the health circumstances evolves and possibilities for actions are open and relevant for each patient and family. Results of this study suggest that partnership-based nursing practice reduced hospital admissions and days spent in the hospital. The quality of life as measured by St. George's Respiratory Questionnaire improved significantly. Depression and anxiety related to hospitalization decreased as well. Adherence to treatments improved substantially. The participatory nature of partnership-based nursing practice might be of particular relevance for people and families living with chronic obstructive pulmonary disease.

While, Forbes, Ullman and Mathes (2009) describe the views of people with multiple sclerosis (MS), nurse specialist in MS, other nurses and other health care professionals regarding who was the most appropriate caregiver for a range of specific needs as a part of a role mapping exercise. A questionnaire was developed based upon the literature regarding role, skills and knowledge for nurse specialist in MS. Findings of this study suggest that neurologist and specialist nurses were the most appropriate professionals to provide specialist care. Specialist nurses were identified as key providers of emotional support. There were also important differences in nominations reflecting perspectives of stakeholders groups and a self-report bias because each stakeholder group frequently emphasised their own contribution to care. As well, patients with multiple sclerosis were also noteworthy with their emphasis on social care and lay support. This study highlights a dissonance in the perspectives of different stakeholders within the health care system. Thus, researchers suggest the division of labour associated with nursing care requires further exploration.

Johnson and Raterink (2009) describe results from a clinic-in-a-clinic model of care delivery founded on the principles of the Chronic Care Model and focused on the outcomes proposed by the American Association of Diabetic Educators. Through a unique health care delivery method which fosters self management support, this project was aimed at improving health outcomes for diabetic people. A key element of this model is self-management support which focuses on providing patients with the skills to make health care decisions. Self-management encourages patients to be responsible for their own healthcare because diabetes outcomes and complications prevalence are associated with self-involvement and self-management support as crucial elements to manage disease. Patients selected to participate in this study chose several topics related to diabetes management for their clinical session. Their level of participation was consistent with regular clinic visit attendance. However, there were some barriers to the program success that were related mostly to both structure and process. Thus, evaluation of further barriers, including provider perspective of the intervention and perceived barriers on their part, could increase the success of the program. This study highlights how as more patients participate in the program the development of follow-up policies will facilitate patient monitoring and enhance patient response to the program.

Gjevjon and Helleso (2010) through retrospective study explore in Norway how community nurses addressed patient care in the electronic patient record and the comprehensiveness of their documentation. In home care the quality and continuity of care depend on the comprehensiveness of nursing documentation. Nurses in home care face different challenges from nurses in clinical settings. Results from this study show how home care nurses documented patient care chronologically rather than follow a logical structure according to the nursing process. This study highlights patients' participation in healthcare. Indeed, 70% of the nursing noted was connected to subjective nursing status. This suggests that the shift in the nursing paradigm towards health care centred on the individual—which is evident in official regulations, research and professional opinion—has had an impact on nursing practice in Norway. Many patients in primary health care, such as people who have had stroke or neurological diseases, have limitations in their ability to communicate. Moreover, nurses are expected to address communication as a part of their care. However, paradoxically, in the nursing notes there was a lack of attention to the patients' ability to communicate. There were no nursing diagnostics related to communication in those nursing notes. This study contributes to identifying areas of improvement in documentation by nurses in home health care in Norway.

Van Herk et al (2009) through cross-sectional multicenter study explore aspects of pain, pain intensity and pain treatment in nursing home population in the Netherlands. A standardized pain questionnaire was used to measure several aspects of pain and its intensity. Most participants of this study experienced chronic pain either in the previous week or at the present time. This was followed by 40% of residents suffering from intolerable pain. There is more interference with activities of daily living when participants were in pain. One forth of residents with pain did not receive any pain medication. Overall, most residents (60%) were satisfied with pain treatment, and 21% were not. In conclusion, residents of Dutch nursing homes do not seem to expect effective pain management. Thus, awareness and knowledge about pain assessment and treatment needs to be raised. This study highlights the necessity to implement pain measurement tools and treatment protocols in daily practice.

Accessing health care in the North. This group of studies assesses health insurance status and health care access of people with chronic illnesses and disabilities in the North. Despite increasing attention to issues of health care for chronically ill people, having no health insurance is significantly associated with health care access barriers in this population (Callahan & Cooper, 2006). Ethnicity and culture disparities as factors in access to health care for the chronically ill are well documented. In fact, access to health services is a major issue in high-income countries, and several surveys suggest that racial and ethnic differences influence access to care for people who are chronically ill and disabled in those nations (Gallo, Penedo, Espinosa de los Monteros & Arguelles, 2009). Drawing from the literature in the North, it is possible to determine a strong association between health insurance coverage and access to primary and preventive care, the treatment of acute and traumatic conditions, and the medical management of chronic illness. Moreover, by improving access to care, health insurance coverage is also fundamentally important to better health care and health outcomes (Hoffman & Paradise, 2008). For chronically ill people, delayed or forgone care may represent missed opportunities to improve functioning, provide preventive services, or delay disease progression (Lora, Daviglus, Kusek, Porter, Ricardo, Go & Lash, 2009; Nguyen, Ugarte, Fuller, Haas & Portenoy, 2005). This section presents a selection of articles that provides data relating to access to health care for chronically ill people in high-income countries.

Campbell et al (2010) explore the changes experienced in primary care by chronically ill people during health services reforms in the United Kingdom. In the United Kingdom major reforms were introduced in the recent years. In 2000, the National Health Service (NHS) Plan made it possible for people to set appointments with physicians at their own practice within 48 hours. In 2004, the

Quality and Outcomes Framework (QOF) was introduced as part of new contractual arrangements for general practitioners. This pay-for-performance scheme was aimed to cover three main areas of practice: chronic disease management, practice organization, and patient experience. Also, in 2004 the General Medical Services Contract encouraged health care professionals to keep their practices open longer to provide extended appointments. These major primary health care reforms were introduced to improve not only quality but also to speed access to health care in the UK. Researchers conducted a cross-sectional design study to determine the impact of these health reforms on patients' experiences. However, for communication, nursing care, coordination and overall satisfaction, there were no significant changes in the quality of care received by chronically ill people between 2003 and 2007. Participants gave lower satisfaction ratings for continuity care and they reported seeing their physicians less often. According to this study, the improvement in access to health care for patients with chronic illnesses was modest. Participants reported that it was somewhat harder to obtain continuity of care. This outcome may be related to the incentives to speed appointments or to the increased number of specialized clinics in primary health care. Thus, the possibility of unintended effects was not contemplated when introducing pay for performance schemes.

Chatterjee, Kotelchuck and Sambamoorthi (2008) conducted a cross-sectional analysis in the United States of 6,294 women from the Medical Expenditure Panel Survey (MEPS) to describe the prevalence of chronic illness in pregnant women and factors affecting access to health care. For this study women were divided into four groups: pregnant and currently not pregnant, with and without chronic illness. Findings of this study suggest that overall the prevalence of chronic illness was lower in pregnant women. Women with chronic illnesses were more likely to have out-of-pocket expenditures, but it did not increase total average health care expenditures, even after adjusting for other characteristics. The results also suggest that the presence of a chronic illness was not related to either decreased access to health care or significantly higher health care costs. Thus, there was no difference between pregnant women with chronic illness and pregnant women without chronic illness in terms of access to health care and total health care costs.

With a retrospective cohort study Goodridge, Lawson, Rennie and Marciniuk (2010) explore the differences in health care utilization and place of death for persons with chronic obstructive pulmonary disease (COPD) or lung cancer in the last year of life in urban and rural areas of Saskatchewan, Canada. Respiratory illness is one of the leading causes of death worldwide, with rates that will continue growing into the foreseeable future. Findings of this study suggest that despite health care needs of people with respiratory illness in the last year of life were likely to be similar between locations, rural-urban differences were apparent in the number of visits by primary care physician and in access to and the nature of home care service provided. People from small urban, rural and remote locations made fewer visits to physicians than those in urban settings. The likelihood of receiving home care services and professional home care services such as palliative care and physiotherapy was significantly lower for people in rural and remote areas. People from rural areas were more likely to be admitted to institutional long-term-care (LTC) compared with residents of urban and small urban areas. Also, low home death rates were found in both urban and rural settings, suggesting that rural families may be overwhelmed by the need to travel frequently or to relocate temporarily to be closer to the hospital where their loved one is dying.

Javier, Huffman, Mendoza and Wise (2010) compare health care access utilization and perceived health status for children with special health care needs (SHCN) in immigrant and non-immigrant families in California, United States. This cross-sectional study used data from the 2003 California Health Interview Survey to identify children with special needs. Chi square and logistic regressions were used to explore relations between immigrant status and access to health care and health status variables. Findings of this study report that immigrant children with special health care needs are more likely than their non-immigrant counterparts to experience reduced access to health services, decreased utilization of health services, and poorer health status. Undocumented immigrant families with children with special care needs are at risk for decreased access, utilization and poorer health status compared to those immigrants with legal status in the country. However, other barriers such as language, insurance status, ethnicity, and poverty status must be taken into account when examining access to health care. Finally, this research suggests how important it is to take into account cultural and linguistic barriers that immigrant families have to deal with so that health care professionals reduce health disparities among minority children and more costly emergency room and hospital services for children with special health care needs.

Si et al (2008) describe primary health care system support for chronic illness in Indigenous communities in Australia's northern territory using the Chronic Care Model. In Australia, Indigenous peoples experience a disproportionately higher prevalence of morbidity and mortality from chronic illnesses such as cardiovascular disease, renal disease and diabetes than non-Indigenous Australians. This cross-sectional study lasted for five years and involved 12 Indigenous communities of Australia's Northern Territory. The Chronic Care Model lately has been used as a conceptual model to understand systems to support chronic illness care and to guide organisational development. This study proved the practical application of the Chronic Care Model concept for understanding primary health care systems in relation to prevention and management of chronic illness in Australia's Indigenous communities. Through the implementation of this model, different areas of strength and weakness were identified. There was strengthened organisational components by inclusion of chronic illness goals into business plans, appointments of designated chronic diseases coordinators and introduction of external clinical audits, but it was weakened by lack of training in disease prevention and health promotion and limited access to the health care system. The community associations were facilitated by working together with community organizations to run community-based programs, but were weakened by a shortage of Aboriginal health workers in the community. Self-management was promoted through patient education and goal setting, but they were difficult to reach because of limited focus on family and community-based activities due to understanding. Decision support was encouraged by distribution of clinical guidelines and their integration with their daily care, but it was impeded by inadequate access to and support from specialists. The delivery system design was reinforced by supplying transport for patients to health centres, specific roles of primary health care professionals in relation to chronic illness care, but it was limited by staff shortage. And clinical information systems were encouraged by wide adoption of computerised information systems, but they were limited by the systems' complexity and lack of technical maintenance and upgrade support.

Gysels and Higginson (2008) explore the experience of breathlessness in patients with chronic obstructive pulmonary disease (COPD) through participants' accounts of their interactions with health services in London, United Kingdom. Data were collected using Grounded Theory approach exploring the experiences of breathlessness among patients with advanced lung cancer, COPD, cardiac failure, and motor neuron disease at different stages of their diseases, and in different care settings. Invisibility is the metaphor that captures the experience of breathlessness in COPD patients. Invisibility is portrayed in these data in three ways: first, it is invisible by its very nature throughout the illness trajectory; second, breathlessness is invisible in the sense that patients try to hide the symptoms socially from others; and third, breathlessness is invisible because of the lack of response from services. Consequently, access for participants to medical assistance, advice on the symptoms management, and offers of effective treatments were limited and difficult. Thus, lack of access to services is an additional dimension of suffering added to the illness experience.

Johnson et al (2008) describe the ethnic differences and treatment trajectories in chronic kidney disease in Latino children in San Diego, California. Through narrative theory, researches elucidate conceptions about: disease process, expression, and treatment; perceived access to care barriers; and potential for treatment non-adherence in children with chronic kidney disease and their families. Findings of this study suggest multiple barriers to accessing appropriate care compared to their non-Latino counterparts. These barriers included proximity to services or insurance status, but also involved more subtle factors such as culturally held beliefs that did not support a biomedical interpretation of symptoms, and failure of doctor-patient interactions to result in appropriate testing and referral. Results also show how Latino children experience delays in diagnosis and treatment of chronic kidney disease that could affect disease progression and outcomes. These barriers seem to be more related to socioeconomic factors than ethnicity. For some families the decision to immigrate to the United States was based on the idea of gaining access to better health care for the patient. Further research is needed to better understand health disparities in paediatric chronic kidney disease and to develop targeted, culturally appropriate interventions to address them.

The cost of chronic illness in the North. This group of studies show the cost of managing chronic health conditions as a daily reality for individuals, families, communities and nations around the world. These conditions impact on health and well-being and represent a significant and growing healthcare and economic burden (Broemeling, Watson & Prebtani, 2008). The following are a few examples of the cost of chronic illness in high-income countries.

Laliberte et al (2009) quantify from a health system perspective the incremental direct all-cause health care costs associated with a diagnosis of chronic kidney disease in people with diabetes and/or hypertension. The study results suggest that resource-use and direct cost of chronic kidney disease management increase with worsening disease severity. The largest driver of the all-cause mean cost difference associated with chronic kidney disease for each cohort was hospitalization cost for diabetes at $6,410, hypertension at $5,498 and diabetes and hypertension at $6,467. Among patients developing chronic kidney disease, all-cause mean annualized costs increased significantly following chronic kidney disease onset, increasing for patients with diabetes to $8,829, hypertension $4,175, and diabetes and hypertension $9,397. In the post-chronic kidney disease period, costs directly related to treatment of chronic kidney disease accounted for 9% to 19% of all-cause health service costs of which 9.2% for patients with diabetes, 11.6% for patients with hypertension, and 18.8% for patients with both diabetes and hypertension. Overall, chronic kidney disease was associated with significantly higher all-cause health care costs in managed care patients with diabetes and/or hypertension. Based on these findings, a chronic kidney treatment that delays the progression of disease could have the potential to significantly reduce the health economic burden of this chronic disease over many years.

McGillion et al (2008) examine the cost of illness for chronic stable angina patients enrolled in a self-management education trial. In Canada, chronic stable angina (CSA) is a major debilitating health issue. A few studies on cardiovascular disease addressed a detailed examination of the impact of interventions on chronic stable angina-related costs and its broader economic burden. This study was part of a larger clinical trial in which the authors sought to determine the short-term impact of a standardized self-management training program on CSA-related costs. Researchers also wanted to estimate the total annualized cost of CSA per patient from a societal perspective. Pre- and three-month post-test cost data were collected on 117 participants using the Ambulatory Home Care Record. The self-management education trial did not impact on costs in the short-term. For instance, direct annual out-of-pocket costs, including money paid for health care, travel to appointments, medication, equipment, and home support were $3,267. On the other hand, indirect costs, reflecting the value of all unpaid time spent by those engaged in angina-related care, were $12,963. The cost paid by public and private insurers was $2,979. Thus, the total estimated annual CSA cost from a societal perspective was $19,209 per patient. Findings of this study suggest that CSA imposes a major economic burden, comparable with other prevalent chronic conditions. Therefore, advancements in self-management training research are needed to help reduce the economic burden of CSA in Canada.

Trogdon, Finkelstein, Nwaise, Tangka and Orenstein (2007) describe the economic burden of chronic cardiovascular disease for major insurers in the United States. Accounting models provide less precise estimates of disease burden than do econometric models. Using econometric models to isolate the proportion of health expenditures attributable to four chronic cardiovascular diseases--stroke, congestive heart failure, hypertension, and other diseases--researchers seek to improve these estimates. Findings of this study suggest that an estimated 17% of all medical expenditures, or $149 billion annually, and nearly 30% of Medicare expenditures are attributable to cardiovascular diseases. Of the four diseases studied, hypertension accounts for the largest share of prescription expenditures across payers and the largest share of all Medicaid health expenditures. The large number of people with cardiovascular disease who are eligible for both Medicare and Medicaid could lead to large shifts in the burden to these payers as prescription medication coverage is included in Medicare. A societal perspective is important when describing the economic burden of cardiovascular disease.

Wilson et al (2005) state the economic burden of home care for children with HIV and other chronic illnesses. They compared types, amounts, and costs of home care for children with HIV and chronic illnesses to determine the economic burden of caring for and home care of chronically ill children. Caregivers of 97 HIV-positive children, 101 children with a chronic illness, and 102 healthy children were interviewed regarding amounts of paid and unpaid care provided. The value of care was determined according to national hourly earnings and a market replacement method. Findings of this study show that chronically ill children needed significantly more care time than HIV-positive children at 7.8 vs. 3.9 hours per day respectively. Paid care accounted for 8% to 16% of care time. In terms of the annual costs, $9300 was per HIV-positive child and $25,900 per chronically ill child. Estimated national annual costs are $86.5 million for HIV-positive children and $155 to $279 billion for chronically ill children. Thus, caring for chronically ill children is higher than caring for children with HIV. Informal care represents a substantial economic value to society.

To summarize chronic illnesses in the literature is described as a unique experience because of the beliefs, ideas, values, social support and many other characteristics of each human being. The literature on the panorama of chronic illnesses has focused on the perception of chronic illness as a disruptive and burdensome situation that overwhelms not only individuals and families but also health systems, societies and countries. Chronic illness is presented in the literature as an uncontrollable enemy that attacks the person's and family's life. In general, chronic illness is something unexpected that disrupts the normal life. The impact of chronic illness also entails the experience with health care providers. Quality of care for chronically ill people has become a priority in nursing. Yet, accomplishing this task has not been easy. Little is known about how globalization forces affect the body of someone who is chronically ill. The need for this specialized knowledge of subjective data is significant as it will assist us to improve our understanding and develop stronger nursing practices for chronically ill people.

Going Beyond the World of Chronic Illness and Globalization

This chapter shows how globalization is understood as an economic process characterized by increased deregulated trade, economic communication, and capital mobility. Yet, globalization is increasingly perceived as a more comprehensive phenomenon that is shaped by a multitude of factors and events, and that is reshaping our society rapidly; it encompasses not only economic, political and technological forces, but also social, cultural and environmental aspects. In this chapter I have aimed to document how different agencies, organizations, disciplines and researchers present and represent the world of chronic illness. There have been many approaches and efforts to understand the epidemics of chronic diseases worldwide. Research and actions, however, are limited. There is a tension between what is reported and what has been done in chronic illness; thus, despite the fact that chronic illness is the greatest contemporary health challenge in the world, policies are not strong enough to fight its magnitude worldwide. Chronic illness may demand new and different approaches from those currently offered since these illnesses hinder the economical and social development of a country.

While the existing knowledge from the South and North offer diverse mixes of ingredients to understand the magnitude of chronic illness, little is known about the meaning of living with chronic illness under the pressure of globalization and neoliberal ideologies. And, also, we know little about the effects that economic, political, cultural and social forces produced by globalization have on the experience of living with chronic illness. This is a perspective that nurses must take into account, because it is from the vulnerable that new ideas emerge (Dussel, 1980). As nurses, we must take into account that capitalism and neo liberalism tend to dehumanize and depersonalize human beings; people become objects of production, and this can affect our way of seeing and caring for our patients with chronic illness. We must be aware of how health care is influenced by the asymmetrical, unequal, competitive and consumerist politics of globalization. Chronic illness is at the bottom of the list of priorities and is waiting for the world's attention; meanwhile, it continues silently advancing and pushing more countries, societies, communities and individuals into poverty. The hope is to connect and present through new lenses our understandings of the many dimensions of chronic illness. In this way, I hope to contribute to our embodied knowledge of nursing with an innovative way to address the impact of globalization on the daily life of chronically ill people.

Chapter III Interpretive and Critical Inquiry as Methodological Way to Understand Chronic Illness in the Age of Globalization

We must therefore rediscover, after the natural world, the social world, not as an object or sum of objects, but as a permanent field or dimension of existence: I may well return away from it, but not cease to be situated relatively to it. Our relation to the social is, like our relation to the world, deeper than any express perception or any judgment (Merleau-Ponty, 2005 p.421).

The Pathway to the Inquiry

Once I had ethics clearance and administrative approvals in Canada and Colombia, the time had come to begin my study. In Colombia, I worked with the Grupo de Cuidado al Paciente Cronico y sus Cuidadores (Support Group for Chronically Ill People and their Caregivers) associated with the Faculty of Nursing at the Universidad Nacional de Colombia. In Canada I worked with the Kidney Foundation of Canada, Alberta and Northwest Territories Branch. My first step was to present my research proposal in both institutions. In Canada, I presented my proposal in September, 2008, during a yearly gathering for members with kidney disease. In Colombia, in January, 2009, I had the opportunity to share my research proposal with the group of professors in charge of the support group in the faculty of nursing. The response from both institutions in Colombia and Canada truly went beyond expected.

I did not have too much time to share with the kidney foundation; however, I consider my experience in the foundation remarkable. During the summer before I presented my project, I was invited to the yearly BBQ. This event gathers people with kidney disease and their families, donors and members of the community involved with the kidney foundation. It was a nice experience to share with them. I met some caregivers who were interested in telling their stories of caring for someone with kidney disease. A woman approached me that day and shared with me problems she has had to face with the health care system when caring for her father. He suffered a stroke and he was deeply dependent on her care. It was interesting to learn that day that the barriers to accessing health care not only affect the chronically ill but also their caregivers. This encounter led me to consider this aspect of chronic illness, one I had not considered before.

In Colombia, with the support group, I had the opportunity to participate in the first opening group meeting of 2009. That day, I learnt about the organization and its pioneering projects. Its work has expanded into other cities in Colombia, Latin America and Spain. For me, as a Colombian nurse, I felt proud to see how nursing is taking a leadership role in research, law projects and proposals to improve the health and well being of caregivers of people with chronic illness. In this encounter I was presented with new plans and strategies for caregivers, such as the incorporations of dyads or triads of caregivers in Bogotá. This strategy consists of pairing experienced caregivers with less experienced or new caregivers as a way to diminish the burden and improve the support for everyone involved. Another strategy includes the development of multidisciplinary teams coordinated by the faculty of nursing to offer legal consultants, pharmaceutical advisement, nutritional education, psychological advice, physical therapy, recreation, and nursing consultations for caregivers and the chronically ill. As well, the group was informed of the development of a law to protect the rights of caregivers of the chronically ill in Colombia.

As the weeks went by in Canada, I received my first call for an interview. I was excited to begin the process of research. Meanwhile many questions came to my mind before this first encounter. What if this person does not understand my English? What would happen if I do not find the right words to express my thoughts and questions? What if I am not able to understand? How do I question something if I do not follow the flow of the conversation? I prepared some questions in advance, trying to rehearse a process of interview in English. It was worrisome for me to start a conversation on chronic illness in a language that is not my mother tongue. But then I decided to relax and let the conversation follow its own flow. My other concern was in regards to the process of recording. I did not want to risk losing the richness of the encounter by the possible failure of my recorder. So I brought three recorders for my first interview. I wanted to be prepared. I know technology would fail when you less expect it. In the end, all worries were washed out of my mind when I came to the home of my first participant. All the anxieties and apprehensions were gone. Through time I became more confident and I ended up just bringing one recorder and my notebook.

Another key point of my conversations was to keep a writing record of my thoughts, reflections and ideas. In my journal I kept notes from each one of my encounters. I tried to keep a record of the encounter before and after. The following is a short example of what I wrote before my first encounter in Colombia:

> *March 12/09 I am on the bus on my way to my first conversation. I am very happy to begin the process of data collection in Colombia. Outside, it is raining but it is not cold. The sky is cloudy and very grey. The map in the bus shows me that the way is long; I have to wait another ten stations to get off. Outside, it is raining and people are running trying to find some protection from the rain. I decided to begin my writing here, taking advantage of the fact that the bus is empty and there are not too many things to see outside. Today, I have my mind open to learn more about the experience of chronic illness. It could be different from Canada. I did work in Colombia for several years. So I know more about the context of chronic illness in Colombia than in Canada. And yet I have been away from the practice of nursing for 3 ½ years now. I wonder if something has changed. I do not know what to expect. Last Monday night I talked to them by phone, they sound really nice and open to participate in my study. My first participants are a couple. Both have cancer. Chronic illness is a difficult topic to talk about. I will keep my mind sharp and open to their accounts. I am sure I will learn a lot today. My stop is close. I will continue my notes later.*

The following is a short example of my notes after the encounter:

> *Today I met Alfredo and Maria, as they want me to call them, for the study. They are really happy to participate. They were open to share their experience with cancer. This is my first time meeting a couple who both have cancer. Alfredo and Maria like to be politically involved. They were members of the union. They are commitmentd with the fact that they have to fight for their rights. Their process of illness began suddenly without any warning. Maria has some chance of recovery because her cancer was found in time. While Alfredo's doctors dismissed his disease for a long time and when they paid attention it was too late to fight back. Maria, the caregiver, needs now to be cared for but Alfredo cannot look after her. For Maria it was her time to be ill. I kept wondering what she meant by that? Was she exhausted by being Alfredo's caregiver? Despite her illness, Maria's role of caregiver has not changed. She continues being with him. It has been an enlightening experience to learn how they are resilient in dealing with the barriers the system creates around them. Despite this, they keep fighting with their illness, health system and insurance company. They both think their illness is a gift to them. Cancer has come to their lives to change; they understood the need to change the path of their lives. My knowledge of chronic illness is limited and yet the world of chronic illness is full of opportunities to explore and understand.*

Overall, institutions and participants engaged fully with the study from its very beginning. Institutions felt this study was an opportunity to learn more about people with chronic illnesses and their experiences. In both countries, institutions wanted to learn more about those things the experience of chronic illness evokes and that cannot be measured. Immediately, they grasped what the study was about. Through this type of study it is possible to assist health care professionals and institutions to improve their understanding and attention for chronically ill people. They knew that the day to day life experience with chronic illness was at the heart of this dissertation. In both places I felt immediately welcomed and they quickly started to help me with the recruitment process. Also, in both countries I met and talked to people with chronic illness and their caregivers, an opportunity which gave me an insight into the process of understanding chronicity. The journey was an amazing endeavour for me not only as a professional but also as a human being.

Being Attentive to the Inquiry

In the search to understand the experience of chronic illness in the age of globalization, I sought a tradition of inquiry that would not misrepresent, add to, or mislead the experience. I encountered that tradition in van Manen's (1997) interpretation of hermeneutic phenomenology. Through interpretive methodologies, the objectives to explain and predict are challenged by the desire to describe and interpret the meaning of human experience in order to seek ways to engage with others and their worlds (Cameron*,* 2006). Hermeneutic phenomenology not only facilitated my interpretation of the structures of the experience of living with chronic illness, but, also, facilitated how things were understood by the participants and by me. Hermeneutic phenomenology identifies the participants' meanings from the blend of the researcher's understanding of the phenomenon, participant-generated information, and data obtained from other relevant sources (Wojnar & Swanson*,* 2007). The interpretation is open to re-interpretation and is dialectical in nature (Gadamer, 1989). So the aim of interpretative phenomenology is to interpret everyday as a pathway that neither attempts to deny nor to overestimate our human experience: in nursing it means that in meaningful ways we may experience and understand the nursing world and the relations that commitment it (Cameron, 2004; Darbyshire, Diekelmann & Diekelmann, 1999). Thus, our everyday way of being-in-the-world is not one of detachment, but needs to be one of engagement, because sometimes the depth of human life may become flattened, simplified, and even polarized by traditional thinking (Bergum, 1989; Johnson, 2000). As humans, we are hermeneutic beings capable of finding meaning in our own lives;

it means that our understanding of the world cannot happen in isolation of our cultural, social context or historical period in which we live (Heidegger, 2002).

Although hermeneutic phenomenology enabled me to understand the human experience of being chronically ill in Colombia and Canada, I wanted to more deeply probe how the effects of social, economic and political forces imposed by globalization affected the experience. I wanted to understand and help to overcome the structures by which people with chronic illness are dominated and oppressed economically, politically and socially. I needed a critical approach that could help me to examine institutional and social practices and processes, and identify barriers and facilitators to change. This understanding is important for nursing as a discipline and practice because, “A critical…approach places the consciousness of nursing directly in relationship with the lifeworld and the administrative system” (Ray, 1992 p. 385). Thus, critical approaches in nursing help to promote change and empower human beings by critically determining the social, political, and economic phenomena that place restrains on them (Driessnack, Sousa & Costa Mendes, 2007).

In my journey, I found the Argentinean philosopher Enrique Dussel and the Brazilian educator Paulo Freire. From different perspectives, they have helped me to critically understand the effects of globalization for the chronically ill. Their ideas are consistent with my research goals and also consistent with my Latin American roots and identity. Both Freire and Dussel felt what it is like to be vulnerable; they experienced poverty as a palpable reality that was impossible to ignore. Their thoughts emerged from South America, a continent that has been living under foreign imposed policies which have led it into poverty, inequalities, oppression and exploitation. However, the physical place of their inspiration does not limit their philosophy, because they reflect a reality that affects the whole world. Using Dussel’s philosophy of liberation has informed my understanding of the experience of being chronically ill and enabled me to explore the various dimensions of that human experience from the periphery, i.e., embodiment, spatiality, relationality and temporality. And Freire’s critical pedagogy has helped me to explore emerging findings of that experience of chronic illness in the context of global inequities. Both Freire and Dussel helped me to understand the complexity of the predicament of the chronically ill from a different perspective, a perspective that comes from the South. It is a perspective that is international in scope because there are oppressed everywhere; a perspective that goes beyond geographical boundaries and creates a language of possibility in which the chronically ill are active participants.

Conversations

The first condition of the art of conversation is ensuring that the other person is with us (Gadamer, 2006 p. 360).

As Gadamer explains, conversations and dialogue are not just a means to use in research, but are what researchers should seek to cultivate with their participants. In this study I prefer to use the term conversation instead of interview. Through dialogue, two or more people come to understand each other. In a dialogue, participants open themselves up to one another. Conversation is a process in which participants truly accept their point of view in such a way that they understand not a particular individual but what the person says (Gadamer, 2006). Knowledge comes out of interaction with other human beings. The word conversation evokes interaction and captures the attitude of that interaction (Bergum, 1989). The atmosphere of the conversation was open and the aim was to gather descriptions of experiences as sources for understanding the lived experience of those living with chronic illness in the age of globalization. The encounters with eight chronically ill participants lasted over a period of nine months, between November, 2008 and July, 2009. Also, I quickly discovered that the process of having conversations was an unpredictable one. It took its own course through a network of people, and it took its own time.

In a conversation, participants have a central focus, different from mine, but it is not one-sided. Conversations were approached as relationships to enter rather than simply as methods. Conversation is a way to an understanding (Bergum, 1989). In conversation, knowledge is not a fixed thing or a commodity waiting to be grasped, or simply something out there waiting to be exposed. Rather, conversation is a key element in the process of understanding. We come to a conversation with our own views and personal vantage point. Yet, the personal viewpoint with which the chronic illness is approached necessarily carries its own assumptions, biases, theoretical knowledge and pre-understandings (Gadamer, 2006).

The process of interaction involves description of the experience and, eventually, reflection of that experience by participants. Conversations need their own rhythm and time. They cannot be rushed by my own priorities. Our encounters were scheduled during a time when the participants were in control of their illness. For instance, Alfredo sounded fine when I called him, but in reality, when I came to his house, he was in pain. So I tried to reschedule the encounter, but he did not accept my offer. He wanted to talk that day. Camille, another participant, had some health issues during our second conversation. She had just received the news that her cancer was back. She was not sad at all but I noticed our conversation was about death that day. Before our conversation Alejandro wanted me to check his diabetic foot. In my conversations I had to switch many times from researcher to nurse. I was willing to do that. Most of my participants were dealing with acute conditions during the period of the study so I did have to accommodate the study to the participants' rhythms of life and illness.

Dialogue, however, is not only limited to the interaction between human beings. There is also hermeneutic dialogue with the text (Gadamer, 2006). Interpretation requires the right language if the interpreter truly wants the text to speak (Gadamer, 2006). Once the encounters with the participants were finished, I began my dialogue with the text. But, different from the one on one interaction between humans, here the text maintains a passive role. It does not respond to the interpreter's action, but, rather, remains as object from the past—a memory. The dialogue with the text is not mutual. In fact, "The interpreter acts upon the text" (Smith, 1997 p. 439). One important aspect of this conversation is that different readers at different times will find different interpretations when reading the same text (Gadamer, 2006). And yet when we approach the text we do so in an open manner to see what we can learn from the text in our particular circumstances (Gamsu, 2008). Thus, gaining a sense of meaning of the text always entails an act of application to current circumstances. One challenge emerging from the interpretation of the text was to keep intact during the translation from Spanish to English the essence of the lifeworld of chronically ill Colombians. There cannot be a perfect translation. The meaning in a translation must be held but since it also needs to be understood in a different context, it must change its original validity to establish itself within a new world (Gadamer, 2006). Thus, taking into account that the translation does not reproduce the meaning of the original, we have to rely on the feeling that all languages somehow converge (Eco, 2001).

Finally, another important piece of my dissertation involved the ongoing conversations with my supervisor, Dr. Brenda Cameron. With her thoughts, reflections, ideas, questions and suggestions, she helped me to maintain the respect for the phenomenon as lived, to understand how the experience of chronic illness comes to life as text and to critically understand the effects of globalization in the daily life of the chronically ill. She followed the inquiry very closely. She was always ready to address my questions. Her respectful suggestions and questions regarding particular situations were highly appreciated. Conversations with Dr. David Smith helped me to understand better the processes of globalization and neoliberalism today after the economic meltdown. I appreciated his expertise, knowledge and scholarship in that area.

Participants

I recruited eight participants with about equal numbers from Colombia and Canada. Participants in this study were eligible to participate if they met the following inclusion/exclusion criteria:

1. Participants eligible for recruitment included adults between 25-75ears old
2. Participants with two or more years living in situations of chronicity regardless of their diagnosis and physically able to participate. I chose this time period, as it is perceived to be an adequate timeframe to avoid potential distress that may be raised for these people by talking about their chronic illness too early.
3. Participants were selected according to their ability to express themselves and the willingness to share their experiences with the researcher.

In the next section I present my participants in this study.

Hannah.

Hannah is the youngest participant; she was 26 at the moment we met. She has been living with chronic illness for 10 years of her life. Her condition began when she was in her last year of school. This experience was very devastating for her. The insidious beginning of the symptoms left her alone in a time of her life that is supposed to be full of vitality. The course of her life changed drastically. Suddenly, she could not go back to activities she used to love such as dancing or cheerleading. Those activities and having fun with her friends were no longer a part of her life. She resented that. She stills does. The pain, which has been part of her life for a long time, is what defines and orients her rhythm of life. The whole experience has been overwhelming for her and her family. At first, they moved from one specialist to another in search of the answer to Hannah's illness. So far there has not been an answer; her illness has continued its violent course while not giving her or her doctors any clue to what it is. She has not come to terms with this part of her condition; it is hard for her to fight against something unknown. Her family, though, has been her pivotal support in the moments of crisis.

Hannah has a mother, father, two sisters, one nephew and a boyfriend. These people are what keep her going, although they do not talk very much about her illness. Economically, chronic illness has been a problem for her parents. In the quest for an answer, Hannah's parents have spent a lot of money trying to solve the puzzle that nobody has been able to decipher. She has a boyfriend who loves her for who she is. Her condition does not stand in the way of his love for her. But in other relations, Hannah had bad experiences associated with being ill. Others did not know what to expect from her, so through time they got bored and left her. Hannah does not have many friends because it is difficult to explain to others the meaning of something abstract and unknown. She prefers to be alone. She got tired explaining to others why she cannot always be active. And like her doctors, some of her friends believe Hannah's illness is the result of her mind. So to avoid social difficulties, Hannah prefers to keep her distance from people.

Despite her young age, Hannah has gone through a lot. Many bad experiences with health care professionals, friends and some relatives have shaped her experience with illness. She became a nurse to fight the indifference she has suffered for a long time in the health care system. She is resilient. She has learnt to appreciate the value of life. She enjoys those days when the pain is gone. She has dreams. I could see that when she told me about her career plans. When Hannah finished nursing, she could not work in a clinical setting; with her pain it would be impossible. So, she decided to change her nursing focus toward occupational health and safety. This is the right place for her. It is part of nursing and she has plans to work with chronically ill people in that area. It does not matter how many times her life has been limited or put on hold by her condition;

she keeps going. Through time, Hannah has learned to appreciate the good in her life. She had to mature when she was very young and in her unique way she has learned to enjoy life.

Camille.

Camille was in her middle 50s at the moment of our encounter. She was a mathematician and she worked as a statistician in the Prosecutor's Office for most of her professional life. Her job and sports were the most important things in her life, until one day excruciating pain began. She went to the doctor right away and her doctor made an appointment for therapy, which she could not attend because her boss would not let her go during the work time. To avoid any conflict in her job, Camille decided to postpone her treatment for six months. When the pain became unbearable in December, she went to Emergency. The discovery of her disease was accidental. Her doctor checked the box for a CAT scan instead of an X-ray; during this exam, multiple metastases were found. She did not respond as other people respond to the news of cancer. She was calm. Camille portrays an image of calmness and peace with her diagnosis. She kept a positive outlook during our encounters. She recognized that she is a "palliative patient" as she called herself but she was fine with that.

The news of her cancer was not well received by her family. Her brother and sister were devastated by the news. She was the oldest sister. She did not have children or a husband to worry about and that helped her to remain calm. She was a single woman without any responsibility. The only people she could have worried about were her parents, but they had died not long ago from chronic illness. However, she felt sorry for her siblings, especially her sister who was dealing with Camille's situation alone. Her sister is her caregiver. She also worried that her only sister would need someone to rely on when she is gone but would not find one. Her brother, on the other hand, was shocked and worried at first but then he became critical with Camille; he blamed her for her condition. He kept questioning her. He invited her to dig deep in her heart to discover the real reason for her cancer. He was tough, but Camille understood him. She knew that he was applying to her the same rough therapy his family received when his only son was treated for addiction to drugs.

For Camille, the presence of cancer was a kind of a blessing in her life. She did not have a social life before. Cancer changed her life and gave her a positive outlook. She kept her old friends and found new ones. Her perception of time changed. What used to be important was not anymore. Her obsession with perfection and vanity ended the day she began her chemotherapy. She was grateful with God for this second chance in her life. She met interesting people along her way, women with breast cancer. Camille was an active member of the support group for women with breast cancer in her insurance company and also she was part of the support group in the faculty of nursing at the National University. Through her illness she developed a sense of solidarity with other people in pain because she knew what it was to be in pain. She described those support groups as the places for community in which members in the same condition support and help others. She loved them.

She had a very good relationship with her doctors, nurses, and insurance company. They always were ready to help her. Her only concern was an economic one. She was living through most of her illness on half of her salary because her long-term disability was not approved. Fortunately, her sister helped her financially. Despite the difficulties, Camille felt blessed for all the support and love she received. But she saw many of her friends having problems accessing the health care system in moments of pain when care must be a priority. Another friend could not adopt a child because the label of cancer is a stigma that cannot be erased. She was also concerned about the lack of politicians interested in the fight for rights for people with cancer.

In our last encounter, Camille changed her tone; her words were full of melancholy. She just received the news her metastasis had come back and, also, some of her friends were dying. We spent most of our last encounter talking about death. We knew her time was coming so the good-bye was really a sensitive one. She told me that we had met for a reason and the reason was that I was the messenger of her story. She wanted to share her experience, her life with others. After that, we kept in touch. In our last conversation she let me know that her brother had changed his attitude and that there was a possibility of doing another round of chemotherapy and radiation, but she was very weak. Camille died in January, 2010 soon after her second round of chemo. Her sister sent me a beautiful note right after with all the accounts of her last moments. She thanked me for being part of her life and telling others her sister's story of life.

Maria.

Maria is a psychologist. When I met her, she was in her late 40s. She worked as a student and teacher counsellor in public schools most of her professional life until she was forced to retire due to her cancer. Maria is the oldest daughter in her family. Her siblings see her as their role model because she was the first in her family to leave her little town and become a professional. Her diagnosis was discovered by accident. Her health insurance company was changed as a part of reforms done by the state. In her first visit to her new doctor, a mammogram was requested even though her last one was done just eleven months before. During the exam, the technician noticed something wrong and decided to repeat the test. When she learned that the radiologist had found something in her breast, she met with him right away and a new appointment was set for the next day to compare her old mammogram with the new one. It was hard for her. When the doctor compared both tests, the news became devastating for her. She needed to go immediately to the breast surgeon. He confirmed that the possibility of having cancer was very high. She needed a biopsy. She kept her news to herself and only shared with a friend because she needed company for her biopsy. Her husband did not know anything about it. She did not want him to know because Alfredo had cancer, too. Later, when the biopsy came back positive and the necessity to go to surgery was evident, she decided to disclose the information to Alfredo. The moment was really hard. Her surgeon scheduled only oral chemotherapy for her.

Weeks passed by and new changes in her health insurance company forced her to change her doctors again. Her new doctor wanted to begin chemotherapy and radiation. She did not want to. Her parents and sibling did not know about it. One by one her siblings learned about her condition. She did and still does not want her parents to know. According to her, they are old so there is no point in making them suffer. Today, she knows her father knows, but they do not talk about it. Support for Maria has come from many places: husband, family, friends and colleagues are part of the support net. During her treatments she continued working until she received her long term disability. She was happy because that meant she would be at home with Alfredo who was alone most of the time. Economically, there were no constrains on her.

Maria has a positive attitude toward her illness, something that has been overshadowed by their struggles with the health care system. She has had many problems when accessing treatments, medications and medical specialists. But with Alfredo, she fought to regain her right to health. They loved to be politically involved. They were members of the teacher's union and the union helped them to fight while they were still teachers, but, no longer teaching, they did not receive any further support from them. After that, they were mostly on their own with their fights. For Maria, it has been hard to recognize that others have cast her aside, but she keeps going, despite that her positive idea of what cancer means to her is challenged every single day.

Alfredo.

Alfredo was in his late 50's when I first met him. He worked as a lawyer and social science teacher for a long period of time. He was the youngest among 14 siblings. Alfredo studied for two careers: first, he finished law school and then he pursued social science. He was really passionate about his two professions. He worked from eight in the morning to noon as a lawyer. He had his group of clients he worked for. When he decided to retire from law practice he was handling more than 50 cases. As a social science teacher, he worked from one to five in the afternoon. He loved being a teacher. Alfredo used to organize trips outside of the city with the students, and he used to be the organizer of soccer, basketball and micro-soccer teams. Despite his spending most of his time working, Alfredo loved to practice several sports. He had two daughters. The youngest one was five years old when his symptoms began. One day, and without any warning, a pain in his back began. He did not pay attention to it. He thought the pain was the result of stress due to the process of his divorce. He used some painkillers to dissipate the pain. Eventually, Alfredo decided to go to the doctor, but he was dismissed because he looked healthy.

After months of going back and forth among physicians, Alfredo was told he had metastatic cancer. He knew there was history of cancer in his family; his mother died of stomach cancer, his father had esophageal cancer and one of his brothers died of prostatic cancer. The news of cancer was another desolating moment that, added to his divorce and his work overload, resulted in his depression. He spent most of the time alone, watching TV. There was no motivation for him. He was also scared because his daughter was so little. He did not want her to suffer emotionally and financially. During this time he met Maria; they were working together. She was his company during chemotherapy and radiation treatments. After five years in the relationship, they decided to get married. His life changed with Maria. She gave him a new beginning, another reason to fight. Alfredo was surrounded by the love and support of Maria, siblings, friends and colleagues. His nephews convinced him to give up his two professions. He was happy to do so. While Maria was working, he spent most of his days reading and going to conferences about cancer and growing personally. Financially, he did not have any problems after his retirement. He was under long-term disability, and, although he was earning less, it did not bother him.

Like Maria, his only problems were with his health care insurance. He was Maria's legal advisor, and both fought when it was necessary. Learning about Maria's cancer was a difficult moment for him. There were moments when he felt bad because he couldn't be more useful to Maria. His limitations with walking did not allow him to be a help for her. When we met, he was suffering from a set-back; he was unable to move without the help of crutches. He was confined to the second floor of his house. It was hard for him to see how he came from being active to being completely dependent on Maria's care. Since my previous visit, he was weaker and mostly in pain. When he was better, we met. That day he was happy to see me. He was happy that the medication controlled his pain and he was able to talk to me. He told me repeatedly that he was able to talk with me because of his pain control. That day he confided in me what his deepest fears were: pain and death. He was scared of pain because pain was the constant remainder of death. He was scared of death because he did not want to leave Maria alone and without protection. That day the conversation changed its rhythm. I turned off the recording and we talked about pain and death. I was there as a listener. At that moment my role changed from researcher to nurse. I knew he needed to talk, so I kept encouraging him to talk. Maria was there but she did not say a word. She could not. He was saying good bye to her. It was hard on her to hear those words so she left the room trying to hide her tears. I felt moved and sad. I kept in touch with them. The last time, he thanked me for calling him and for not forgetting him. We did not speak long; his breath was very laborious. His last words to me: “Pilarcita, you are a wonderful woman. La Virgen Maria la llene de bendiciones a usted y a su trabajo/The Virgin Mary blesses you and your work.” He died in December of 2009.

Alejandro.

Alejandro lives in the south of the city. Alejandro’s apartment building is not very accessible for him; he lives on the third floor. The stairs to go to Alejandro’s apartment do not have proper light so going up and down becomes a dangerous task for someone like Alejandro. Alejandro’s apartment has three small rooms. His favourite place at home is the dining/living room where he likes to sit in a corner close to a big window with a view to the mountains and other apartments. From this place he has a good view of the outside to see who is coming or going. This is also the best place in the room to watch TV. He was seated there in the small room watching TV when I walked in. On the table he has his glasses and an old newspaper. When Alejandro’s wife invites me to come in, their birds begin to chirp and move almost frenetically from one side of their small cages to the other. For a moment he compares his life with the lives of his birds. When I walked in, his first words were, “Doctora mire mi piecito/Doctor look at my foot.” I was concerned with what I saw. That foot was showing some signs of infection. I asked his wife how she was doing the cleaning. But they told me nobody taught them what to do. Clara was only applying jelly petroleum in the wound. He was wearing closed shoes. So I explained how to do the cleaning and what type of shoes he should wear. They did not have any health care supplies to clean his foot. So at home, I called some of my friends in nursing and asked them about affordable ways to treat his foot. Once I had that information I called Clara and let her know that information. They were thankful with me.

Alejandro is in his 70’s. He was retired at the time of our conversation. As a foreman, he worked for the government by building highways across Colombia. He was married to Clara. His diabetes was diagnosed when he was young. He knew it could be that way because all of his family members from his mother’s side were diabetics. When Alejandro was young, he did not care too much about his health. He took his medications but he did not follow his diet. In 2001, he retired from his company. For a while, he continued travelling and working with his friends until his health did not allow him to. Today he is living with the consequences of his lack of care. He had a heart attack, a stroke, and two retinopathies; as well, his kidneys started to fail, and he suffered from a diabetic foot. When he wanted to take care of his health, it was too late. He misses his old life. Clara, his wife is his only company. They have children but they do not live close to them. Being at home has made him be more aware of his disease, more cautious. Alejandro's social life has been limited by his illness and his friends do not call him anymore. From being active, he is now secluded and alone in his home. Lately, he faced an amputation because his doctors did not pay attention to him. Alejandro does not complain about his health service despite all his health problems. He never complains, maintaining a silent position because he does not want to jeopardize his medical attention. His chronic conditions are expensive and sometimes he has to pay personally for his medications. His wife Clara has diabetes and hypertension medications, so treatments for both of them need to be taken into consideration. Clara maintains her role of caregiver despite that she also needs someone to take care of her. During my encounters with Alejandro, she was hospitalized twice. He cannot help her because he is limited. When she notices he is depressed, Clara encourages him to keep going. Life has been very hard for both of them. He was happy to be part of the study, especially to do something different as a way to change the routine of his daily life.

Sarah.

Sarah is a retired realtor in Canada; she worked for many years until she decided to step down and leave her job to her daughter. After recurrent kidney infections, Sarah's aunt asked if she was already tested for the condition her mother had--polycystic kidney disease. Her doctor ordered a test for her and when the test came back positive, Sarah was advised to have a tubal ligation. After discussing the request with her doctors and husband, Sarah accepted. She already has two children so not having more was not really a big problem for her. Her disease did not cause too much trouble in Sarah's life. She carefully followed her doctor's recommendations but other than that her illness was not a problem in her life.

She has always believed in the importance of being her own advocate. As a part of her role of advocacy she became a member of the Polycystic Kidney

Foundation in the United States and began to learn more about her illness. She went to her doctor many times with new ideas from conferences but her knowledge was not accepted by her physicians. Her ideas of visualization of her kidneys to aid their becoming healthy and small and her use of other resources to improve her well-being were not accepted by her doctors. But she did not care. She kept going to those encounters to learn more about how to improve her health.

Sarah received a renal transplant in 2007. She was a little reluctant to do it but after a while she decided to follow her doctor's recommendations. After her transplant, Sarah could understand how ill she was because she was not tired anymore. It was a relief, a new beginning. Her only concern is with the medication she takes for her transplant. She knows about the potential for some side effects, mostly skin cancer and cardiovascular disease, with each of the medications. The medications require strict follow up, but Sarah's doctors consider her concerns unnecessary and excessive. Although Sarah has struggles in her role of advocacy, she feels her life has been good. Her life did not suffer too many changes. Being proactive and attentive to her health are her priorities in life.

Jon.

In 1998, Jon suffered the first symptoms of his disease. He was tired all the time; his doctors did not know what was happening to him, until one day at work he fainted. He received the diagnosis of chronic kidney failure and almost immediately he had to be haemodialysed. His family was away and he was alone and scared. His oldest brother suffered the same condition in 1968 and died. His little daughters were in his mind the whole time. He is worried for them because he does not want to leave them. His first dialysis was a frightening experience for him; he was dialysed very quickly and with the wrong size of filter. Since then, he decided to be an active participant in his treatment and care so he began to read about his condition. Also, he paid attention to all the things related to his disease, such as how the machine works and what the nurse records in his chart. He never complained about the attention; on the contrary, compared to the attention his brother received in the 60s, he was doing great.

At this time, getting better for him was his priority, mostly because he wanted to go back to his job as soon as possible. He even sought to go back to work when he was in dialysis part time. His company replaced him at work right away, but he understood. Overall he received a lot of support from family, colleagues and friends. His family was important to him. To keep the lives of his daughters as normal as possible, he scheduled his dialysis at night. His wife went back to work. They worried for him but overall he kept the dynamic of his family's life intact. After his renal transplant, Jon wanted to go back to work but the company was afraid that he could not fulfill the demands of his job. A new goal was set in his life: to demonstrate to his bosses that he could work as well as other younger and healthier employees. Little by little, Jon has recovered the trust of his employers and now he works and travels like other employees.

Jon did not have any financial difficulty. His bank covered his short term disability; however, he had to fight to get it. Jon thinks that there should be more laws to protect employees with chronic conditions and allow them to get back to work. He wants equality and respect for people who want to work no matter what their health status. Jon had rough times but he prefers to remember the good ones. He has maintained a positive mind during his whole life. He wanted to participate in the study to let other people with chronic illness know that it is possible to overcome their situation.

Maurice.

Maurice is a teacher in his late 50s. When he was a teenager, his health problems as a diabetic began. Later, with the evolution of his disease, he suffered from retinopathy and kidney failure. He received kidney and pancreatic transplants in 2003. For him, growing up with diabetes was not an issue. Despite that his diet was different and that he had to pay more attention to his body, he continued living like his friends. Because of his positive outlook, nurses and physicians asked him to encourage a positive attitude in others in the hospital.

Maurice's wife has a different story. She is a nurse; she sees people dying all the time. She worries for him a lot. For her, even today talking about Maurice's moments of illness is difficult. After Maurice's transplant, she thought he would not come out of the hospital. It was hard for her. Their children were fine because despite that Maurice and his wife were usually open to them, they did not want them to worry during this moment of crisis. Maurice also has received a lot of support from family, friends and colleagues. For a time, his only concern was related to the lack of access to life insurance and driver's licence for people with diabetes. To obtain the latter, he always needed an evaluation from his doctor. The former was impossible to get so he gave up trying to secure the financial future of his children. In general, he believes that with chronic illness one makes a choice about how one is going to allow that chronic illness affect one's life.

Consciousness raising group

After I had completed the conversation experience in Colombia, I implemented a consciousness raising group. A consciousness raising group is an educative encounter between the researcher and participants to create individual and social change (Carey, 1994; Henderson, 1995). The goal of this consciousness raising group was to address complex issues involving many levels of feelings and experiences about chronic illness. Through recognition of social, political, economic and personal constrains, consciousness raising groups provide a forum to take actions against those constrains (Henderson, 1995). To prepare, first, I explored the findings of each one of the conversations to formulate broad concepts to be explored. From these concepts I got four guiding questions for the session. The consciousness rising group requires dialogue and interaction between researcher and participants, in which the latter become aware of their problems as a group rather than their own individual problems (Freire, 1973). For me, this activity was really rewarding and fascinating.

As a group, we decided to do the activity in the house of Alfredo and Maria due to his illness. He was very ill, so the other participants decided to go there. Camille's health was not good, and although I was planning to give her a ride, she decided not to go. When we arrived, I introduced Maria and Hannah. Maria told me that Alfredo was in very bad shape. Due to severe pain, Alfredo could not participate in the activity. The night before was not a good one because he was in pain and the painkiller was not working. She even told me he was vomiting for the first time since his cancer began. She was distressed so I asked if she wanted to continue with the activity. She said, "Yes, I need to keep my mind occupied." For her it was difficult; she was not sleeping at all. During the night, she was constantly checking to see if Alfredo was still alive. This was taking a toll on her: her back was painful and she was under a lot of stress. I asked if I could go upstairs to say "Hi" to Alfredo. Alfredo was happy to see me. He barely moved his head toward me. I asked if he was in pain but he did not answer. I touched him and talked to him for a while but he was really weak so I did not want to bother him too much. He was pale, sweaty and cold. He said to me: "Thank you Pilarcita." While waiting for others to arrive, Maria and I talked about Alfredo's health. I gave her some advice on what to give him in case of nausea. Hannah related her experience of pain with Alfredo's and gave Maria some tips. When Alejandro, Clara and their little granddaughter arrived, we were talking about how stressful pain was, not only for the person experiencing it, but, also, for the family.

They were happy to be there, but Alejandro was having some problems walking. After all the introductions, we decided to meet in the dining room. We started introducing ourselves and telling something about ourselves. Then, we started talking about chronic illness; however, for a moment during the session my recorder stopped working. It was wet, but Hannah repaired it and I continued recording. As a group, we considered that there was a process of transformation in each one of us. During the implementation, I explained to them the rules of the session. I encouraged participation and carefully paid attention to the responses of my participants. I summarized before we moved to the next question or topic. The session did not follow a rigid structure. I came to the dialogue feeling humble and ready to learn with them. My idea was oriented toward dialogue and interaction among participants. They enjoyed the opportunity to participate and the space to speak out. In Chapter VI, I presented the results and my analysis of this activity.

Data analysis

Data analysis included:

a) Written direct descriptions of participants' experiences. Once the conversation was completed, the audio-tapes were played and re-played and the conversations were transcribed. I chose to write immediately, while the experience was still fresh in my mind. In a further reading of the transcripts as a whole, then as sections of descriptions and stories, then as phrases and words, I also kept in mind, the tenets of Freire and Dussel. While I did not let these overshadow the lived descriptions, their notions enabled me to ask questions of the data and to probe deeper. I especially foresaw that these perspectives enabled me to ask additional focus questions in the consciousness-raising groups along with topics coming from the individual interviews.

b) Development of thematic moments was developed reading and re-reading the transcripts and also re-playing the audio-tapes to ensure turning to the essence of lived experience. As Bergum (1989) says, "As I read the stories, I began to notice that each story somehow characterized a particular theme" (p. 50).

c) Reflecting on essential themes. The researcher is encouraged by the object in a full and human sense in which superficialities are not allowed (van Manen, 1997). The themes are the central and meaningful structures of the experience. However, I took into account that my description was only one possibility among many to interpret a human experience, I opened my mind to potentially richer or deeper descriptions to understand chronic illness as experience in a contemporary global context.

d) Writing and re-writing. According to van Manen (1989, 1997), writing in hermeneutic phenomenology is an artistic activity in which the author like the artist goes back and forth between the whole and the parts. It is a process in which the whole is as important as each one of the parts of the phenomenon to end up "at a finely crafted piece that only reflects the personal signature of the author" (van Manen, 1989 p. 242). Thus, writing increased my understanding of the world of people chronically ill in which things that I could not see before became more apparent.

The analysis was done separately with each group of participants and written as findings of two groups. These findings addressed the topics and questions for the consciousness raising groups that I explained above. The analysis and interpretation of the consciousness raising group followed the similar steps for the individual conversation with the added dimension of the group context (Corey, 1994). Then, I wrote direct descriptions of the groups' experiences; I developed thematic moments through reading and re-reading the transcripts and also re-playing the audio-tapes to ensure turning to the essence of lived experience; I reflected on essential themes; and I wrote and re-wrote.

Later, the findings were consolidated as a global chapter with recommendations for practice, research, and health policy development. Understanding was sought concerning alleviation of suffering in light of the lived effects of globalization processes that inflict unnecessary and undesirable pain for the chronically ill as well as suggestions for policy and best practice changes.

Scholarly Rigor and Credibility

To maintain the rigor and credibility of this study, Meleis's (1996) eight criteria to work on culturally competent scholarship in nursing were used. The eight criteria include: context, relevance, communication styles, awareness of identity and power, disclosure, reciprocity, empowerment and time. To understand the experience of living with chronic illness in the context of contemporary globalization forces, respect and commitment toward my participants were my priorities in order to get their trust during the whole process of research.

Context involves a sensibility that has an awareness of the other person's socio-cultural past. Sensibility was at the core of this research; it was a requirement in order to understand the experience of living with chronic illness in the context of contemporary globalization forces. The context also helped me to address not only the conversations but also my interaction with the participants.

The relevance criterion refers to the extent to which the research questions are considered meaningful and significant for the population studied. As I described in Chapter II, chronic illness is a major threat worldwide that has received little attention from the heads of state, worldwide organizations and private investors. Research has oriented its efforts toward specific In research, many studies have demonstrated the economic cost and burden of chronicity (Bukstein, *et al,* 2005), the effects of barriers in the health system (Valverde, *et al.*, 2006), the importance of self-management programs to change risky behaviors (Boldy *et al.*, 2006), and the need to develop culturally-sensitive initiatives of prevention (Astin *et al.*, 2005). Yet, knowledge is limited of how the social determinants of health affect the experience of living with a chronic illness. We also know little about how the convergence of social, political, educational, and economic forces acts on the body of someone who is chronically ill. As a result, the questions for this study emerged from a reality of the world, a reality for people who are chronically ill.

According to Meleis, to be culturally competent the research must demonstrate critical understanding of preferred communication styles, variations of language, symbols and communication styles of the population being studied. Using the participants' own concrete reality as a point of departure to communicate with them was my endeavor as researcher and as a way to respect them and make them an active part in the process of investigation. Meleis also invites researchers to be aware of the identity and power difference between researcher and participants. For my study, I kept in mind that "…regardless of one's social and economical function, all human beings perform as intellectuals by constantly interpreting and giving meaning to the world and by participating in a particular conception of the world" (Freire, 1985, p. xxiii). Following what Freire says, I was able to establish more horizontal relationships with the participants. Each one of the encounters with them was a process of mutual learning and togetherness.

Disclosure is the uncovering of the marginalized population's experiences in such a way that they are authentic to the researcher and understandable to the audience (Meleis, 1996). It means approaching the other with respect and recognition of the other's world. As a researcher, through ongoing dialogue and continuous interaction I set up the base of a trust-building relationship in which mutual respect and recognition were part of the openness to the other's world. In those moments, approaching included a feeling of unity as human beings.

Reciprocity means that both researcher and participant meet their goals from the research process and through the research findings. As a researcher, I gained understanding related to the experience of living with chronic illness in the context of contemporary globalization forces and how these forces affect the body of my participants. For the participants, sharing their experiences gave to them new levels of self-awareness, and possibilities for changes in life style, and for shifting priorities of living. However, I was aware of their goals, needs and priorities during the whole process of research. Together, the participants and I gained knowledge exploring the findings of the first part of this study in the consciousness raising group. In Meleis' work, empowerment is a process of working together, the participant and researcher, to increase control over one's life. In this study, first through each one of the encounters and then through the consciousness raising group, we encouraged them to increase their self-awareness and control over their lives.

Time, as a flexible approach used by culturally competent researchers, entails trust and it is described in terms of quality, quantity, fluidity and constrains to develop a relationship with the participant. To understand the experience of living with chronic illness in the context of contemporary globalization forces respect and commitment toward my participants were my priority in order to get their trust during the whole process of research.

Attentive to the Ethics

A profession such as nursing, humans acting for each other who experienced vulnerability in various forms, requires moral and ethical insight (Cameron, 1998 p. 128).

Health research involving human beings cannot be merely a scientific pursuit. It cannot be the result of political, economic and commercial activity; that creates the possibility of dehumanization, depersonalization, injustice and exploitation. In nursing, the aim in research is to investigate phenomena relevant for nursing, such as the situation of chronic illness in the world today. As Rapport and Wainwright (2006) write, "...it is the patient's experience of illness—the lived experience, not amenable to empiricist approaches—which nurses must study" (p. 228). Viewing chronic illness through this subjective lens reframes illness from being a simple matter of functional impairments and physical discomforts. In the process of exploring layers within which people make meaning of chronic illness, it becomes apparent that chronic illness is powerfully shaped and influenced by the social, economical, cultural and political context in which it occurs (Thorne, 1999).

As nurses, we need to wake up to the reality that in globalization, ethical principles are forsaken for economical reasons. We live in a world where power dominates all human values as if lives are only merchandise to trade. Health becomes something that is a trade item in a business deal. Health care is seen as a tool to repair human beings, as if they were machines to increase productivity and capability (Illich, 1976). The generation of knowledge through research involving human beings represents a challenge for health professionals. Therefore, as health professionals, we cannot restrict our understanding to capitalistic terms; we must never forget our purpose to treat each person as a unique human being with diverse needs. So health research involving human beings requires a moral commitment that cannot be avoided for the welfare of just a few.

This study has been rooted in ethical values and principles to avoid exploitation of the vulnerable. Research cannot be seen only as a scientific pursuit. In order to have equality in research, it is necessary to put aside ideas of domination, exploitation and imposition. The research process requires building a solid alliance in which both sides receive positive outcomes. Research with chronically ill people should look for the balance between researcher and participant so that both sides feel comfortable with one another.

Chapter IV Engaging into the World of Chronic Illness in Canada

[E]ach of our voices has something unique to say. Not only should I not mold my life to the demands of external conformity; I can't even find the model by which to live outside myself. I can only find it within (Taylor, 1995 p. 229).

It never was an Issue to Deal with this Disease

> *I had the kidney infection when I had a baby who was about 9 months and a little one who was about 2 ½. So I had called an aunt of mine to come and stay and help me with the kids, because I was really sick. And she came, and she said, "Have you ever been tested for the disease that your mom had?" and I said no, I hadn't. She said, "Well, when your mom was sick and ultimately passed away, she had been told that all of us kids should be tested for this genetic disease." And I knew that Mom had had kidney failure, but I guess at that stage of my life, I didn't know that it was a hereditary disease. When I went back to the doctor for the follow-up visit to make sure the infection was gone, then I explained to him about what Mom had had, which of course was polycystic kidney disease, and so then he said we should test for that. So initially, they did an IVP, which is an Intravenous Polygram Test and it was inconclusive. So they suggested that I should have a more invasive test. At that time, you had to be an in-patient in the hospital to have it. So I agreed to do that, and I had to stay for 24 hours. So the urologist did the test, and about 3 hours later, one of the nurses came in and she said they were going to be moving me to the women's pavilion. So I said, "Why?" and she said, "Well, you're scheduled to have a tubal ligation—your tubes tied—tomorrow." So I said, "No, no, I'm not." She said, "Yeah, you are, because you have this disease." And [person A], fair enough to him, when we consulted about it, said, "If it's conclusive that you have the disease, you really shouldn't have more children, and you shouldn't have them for two reasons. One, because it's hereditary, so you have the risk of you passing on that gene; and second, it's hard on your kidneys, so you shouldn't have more children." Okay. But after the test and prior to the nurse coming and saying I was being moved, I hadn't even been told that I had the disease, let alone that they were moving me to the women's pavilion and booking me for a tubal ligation. But in any event, I said no, "I'm not agreeing to a tubal ligation without talking with my husband. I mean, I'm just not." But anyway, they finally convinced me that it was okay to move to the women's pavilion. So I moved, and my husband came, and then ultimately, my urologist came, and then my gynaecologist or obstetrician at that point came, and we talked about it, and we, in a very short time, made the decision. So we went ahead and I had the tubal ligation, and I probably went home about 3 days later. That was my very first realization that what Mom had, I could have, and that I have it. Everything happened so fast and I've not ever regretted not having more children; I'm totally happy with two; that's never been an issue for me. It honestly never was an issue, really, dealing with the disease because I was well, I felt well. I felt concern for my children, concern for my siblings, but as far as it impacting my life in a great way, I didn't feel like it did. So I didn't really ever feel limited or that I couldn't lead a normal life; I just didn't ever feel it, at that age. I've perhaps made some personal choices as a result of my illness that perhaps I wouldn't*

> *have made had I not had kidney disease, but they've only been positive changes, positive lifestyle changes, regardless, so I'm lucky, probably.*

At 21, Sarah feels invincible. She is married with two children. Her life is well organized until one day without warning an illness strikes her world. She now faces a chronic condition, something she inherited from her mother without realizing it. After the procedure, a nurse approaches her and to her surprise she is going to be moved to the women's pavilion for a tubal ligation. At first the tests are not conclusive; however, her doctor advises her to have her tubes tied if the results of the IVP are positive. After she discusses with her husband, urologist and gynaecologist the pros and cons, she decides to go ahead with the tubal ligation. She has accepted her fate without any trauma. There are no really traumatic changes in her life. Sarah continues with sporadic follow-ups with her doctor. Apart from an increase in her blood pressure there are no other significant changes in her body. She has a good way of coping with her disease. Chronic illness has not struck her life in a hard and painful way. Chronic illness has not controlled Sarah's life; she is controlling her disease. Her illness has not obliged her to change the course of her life in as drastic a way. The presence of her illness is something new to her life that is accepted as it is. Sarah does not really pay too much attention to the drastic changes that have been added to her life. She continues living in the way a 21 year old woman would. Why? Perhaps the fact of having mild symptoms makes a huge difference in the way Sarah perceives her illness. Life has not had a drastic change for Sarah at this point. Visits to her doctor are added to her life, but there is little drama in her health story. She has decided her condition is not going to invade her family, so she keeps living a normal life.

Dialysis was Terrible

> *I was working at the time, and it happened in '98 in June; I wasn't feeling very good; I was feeling cold all the time. I was driving a lot, and I go out to put on my clothes, my work clothes, and bend down to lace up my boots, and I just about passed out; you know, I was really dizzy and stuff. So finally, after about a month of this, I went to the Emerge—I was living in [location A]—and walked in, and then they took my blood pressure, and my blood pressure was 230 over 130. So that's how I discovered. Then they right away checked me out; they tried to lower my blood pressure and they couldn't. So the doctor took blood, and within 20 minutes, he came back and said my kidneys had failed. My creatine was over 1800 and my potassium levels were 8.5. So that's how it was discovered, and within an hour, they had me flying to [location B] to*

> *[hospital A]. I thought that life was over for me. When I flew out of [location A], I thought I'd never see it again. Because I had a brother that had failure, too, kidney failure, and he lived 7 years with transplants and then he got cancer of the stomach because of the meds and passed away. Once they finally got my blood pressure lowered with different medication, and then I was at [hospital A] in [location B] here, and they prepared me; they installed a central line in my carotid artery, and they dialyzed me within—I think it was 2 days after I arrived I started dialysis. And dialysis, it was terrible. The first time I got dialyzed, they dialyzed me too fast, they dialyzed me with the wrong size filter. That night, I was delirious; I felt my fingernails moving and everything was moving on me. I thought that was just horrible that night. But then I got better, and then my next dialysis, I got a little better, and after the third and fourth dialysis, things were starting to settle down.*

One month after the appearance of the first symptoms, Jon goes to the hospital. His story is another example of how unpredictable chronic illness is. Chronic illness causes physical and emotional changes that can be difficult to adjust to. Jon's life changes: from being an active worker he becomes subjugated by his ill body. Like Sarah and the other participants of this study, Jon's life has been abruptly impacted. He is getting ready to go to work when without any warning he almost passes out. Before this episode, Jon's body sent him some warning signals. He did not pay attention to them; he had gone to the doctor but the random set of symptoms did not help the health care professionals to determine what condition he has. Until one day Jon's body gives up; it almost shuts down. Health care professionals have difficulty lowering his blood pressure. They do not know what is happening to him until his doctor has the results of the blood work. The results are devastating news to Jon. His kidneys have shut down. Like his brother many years ago, Jon is facing the fact of having a renal failure. Jon's world falls apart. He does not know what to do. The new set of circumstances in his life is overwhelming. Everything happens so fast that he is not capable of digesting the events. After a while he accepts his fate. Like Sarah and the other participants, he keeps living. His illness is a turning point in his life that makes him realize how important it is to take advantage of the remaining time. There is no point in giving up, and he decides to be in charge of his life. Like Sarah and the others, Jon has to face the imminent impact of chronic illness; however, his story differs from Sarah's in the way his disease advances so rapidly. There is some drama in Jon's story. And yet he overcomes the traumatic turn of events to be an active participant and advocate for his health. Chronic illness has turned his world upside down, but he is ready to accept the challenge.

I Would Bounce Right Back

> *I was 12 years old, and it came rather quickly. In a period of about a week, I experienced all the classic signs, so increased thirst, drop in body weight. My mom became concerned, took me to the family doctor who diagnosed me with Type I juvenile diabetes and sent me to the hospital that evening. Then I spent a week in the hospital and trained how to do insulin therapy, diet, management of my disease, and then I went home after a week. I'm blessed with a very positive outlook on life, so the only person that I knew that had diabetes couldn't eat candy, so I said, "Okay, it's no big deal. Don't eat candy." That was my understanding at that time. Afterwards, when the diet became more stringent—I was a growing boy, I was very hungry, but I couldn't have any additional food—I found that was often hard, so I was constantly going back for adjustments to my diet and then trying to manage the food. I had occasions, especially when I was really hungry and my mom couldn't give me any food 'cause I was on a strict diet, I think then—so I was 12 or 13—so then it was always—then you're not thinking so much your reaction, so then it was, "Why do I have diabetes? Why is this happening to me?" If you're younger, you would feel that way, but for the most part, because I was naturally a positive attitude, I would feel—I would bounce right back. So I wasn't really treated as being different by my mom; she always treated me same as the other kids. As I got older, I realized that I had control over my attitude. I can choose, and I simply didn't—I'd choose not to play the victim role. So then I never felt victimized in any circumstances, irrespective of all the different conditions that were adding on to the diabetes such as the kidney failure, the retinopathy and the neuropathy.*

At a young age, Maurice learns that he is diabetic. Like Sarah and Jon, Maurice's illness develops quickly. The symptoms show up progressively. He does not know any person with diabetes so he has a limited understanding of the disease when he receives the news. Maurice learns to manage his diabetes very successfully. His disease becomes just another thing he has to work on. And yet, his knowledge is superficial; he does not know anything until he confronts the true nature of diabetes. His mother makes things easier for him. She tries to incorporate Maurice's health requirements into the family's life style; she does not want him to feel different. He is a growing young man who requires a lot of adjustments to his diet. At this point, life becomes hard for him. He wants to eat more but he has to follow diet restrictions, and he begins to question why he has diabetes. It is a difficult period of time in which he faces the dramatic change in his life. Suddenly, his life has changed forever, but he is able to accept the changes as they come. His positive attitude makes it easier to accept his new condition and all of the changes his body endures during the progression of his illness. His friends and teacher know about his condition but he does not discuss in detail what he is going through. It is embarrassing for him as a teenager to let others know about procedures like measuring the glucose level in his urine. Maurice comes to terms with his illness and it becomes a routine part of his daily life.

Although their bodies are affected by diseases, some people are not affected mentally or emotionally in any serious way. Why for Jon, Sarah and Maurice is it easier to accept what is so hard for other chronically ill people to accept? What in the life of the person determines the impact of chronic illness? They have been unexpectedly introduced to the fragility of life, but somehow they have learned to coexist with their conditions. It is through this process that we and those we love learned that we are not immune. It is through the process of illness we discover our vulnerability as human beings.

Jon does not feel sorry for himself because of his condition. It was hard when the situation unfolded abruptly in his life and he felt bad because of the changing circumstances but after a while he learns to coexist with his condition in peaceful terms. The conviction to accept change comes from deep inside Jon. He knows taking care of his condition is his responsibility and he assumes it. Seeing other people with the same condition reassures Jon's perception that he is in good shape. When one is sick, to be told something positive about one's illness can be very important. He feels some relief comparing his situation with other people. Jon realizes his situation is not that bad at all. Going back to work is what keeps him going through the whole process of illness. He wants to heal himself to regain his old life, to be productive. After his transplant, Jon does not define himself as sick or ill. He does not like the connotation his condition brings to his life. He does not understand why it is necessary to label someone as sick when the person feels great. A label is, etymologically, the tag or slip containing the description of an object (Skeat, 1963) and Jon feels that his label is inaccurate. Then, socially and due to his condition, Jon carries the stigma of being an unable, unproductive and ineffective person. He is not. Through the improvement in his health, Jon tries to show how wrong society is. He is fine and he can do what other healthy people can do. It has been hard for him because he has to prove to others he is healthy again. The main cause of discrimination and stigmatization for him emerges from the organization of people according to levels of personal health. He wonders why people label others as sick when the majority of the population receive medications. Socially, almost everybody wears glasses but people with glasses are not labelled as sick. He can work as hard as many of his colleagues, so for him classification of people in groups according to their state of health is wrong.

My Body is—it's like a Car

For Maurice, detaching his being from those labels is an easy thing to do mainly because he does not associate what he is with his ill body:

> *My body did not change, because I don't associate strongly who I am with my body. Our bodies change as we grow up and then as we age, and so if you take the viewpoint that your body is—it's like a car, right? You get into your car and you drive your car; now, you could have a nice car or your car could be a wreck, but the car has nothing to do with who you are. You get out of your wrecked car and you go into a new car; you haven't changed at all; you're still the same person. So I view my body as being that way; so it's going to change, but it's not who I am, so it's just, like, okay, it needs new tires. I tried to keep my car running as best as it could, given the circumstances. But it didn't bother me; I didn't feel that, because I don't have a connection too much with my body or how I look; it's not who I am. So I found it easy to accept the changes, and the changes were, over the course of the years, drastic. I don't associate myself with labels. It's not associating myself with the body, so yeah, there's a detachment. So the label itself, chronic illness, diabetes or juvenile diabetes didn't really have a lot of meaning to me. I didn't have an opinion on it, negative or positive versus chronic illness. I knew I had a chronic illness; that's what diabetes is by definition. So that's okay; we label.*

He does not care what other people think about him. His life has never been ruled by others' perceptions. Then, the label of being diabetic or chronically ill falls short of describing what Maurice indeed is. Those labels really have no deep impact on his life. Socially, labels are common but how they affect and rule one's life depends on the person. Maurice does not have any issues with his body. His body does not define who he is. He continues trying to keep in very good physical shape. He knows how important it is to follow a routine of exercise to help manage his diabetes. The body changes but who he is has not changed. Despite his diseases and the drastic changes in his body, Maurice is the same person. Because he has never felt connected to the physical appearance of his body, thinking in this way makes it easier for him to manage the changes. His body is a tool that helps him to perceive his world but also it is the object of his illness. How you feel depends for many people on the condition of your body, but he does not feel bad because of his body. His ill body, he feels, is just a small part of who and what he is. Through all the complications and setbacks of Maurice's diseases, he does not dismiss or ignore his body: he takes care of his body. Maurice's body is like a car that when it is new it does not have any problems but once it begins to be used, the machinery begins to deteriorate. Like an old car, Maurice adapts his life to the changes that happen in his body. He does not seem to care how others perceive his ill body or how his body looks from outside. It does not matter because what is most important to him is what he thinks or feels regarding his disease. New perceptions come with new changes in his body. Everything seems to work perfectly for him.

Why don't I have a Waist?

> *Well, that progression has been more noticeable and probably more difficult for me, because my kidneys are big, so then I have this, which I absolutely hate. And I have—I haven't had a waist for most of my life. I always thought, "Why don't I have a waist? Like, all my other friends have waists; why don't I have one?" Now, whether that was in my head or whether it wasn't in my head, over the years, it's been more noticeable for me, because even when I weigh what I think I should weigh, and I'm exercising so that I'm in fairly good condition, I still have this, which really irritates me. My clothes don't fit the same, and I don't like how I look in them. But I've come to the realization that I have, I don't know, 10 pounds of kidney, or maybe I have more--15 pounds; I don't know how many pounds of kidney I have in there—and they have misplaced—displaced all the organs. And on the anniversary of my transplant, my sister and I and her husband went to Telus Body World, so my impression was that my kidney should be this size, because it should be about the size of this. But when we went through that display and I saw the polycystic kidneys and I saw the healthy kidneys, I guess it helped me better visualize what was happening inside my body so that I understand where they are and how they should fit, and now how they have had to move things around to make room for these things. So although I don't like this, I realize they aren't going to take it out, and I don't particularly want them to, because then I would have other medical complications that I don't want. I prefer not to have it, but I have it! I prefer not to have had polycystic kidney disease, but you know what, I have it; I have it. So I can't change it. So at some point for me, it's a matter of working through the process and getting to the stage where OK it's all right. I certainly resisted it for a lot of years; I resisted this change in my body.*

Different from Maurice, Sarah has some issues with her body image. Sarah finds it difficult to accept the physical changes of her body. It does not matter how much she cares about her health and how much effort she makes to take control of her disease, she has not gotten used to the weight gain due to her illness. Sarah has been very careful with her diet, but despite that she follows all of the doctor's recommendations, she keeps gaining weight. It seems impossible to her to understand what is happening inside her body. She never had a waist, not even when she was really young and skinny. She did not understand how her kidneys look until she saw them in an exhibition after her transplant. She was really enlightened by seeing how her body has to accommodate her old kidneys with the new ones. According to her, her illness is not the only culprit: as a part of her transplant she is taking steroids which are also responsible for her gaining of weight. She accepts her body image now, but at first it was difficult for her to assimilate the changes in her body. The presence of her condition is portrayed in her body. After her transplant, the lack of physical activity has brought more weight gain for Sarah, who has decided to go back to work again. Keeping active seems to be the only way she stays fit. She has to take care of herself because one of the consequences of organ transplant is cardiovascular disease. She wants to avoid that kind of complication. So she decides to keep herself busy. Ultimately, she accepts her extra weight is part of who she is.

Once we got Hooked up, that's when Time Stopped

> *During my haemodialysis time was like it stood still; it took forever. During this time there was a lot of thinking, like, "Is this ever going to change? What kind of a life is this?" But I'd started—after I got dialyzed a while, then I started to bring—I had a radio and we had some TVs we could watch. I mean, it was hard, because on dialysis, if I watched a TV show that something bothered me, I could make the machine alarm because of my blood pressure changes. So it had a big effect on me, and especially—like, sitting in one position for so long, I had lots of back problems. But I don't want to think back about that, because it was not a good time. Especially getting the needles; it was sore. And I always thought about good things when they were poking me with the needle so I could shut out the pain, 'cause that was the worst. It was difficult. It seemed like it took forever to go through the run, and especially I had to stay a lot of times a half hour longer than any other patients because I had a bigger body and more blood to clean. That's when it took forever. That 4 ½-, 5-hour run, it was like 8 hours, seemed like. 'Cause I'd dialyse in the evening. When I was on dialysis, when I got to dialysis, you know, you meet with all the patients and you'd have a good time because you're joking and talking, and then when they got hooked up, that's when time stopped. Since my transplant, time is flying; like, where's it gone? Like, it's been 8 years and it doesn't seem like it; it's just—it's gone. So I guess it's true what they say: if you have a good time, time goes, time flies.*

> *Now time, it's happening too fast; before, it was too slow when you were sick—when I was really sick.*

Time seems to stop when haemodialysis starts for Jon. It takes forever, the five hours he is hooked up to the machine. It is hard. The whole process is overwhelming for him. And, yet, he is exposed to this process three days a week. Everything seems out of control. Haemodialysis has a big effect on him physically and mentally. He has back problems that come out during this procedure. Jon uses good memories to cope with the painful memories of his illness. Also, radio and TV are used as means to forget for a while how hard haemodialysis is; however, during those times, information presented in the media sometimes produces changes in Jon's blood pressure when he reacts to dramatic or upsetting situations. Time seems to stop when he gets into the procedure. It takes an eternity to finish but he has to attend because it is the temporary solution for him now. When there are no machines for dialysis available in his unit, Jon has to go to other units, but he does not complain about it because he enjoys interacting and getting to know other people. Through time and despite the negative aspects of haemodialysis, Jon has learned to love his only chance to survive. After his transplant, the meaning of time changes drastically for him. He does not have enough time to do what he wants to do.

I have a Need or a Desire to not Waste my Time

> *Until my transplant, I had a normal—what does normal mean?—a normal amount of time—now I'm talking lifespan. I still don't necessarily think that I won't live to be an average lifespan of a woman; I still believe that I will. Since my transplant my quality of life right now is probably the best it's going to be in the rest of my life, however much time that is. So I have a need or a desire to not waste it, so that if I want to do some travelling or I want to do some things, some hiking or some things I really like to do, then I want to do it. So I think some of it is as a result of the realization that my kidneys failed or were close to failure, and I required a transplant to maintain life, and part of it is my age. So I need to, or I want to do the things that are important to me and the things that I enjoy while I'm able to do them, whether that be as a result of the chronic illness or whether it be a result of how old I am. I recognize that I have it and where it is, and so there are certain things that I choose to do or not to do as a result of it.*

Sarah, unlike Jon, does not feel any difference in her time. She tries to pursue as full a life as possible. Her disease has not brought any disadvantage compared with other healthy women. She is in charge of her life. Like Jon and Maurice, Sarah's illness does not dominate her whole life and world. Her resilience is portrayed in the way her disease is not evident in her body. She has done everything and will do anything she can to maintain as good a healthy state as she can within her circumstances and given that she likes to be involved in her care. Sarah really likes to take care of herself. Chronic illness has had a positive effect on her life. She readily accepts commitment to maintain an optimum quality of life. For Sarah, following all the medical indications and diet regimes grants for her the possibility to improve her health. Her condition is almost imperceptible. Before and after her transplant, she decided not to waste her time. Her condition has not been a barrier for her; her condition has made her aware of how important it is to continue living despite the circumstances. Time in chronic illness is certainly perceived as short but it also brings the opportunity to live a full life.

Living on the Edge, Pins and Needles: Family, Friends and Social Life in Chronic Illness

Living with someone who is chronically ill alters the family dynamics. When chronic illness is discovered, the family momentarily loses its sense of autonomy. The illness controls the family's life. And yet, to face the situation, a family as a whole develops strategies in order to preserve the unity among its members. During the period of illness, a family's life is on a roller coaster careening from hopeful when the situation is under control to hopeless when the situation is uncontrolled (Hopia *et al*., 2005). Jon's story clearly portrays the effects of chronic illness in his family life:

> *My family was devastated at the time because they didn't understand how bad it was, and they thought that I would never survive this, especially my girls; I had two young girls at the time. My oldest at that time was in grade four, so things were pretty devastating. My youngest, well, she was not even in playschool yet. So it was hard on them. In August of that year, we moved to [location C] from [location A], and then things started to get a little better because they were close and could be here at times. But they were quite worried, especially my older one, she was quite worried. She even came and watched me on dialysis sometimes; she sat there. So she understands; they know. My younger one, she was pretty young, but she saw it, too, so she knows; she knows all about it. They're living on the edge, pins and needles, because they were always worried; they didn't know what would happen to me. And a lot of times, I had infections because of my central line. I was using central line for the first six months or so until I had my fistula, because I had a fistula put in. But that was the worst; I'd get infections all the time and I'd be down at the Emerge, sitting for hours, waiting. That was the*

> *worst. So they had to go through that part, and that really bothered them; it concerned them.*

Jon's relationship with his daughters and wife changes once his kidney failure begins. His family is overwhelmed by his condition. During the first crisis of illness, he is alone in the hospital. His wife and daughters are living in another city. The separation is overwhelming for the whole family. When they move to live together, everything becomes easier to handle. It is difficult for his daughters to understand what is happening to him. It is hard to be far away when a crisis in the family begins. Once they are together in the same city things become easier to overcome for the whole family. His daughters are really young and although they do not understand what is happening to him, they suffer with him. It is hard for them to see how their active and independent dad has to accommodate his life to the new set of circumstances. During this time, he tries to bring them to his dialysis; he tries to unify his two worlds. He makes them be part of his new world. Jon is trying to help them to understand what is happening to him. He used to be active and now he is restrained by the routine of haemodialysis. He is not working anymore. His whole life has been affected by his condition.

> *So many people would be on dialysis and they would go home and disrupt the family life to them. I tried not to; I tried to live like the family, stay in their routine. That's why I chose to dialyse from 5:00 in the evening until 11:00, because I didn't have to interfere with my daughter `s lives. So I'd be home, I'd see them during the day, but at 5 o'clock, they came home, they'd have homework and go to bed or dance or—they're both in dance, right—where here, I'm going through dialysis, and I'll be home; after 11 o'clock, midnight, I was home. See, they're sleeping; it doesn't affect them. They don't see me when I'm all tired from dialysis. 'Cause dialysis really takes it out of you. So that worked better for me, 'cause in the morning, I was there, I could drive them to school or be with them, help them in school, and then it worked out for us.*

However, in an effort to prevent his condition from interrupting the flow of his family life, Jon decides to plan his haemodialysis for a time suitable to the whole family. Three times a week he is dialyzed. He does not want to disrupt his daughters' and wife's lives: he does not want to impose his illness on his family; he wants them to continue living in the way they are used to. And, yet, there were difficult times for the whole family, times in which his chronic condition reminds them how unpredictable its pathway is. One of those times happens when his family witnessed how his central line is withdrawn. They witness for 40 minutes how physicians struggle to pull out the catheter. Despite Jon's cautious attitude about causing suffering and anguish for his family, it is impossible to avoid when procedures go wrong; family members are often, if not always, exposed to the ups and downs of the whole situation as it relates to chronic illness.

I Have an Impairment, but I'm not Sick.

> *My friends thought I was sick, I was—you know, I can't do this and I can't do that; they sort of felt sorry for me. I know a lot of people would say, "You'll never be able to do this again." Why? I asked them why. And I am doing what I was told I wouldn't do again. So I think now they've changed, but they always keep telling me I was so lucky. Well, I don't know if it's all so lucky; I think it's a lot of what I do myself to help myself. 'Cause I know I flew to Kelowna one time; my dad was very ill at the time and I had to dialyse—make arrangements to dialyse in Kelowna. And I flew, and my sister and brother-in-law picked me up from the plane. They hadn't seen me since I'd been on dialysis, and they said to me, "You don't look sick." I said, "I'm not sick. I'm not sick, right? And I wasn't. I had one failure, and that was kidney; I had no other problems. I believe if you believe in that, it helps you. I think that's why I've had success; I didn't give up. I have an impairment, but I'm not sick." That's what I told myself. The hardest on me was my social life, because socializing at work that was my life; all of a sudden, I had nobody at work, and I had to make a new life. My life was dialysis, the nurses, coming to the hospital; that was my new life. I had to meet new people, because we had just been transferred to [location C], so it was all new for me. That, to me, was the worst; if I could have worked part-time, it would have been the best for me, but they wouldn't let me; my company didn't want me to work. That was the hardest, because I'd worked for them for seven years, and worked a lot of hours, a lot of days, and wanted time off, and you just couldn't, and the moment I got sick, they told me—they replaced me within five minutes and said, "We don't need you anymore." So that is the hardest, is being told all of a sudden they don't need you. Because you're sick, everything goes through your mind, and then they don't require you at work. That was the worst.*

Unlike his family's perception, Jon's friends see him as sick. His friends have defined his world in terms of his kidney failure. For them, it is difficult to understand how someone who is chronically ill has a different perspective about his life. They limit his world because of his condition. Jon refuses to consider his life to be entirely defined in terms of his disease because he has learned to accept his condition as being only a small piece of his life. Why cannot his friends accept this? Probably the answer to this question dwells in the way society perceives chronic illness as a crisis that turns people's worlds upside down. Jon was disoriented at the beginning but later he regains control of his life. Kidney failure has never defined his being although he is aware of the seriousness of the disease, because his oldest brother suffered from kidney failure. Survival rates for people with kidney failure were different at the time that his brother was ill. Now things have changed: the possibility of survival has increased and that contributes to the positive attitude Jon has about his health. While attending haemodialysis, he feels he helped a younger person with his negative ideas about his condition. During haemodialysis, he tries to cheer him up. He tries to instil in his partners of haemodialysis how important it is to keep a positive attitude in order to promote good outcomes. There have been negative aspects in Jon's experience; however, those negative experiences are overlapped by the positive attitude he builds around his condition. One of the negative things that Jon has overcome is the loss of his work. It was hard for him to assume that his situation changed his future forever. He is not productive anymore. It was hard for him to learn that he is not indispensable. For Jon, his employer's not wanting him back on the job is hurtful. He wants to be productive but he is not healthy enough to fulfill the requirements of a difficult job. Health, then, plays a key role in defining who can be part of the work force and who is excluded. For Jon, working is a fundamental part of his life, and not being able to do what he likes becomes traumatic and unacceptable for him. He gets used to his situation but deep down he wants to go back to work. Six weeks after his transplant, he comes back to work. This is what makes him feel alive. As he says:

> *Work was great. My reintegration into the work life was not difficult, because the employer, they all looked out for me. They tried not to push me too hard. I pushed myself to prove a point that I can do it, and now it's not a problem. I had to build confidence in the employer. Because I was, I believe, one of the first persons to go back after a transplant to do that work. Because it's out in the oilfield, it's 24 hours, it's not good conditions a lot of times, and you're not eating regular meals. So it's a lot of that, so a lot of people, once you've had a transplant or any kind of a chronic illness, they don't go do that type of work; they stay away from it. But I feel, why can't I do it? I'm doing it. And you have to want to.*

Once Jon comes back, he feels the necessity to regain his boss's trust. He wants to show him that he is able to work as well as younger employees do. His condition is not a barrier to his showing how productive he can be. Jon wishes to regain the control of his work life. His life as an employee is the only thing his kidney failure does not allow him to go back to. His work requires a lot of physical sacrifice and endurance and his employers watch out for him. Little by little he regains control of his life. The power of the mind, he feels, enables him to do the very demanding job.

We Showed the Kids Right Away How My Dialysis Worked

> *My diseases were part of my life, and we kept it very open, so we showed the kids right away how my dialysis worked. I have three little ones, and Dad's got a tube in his body, what's the tube for, and we explain the dialysis, and you put the tube in and you take the tube out 'cause Dad doesn't have kidney function. The kids just accept it, 'cause basically they saw, "Okay, Mom and Dad are not stressed out about this"—at least not that they're showing—so they were fine about it. They always were. They knew the situation, they knew I was waiting for a transplant, they knew what that meant, and they just—my daughter was a little bit older, so they were just more concerned. I think it was hard on my wife, 'cause she's an ICU nurse; she's very familiar with what the prognosis is for. She was kind of my advocate all the time because she understood the health care system, how it works, so she was always there with me, by my side. But she later explained to me afterwards that this was a huge shock for her, and it required a lot of adjusting for her, because she, as a nurse, sees the worst of things.*

Maurice does not hide his illness from his children. He keeps his condition real for them by showing how diabetes and renal failure are part of his life. He explains to his children about the process of dialysis and waiting for a transplant, as well as each of the stages of his disease. There are no secrets in his family and they seem to understand. They are not worried because their parents do not seem to be worried. Maurice's positive outlook has helped to make things easier. Like Jon and Sarah, Maurice makes his children part of the process. His condition does not seem to disrupt the dynamics of his family. They overcome the concerns about his condition with a positive attitude; however, his wife, who is a nurse, finds the situation more difficult to accept. She has firsthand knowledge of how things can go wrong with someone who is chronically ill. She worries for him in a deep way but is able to hide her worry from their children. Her experience as an ICU nurse makes her aware of the potential setbacks of Maurice's diseases. A balance is achieved in the family because their attitudes and points of view complement each other through their perceptions of illness and health. Their goal is to keep family life as normal as possible without abstracting completely from the reality of Maurice's illness. After his transplants, life becomes difficult for Maurice because he has to stay in the hospital 26 days. His wife continues to worry about his condition. The children wait for him to come home but Maurice's condition does not allow him to fulfill this dream. He has to wait until all of the health problems are resolved. His wife feels anguish but is able to hide it from Maurice. She suffers the setbacks of his condition alone. Chronic illness seems to have a deep impact on Maurice's wife. However, Maurice understands how hard it must be for her to be exposed to the experience of a loved one suffering from a chronic illness. It is a difficult time for the whole family.

My Friends and Colleagues Seem Primarily To Be Looking At It Through Their Own Lens

> *With my friends and colleagues it was interesting. What was interesting about it was different people react differently. They seem primarily to be looking at it through their own lens of "How would I feel if this was happening to me?" So some people were very curious; other people, it was, like, "Don't tell me about it because I don't want to know about this." So the attitudes varied, and I try to respect a person's attitude. For instances, I went to my boss and I explained to him that I was on manual dialysis and that I was going to have to be doing an exchange at the office. At first, when we were talking about the logistics about where I was going to do the exchange. I said, "Well, in the bathroom, there is a large locker room area and shower area; I could do it there." So he was under the understanding that's where I was going to do it. When I received the training and understood how critical it was to be in a sterile environment, I figured that's not a good place; in my office is a better place. So when I discussed that—when he then learned that I was doing it in my office, he was saying, "Oh, I thought you would be doing it someplace else," and it was then that I understood that, from his point of view, he probably thought I should be more shy about it.*

Maurice's work life has not been affected to any great extent. He tries to inform his colleagues and friends about his condition. Some react positively and want to know more about his disease. Others have the opposite reaction; they do not want to know anything. Overall, Maurice tries to make his illness part of his whole world. When he starts his peritoneal dialysis, he talks to his boss and informs him that he needs a place to do his noon exchange. Without full knowledge of the requirements for the procedure, Maurice asks for permission to use the bathroom which has an area that could be used as a place for his dialysis. However, when he learns how important it is to keep everything sterile for dialysis, he has to change plans and use his office. His office has a big window so his exchanges are not hidden from anybody. His boss is surprised when he finds that Maurice is doing the exchanges in his office in plain sight to everybody. His boss does not feel comfortable with this display. Some friends, out of curiosity, come to learn what he is doing. For others who live with chronic conditions, it is a reminder of what is going to happen to them and they do not want to be involved in Maurice's situation. He does not feel bad about this attitude because he understands how hard it must be for these people to see their condition reflected in his life. Maurice is not that concerned with what other people think; he welcomes whoever wants to learn about his disease and see what he does. However, he thinks the perception of any chronic condition depends on the person's point of view and that shapes whether they want it to be private or not. Everything depends on the person's view. Some people with chronic conditions have apprehensions about visiting him during the exchanges, whereas for others there is no problem. Maurice's interaction with friends and colleagues is dependent on people's points of view of what health is and their need for privacy.

We Have Such a Cookie-Cutter Approach to Medicine and Health

> *In 2000, I attended a conference in Chicago. I'd been a member of a group out of the United States called the Polycystic Kidney Foundation. I attended that conference, and I took both my girls with me, and they were adults this time. One of my girls has been diagnosed with the disease, and the other one has not. And I felt like it'll be good for us all to learn more. Some of the courses, the classes suggested that, as a person going through deteriorating renal condition, I should be maintaining a lower level of protein intake, because protein's really hard for the kidneys to break down, and so I should be seeing a dietician and I should be eating only a certain amount of protein each day. So I came back, I went to my nephrologists and I told him I had gone to this conference, and I told him what I'd gone to, and what I'd learned, and what the recommendation was. And he said, quote, "You don't need to see a dietician. I don't want you to decrease your protein. You need your protein. You'll need it the sicker you get. You need to have that, so I don't want you to see a dietician." So I said, "I want to see a dietician," and he said, "You think that you attended one conference, and you know more about your disease than I do." I said to him, "No, I don't think that at all. Actually, what I think is that I have the disease, so it's very personal for me. You don't." So I said, "If I think I can help myself, I want that opportunity." So he did; ultimately, he gave in and let me go, but he was annoyed, and he was annoyed with me for two or three years. He was an older man, and the older doctors seem to have more issues with people wanting input, I guess is how I thought. But I never felt that from nurses or really other health care people.*

Sarah and her doctor have different approaches to her illness. She is an active member of the *Polycystic Kidney Foundation* in the United States. During a conference in Chicago, Sarah learns that for her condition, protein must be diminished. Sarah is eager to share with her doctor what she learned in the conference but the results of her sharing are not what she was expecting. Her doctor does not want her to diminish her amount of protein in her diet. For her it is clear that she is just a spectator in her treatment. To be informed and to practice what she learns about her condition are very important and basic issues to her. She requires being an active member of her health team. However, her physician believes Sarah does not need any more knowledge about her condition other than what he is giving to her. Treatments and procedures to improve her health that are prescribed outside of Canada are not considered by him. According to her doctor, going to one conference does not make her an expert like he is. It does not give her any right to challenge the knowledge of her nephrologist. For her, physicians tend to deal with the test results instead of the whole process. For example, if someone has high cholesterol, they will just treat the cholesterol levels. Sarah has learned how important it is to view the disease within the context of the whole person. She prefers to be an active participant in the process of care. She prefers to do everything to try to keep her kidneys as healthy as possible for as long as she can. She does not agree with a traditional approach in medicine in which patients are the passive recipients of treatments or in which physicians are the sole owners of knowledge. She wants to be an active participant or an advocate for her own cause. But why is her view not taken into account if she is the one who is living with this condition? Sarah, like the other participants of this study, considers her situation as very personal because she is the only one living and dealing daily with her disease. Physicians must not deny the patient's knowledge or desire to participate, because, as Hannah says, "I am the one who is ill. It is my body." Thus, they need to be active participants in their care.

> *A few weeks, months ago, I was involved in a study, a fitness study; I got in the lifestyle portion. So when I had to have the follow-up visit with the young man that was doing the study, I also had to have a stress test at the beginning and at the end. So I did the stress test, and they'd have cardiologists there when I did the stress test part. So he said to me when he came in something about—something about being the ill one, or being ill, and I said, "I'm not ill." So he said, "Why are you here?" So I said, "To do a stress test." So he said, "Well, then"—it was as if he wanted me to say I was sick. Afterwards, as I reflected on it, I said to him, "I'm not sick. I had a kidney transplant, but I'm not sick." So if you ask me how I am, I'm going to say I feel great. We have such a cookie-cutter approach to medicine and health that it's hard for the medical profession to deal with so many people who all really need to be dealt with a little bit differently, at least on an emotional level.*

Like Jon, Sarah does not define herself as sick. Of course she has a condition but that condition does not control her life. For others, Sarah is sick. The labelling by others surprises Sarah because she does not feel sick. Why is it so hard for others to understand how she feels and how she deals with her condition? In a very brief encounter with a cardiologist the label of being sick emerges again. Their perspectives on her condition are very different. Overall this encounter defines for her how this doctor sees Sarah in terms of her pathologies, not in terms of how she sees herself. He sees her as the diseased body asking for a cure, while she sees herself as the human being who wants to improve her health. Her perception of her illness does not fit what is expected of her as a patient. She needs to be treated as a normal person. Like Hannah, Alfredo, Jon, Camille, Maurice, Maria and Alejandro, Sarah does not want to be a mere spectator of her care: she claims an active position in the process of care for herself.

I Wanted to Understand How I Could Improve Things

> *First, it was overwhelming because I just hadn't seen this before; I mean, my brother had, but it was totally different when he was on dialysis. It was a lot to learn. It was a learning experience for me, and because I was interested in a lot of the mechanics and the machinery, I took an interest in it and I paid attention to my dialysis. I would read my charts. Even though I wasn't supposed to read my charts at that time, I would read them because I wanted to understand how I could improve things. During haemodialysis I always made sure they always had the right chemical dialysis flow and the right filter size. I always read my charts, so I knew. One time the nurse came and it wasn't right, and I told her, and she's, "No." I say, "Yes. Check the charts." Came back and said, "Yeah, you're right." Nurses are busy, someone puts the stuff out, it gets mixed up, and things happen, right? That's why a patient has to take charge of their own life, because no one else will.*

Jon is knowledgeable about his condition. Being informed seems basic and important to Jon. As with Sarah, he does not leave anything to chance. Through learning Jon tries to control his disease. In haemodialysis, he learns about the process, the dialysis machine and how it works. Jon knows that knowledge will improve his quality of life and his participation in the process of care. He does not have access to information about what is happening to him. After six months in dialysis he has a lot of questions but his health care providers do not seem to know how to address them. He keeps trying to understand and make health care professionals accept his input as part of his care. In order to be part of the process he decides to view his records, something which was not allowed at the time, but he does it anyway because being part of the process makes him have some control over the uncontrolled condition he has to deal with. He wants desperately to be part on the process of care because he wants to get better. Despite his being connected to a machine three times a week does not sound very good, for him that schedule provides the only possibility he has to survive and he takes advantage of it. He wants to live because he has a family to look after. It was not difficult for him to adapt. Others around him do not seem to share his way of thinking. Since haemodialysis is the only chance he has to survive, what would be the point to hate it?

The Left Hand Doesn't Know What the Right Hand Is Doing

> *The only thing you would note is the left hand doesn't know what the right hand is doing. What that means, of course, is that you're seeing typically five or six different specialists, and they don't all have access to the same information, so you could end up with different viewpoints on medications. So they might be adjusting the same medications differently without consensus on how that should be managed. And you saw that in general in the health care system where the information was not being easily shared, so they had their own set of charts, their own files, their own history; it didn't move around with the patient so much. So there was always a chance for information gap, 'cause they didn't all have access to the same information.*

For Maurice, when he learns about his diabetes, the possibility of complications becomes very real. He knows there is a high risk of developing other illnesses resulting from his diabetes. He seems to accept as a part of his condition the inevitable changes to his body. He has a concern, however, about how his physicians do not communicate with one another. Treatments that seem good by some physicians are not considered by others. The structure of the system and the specialization within the medical professional affects the way physicians interact with their patients. Why? Perhaps it is to create more effective and productive physicians but, in the end, people with conditions like Maurice's are left on the periphery of the treatment process.

No Political Air Time

> *Politicians are self-interested, and they're interested in issues that get them re-elected. You have a few politicians who are interested in the more general good for the population, but for the most part, it's a self-serving interest. So this is not a burning issue for them, and so they have other issues that are simply more—higher in their priorities. So it seems we don't really have a very good system to address all the different issues. Of course, we, being we as the collective we as transplant patients or people that have gone through the process, have our issue, and every other different group has their own issue. There are over 4000 Canadians currently waiting for a transplant. We also know half of*

> *those will die during that waiting period, and that the number of people that are going on these transplant waiting lists is escalating. So the politicians—there have been a number of private members' bills that have been put forward in order to be able to address the situation, but because this affects a fairly small percentage of Canadians, it receives no political air time; in other words, it doesn't matter; it affects 4000 Canadians; who cares.*

According to Maurice, politicians do not seem to care about chronic illness because they are focused on programs and projects that make them popular among voters. Despite the magnitude worldwide, chronic diseases are not a priority for the general population. Why? Probably because there are many chronic conditions with different needs. However, there are some similarities in chronic illnesses, such as, for example, the lack of social visibility; this is the result of individualism. Socially, people are not interested in situations that are not related directly to them. Maurice is concerned about the lack of awareness for organ donation in Canada. Low organ donation rates probably are the result of ignorance about how important it is to donate. There is no law in Canada that rules the whole situation of organ donation so it becomes difficult to accommodate people who need transplants. Each province is different, which makes it difficult to have a general law that protects people who need or have transplant procedures. According to Maurice, although the state has not sponsored a bill, initiatives have come from private investors. There are 4,000 Canadians waiting for organs and the investment from the state falls short in sponsoring those programs in Canada. Canada has a low donation rate compared to other countries with larger investments in transplant programs. Maurice does not limit himself to point the problem out; his solution draws in the importance of education. Education seems to be the solution to create awareness about the constant issues people have to go through when they are waiting for their transplants.

> *People are starting to realize, but I think it's still a long ways to go, because there's still—I think the politicians could change this so that the employment industry will allow more chronic illness people to be employed. I think it's happening slowly, but it's not happening fast enough. Because there's a lot of people out there that, I think, give up because they're tired of having to fight and fill out forms all the time; I think this is what the problem is. See, I've been pushing it, but a lot of people won't do that. I've been told by friends, "Why bother?" Well, I think there should be a change; there has to be a change, because more and more people are becoming chronically ill, and you have to have the*

> *people, right? If you're not going to go back to work and be able to work, then why do all this transplants which people aren't going to use if they're going to abuse it? I think that you have to go back and do something in society. It's not just for living. Because if it was just for you to just live, I don't think you can stay healthy. Because I like to work to keep my mind off what my condition—I don't feel I have a condition; I feel healthy like anyone else.*

For Jon, the concern is related to the lack of attention to the increasing needs of people with chronic illnesses in the workforce. According to Jon, employees tend to discriminate against people with chronic illnesses. When he was on haemodialysis he wanted to go back to work; he wanted to feel useful but he was denied the possibility. He had to wait until he was completely recovered to return to work. He believes there should be more initiatives to allow people with chronic illnesses to return to the workforce. Returning to work is a key factor in Jon's recovery. He does not want to be discriminated against because despite his taking medication to avoid the rejection of his new kidney he still likes to do the same activities as his colleagues. For him, politicians should work harder on inclusion of chronically ill people in the workforce. Like Maurice, Jon believes there is nobody fighting for them at the state level.

Feeling Discriminated

> *The only time I ever felt—and discrimination is the wrong word; I just don't know what the right word is—was life insurance; I couldn't buy life insurance. Which I still don't really get, but anyway, that's their choice, and that was the way it was. But because of my disease, I'm just not eligible to buy life insurance because I have the gene, have the chronic illness. Once my children reached adulthood not having a life insurance didn't really bother me. Because that was my biggest concern, was that I lived long enough for them to be adults and be able to take care of themselves, and once they were able to do that, well, the need for life insurance went away and I wouldn't have bought it anyway! As far as society was concerned that was the only sort of discrimination I have felt. I was disappointed and surprised, mostly surprised, because I felt well. And the typical progression of the disease that I have, usually end-stage renal disease doesn't occur until you're in your 50s or 60s. At 25 or whatever I was at the time I applied, that's a long ways away. So I guess I didn't really grasp what the gravity of it was and why they were resistant to insuring me.*

Sarah cannot purchase life insurance because of her condition. The first time she applies for insurance she is hopeful but when her application is rejected, she is surprised because she is not having any symptoms. Why was her application denied? She very quickly came to understand that she is not insurable due to her condition, despite the prognosis of her disease. Today, she does not seem to mind, mainly because her two daughters are adults. So there is no point for her to worry about financial difficulties for them. Sarah has accepted the situation and moved on. She cannot change the way people in insurance companies think about her. Through the last years she has lived without insurance. It is discrimination but she cannot change the polices of these insurance companies.

> *The only problem I had was with disability insurance with my bank. Because I had a disability, and they didn't want to pay it because they told me that I'd given false information. Because I had told them that I had previous kidney problems and I didn't tell them this. What had happened is my insurance agent with the company, I showed him the letter, and he said—he called the bank and he said—in the year prior to this, I had to do a medical to be put on the disability insurance from my company, and he said there was nothing showed up. I mean, the doctors did this; nothing showed up, so how can you say that I had lied about my condition? He said, "If you don't want to do this, I'll get a lawyer and we'll fight this." Then they paid me my disability. But I had to go through this to fight to get it. And it's been ongoing; any time you want insurance, it's always you have to go and fight and get reports and letters, and finally they'll pay you—but you've got to go through all these hoops, you've got to jump through this all the time.*

Jon's bank does not want to pay him because his previous condition has not been reported by his physicians. He has to go back and forth with reports and letter to obtain his disability insurance. It is a difficult process for him, especially when he is going through haemodialysis. After Jon has his transplant, the attitude in his insurance company changes because he wants to go back to work as soon as possible. According to Jon, people normally do not go back to work after a transplant but he wonders what the point of receiving a transplant is if one is not going to go back to work. For him, being productive is one of the most important things in his life. His bank supports his decision to return to work. Later, Jon tries to remortgage his home but his previous conditions do not allow him to receive mortgage insurance. Like Sarah, he thinks this is unfair. Why does society keep labelling him as sick when he does not feel that way? He feels he is fighting alone. He thinks health care professionals should have a say regarding this matter. He is healthy. He was told after his transplant that he was not ill anymore so why do people keep telling him that he is?

The Entire Life Insurance System Has Barriers Against The Diabetic

> *When I was younger, it was difficult for me to get a commercial driver's license, so my doctor actually had to lobby on my behalf, because, automatically, they would not have assigned me a commercial driver's license because I was diabetic. So she actually had to write several letters to the licensing board which was in [location D] at the time in order to be able to get them, to make the point it was well controlled. He sees me on a regular basis, there's no reason why he should not have a commercial driver's license. There's a barrier in the insurance system, life insurance, for example; I was not eligible for whole life insurance. The entire life insurance system has barriers against the diabetic. I found going through the process of trying to get life insurance for myself and receiving a number of rejection letters, "I'm sorry; you're not insurable," was challenging because I was trying to—I only considered life insurance when I had children and I needed to protect their financial future. As a transplant recipient, with the medications—they essentially ask you for your medication list, and as soon as they see your medication list, "Oh, you're not insurable."*

Like Jon and Sarah, Maurice has administrative difficulties because of his illness. He finds it difficult to obtain a commercial driver's license. After a lot of paperwork that requires letters from his doctor he obtains his license. However, he has to be seen by his physician regularly to keep it. As with Sarah and Jon, Maurice cannot be insured due to his previous condition. Like Sarah, he in unable to protect his children financially. Going through the rejection was an eye-opener to see how people with diabetes or kidney failure face discrimination. Like the other Canadian participants, his transplant does not change his health status for insurance companies. On the other hand, after his transplant, Maurice does not need to go through the whole process to renew his driver's license every year. At least in this government department, he is not diabetic anymore. It has been a relief for Maurice. But in general the discrimination of society is basically out of his control, so he has to accept the reality because there are no other options.

Living with Chronic Illness in Canada

Illness is an introduction to the fragility of life. Illness is an unpredictable event that requires constant readjusting. Through illness we come to understand that life and death are intimately and ultimately connected for everyone. It forces us to acknowledge our temporality and to place our lives in perspective to others and to our world. With chronic illness, people are likely to endure multiple losses that may include the loss of control and personal power, which is an important contributor to self-esteem, as well as loss of independence, loss of identity, loss of financial status and loss of their customary lifestyle (Cashin et al., 2008). Chronic illness is a long lasting condition that challenges the person as a whole. It does not matter whether chronic illness begins as a physical or a mental problem, being ill most of the time affects the dimensions of the person who is ill (Dreyer & Pederson, 2009). Sometimes chronically ill people are isolated and feel despair and at other times, like the Canadian participants, chronic illness is an opportunity to find support and transformation in unexpected ways.

How does healing happen and where does it begin? Probably the healing begins with hope. With chronic illness, hope is the space between symptoms and diagnosis and between diagnosis and prognosis. Indeed, chronic illness is a journey to an unknown destination, a journey that swings back and forth between periods of being hopeful and being hopeless. Etymologically hope means to expect and desire something (Skeat, 1963). For participants of this study, hope is to expect someone is helping, that family is never far away, that the health system and the state cares, that the treatment received is given humanely and with the best technology. Hope, for the participants of this study, means being treated, not as another case or pathology, but as a person, by people who understand that this could happen to them as well.

Chronic illness is never a welcomed guest in anyone's life. However, how people cope with their illnesses will determine, in great part, how well they will live their lives. The lives of participants have abruptly changed. Suddenly chronic illness has become a part of their lives. Chronic illness has changed the lives of these three participants forever. It was hard. One day they were working or living a normal life when suddenly, and without any warning, chronic illness comes into their lives. They felt overwhelmed by how quickly their lives changed and by their inability to control their situations. Life becomes difficult for all of them. For Maurice, being ill does not cause any drama for him. He accepts complications as a part of his illness.

Symptoms are a key element in the way participants of this study respond to their illness. For those with abrupt and uncontrolled symptoms, life is full of suffering and drama. They do not know what to do or where to go. Life becomes a nightmare. They mostly asked, “Why me?” Or “What I am going to do from now on?” Perhaps there is a sense of disbelief and disappointment for the abrupt way illness shows up in their lives. For Jon, Sarah and Maurice the situation impacts on their lives but they do not stay in a state of agitation. They adapt their lives to the new set of circumstances. Overall, the Canadian participants think their experience has changed their lives in a positive way. They have learned to be patient. Jon, Maurice and Sarah move on with their lives. Although they are not in complete control of their lives, the routines of procedures and treatments become a stabilizing part of their lives. Not having a supporting system makes the experience of being chronically ill in Canada overwhelming. It is hard for them to come to terms with their illness when they are constrained by others. Jon, Sarah and Maurice have a different perspective, probably as a result of the good outcomes their illnesses have. The three of them received transplants. They continue to monitor their conditions. So everything, even the access to health care, has not been a problem for the three of them. They accepted their conditions right away. They became active participants in their care. They appreciated being informed. For them, there was no pressure or alienation from the health care system. Those aspects have a profound impact in how participants perceive their experience.

With chronic illness, each member of the family learns about the situation and how to deal with it. For the eight participants in this study it is really important to have someone to rely on. Family plays a key role. The dynamics and the routines in the families are affected by the presence of treatments such as dialysis and chemotherapy. Support from the family helps the participants to cope. For these three participants the bonds with friends and family are strong. They are there with them for the whole process of illness. For Jon and Maurice, the exposure to invasive treatments or procedure opened up the opportunity to interact with other people who were suffering from similar conditions. During haemodialysis they found new friends who were going through the same processes. Those friendships gave them reassurance that helped them to cope with the struggle. Sarah did not perceive any extreme change in her social life. Her condition brings some sympathies and solidarity but in general her mild condition does not create any difference in her social life. She continues living in the same way she used to before her illness. Maurice finds it hard to integrate his dialysis into his work life. For some of his friends without chronic health problems, Maurice’s dialysis is a process they want to know more about, whereas others who have diabetes or other chronic conditions would prefer to distance themselves from the issue. Maurice’s disease was like the reflection of a future they did not want to look at.

Participants who are parents worry about their children and try to make changes that will make life easier for their dependants. They think of the future and what will happen financially if they die. Sarah, Jon and Maurice try to secure the financial future of their families. Jon tries not to disrupt the routine of his daughters by scheduling his haemodialysis late in the afternoon. How important is the support of the family in the moments of crisis? Support of loved ones is extremely important; it is a critical element, especially during setbacks in their health.

Time is perceived differently when one is living with a chronic illness. Time is rooted in the needs of the ill body, a body that makes it difficult to know how to plan for an unstable and frightening future. Illness strikes the lives of the participants in a deep way and one of the effects is the change in the perception of time. Prioritizing what is important is the most common activity for the participants. Being ill creates the need to attend to aspects of their lives that were otherwise ignored. As well, the ill person has to learn to improvise because of the unpredictability of the disease. Chronically ill people are caught in a time frame that is shaped by changing health conditions and the routine of treatments. All the actions now must be focused on the requirements of the body. Although, for some, the impact of the illness strikes them heavily at first, for others it is not as severe; they have time to change their feelings about their bodies. For Maurice, the body is just a facade that does not represent who he is. Jon, though, is affected by the symptoms, but once he adjusts to his illness he is comfortable with his perception of his body. When he compares himself to others in haemodialysis, he feels that his life is improving. For Sarah, her physical appearance is a problem. It is hard not having a slimmer waist, but she comes to accept why it is not possible. At first, she will not accept that her physical shape is the result of her illness, but after she sees in an exhibition how her kidneys fit into her body, she understands why she is shaped the way she is.

The doctor-patient relationship must be built within parameters of mutual respect, trust and acceptance. Physicians must always respect and recognize the experience of the patient. However, sometimes participants of this study from Canada feel that their doctors treat their diagnoses rather than treat them as human beings. Body functions, pathologies and medications are the centre pieces of attention for physicians, forgetting to view the patient as a whole. For the participants of this study, their being part of the process of health care is important. They want to be active participants but it seems their physicians do not allow them to do so. It seems that their physicians have forgotten how illnesses extend far beyond the symptoms as described in medical text books. Chronic illness invades every aspect of the person's life. Every day they fight their illnesses as well as the side effects of the prescriptions used to treat their conditions. Chronic conditions can also take away many things in people's lives, such as hobbies, life goals, life possibilities, friends, time and energy. In fact, chronic illness takes away much of what fills most people's lives. How is it possible for physicians to ignore all these important aspects of chronic illness? Is the doctor-patient relationship a mere service in which both parties have predetermined roles to attend to? Or is it a particular kind of interpersonal relationship? Jon and Sarah fight back when they are ignored by their physicians. They reclaim the right to be part of the team fighting for their well-being. Physicians in these narratives are focused on what they consider to be the most important part of illness, the treatment. Often, disease is confined to the organic level. Certainly, disease reduces one's experience in that the body becomes an object that needs a cure. Even though a disease *per se* could be presented with the same pathological signs, one's perception of illness and how to deal with it is unique, because each human being is different. The meaning and uniqueness of the moment of being ill is based on the person as subject. The problem with this approach is that what medical personnel consider to be unimportant and not worth discussing is a side of illness that is in the forefront of the sick person's life.

Canadian participants have not faced financial difficulties resulting from their chronic illness. On the contrary, all the participants are grateful for being able to continue living their lives without any financial difficulties. There is always the tension and the stress of leaving their children unprotected but once they secure the financial future of their children they continue living life as it comes.

The perception and the labelling of the participants as being ill limit their worlds. Financial institutions, government bureaus and insurance companies relegate the participants to a lower status in society. Canadian participants are marginalized by banks and governmental institutions. Why are they discriminated against? Is it because a mortgage is a long-term financial commitment and people with chronic illnesses do not have a secure future? According to Canadian participants, insurance companies have chosen not to insure them based on their diagnosis. Participants who applied for life insurance to leave monetary benefits behind for their loved ones had their applications rejected because of their medical situation. The decision to deny an application for life insurance is done strictly from a risk standpoint. Life insurance companies want to make sure that people are healthy enough to live until their premiums are paid. Therefore, it is logical for them to deny coverage to people who exhibit factors that can increase the possibility of death before their policies mature. Demographically, Jon, Sarah and Maurice are considered to be people with a high risk of early death. Due to their conditions and despite that they have received transplants, they cannot be insured.

Findings from this study suggest that there is a lack of representation in politics in Canada. Despite its magnitude, chronic illness has not received the proper attention. Consequently, people such as the participants have to fight their battles alone. As Maurice says, politicians are driven by self-interest and do not care about chronic illness. Socially, there are many associations but their advocacy role does not reach the level of politics chronic illness is asking for. Political representation is the activity that makes citizens' voices, opinions and thoughts visible to others in society (Reutter & Kushner, 2010). Jon wants more attention from the government to allow more participation of people with chronic illness in the workforce. Maurice wants to raise consciousness in general about the necessity of organ donation. Sarah does not find any support from the government: she believes the only way to overcome her health issue is through her own advocacy. Being ignored by policies and health systems makes these participants second class citizens. Despite its presence, there are neither organizations nor nations nor communities facing the problem with real commitment. Apparently, part of the root of the problem is with the lack of resources and policies for prevention; however, chronic illness is here and the solutions cannot wait. Basically, despite the lack of public commitment, participants show how to deal everyday with chronic illness and how they can survive because love, empathy and personal commitment enlighten their pathway.

Chapter V Viviendo/Living with Chronic Illness in Colombia

Victims appear before us: someone is begging, someone is injured beside the road, a street kid is cleaning our car, we encounter a victim of repression, we meet a woman Who has been brutally beaten, we speak with a student unfairly treated by the teacher. The victim is another whose accusing presence we can no longer "shake off' when it comes to our obligation (Dussel, 1999 p 126-7).

Undertaking this study with chronically ill people in Colombia has meant being attentive to the different spaces the experience of chronicity unfolds. Chronic illness is an emotionally as well as physically depriving experience. The lasting characteristic of chronic illness is the threat to the person's sense of well-being, competence, and feeling of productivity. They have to strive to attune themselves to the complexities not only of their ill body but also the unpreparedness of the external world to the demands of their ill bodies. Life is not easy for them. Their lifeworld is loaded with unexpected symptoms, advances of the disease, medical visits, treatments, diagnostic tests and hospitalizations. They do not have control over any of those spaces, leaving their future in the hands of people who do not understand the immediacy of the demands of chronic illness. To obtain authorizations for specialized medications, diagnostic tests, procedures and referrals to specialists their lives fall into the hands of bureaucratic and rigid structures that delay their recovery. All of this creates cracks in their worlds that claim a sudden shift of attention toward their condition.

In this study, the participants show that living with chronic illness is not easy and the way society and the health care system are organized do not make it any easier for them either. Health, in Colombia, is claimed to be a human right, a human right that must provide all citizens with the possibility to live a full life. And, yet, for these people, health becomes a commodity that sometimes they cannot afford. Some of them fight back to obtain services and attention, whereas, for others, adaptation and resignation are the only solutions.

Using the four existentials--lived body, lived relations, lived space and lived time--I explore the structures of human lifeworld, the lived world as it is experienced by chronically ill people in Colombia. These four lifeworld existentials as heuristic guides for reflecting on human experiences have been used to guide my phenomenological questioning, reflecting and writing (van Manen, 2002). The result of an interpretive phenomenological inquiry is a text or story that gives insights into the phenomenon under study and the meanings associated with it (Bergum, 1999; Cameron 2004; van Manen, 1997). On the other hand, critical pedagogy as a theoretical perspective has been used to examine emerging findings in the context of globalization and resulting global inequities. Together, all the parts support the urgency to address the experiences of the chronically ill in the context of contemporary globalization forces and how these political, economic and social forces physically affect the chronically ill.

El Llamado/The Call of the Body Ill

Hannah

> *February, during my last year of high school, a severe pain in my right knee began. At first, without other symptoms, the doctor thought I had only a simple growing pain. "Nothing really to worry about," he said. He gave me some painkillers and sent me home. A few weeks later, the simple joint pain came back, but this time it was not only affecting my right knee but also my left knee, hips and back. This time, my visit to the doctor ended up with a long list of blood tests and X-Rays to do. All of them came back normal. Again, it was nothing really to worry about. Those first months, I spent most of the time back and forth among many medical specialists and, yet, they did not know what was happening to me. So they suggested to me that I drop out of school to determine the cause of my pain. I rejected the idea for two reasons: first, I did not want to be secluded in my bed, and second, I had this silly dream since I was little to finish my last year of high school with the classmates I began my studies with in elementary school. At 16 years old it never crossed my mind that my symptoms would last this long. So, I did not consider the seriousness of my situation. I was young and naïve. How could I guess? At 16, life is supposed to be a time to have fun and to enjoy with your friends. Also, it is supposed to be a time to dream about the future. But everything and everybody changed. I changed. My life changed. My friends changed. I learned this the hard way.*
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> *When I came back to school, I was so limited that even taking the stairs was a big deal for me. During the breaks while my friends were going out, I had to stay alone in the classroom. From my desk, I could hear in the distance all the laughs, yells and fun of my fellow students playing outside while I was sitting in my desk watching the black board and the empty desks around me. It was hard to be there alone. The only time I saw my friends was during the class time in which we barely spoke. Suddenly, everything changed and my silly dream was gone. I was even having academic issues with my teachers and principal due to the permissions to go to the doctors and all the leaves I was forced to take for my disease. They never understood what was happening to me. After a while, I was confined to bed, so, definitely, I had to drop out of school. My friends left me, because, well, no one understood what it is like to be in pain. They never understood why I was moody or depressed most of the time. They did not know I was scared of not*

knowing what was happening to me. I never told them. So I ended up without friends. All of them moved on with their lives and I stayed behind with my joint pain and surrounded by just my parents and sisters. Today, I am still mourning for what I was and what I could not be anymore.

This experience has been overwhelming for my whole family. At the beginning, they did not know what to expect or where to go to help me to alleviate my pain. We went to a lot of medical specialist, psychics, fortune tellers and traditional healers and yet we did not have any answers to what was happening to me. We were clueless. We did not know where to go or what to do. I was anxious to have a name for the disease, to have something concrete to fight against. As well as my family, my physicians were also overwhelmed by my situation. They said, "There is no physical explanation for your symptoms so we believe it must be your head making up all these symptoms." Following this comment, they asked, "Do you feel sad or unhappy? Do you feel tired, low on energy or unable to concentrate? Hannah, are you suffering from a lot of stress lately?" I was shocked. But how could I not believe them if it is not only one, but two, three, four or five physicians with the same conclusion? So at some point, I believed them and I began to feel as if I was a hypochondriac. What else could I do, if all my blood tests and X-rays and other exams came back normal? Even for my family, it was shocking to hear that. So I ended up with antidepressants and with multiple referrals to psychiatry. I was brainwashed by this predicament of psychosomatic disease so I learned to shut up my body when the symptoms appear. A couple of weeks ago, I was walking through the university when suddenly I had this severe chest pain and my first thought was, "How much of this pain is real and how much of it is just the result of my mind?" I always have to ask myself the same question because that is what I learned from my physicians. I learned to disregard my symptoms and to dismiss my body.

In 2008, after many episodes of joint pain, migraines and paraplegia they discovered an Arnold Chiari Malformation. I was so thrilled and relieved. "Finally," I said. It was real what I was feeling all this time. It was my confirmation that I do not have a mental illness. It is a physical disease. However, all that happiness was soon washed from my face when after the surgical correction of my malformation all the symptoms came back again. With further studies one of my doctors discovered I do have a Raynaud's disease too but it does not explain many of my symptoms which means I do have something but we still do not know what it is. It may be something autoimmune. But again, I do not have a diagnosis yet. At least nothing concrete. Something that says all your symptoms fit within this disease and the treatment to follow is this one, but no, I am 26 and still I have to live with the uncertainty. That is difficult to accept especially because I see how every time my symptoms last longer and become more difficult to handle. Nobody really understands but me what it is like to live scared of the unknown. It seems like this disease has come to me as a thief, a thief who steals little pieces of my youth and my life one by one. All

> *these things just make me wonder: what if one day the manifestations of this disease become so aggressive that my body cannot handle them? What if one day this disease does not give me the chance to fight back? What if I die?*

Esta enfermedad es como un ladrón, un ladrón que roba uno a uno pedazos de mi vida. What is it about chronic illness that brings us to attention and sets it apart from all the other events in our day? Joint pain has brought in a big shift in Hannah's young life. From being an active, sociable young woman she has been progressively confined to a solitary world, the world of chronic illness. Joint pain and disability have disrupted her very way of being. Life has to be adjusted to compensate for the changes of her body. Her life is at the will of her body. The shift is too traumatic. Her body seems to just turn against her. Hannah is in pain all the time but still she forces herself to go to school. She wants to do things her body is not able to do anymore. Important aspects of her life are on hold. Can Hannah truly find her way through this situation?

Dreams and youth are exchanged for pain and disability. This is not how it is supposed to go. She feels demoralized. Hannah does not know what to do or where to go. It is like being thrust onto a foggy place without a compass or map. On a foggy day the gloominess and poor visibility add to the experience of confusion and disorientation of trying to find one's way through a once familiar area that suddenly appears to be completely foreign. Hannah is walking painfully into the foggy world of chronic illness. There is no map to guide her way out of this world. Her body sets the leads to follow. Sometimes those leads light up without a predictable order: one day she has joint pain, the next half of the side of her body is paralyzed. Thus, her symptoms are most of the time different, mixed up and not even related to one another. Yet, living with chronicity means surrendering control to the body which may interrupt daily life, and the plans for the future may have to change.

Hannah has been dealing with her condition for 10 years. Every day in her body she lives the disease and, yet, according to her medical tests, she is healthy. But how could she be healthy when she is suffering from excruciating pains? As Gadamer (1996) says, "Health does not actually present itself to us" (p. 107), health is a real mystery, a fact that dwells inside of each one of us, that we are not aware of until the moment that we do not have it anymore. In everyday life the body is taken for granted and an unnoticed partner as we are immersed in the world. Illness, pain, hunger and disability can disrupt this taken for granted state (Gadow, 1994). Then, through illness our unnoticed partner draws our attention to itself. Hannah's mind constantly spins around the same question: what is happening to me? She does not know the answer to that question and it is for others to name her problem as disease or sickness. She has undergone several tests for many conditions, seen several medical specialists and even psychics, fortune tellers and traditional healers but she is yet to have a formal diagnosis. Her dialogue with her doctors is often asymmetric and is surely bizarre. Her doctors believe Hannah's mind is making up the disease. It seems that in medicine when there is no concrete evidence for any disease in the body the doctors turn the quest for answers to explain the symptoms as something psychosomatic.

The doctors think Hannah's body is a separated entity from the whole and disease is something that invades it, the object (Boyd, 2000). How does she deal with that? No one believes her. The doctors' response stuns her. This new set of circumstances demands a totally different response. She struggles to improvise. She learns to keep her body quiet. Her body is unworthy of trust anymore. Is the body merely a physical representation of ourselves in the world? Is our body simply an executor of orders? Why do we have this tendency to disengage ourselves from embodiment and to enclose ourselves in human conditions that we consider to be ideal? Is this part of our intellectual tradition? Is this tendency inherent to our being? It is too traumatic when there is nothing concrete to fight against. The nature of autoimmune diseases does not allow them to be concrete. Sometimes they show up when it is too late to act upon them. As she waits, Hannah finds herself in a state of wretchedness. Her waiting is exasperating. Every time her symptoms come back she feels like her life is fading away and she cannot do anything to stop it.

Being ill seems to upset the flow of our life, making it impossible to go forward until we deal with the situation unfolding around us. At the moment it comes up, it forces itself upon us. To use Mairs' (1994) words, living with chronic illness feels like the person is "haunted by a capricious and mean-spirited ghost" (p. 269). Is it possible to get control in illness? Or is it lack of control which reduces the body as an independent and mechanic piece of the whole? Regardless of our intellectual tactics to resolve the situation, we feel that a lack of knowledge causes us to be out of control. It is a feeling of suffering resulting from our not knowing, our ignorance about what is happening to us. Being ill, in some sense, challenges our confidence and security in the future.

Before a disease appears, sometimes we feel the presence of illness, and sometimes illness exists where no disease can be found (Boyd, 2000). Yet disease cannot exist without the presence of illness because disease means in principle that its presence exists for whoever experiences the illness and explains it. Therefore, the appearance of disease and the perception of illness are sometimes not related. Or both situations may be related but sometimes they do not appear at the same time. In Hannah's story she feels the joint pain, she cannot walk, but many tests indicate that she must be healthy. Pain is a subjective experience. The uniqueness of the experience of pain is always preserved. Pain could be described in numerous ways. It can be measured with many scales. But these do not get any closer to what the real experience of pain is for each human being. Hannah's doctors understand pain from a pathological, physiological and even personal perspective but their knowledge and experience do not get them closer to what Hannah is dealing with every day. Being in pain means to be forced into this constant state of wakefulness. This is one of the hardest things in Hannah's life to fight against: something abstract, unknown and yet destructive. How much more can she take?

Maria

> *Two years ago the government changed our health insurance company so I had to go to a new gynaecologist. My new doctor sent me for a mammogram despite that my last one was only done 11 months ago. I was not worried about this test because, well, the last one was normal. So what could go wrong? During the exam the technician found something wrong with my test. In fact, she thought that the equipment was failing so she decided to repeat the exam. The second time, she called the physician and showed him my results. Right away the doctor called me to his office and explained to me, "There is something in your breast. I do not know what it could be yet. But it would be helpful if you have another mammogram to compare the new findings. If you want we could get together tomorrow morning and compare both exams." The next day early in the morning, as we planned, we met in his office and he said, "Yeah. There is a something here that was not in your previous exam. You need to go to the specialist right away." A couple of weeks later, I went to the breast surgeon who confirmed there was a suspicious lump in my breast. "It could be cancer or it could be nothing so we need*

to schedule a biopsy to determine the course to follow," he said. I let him do the talking.

This first moment was unforgettable, it really was. My heart sank. In just minutes my life changed. I was confused and mixed up at first. I did not know what to expect or what to say. I was overwhelmed with anguish and anxiety. In my head there was always the same question, "What to do?"That first week was one of the hardest in my entire life. I was drained by the whole situation. I was in despair and disbelief. It was hard. I kept to myself my possible diagnostic of cancer. How could I not? My husband is in the last stage of cancer. In our marriage, I was the healthiest and strongest one. So I kept wondering how to break such devastating news to him? I was his shoulder to rely on in his moments of crisis. How could I rely on him? I could not do that. So I kept this bitter information to myself. I just wanted to close my eyes and not allow myself to think or to feel anything. I just tried to forget it but it was really hard to keep all the fear and despair I was feeling out of my mind. So I kept working as a psychologist in my school as a way to try to keep all of this anxiety at bay. However, there were times in which I could not help but to think, "I am the psychologist here, teachers and students come to me for advice and support but who is going to advise and support me, the advisor?" I was completely alone.

When the time to go for the biopsy came I was forced to have a companion for the procedure, so I told one of my best friends. However, I did not disclose all the information to her. I just told her that my doctor found something in my mammogram, something that he needed to explore further because he was not sure what it was. So she said, "No! No! I don't think there is something wrong with you. Don't worry Maria, it must be nothing. It must be a mistake." Her words were a relief for me even though my senses were tingling and I just had this feeling that I had cancer.

Once my biopsy came back positive for cancer another struggle came to my life, how to break the reality to my husband. It was hard. One day, in the bathroom, I rehearsed the whole moment: what to say and how to say it and what his reaction would be. The whole day I hesitated. That night there was a lot of opportunities to speak out about my cancer but I simply could not do it. I kept wondering if Alfredo would suffer a setback in his recovery due to my news? The perfect moment came at night when we were watching TV. I was scared; my hands were trembling and sweating. My heart skipped several beats. My voice was broken but finally the words came out of my mouth, "I have breast cancer." Finally, I told him. It was a sad relief. At first, he was pale, in disbelief, almost in shock by the news, then, he cried. We both cried and hugged. It was a very emotional moment. This was one of the few moments I have cried during my illness. It was hard. Before my diagnosis, my only knowledge about cancer was through my husband's experience. Yet it never came to my mind that this could happen to me. My whole life I was so healthy. There is no history of cancer in my family. Before the exam I did not have any pain or discomfort. I was fine. At first I was not only shocked but also grateful they found my disease on time. I do not consider my

> *experience negative; on the contrary, I think cancer has brought an amazing opportunity to strengthen the bonds with my husband and family. My breast cancer came to my life for a reason. Our diseases have significantly strengthened our relationship. Through time I have learned to take things easy, to be calm. That is the way I have learned to face our situation.*

What could go wrong? This seems ordinary enough—one day the government decides to change the health insurance company of a group of workers and they have to arrange for check-ups with new doctors. Maria arranges for a check up with her new gynaecologist and he sends her for a new mammogram despite that the last one was done just 11 months before. She is sure her new mammogram will show that everything is fine. Why would it not be? Her last test showed no problems and she does not have any symptoms.

Apparently, she is healthy. Why does she feel this way? Perhaps there is no boundary between health and sickness. The meaning of health is ambiguous and specific to the individual; the imposition of standards can cause the labelling of healthy people as ill or the opposite. As in the case of Hannah, Maria struggles to improvise. However, different from Hannah, Maria has never had symptoms. Maria's body keeps quiet. It does not ask for any attention, whereas Hannah's body shouts to be heard as it twists in excruciating pain. Hannah has been battling for 10 years to find the name of her autoimmune disease while Maria, without looking for it, finds a disease. What is it about chronic illness that sometimes makes the body speaks so loudly, almost yelling, and other times it keeps the body quite and shows up when it is too late to fight against it? To use Gadamer's (1996) words, "No illness manifests itself in exactly the same way in every individual" (p. 111). Thus, even though disease per se could be presented with the same pathological signs, one's perception of illness and how to deal with it is unique, because each human being is different. The meaning and uniqueness of the moment of being ill is based on the person as subject. Maria's confidence is gone when a lump is found in her breast. Then, her confidence about her future is stripped away when she finds out she may have cancer. A routine test has introduced a change in Maria's life. She feels that her life is out of control. It is traumatic to discover her normal life has come to an end. Another life takes its place (van den Berg, 1987 p.233). She is shocked by the doctor's findings. This new set of circumstances calls for a different response. Maria's expectation of how her life events will unfold suddenly crumbles as the situation around her reconfigures itself into something completely different. Maria's planning does not help when the certain becomes very uncertain. When it happens, she is driven into an unexpected and compelling moment—she may have cancer. How to face this new devastating reality? Her future is now unsure.

Maria is bewildered and confused by the bad news, but she keeps the information to herself. Neither her husband nor her friends know about her condition. Through working she tries to forget her disease. But in her work, as a psychologist, Maria struggles with how to advise and support other people when she struggles with her own life. She does not have anyone to rely on. One day she decides to relieve her load with one of her best friends just a few days before her biopsy. The information she gives is incomplete. She does not want to face reality. Also, she does not want to bring suffering to her husband. He has cancer, too. How can she bring such overwhelming news to him? She does not have a history of cancer in her family. She was healthy. Being the caregiver of her husband is the closest she has ever been to the experience of cancer. Through her husband's eyes she has witnessed the experience of cancer. And yet until now she does not know in her own flesh what it is like to live with cancer. She is scared. Her flow of life has been upset by this new set of circumstances and she cannot conceal the true any longer. Her husband needs to know she has cancer. Maria has everything planned in her mind. She rehearses the whole conversation: what she is going to say; what kind of words she is going to use; how he will respond; and, finally, she imagines how they will come to accept the cruel twist of life. Maria's planning does not help when her problem is revealed. Thus, in reality there is no routine response or handbook for reference to deal with such tragic circumstances.

Through time Maria has learned to accept her illness as a part of herself and she found some positive outcomes from her illness. Her illness has become a special part of herself in a different and new way of life.

I was in shock by the news. By its nature, chronic illness is disruptive. It addresses the life of the person. Chronic conditions seem to upset the flow of people's lives, making it impossible to go forward until they deal with the situation unfolding around them. Hannah lives with unbearable joint pains. There was no going back to Hannah's old life. She has to deal with the new circumstances of life. Maria was expecting good news from her mammogram but the news came back the opposite. The idea of cancer had never crossed her mind because her original mammogram 11 months ago showed no problems. Chronic diseases catapult people into a different space. They are forced to grapple with a set of emerging circumstances that they neither anticipated nor want. Every day, normal expectations are forced out of the picture. Another story of a chronic condition, another life touched by the unexpected is Camille's story:

> *In June 2006, I had some back pain. It was not that severe but I went to the doctor just in case. He thought my back pain was a simple neuralgia as a result of excessive stress in my job. He sent me for some therapies and that was it. Well, to be fair with him, I did not have the look of a sick person. I was fine. So the doctor did not send me for any special test or medication, just the therapy. I was to follow 10 days of therapy to improve my back pain but I only had one because my boss did not authorize any medical or, in my case, any therapy appointments during working hours. It was unfair what he said to me, "Camille, I don't know what are you going to do with your therapies but they don't fit within our work schedule. Why are you scheduling therapies during your working hours? What are you doing during your weekends? Sorry, but I cannot grant you another permission to go at this time." I was mad because he was unfair. It was my health at stake and he did not care. The only thing he cared about was to complete our work in time.*
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> *Due to his attitude, I decided to postpone my therapies until the end of the year during my vacation time. I continued with the pain but I did not really pay much attention to it, mainly because everybody had an opinion about it. My friends told me, "That's the result of your workload" or "Camille; this is just the result of dealing with the disease and death of your mother and father in the last two years." Even my sister thought I was making up my pain. One time she told me, "That's nothing. You just want to be the centre of attention within family and friends." Later on she changed her mind to, "I think this is a simple neuralgia due to stress." Well, nobody thought it was serious but me. I thought, "This pain cannot be a simple neuralgia. I feel that it is something else."*
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> *In January 2007, I sought some medical help because I could not move. I was almost paralyzed. I had to walk with the help of objects such as tables, chairs and brooms. Sometimes I held onto the walls to avoid falling. Really, I could not walk by my own means. So I went to emergency with my sister. We waited in observation the whole day. They put me on some IV painkillers and sent me for a CAT scan of my brain. The CAT scan was a mistake because what the resident wanted was an X-Ray of my back and head but the intern misunderstood the orders and sent me for a CAT scan. Later, when the pain was almost gone, the doctor sent me home with a lot of blood tests to do and to bring to my doctor, some prescriptions with oral painkillers, and, of course, more therapy. I was feeling OK when they discharged me so I decided to go to my health insurance company to request my prescription and make an appointment with my doctor. Meanwhile, my sister was waiting for a summary of my records. The intern gave them to her but*

> *they were incomplete. The result of the CAT scan was not there. So my sister called the nurse and asked for the results. The results were misplaced, so my sister had to wait there for some time. Suddenly, the nurse called her to go inside and asked her, "Where is your sister?" My sister answered, "Why? What happen? She is in the other building authorizing what you gave to her. Why?" "We have made a mistake. Your sister cannot go because there is a chance your sister has multiple myeloma. We need her here right now. Please call her. She needs to be hospitalized," the nurse said. My sister called me and told me the news when I was in the other building doing all the administrative procedures to get my appointments and medication. And I just thought, "There it goes, my simple neuralgia".*

Back pain is the only symptom Camille feels when she goes to the doctor. As the pain continues, Camille feels that something is not right with her. Something is not normal. She feels her pain is not a simple neuralgia. She seems healthy to her doctor so he only sends her for 10 sessions of therapy. Her family and friends think Camille's pain is the result of stress. A simple neuralgia, they call it. Everybody dismisses what she is feeling. Why do people deny the reality of others? Why Camille ignores her body? Being sick means that something has changed in that person as a social human being. It just reveals the personal situation to others and how they perceive it.

At the office, her boss grants authorization for only the first session but she cannot go to the others. She has to find another time to attend to her health. For her boss, there is no time for therapies; there is no time to be ill. The only time available is the time to be productive. She considers her boss' decision to be unfair. And yet she keeps working. Why does she do this? Perhaps the social role of being sick enables the ability to conform one's life to the rules and protocols of society or, as Wendell (1996) points out, conform "to subtle cultural factors that determine standards of normality and exclude those who do not meet them from full participation in their societies" (p. 36). Camille dismisses the call of her body. She needs to be healthy to keep working. Being sick means having something wrong with oneself compared to others; it means that the human being as a whole is divided as an object according to parameters of health provided by society at large (Brody, 2003). A sick person may feel that the world will fall apart because he or she cannot pursue the expected activities. However, being sick does not stop the world. Everybody else goes on. It seems that life changes the roles and the variety of characters that we assume socially.

Camille postpones her treatment six months until her vacation time. During this time the pain becomes unbearable. It becomes constant. She has great difficulty walking. Her pain and suffering become immeasurable, beyond comprehension. She cannot get it to stop. She loses control over her body. Through time, Camille grows even weaker and she is forced to go to emergency. Pain has affected Camille's ability to be involved in what really matters to her. Pain limits her. Pain controls her. It disrupts the "harmonious balance of [her] bodily process" (Gadamer, 1996 p. 108), and brings uncertainty to Camille's life. Regardless of her pain, Camille's face does not display the common picture of illness so again in emergency her pain is not considered a life threatening issue. She is sent back home with painkillers, a referral to physiotherapy and blood test. She looks healthy. But a doctor's mistake put her on the right pathway to discover the hard reality that she has cancer. Camille is not prepared to face the magnitude of her disease. In a short period of time her world has been transformed. As with Hannah, Camille's body is willing to speak. And yet nobody seems to hear its claims. There is a lack of support when the disease is not externally apparent. Hannah and Camille face the reality of pain. Hannah's pain is disregarded by her own physicians. Camille, on the other hand, tries to pay attention to her pain but the demands of her boss surpass the claims of her body. Both have to endure a new life, a life full of un-sureness about the future.

Alfredo

> *Eight years ago, I was a healthy man, an athlete, who loved sports, especially, soccer, mini soccer and basketball. I used to practice twice a day. I never smoked or drank. I was mainly focused on my wife and my little daughter. The year the doctors discovered my disease I was going through a bitter process of divorce. So I think that was the beginning of everything. Indeed, I was emotionally drained by the whole situation. I wanted to get out of Bogota so one day I decided to take a trip to Buenaventura. I took the bus, but when I arrived I had the worst back pain I ever felt in my whole life. I thought the pain was the result of the 10 hours' trip. So in Buenaventura, to get rid of the pain, I applied an intramuscular painkiller. The pain was gone. I did what I went to do and came back to Bogota. Two months later, in Bogota, the pain came back, but this time it was more intense, almost unbearable, so I decided to go to the doctor. The doctor told me that it could be a bursitis so he provided me with some oral painkillers and that was it. I took the medication for a while until the pain was gone. Months go by with the same pain and over and over again I hear the same answer form my doctors, "Don't worry. It is only a bursitis. Take this prescription three times a day." I was tired of the same answer. So again, I went to*

> *another doctor but this time before she said it was a bursitis and here is your prescription, I told her, "Look Doctor. I don't really think this is a simple bursitis, because in my life as an athlete I know what bursitis is, a twisted muscle or a torn muscle. And I don't think this is a damaged muscle. I think I have something else." Well, at least she listened to me and sent me to the specialist. But still I had to wait another month or so until one of my tests came back with my final diagnostic: prostate cancer with metastasis to the right femur and hips.*
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> *We were too late. My world just fell apart in front of my eyes and I could not avoid it. I still remember those two first thoughts I had. First, I am going to die soon and second, my little daughter is going to be alone. My whole life was just upside down and I could not stop it. My divorce, family and career were left in a second and third place. I did not care. I locked myself within myself. During those two years I lived in complete solitude and bitterness--until the day I met Maria, who is now my wife. She brought me a new beginning and a fresh air in my life. Everything is better because she is here with me.*

Mi mundo se me vino encima y no pude evitarlo. During a long trip, Alfredo's life is unexpectedly interrupted by pain. He goes to see doctors but they dismiss his pain. Why? Perhaps it is because he is an athlete. Athletes are exposed to a lot of injuries in their bodies. He fits the profile. He trains twice a day. However, Alfredo knows his body. He knows the pain he is feeling is not normal. He feels something is wrong with him. Does his heart, gut, or soul--something deep inside him--know something his head does not? Regardless of his pain, Alfredo decides to wait. As he waits, the pain becomes part of his life. Painkillers are part of his daily routine, a daily routine that includes keeping his own body quiet. Through pain, the body tries to get attention, to be noticed because it needs to be cared for. He goes to many doctors trying to find the answer but there was not an easy answer for him. Like Hannah's, Alfredo's body is a difficult puzzle to be solved. The easy answer used by his physicians is that he has a simple bursitis. As the time goes by his uneasy feeling grows exponentially. When he finally gets a doctor to listen to him, it is too late. Some blood tests and other medical tests show he has a metastatic cancer. His life spins completely off course. The simple becomes complicated. And yet he keeps wondering what if someone would have paid attention to his pain? But the reality is that they did not pay attention. And now he has to face the reality of his disease.

Despite its claims, Alfredo's body does not receive immediate attention. It seems that the body sets a window of attention and as the window closes the possibility of recovery decreases. His physicians never thought his situation was serious. A simple pain turns out to be a metastatic cancer. He is at the edge of life. His future depends entirely on how long his body can resist the battle inside of him. As his doctor talks, Alfredo struggles to digest his new reality. He keeps quiet. He has two concerns, the proximity of death and the consequences of his premature death on his little daughter. He is facing a reality of life: death is somehow more touchable, closer to him than life. Death is going to take away his daughter. Death will separate daughter and father. It is too dramatic for him to face that his life is coming to an end. He cannot prevent it. He is bitter. He blames the circumstances of his divorce as the main cause of his disease. His life, as he knows it, stops. The safety of the present is interchanged for the uncertainty of the future. Now he is forced into the unknown world of cancer. The reality deeply hurts him. He finds himself suspended in the moment. Alfredo feels his life grinding to a halt. Until he gets out of this situation the rest of his life is on hold. But he is not alone. Alfredo has Maria, his wife, who helps him to overcome the circumstances of his disease. With her company and love she brings hope for a better future.

Alejandro

> *Everything began in the ‘80s. I was thirsty all of the time. It was terrible. So I went to the doctor, who ran some blood tests for me. My tests came back showing that I was diabetic. It was not a big deal for me. I mean, I knew someday this would happen, especially because I know diabetes is something hereditary. In my family, my mom and most of my uncles and aunts were diabetics so it was not really a big surprise for me to learn I was a diabetic too. It runs in the family so there was nothing I could do to prevent it. Sooner or later, I was expecting it. It was like you always expected the worst. So I took my diagnosis very easy because I cannot go against nature. I know this disease does not have a cure so there was no point to be thinking too much about it or to suffer for it. There was no point. So I kept my life the same, working as a young foreman for the government by building highways across Colombia. I took my medicine, but nothing else. I did not follow any diet because it was not possible in the places where I was working. I had to eat whatever was available there. Generally, there were not healthy choices for me. So I ate a lot of things as a diabetic you are not suppose to like rice, potatoes, plantains and cassava. If I was thirsty the only beverages available for me were soft drinks all loaded in sugar because, well, what else you can drink when there was no clean water available. I recognize that it was not really healthy but I did not care too much because I was fine. I was young.*
>
> *At that time I did not stop to think about the consequences of my choices. I never thought I would end up with a diabetic foot. I never thought I could have a stroke or a heart attack. When you are young you never*

> *stop to think. Clearly, I underestimated the magnitude of my disease. I took my medicines but what are the medicines without the diet? Perhaps I was just following what my mom did with her disease. One day she told my dad, "I don't want to suffer more hunger. I am going to eat whatever I want and I don't care if I die" That's true; this is the disease of hunger. You are hungry most of the time and you have to restrain yourself from all the food you really like. My mom, for example, she was tired with her diet until one day she began to eat all the food she was not even allow to. Really, I do not think her diabetes killed her. She died due to a heart attack and a stroke but not the diabetes.*
>
> *In 2001, after my retirement, I decided to take care of myself but I think it was too late. Well, what else I can do if being sick is part of becoming old. There is nothing I can do. Now I just live with the consequences of my decisions. For example, I have had two retinopathies in my right eye, causing me to lose 80% of my vision and in my left eye I lost 20%. I had one stroke, one heart attack and my kidney function has been reduced 38% according to my last exam. Last November, when I was dealing with my heart problems my physician and I did not really pay attention to my blood sugar that was in the 400 range so I ended up with an amputation of my second toe of my right foot. Well, I am old, what else I could expect? When you are old, the normal thing is to be ill. It is just part of life.*

When you are old, the normal thing is to be ill. Alejandro was thirsty. His doctor ran a blood test to determine his glucose level. The report determined that Alejandro is diabetic. He was not overly concerned about this result. Diabetes runs in his family. There was not too much to think or to do about it. He knew sooner or later he would be affected by this threat. For him, there were other priorities in life; health was not one of them. According to Alejandro, there was not too much to prevent his situation. He had to deal with this new set of circumstances. The doctor prescribed some medications and diet to control his blood sugar. He did not stick to his diet. He worked in areas of Colombia where it was difficult to follow the dietary restrictions of his disease. Taking the medicine to control his sugar levels became the only strategy Alejandro used against the advancement of his condition. He did not consider the consequences of his acts until it was too late. At this point the future was not significantly important. During these first years it never crossed his mind that the future would hold a lot of health complications due to his careless behaviour. At this time his present did not bring any complication of his disease. He saw his mom's disease as a mirror of what could happen to him. And yet he disregarded the call of his body. In fact, he neglected his body for 30 years. He does not want to go against nature. Why should he bother? In those first years there were no setbacks for Alejandro's condition. The fear of complications developing from inadequate diabetes control seemed not to worry him.

Alejandro is resigned to his fate. In the last ten years he suffered one stroke, one heart attack, two retinopathies, two toes amputation, and some complications with his kidneys. He really underestimated the magnitude of his disease. So today he has to deal with the consequences of his reckless decisions. Alejandro does not want to go against nature. Illness, he believes, is part of getting old. There is nothing he can do to stop that reality of life. There is a lot of resignation in Alejandro's story. He assumes his responsibility. Alejandro decides to take things easy. There is no sense of tragic drama in his story. There is no suffering. According to him, there will be no cure, so what is there to worry about? Like Alfredo, Camille or Hanna, Alejandro's body cries for help but, different from the others, he disregards his body. He does not pay attention to the call of his body. What is it about chronic illness that some people worry too much about it and others like Alejandro are able to accept the illness?

The Body of Chronic Illness

When we are ill, we try to manage our situation. However, we quickly become aware that we do not always know what to do. We try to cure the disease or at least try to get some relief. But sometimes, as in chronic conditions, the way out is unclear. It is like being lost without a map to guide one's way forward. To suffer any kind of illness is a unique, personal event, but living with a chronic illness deeply affects one's everyday life physically, emotionally, socially and spiritually.

Chronic illness is immune to planning and preparation. In fact, illness "confronts us as something opposed to us and which forces itself on us" (Gadamer, 1996, p. 107), it is like a roadblock thrown in our path. It is something that prevents the normal flow of our life as we struggle to understand what is going on. Some chronic conditions are more devastating than others; consequently, the reactions and emotional processing involved can be very different from one person to another. Maria, Camille and Alfredo face the reality of cancer. Camille and Alfredo have metastatic cancers. Their lives come to a halt. It is too traumatic for them to accept that their lives are coming to an end. They have to adapt their lives to that reality. The diagnoses always carry inevitable thoughts, which can, themselves, alternate from imagining the best case scenario all the way to the worst. Depending on which disease a person faces, he or she needs to make adjustments. Whereas Alejandro does not adjust his life to what his body demands, Alfredo, Camille and Hannah adjust their lives to the changes of their bodies. Chronic illness is like a cloud that from time to time hangs over a person between periods of relief. Hannah perceives this very well. She has to accommodate her life to the transition between her cloudy and her sunny days.

The disruption of life comes as a surprise and there is little time to adjust to what is happening. The body can no longer be taken for granted, and the disruption needs to be attended to and interpreted. It is as if the illness is a separate entity of the being. Does illness possess an independent existence of the being? According to Gadamer (1996), "illness is treated as if it possesses an independent existence which we must seek to destroy." But chronic conditions are not always easily destroyed or dismissed. It is always an unpleasant surprise to wake up to the reality of having a chronic condition. It is overwhelming and frightening. The body reveals a nasty side and there are a lot of discomforts such as pain, thirst, and weight loss. Chronic illness can haunt a person's life. Hannah, for instance, was unable to put her condition in a box and keep the lid closed. How could she forget when her joint pain is a continuous reminder of the presence of the disease in her vulnerable body? Maria shut away her condition for a time. Camille and Alfredo were obliged to close the lid on their illnesses and try to forget about them. When they came back to check up on their problems, it was too late. Alternatively, Alejandro did not let the disease haunt his life. He kept it out of his mind, despite his careless behaviour having brought devastating consequences for his life.

For most, chronic illness is a disturbing event that intrudes into the course of their lives. It is a crisis which, according to Bollnow (1987), is a critical moment of great significance. For Bollnow, to exist means to be in crisis; it is a condition of humanity. Crises are necessary to live life at a higher level. Human beings actualize their existence only in and through crisis (Bollnow, 1987). However, to live with chronic illness means to live permanently in crisis. These five people are living a crisis of life, acutely aware of the limitations imposed on their existences, an actualizing experience, certainly, but not sought and definitely not pleasant. Others also perpetuated those crises. Maria had to go back and forth between medical specialists as the government changed her insurance company. For instances, Hannah's school became a barrier instead of being a supporter in the process of illness. Clearly, her school was not prepared to her condition. During the moments of interaction she kept isolated in her classroom. The principal, teachers and classmates left her alone. Camille missed her appointments because they did not fit into her job schedule. How does globalization create or contribute to a crisis? Do these forces have an important impact on the chronically ill? Are external forces affecting the lives of these five people? Are they living in a perpetual crisis? Seemingly symptoms can necessitate missing work, school, or social obligations, causing activities to pile up and misunderstandings to arise.

Currently in the world, political power has changed its task to that of administering life as machinery of production so that human beings have to adjust to the exigencies of the individualized, competitive and consumerist market in order to survive (Bourdieu, 2007). In Foucault's (1991) perspective, once the body was discovered as an object of power, it was shaped, trained, disciplined and manipulated to become skilful, thus increasing its productivity. Productivity is what the world strives for today. People are cured, disciplined and educated to follow the mandate to produce economic reward, while those who cannot fit into this capitalistic value of production are marginalized. The way the world is organized today does not allow the body to heal. Being chronically ill does not match with being productive. Thus, attention to the body is postponed until a suitable time arrives. The result is that a docile individual emerges, to be transformed, analyzed, used, manipulated and improved, a docile body and a docile mind disciplined to produce economic profit. What is the effect of economical profit on human lives? What kind of human beings are created under capitalism? In neoliberalism, competitiveness is a problem because individualistic goals supersede the general well-being of society. As Kachur and Harrison (1999) say, "globalization involves the worldwide extension of a specifically capitalism form of production, including a global division of labour and the promotion of rampant consumerism and competitive individualism" (p. xvi). In education, it means human beings are educated to produce, and human values and moral principles are displaced. The important principle is the production of a workforce to compete in the global market. In health, it means exchanging quality for quantity and the eventual result is a health care system that is seen as a market with goals that focus on supply, demand and competition, thereby reducing the patient to being a mere consumer. Thus, the attempt is always to make some sectors of human activity such as education and health more productive, more competitive and in the process to act as a means to create human beings who are more productive and capable to compete in the workforce. Camille, Hannah, Alfredo, Maria and Alejandro were part of this machinery of production until they got sick. They were governed by economic, social and political rules. For instance, Camille juggled with the necessity to be productive and to attend to her illness at the same time. Her boss ignored the existing work laws that are supposed to protect her against his abuse. He did not respect the Colombian labour code. Camille's story reflects the vulnerability of workers when they are ill. She did not push herself forward. Her boss ignored her condition and so did she. Hannah's issues were directly associated with her youth, her social vulnerability and her education. Neither her classmates nor her teachers understood what was happening to her. They did not understand the comings and goings of her disease. She had to drop out of school. She ended up alone with her family. Alfredo's doctors dismissed his pain, presuming it was the result of his life as an athlete. His doctors took for granted that he was healthy. As an athlete he perceived that something was wrong with him and yet he decided to wait. He kept pushing his doctors for attention but nothing happened. Alternatively, Alejandro disengaged himself from what he feels and chose his work over his health. His being ill, he felt, was not something to worry about. He did not stop to think about the consequences of his choices. It never crossed his mind that he would end up with a diabetic foot, a stroke or a heart attack. He was young. He underestimated the magnitude of his disease.

There is a trend in these stories to dismiss the symptoms. The call of their bodies is dismissed by others such as teachers, classmates, boss and physicians alike. Why? Perhaps it is because many diseases are invisible to the casual eye. At the beginning, people chronically ill appear to be the very picture of health like Alfredo or Camille. Hannah was not the very picture of health but her tests represent her as the opposite. Maria seems healthy but her test showed the contrary. Alejandro dismissed his symptoms to live his life as it was. They have taken a position on the periphery as described by Dussel (2000), a position in which the politic of imposition without inclusion is the pattern of work. According to Dussel (1980), the center and the periphery are positions that evolve from the "I" in charge to classify and organize human beings from those closest or those having more meaning to the "I" to those peripheral beings furthest away and with the least meaning. Thus, people in the periphery do not have voice or vote; they live under the centre rules. There is no middle ground in the world today. Then, participants of this study find themselves on the periphery, a periphery that must accommodate their needs to the center. We still live in a postcolonial world in which systems are structured in ways that have the potential to perpetuate inequities.

People chronically ill require education about chronic diseases to achieve adequate control and prevent adverse health outcomes. Patients with chronic conditions may need to understand how to properly take multiple medications and modify their lifestyle by, for example, following a low salt or no sugar diet, exercising, or losing weight (Cannon, 2008). Clearly, not all chronically ill people fully understand the significance or seriousness of their situation. Alejandro has the fatalistic idea of being ill as a part of being old. He says that he knows the consequences of his decisions. He sees in his mom's situation the mirror of what could be his future, but how much knowledge does he really have about his disease? And, how easy is it for people generally to become informed about their condition?

Traditionally, some health education relies heavily on written material about disease processes, medical management, and self-care instructions (Williams, Baker, Honig, Lee, & Nowlan, 1998). This kind of care diminishes the patients' critical abilities. It is not the situation which oppresses them, but rather it is this banking type of education that makes the oppressed consciousness passive. Freire (2002) posits that there is no education with banking education, only domestication. Sometimes people such as Alejandro, Hannah, Camille, Maria and Alfredo find themselves lost without a guide into the technicalities of language of the medical world. Hannah was a high school student when her disease began. She did not know what was happening to her. She relied on her doctors for her life and health. It is difficult for her especially when her doctors do not know the answer to her health problems. Ultimately, they thought

Hannah's health problem was the result of a mental condition. She believed them and began to perceive herself as a hypochondriac. Her blood work, X-rays, and other exams came back normal. She ended up with antidepressants and referrals to psychiatry. Before her diagnosis of cancer, Maria has some experience of cancer as Alfredo's caregiver and knows, then, a little of what it is like to live with the disease. She knows the disease from the outside. Her perspective is a different one. There is a continuously lack of attention to the needs of these people. Their physicians did not see them as whole. They did not seem to recognize that beyond the kidney, leg, brain, diabetes or cancer dwelled human beings with feelings, thoughts, family and relations. Participants were not just requesting for cure. They were asking for understanding and compassion. As health care professionals, we are falling short to understand our patients. We are illiterate in their worlds. The illness is perceived, but its true nature and magnitude is not recognized until, like in Alfredo and Camille's cases, it is too late. Hannah is afraid to fall under the same pattern of abandonment. She feels something is wrong with her body. She feels it but her disease is in a developing state. She has to wait and yet she is afraid to wait. She asks herself, what if it is too late? What if the answer to her health issues comes too late? She knows she could die waiting.

Education is a key element for health. Health literacy plays a key role in both personal and social development for a person with chronic illness (DeWalt & Hink, 2009). For health care professionals, health literacy does not conclude with the ability to know about pathology, physiology or pharmacology. For our patients, health literacy does not finish with the ability to read health related information and to go to the doctor's appointments. Health literacy is related to the ability to critically analyse one's own experience of health within the larger context of health related knowledge (Speros, 2005). As health care professionals, we need to critically question the reasons behind why our patients do not comply with treatments, appointments or tests. We need to act against oppressive structures that limit and perpetuate inequities in Colombian society. Being literate and, in this context, being health literate lead to what Freire calls, 'conscientization'. Conscientization, for Freire, makes the world a place full of possibilities. Education influences employment opportunities and income, which in turn influence health, housing, community participation and other social determinants of health. People with a lower level of education are more vulnerable.

Through these experiences of chronic illness people may surprise themselves with what they can do; they may discover depths and strengths they did not know they had. As well, they discover their limits, their finitude. Perhaps they learn more than they ever wanted to know about themselves, about suffering, pain and loss. Nevertheless, the nature of a chronic illness provides a window for all—the stricken, the family, the caregivers, the community--to discover, to learn, to grow, and, together, be stronger and more compassionate.

Conviviendo con Otros cuando se es Enfermo Cronico

The Other remains infinitely transcendent, infinitely foreign: his [her] face in which his [her] epiphany is produced and which appeals to me breaks with the world that can be common to us, whose virtualities are inscribed in our nature and developed by our existence (Levinas, 2002 p.515).

Hannah

> *My family is divided by my disease. For a few relatives my condition is real, so when I am in crisis they call me all the time to ask how I am doing or if I am in the hospital they go to visit me. But for the majority of my relatives, I am making up my condition or they say that my disease is either the result of too much stress or me wanting to be the centre of attention in the family. So when I am in the hospital they don't really care. The few who support me are the important ones. They are of pivotal importance during the moments of crisis. For them, I am the role model for my younger siblings. They say, "Look at Hannah. Despite all her health problems she finished her career." That is annoying for me because I don't consider myself a role model. I don't want to be a role model. I'm a simple human being with a health condition trying to survive and live my life in the best possible way.*
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> *My parents and my sisters are the ones dealing with my condition since it began. In times of pain, my parents become overprotective and want to know my whereabouts. They want to know everything about my life. If I'm late they call me more than ten times a day to ask me, "How are you? Where are you? Don't stay late." They want to have me with them all the time. They cry with me. They are really worried all the time. They pamper me. They treat me like a Chinese porcelain doll, something delicate and fragile; a Chinese porcelain doll that could be broken with any careless movement. So when I am in pain my parents don't know where to put me or what to do with me. Certainly, at that moment I don't fit in any place. That's my life with pain. I can perceive their stress. But the opposite also happens when I am without pain; at those times they don't care about me. They just say, "How are you? And what are you up to?" I don't like to be overprotected in my moments of pain but I miss them when I am fine. I feel a little abandoned during this time. So I live under two extreme opposites. And yet I don't think they have understood the magnitude of my situation.*
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> *The last ten years I have blamed myself for all the suffering my situation has brought to my family. It has been hard to see how my family suffers in silence. They have not told me how they feel but I know. During the first years, my parents tried to pass on to me that sense of serenity by saying, "Do not worry; everything is under control," but it was not. I knew it. They knew it. There is no peace in your life if you do not know what is happening to you. And yet they tried really hard. For example, I remember the big smile my mom gave to me when she was bringing my breakfast every day. She just tried really hard to hide her suffering with a quick chit chat about other things. But later when she thought I could not hear her she was sobbing. I was the one to blame for her tears. My dad never told me anything. He did not want to go into my room and talk to me. He used to stand under the doorframe of my room and say,*

> *"Hannah, my poor little Hannah." They have not understood what the doctors have been saying about me. Today, I have tried to explain in plain terms what the doctors say but most of the time I keep my condition to myself. I just want to avoid them more suffering. I have two sisters; the oldest one has a baby and when I am in my moments of crisis she always says to me, "You have to take care of yourself Hannah. You have to be healthy because you will be in charge of my baby if something happens to me." My younger sister also worries about me.*
>
> *I have a boyfriend. He is more than a boyfriend because he is like my best friend. He knows about my situation. I always ask him, "Do you think I am crazy? Do you think my mind is making up this disease?" He always answers, "No, I don't think you are crazy. If you were crazy I wouldn't be here. I would be the result of your mind and I am real. I know you have something I can see it. But it hasn't revealed in your body yet. We have to wait." They all love me unconditionally. However, this disease has been a turning point for my whole family. Many times, I ask myself, how much have they missed in their lives just to be with me during my moments of pain? How much are they missing to be with me? How much of his youth my boyfriend is losing just to be with me?*

Living as a Chinese porcelain doll.

What is it about the dynamic of chronic illness that brings sometimes unity and other times division to the family affected by its presence? In Hannah's story, chronic illness has changed her social life. During the first year of pain she lost all her friends. She was alone as the result of her unknown disease. Hannah has learned to improvise in her life. Etymologically to improvise is to perform extempore, to build from materials not intended for the purpose (Skeat, 1963). She has to rebuild her life around the new set of circumstances. As the musician, Hannah has to perform extempore what others expect of her. As she improvises, Hannah finds herself in a state of wretchedness. It has been a devastating experience. Her only company during these moments of pain is the unconditional love of her family. Yet, even the dynamic of her family has been affected by her condition. It has changed mainly because plans and life have to be organized according to her condition. Her family has been divided. For some, her disease is the result of her mind or too much stress. Then, when she is ill they do not even bother to call her. For just a few, her disease is real. Hannah takes her strength from that little portion of her family that believes her chronic condition is real. They deeply care about her condition. There is a lot of empathy when she is ill. Her condition sets an example to be admired and followed by her siblings. And yet she does not want to be a role model. Hannah is just trying to live one day at time with her condition. She is trying to survive. Chronic illness has taught her how to survive. Chronic illness has helped her to adapt her life to the new set of situations and changes in her life. Something that for others seems admirable or an example to follow, for her is just the way she has chosen to live her life.

At first Hannah's parents do not know how to react to the new set of events unfolding around them. They try to be calm for her because they want her to avoid any suffering. Their child has a condition that they cannot terminate or prevent. They now have to deal with the uncertainty about the future. They try really hard but Hannah knows something is wrong. She knows her parents are suffering. Her dad never says what he thinks keeping to himself the suffering and pain of seeing his daughter ill. Her mom does the opposite by crying a lot but hiding her suffering from Hannah. Hannah's sisters are with her supporting her. When she is in pain her oldest sister tries to lift her spirits by reminding her that the care of her nephew is in her hands. Hannah also has a boyfriend who has lived with her most of the last years of her disease. She wonders whether her boyfriend is losing time of his youth just to be with her or not. Believing her disease is real, he gives her support and companionship during the uncontrolled periods of her disease. But still she wonders if she is hindering the life of her boyfriend and his family life by being with someone chronically ill.

What is it about chronic illness that turns the family's life upside down? Hannah's condition has affected the many aspects of her family. She can feel it during the moments of crisis. During this time the dynamic of her family changes. Her parents become overprotective and they want to know everything about Hannah's life. The whole family guards against the enemy. It is a war against a mutual enemy. Family gathers around her. Her fragility is cause for concern for her parents. She sees herself as the Chinese porcelain doll that needs special care and attention because of its fragility. Her ill body needs to be handled according to its needs. It needs to be held with precaution. Her parents do not know where to put her or how to alleviate her pain. It must be hard for them to be silent witness of how a disease transforms the life of their daughter and sister, how her life spins at the will of her body ill. They are silent spectators and as spectators they are suffering from the outside, feeling helpless in the face of chronic illness. Hannah knows her family is suffering and acknowledges the effects of chronic illness on her family. She recognizes that the presence of her disease has brought disruption to the family. Chronic diseases are unexpected visitors that affect the lives not only of the people who suffer from them but also the people around the patient. It is like a ghost or a silent enemy who attacks without any warning or incitation. By its nature, chronic illness means battling against challenges in which natural bonds between family members emerge in order to survive the situation (Ray, 2006). The magnitude of chronic illness is not understood if the person has no knowledge about health sciences. It is a painful process of learning for the whole family. They do not know what the consequences of the problem that they face are. They do not know how much time they have until the next setback. They learn the meaning of patience.

Yet, when Hannah's disease is controlled, they do not pay attention to her. They ignore her. She feels abandoned. Pain defines the dynamic of attention and care in her family. Hannah thinks her parents do not understand what the reality of her condition is. She explains to them what she knows or what the doctors tell her in simple words but she keeps to herself most of the information, information that could hurt them. She is protecting them. There is a shield that she uses to protect people she loves from suffering. Overall there is a lot of unconditional love and support from her family. She wonders how much her family is restrained due to her condition. Disease directs not only her life but also her family life. Providing long term care for people with chronic illness can disrupt the normal functions of families and it causes stress. When chronic illness is discovered, the family momentarily loses its sense of autonomy. Why? Perhaps it is because daily routines may have to change, especially when the limitations of the ill member and the demands of treatment require siblings and parents to be more available. Her life swings between periods of independence and dependence and she wonders how much more she and her family can withstand.

> *With my friends I have had the same experience as with my doctors: they think my situation is psychosomatic. With my paraplegia my friends who are nurses told me, "Hannah, you need to control yourself. Take control of your stress." I was mad to hear that because I was returning from a vacation. What stress were they talking about? They are not educated about my problem so they don't really get it. That mortifies me a lot because in the end they are questioning my mental health. I did not say any word to them. As always I kept my rage to myself. That day, I took a deep breath and counted to 100.*

> *A couple of weeks later when I knew I had this malformation in my brain, I met with them again and they said, "Wow! You are really in bad shape, Hannah. You are so skinny. What is wrong with you?" "I'm having surgery on my brain," I said. It just felt good to shut them up. Mostly, I feel it is unfair to qualify what I feel as simple. So it has been hard to find real friends who understand my situation. I would like to be surrounded by people who are not going to judge me. I have friends but the real ones are just a few. People get tired of me easily. They get bored of my mood swings. They get bored of me. I recognize my illness turns me into someone moody and aggressive. In days without pain I am fine. I am happy. I laugh because my illness is under control. On the days I have pain I know I could be depressed, angry and/or sad. People get tired of that. I had had other relationships and all of them failed because of my illness. My ex-boyfriends got tired seeing me very well one day and the next day in the hospital. It is hard to make other people understand. If my friends call me to hang out with them, I always have to refuse because I always have to think about the next day. If I go out with my friends to dance or practice some sport, I know the next day I will be secluded in my bed with joint pain. If my friends call me to have some drinks with them, I have to refuse because I'm taking medication that cannot be cut off or taken with alcohol. Some of my friends do not really get what's behind my negative answers. They do not comprehend that I need to take care of myself. They don't understand that I don't have the freedom they have with their bodies. Before I accept, I have to consider the possible consequences of my decisions. So despite that I would love to dance, drink or play any sport I have to consider what the future holds for me. There are not many options for me. I know dancing, drinking and having fun with your friends are the normal things to do when you are young. In my case my priority has always to be my body. People get bored of that and I get used to the idea of people coming in and out of my life. They barely stay. Recognizing that has been one of the hardest things I have ever done in my entire life. However, I don't like pity from anybody; I don't like to hear, "Poor Hannah, she cannot do anything. Her doctors do not allow her to do anything." Saying "No" doesn't mean I don't like to go out or that I don't like to take advantage of my healthy days because I do. I never know how long they will last. I like simple things. This disease does not take away my desire to study, smile, joke, to live life. I'm aware that I have to live differently from the way people of my age do. I try to enjoy life the way it is but people limit you. And people do not get that this disease is part of my life, but it does not define who I am. Despite my condition, I'm a person, a nurse, a daughter, a girlfriend and a friend.*

Esta enfermedad es parte de mi vida pero no define quien soy yo. In Hannah's story the isolation produced by chronic illness materializes as she socializes with her friends and comes face-to-face with an unexpected turn of events. In terms of friends and relationships, Hannah has not been lucky. The weight of knowledge she has about her body has not been well understood by her friends. They are watching the bullfight from outside. Opinions are easy to give when you are healthy. Looking for understanding from others has been a difficult task for Hannah. It is complicated. Life is upside down and what Hannah needs is reassurance of her friendship, but she does not find any support. Her friends seem to be bored by her condition. They do not get that she has to take care of her body. Behind a negative answer to go out and have fun lies the uncertainty of the unknown tomorrow. She has to take care of herself, not jeopardize her life by going out drinking and dancing. Activities that seem normal for others require her full attention and decisions cannot be made without thinking about consequences. It could shorten her days without pain. Things that seem to be important to others lose their value when you need to protect your body. She feels relegated to being an outsider by her friends. She has had other relationships but she says they get bored of seeing her fine one day and the next one crying from her pain. True friends are few when you are ill. She does not tell everybody about her disease because she wants to avoid the stigmatization of her condition. Also, she does not want pity because being ill is just a small piece of her life. It is not what defines her. It is just a small piece of the whole. And yet that small piece can dominate the whole existence when it is strong. Despite her illness life goes on. She likes to laugh and joke when illness allows her and in that way her life is not different from other young people. But everything changes when she is ill. Life becomes difficult and is like a roller coaster with all of the ups and downs. Hannah is acutely aware of the unknown: she does not know when the next episode of pain will be; she cannot predict the course of her illness. Her social life has been shaped by the demands imposed by her chronic joint pain.

> *In the last ten years of my life I have been a guinea pig for my doctors. Definitely, whoever has the knowledge has the power. In my case, my doctors have all the power over me. When I was young neither my parents nor I had any saying in my health because we did not have any knowledge about my condition. So we just followed what the doctors were saying to me. They still have the last word in my treatment. This has brought a lot of disadvantage for me. For example, in January, 2008, when I came back from vacationing outside of the city I had a terrible headache. At first I thought it was my migraine again so I took the medication I have for those episodes. However, the medication did not work so after a while I decided to go to emergency. In emergency, the doctor asked me, "Have you looked at your face in a mirror lately?" I said, "No, why?" He continued, "Go to the bathroom, look at your face in the mirror and smile and let's see what you think." I went to the bathroom and looked in the mirror and smiled. When I smiled, half of my face was down. In the bathroom I started to panic. I cried. My heart*

skipped several beats. And I thought, "Oh my God! I had a stroke." I did not realize how bad I was until I saw my face in that mirror. When I was going to the hospital, I did notice I was limping but I did not care because I thought it was the result of my lack of sleeping and eating for several days. Indeed, I did not pay too much attention to my body. In emergency, they explained to me that I need to stay in the hospital to run some tests and see what was happening to me. I did not receive any further information about my condition or future tests. They might have talked to my parents but I did not know anything. At 5:00 AM in the morning I was sleeping when a nurse came in. She gave me a gown and told me I needed to be ready for my tests today. She did not allow me to ask any questions about the tests or tell me I would not have breakfast that morning. So I got ready. At 10:00 AM an orderly wheeled me to my first test. I had no idea what test it was. So, when I came into the room I asked the doctor about it. He explained the procedure while he was applying some anaesthesia in my throat. He didn't allow me to ask any more questions. He just said, "We are going to do a trans-oesophageal echography. The procedure is not a big deal. It is like an endoscopy." I have not had an endoscopy in my life before so I did not know what he was talking about. So, imaging how terrified I was. He said it was not a big deal but he was brief in his description. This test was really unpleasant. I did not have any idea. After this disgusting test, I was informed that I was heading to another place for another test, a Doppler carotid. I was so vulnerable. I did not know what to do. I felt so abused that on my way to the other test I began to cry. I was alone without my family. I felt vulnerable. On the way to the other test I ran into one of the medical interns in charge of my attention. She asked me, "Why are you crying?" I told her," I don't understand what you guys are doing to me." She responded almost impatiently, "We think you had a stroke and we are just searching for sources of clots. We need the ECO to see if your heart is creating clots that are going to your head. Don't cry. Don't be a fool." It is difficult having to handle aggressive diagnostic tests without previous explanation and without my authorization. Also, I have to tolerate being called stupid by a medical student! I am not stupid. I'm the one living with this. I am the one suffering. It's me. I have the right to information; I am not an object for them to practice on. But they don't get it. They think it is fine to treat people like that. It is worrisome how physicians are becoming more and more specialized. They are so specialized that they don't care what you think or what you feel. They only want to cure a piece of flesh, that's it. I am scared. As my disease advances, I know how more aggressive and specialized the tests are going to be. I know they have to be done but without any knowledge about them it's really hard. What different outcomes I would have if I were receiving more information about those tests. It would be nice during the test to have the doctors explain to me what they are doing or at least if they would just check from time to time on how I am doing during the exam. If the doctor finds something it would be nice to hear, "Well, you just need to set a time with your doctor who will explain to you in detail what the findings are." That would be different. But in reality nobody says anything. I felt like an object during the procedures; nobody speaks to me and nobody explains anything to me. Health care

> *professionals are aggressive. For example, if you have pain in your knee they do twenty movements to see if the pain is real. It hurts you. There is no consideration for the other person's pain. That time they did not find anything in my tests; then, as always, I ended up with a referral to psychiatry. I was so mad. Because I was coming from a trip, they thought I had too much stress to handle. I told that to the psychiatrist and he said, "When we physicians don't have a physical explanation to the health problem we go and investigate and evaluate the mental health of the person." After many episodes of paraplegias they found my malformation and yet I suffered a lot to get this diagnosis.*

Being a Guinea pig for my doctors. There is a lot of miscommunication between Hannah and her physicians. Hannah is bewildered. It is dramatic. Her physicians have the power over her health because they have knowledge. Foucault calls this bio-power, which employs different mechanisms to discipline individuals, bodies and populations in health care (Perron et al., 2004; Gastaldo, 1997). From this viewpoint, the body was the focus of analysis as an individual entity. As Gastaldo (1997) says, "The body was 'invented'" (p. 114) and many techniques have been developed to create docile bodies so that they can be used, transformed and improved (Foucault, 1991). The employment of disciplinary power divides the body into parts with the aim to create a more competent whole (Gastaldo, 1997). Then, the body becomes an object of knowledge because knowing about each human being is a way to control and facilitate the management of the whole population. Individuals are reached by techniques such as statistics, body assessments, evaluations, registers, all of which comprise the social body. Hannah's interaction with physicians has been difficult. She lives with many symptoms that need to be controlled, and yet she does not receive the proper attention her condition requires. The doctor in emergency sends her to the bathroom to look at her face. She is alone in the bathroom when she discovers something is wrong with her body. She is a nurse so during this time many thoughts come to her mind and Hannah is afraid. Health care professionals are supposed to protect their patients. Information must be provided in certain way with tactfulness. The way she receives the news is devastating.

What makes these physicians act in that way? Perhaps the way the health system is organized kills the humaneness of health care professionals. Probably the tests were done on time but promptness should not exclude respect and understanding of the other human being. Are people with chronic illnesses incompetent to fulfill the economical, social and political necessities of a country? Today, worldwide, human beings dehumanize and exploit each other for the sake of economic profit and technological advantage. In some sense, there is no place for respect or ethical values, neither for self nor for the other. Both respect and ethical values are treated with indifference. Regardless of the effects of globalization on health status, much of the health care work has been addressed toward the management of pathologies—indeed, it remains highly medicalized. Health systems organize themselves around the idea of disease care, rather than health care (Illich, 1976). In Hannah's story it is overwhelming to be wheeled to tests without knowledge of the procedure. It goes against her rights as a patient. Who received the information? Who authorized these sets of tests? Who is protecting Hannah's right to information and decision making? We do not know, but certainly there is a fine line between respect and disrespect when health attention is provided. She feels dehumanized by the lack of attention. She feels like an object in need of study. Her humanity is left outside of the room where they perform the tests.

How is Hannah's relationship as a patient with the nurses? Are their interactions different from the physicians?

> *Due to my condition, I have been in the hospital many times. In one of my crisis of pain I went to emergency. I had an excruciating chest pain. I was gasping for air. The doctor feared I could have a pulmonary embolism so he decided to keep me in for observation that night. After the nurse auxiliary set my IV and took my blood test, she put me into a small room in a wheelchair because emergency was overcrowded. In the room I couldn't take my mind off the words of the physician. Just the mere idea of having an embolism made me think constantly about my condition. I am a nurse and I know what an embolism is so I was really scared of my situation. I kept thinking, "What if it is this or that?"But also I was so cold and uncomfortable. I wanted to lie down but there were no stretchers for me. When you are in pain, the wheel chair is not the best place to rest. Many times I tried to call the nurse but they did not seem to hear me. They were running from one side to the other, moving patients from one side to another but not me. It was complete chaos. I understand they were busy but I was ill and I just needed at least one stretcher to relieve my painful body. I kept trying to call them but no one answered. When they finally paid attention to me, the answer was, "But we've already started the painkiller. Give it some time to act." After 2 hours of pain, I decided to call my mom, who was outside in the waiting room, just to see a friendly face. Also, I told her how bad I was feeling and how little attention I was receiving. So my mom on her way in talked to the registered nurse and told her, "My daughter is your*

colleague. She is a nurse too and she is suffering. She is in pain. She cannot wait any more in a wheelchair. Please help her."The nurse answered back with indifference, "Sorry, I can't help her. She has to wait for the doctor; her problem is the doctor's problem." I know it was not her problem because it was not her body that was in pain. It was my body the one in pain. I was the one in pain. In the end, what could I do? I got used to the idea that being a nurse does not make any difference when I need to go to the hospital as a patient. After a while and when I had lost all faith, an ex-classmate of my nursing program came to my room. I was happy to see him. We studied together in our nursing program. We even had written some final papers together. So when I saw him, it was a relief. He was nice when he greeted me; he said, "Hey! How are you? What are you doing here?" I told him my story, expecting his help, but once I finished my story he told me, "OK, see you around." He turned his back and went out. He did not care. I was astonished. We studied together. In my mind, I was expecting more compassion from him. I was expecting he would find my doctor and ask him for more painkillers or at least I was expecting he would find me a better place to lie down and relieve my pain. He did not. I still don't think I was asking too much. I was not asking for VIP treatment for being a nurse, no, I was just asking for a little compassion. It's sad to see how we are prepared for one thing but in practice we do a different one. We learned in nursing how important it is for the person to ask how they are doing, to give information to the patients and family, to be there. However, in reality you see nurses doing everything but caring for people. They come to your room when they are doing the administration of medications or when they are doing a specific nursing procedure for the patient. I have been in the hospital many times but I have not had the opportunity to interact with my nurses in the way I always expect to. Sure, I know them; I know who is coming in the morning, afternoon or at night. But I have not had the opportunity to talk to them, to know about their education or to let them know a little bit of myself. I haven't done that yet. The health system has not been organized to allow the nurse-patient interaction. It's hopeless. In school, we learned how important it is to communicate with the patient when you are doing a procedure, how important it is to make the other person feel comfortable, but overall how basic and important it is to introduce yourself when you meet them for the first time. All this information helps the nurse build the trust with the other person even when the person is intubated. That is respect for the other person.

As a patient, in my moments of vulnerability, I like to see that there are friendly faces for me. When you are ill you always need a friendly hand helping you to go through the moment of crisis. During the moments of illness what a person needs is the support, the friendly hand that touches you and let you know everything is going to be all right. When you are a patient you need a shoulder to rely on, someone who makes you laugh, and someone who recognizes you as a human being. There is something else besides the painkiller or the nursing procedures and it's the presence and understanding of the other human being.

Sadly, this story is lived everyday and everywhere by many people in Colombia. Despite their nursing mandate to care for human beings, Colombian nurses have been compelled to work under precepts of competence, consumerism and individualism of the health care system (Guevara & Mendias, 2002). Today, not only globalization exists as a treat for the health of those for whom nurses care, but also it is a threat to nursing as a profession itself. Especially it is a threat by those affected with chronic conditions. People with chronic illness have to deal everyday with the marginalization, dehumanization and stigmatization by the health system. In nursing, we learn how important it is to relate with one another. Relate with our patients. In this story it seems Hannah has lost her voice and vote. Why? What prevents nurses from providing appropriate health care? What restrains nurses to care for Hannah as a human being? Is this care? In her situation, care has been reduced to mere actions of nursing in which patients, as human beings, exchange their names, identities and being for acute or in this case chronic diseases ready to receive treatment. For the patients, being in emergency overwhelms them and they cannot fight against that feeling of powerlessness and disruption; they only wait to be cured when the cure is available. Living in the world is a unique experience for all. What do we do, however, when the experience involves marginalization and alienation like the story above? Judgments must be made and actions must be taken which bring about positive change in those situations.

Being ill needs a lot of patience from others. Hannah asks for compassion from her nurses. She is not asking for VIP treatment for being a nurse. Her request seems fair, and yet she is desolate, ending up feeling misunderstood. She needs someone who has time to ask her how she feels. That was the only effective treatment for her, being listened to, instead of only being heard and ignored. What does nursing teach us in our day to day work? What is the wisdom of nursing? And how can we reach that wisdom without taking ourselves out of the pathway of care? Hannah's nurses work with her most of the time under the influence of indifference; she is merely a spectator of their actions. Why are her nurses focused on physical things, forgetting her? Perhaps they are afraid to see in her face the reality of life, the reality of chronic illness in a young human being. Why do Hannah's physicians not pay attention to her? Perhaps it happens because everybody is focused on her physical body and how to meet all the necessities in order to keep her alive. They work over her ill body as if she were a car or another object in need of repair. They act over her mechanically without consideration of the being. She has been forgotten about for the sake of technology. It happens when everybody is focused on the battle against death; we fiercely attach ourselves to protocols, technologies, and procedures. However, when they become the centre of our action, indifference towards the other appears, as is happening in this case in which care has been left aside.

Technologies, procedures and techniques are the focus of her nurses' actions. These technologies, procedures and techniques have perpetuated self-centeredness and indifference towards Hannah. Therefore, while technology and protocols are important, they should not always be the main focus of our attention. Our attention must be on the human being as a whole, not on machines or techniques. Human beings are the challenge to understand; machines are simple and once one learns how to use them, the emotional connection disappears. Human beings are full of different thoughts, feelings, and opinions; indeed, each human being is a different world—the emotions and the challenges never end. Thus, in our professional lives it is necessary to understand and listen to the other person in order to establish an active relationship with him or her. Care for the other is not only something written down, but also it is something to put into practice every day in our profession.

Camille

> *Outside of the room another doctor talked to my family. I can't imagine how terrible this experience for them must be because they were not able to talk to me after that. They sent the doctor to give me the news. When the doctor came she explained to me, "Your condition is serious. You're a palliative patient. Don't ask me how much time you have. In your condition we have had patients who have lived one year and ten months, others one year. But we don't really know with you. It could be at least two years." Then, I said, "Look Dr. I don't really care how much time I do have to live. Just tell me if there is any treatment available for me and I will follow it." I was calm mainly because I am single and I don't have any kids. I am the oldest in my family. I have one brother and one sister. My parents died not long ago so my responsibility was almost done. I did not react in the same way many patients with cancer do. I was calm and despite my mood she referred me to psychiatry. With psychiatry I did have some sessions but he ended up frustrated with me because I was not serious. I used to joke and I made fun of him. I was not ready to talk. He came four times and the last time he said, "I am coming here to speak to you and you are laughing at me all the time and joking about other stuff. I am not going to come back again if you think you don't need me*

right now. This is my business card in case one day you decide you need someone to talk to."At that time I did not need him. I was fine. I just needed to adapt to the new circumstances. I know my treatment is palliative and there is neither cure nor complete recovery for me so I am and I was aware of that. I am at the end of the road. I cannot go back in time and relive my decisions.

So when the doctor said to me, "You have cancer" I felt a relief because my parents were not here to suffer for me. I feel bad for my sister and brother because they are the ones experiencing this situation with me. My sister was the most affected. She never thought that my situation was serious so when the doctor told her she cried. She cried a lot. It broke my heart to learn she was suffering. My poor little sister! She was the youngest one. The one pampered by the whole family. She was the one who had to face our parents' illnesses and deaths. And now she is the one who has to face my illness and death. That situation really broke my heart. I did not want her to suffer for me.

For my brother it was a completely different experience. He is married and has one son. For a long time his only son was addicted to drugs. During three years he and his wife struggled to accept his condition. It was hard for them to recognize and accept that his only son is addicted to drugs. The therapy in rehab is brutal. In rehab, they told him that his son was addicted to drugs because the whole family was sick. That's pretty hard to digest, especially when you think you have worked hard for your only son and the result is different from what you expected. So the therapy was tough. My problem with them was that he applied that tough therapy to me. But he was not like that all of the time. When he learned I was ill his first reaction was sadness. He cried a lot. After that he accused me as the one to blame for my cancer. I was the one to blame because I never took care of my life. He was a tough judge with me and he might continue being so. He was not like other people that feel sorry for you. No, he is a tough judge. It was not the kind of support I was expecting from him. He told me that my cancer was the result of not facing my problems in life. According to him, I never assumed responsibility for my life; I was not in charge of my life; I never cared about myself because there were always more important things like the health of my parents, my sister and my work. Then he asked me, "What about you? Did you stop for once to think about you?" My cancer for him was the result of my abandonment of personal needs, lack of love and inability to be myself. With this condition, you expect other kinds of words. But I did not care because I liked his honesty. It was hard to hear his words because nobody talked to me like that before. So I had this inclination to understand more and to learn more about what he was saying. Then I remembered, "The psychiatrist. I need to set a time with him." Finally, I did not care too much about my brother's comments. They challenged me and I like challenges. What hurt me the most was to see how my sister needed a shoulder to rely on and she did not get any support from him. She was alone with my process. She needed a different support and different words but he was not there for her. My sister was alone processing this whole reality.

With this condition, you expect other kinds of words. What do we do when we face devastating news? For Camille there is no option: she decided to resume her life. Breast cancer has changed her life forever. Initially, her family is broken by the devastating news. They do not want to talk to her. It is dramatic. Like Hannah's family, Camille's family tries to improvise their response to the news. Her responsibility for others is over because she does not have parents, children or a partner to worry about.

When you are ill, talk about the topic cannot be forced. Trying first to adjust herself to her new situation is Camille's priority. She is aware of her condition, the consequences of her illness and the presence of the unavoidable ending. Camille is aware her condition does not have an easy solution--she is a palliative patient. There is no available cure for her but there is no drama there for her. Her concern is rooted in the idea of suffering. Cancer or any other chronic condition brings a lot of suffering for the people surrounding the chronically ill. Meanwhile, her family has decided to avoid Camille. It must be painful for them; the world has just crumbled in front of their eyes and they could not stop it. Unexpectedly, chronic illness has shown up in Camille's family. For her family it is shocking to learn that she has this disease. At first there is a lot of crying from her sister and brother but later they react differently. Her sister becomes her caregiver. And her brother becomes Camille's judge. For Camille's sister this is the third time she assumes the role of caregiver. Her sister had to live the situation of illness and death of their parents when she moved out of the city to take care of them. Her sister has the knowledge and yet she suffers. They have to assume how the situation will unfold. When Camille hears the news from the doctor she immediately wants to know if there is some treatment for her. She does not stop to cry or to regret her life. She accepts her life as it comes. And yet she wants to avoid any suffering for her sister and brother. There is always this tendency in chronic illness to try to avoid suffering for others. However, it seems suffering is bound to the experience of chronic illness.

Etymologically, suffering comes from the Latin word which means to bear pain, grief, defeat or change (Skeat, 1963). Chronic patients seem to undergo a lot of pain, grief and sometimes defeat from the change in their lives. Sometimes the pain they suffer goes beyond the physical pain; they suffer from emotional pain because their condition inflicts a lot of suffering on others.

Hannah's parents are alive; she is worried because they are suffering for her. They have to organize their lives around Hannah's disease. But for Camille, parental responsibilities have finished. Her parents are dead. She has been on both sides of chronic illness. As a daughter she lived with and took care of her chronically ill parents. She has firsthand knowledge of what the effects of chronic illness are for the family. Now she has to deal with the devastating news that she has cancer. Despite her illness, Camille feels she must provide support for her sister. Camille is going to die and her sister needs support when she is gone. Her sister is the youngest one in the family. She was pampered by the whole family and now she has to assume the role of caregiver. The health and well being of a family member is at stake. With Camille's brother, the story is different: his only son is suffering from addiction to drugs. He and his family are going through a tough process of therapy. This therapy confronts the family with the reality of drug abuse. They examine the life of the family to see the source of the whole issue. Camille's brother applies this though therapy to her. According to him, she needs to confront the ghosts of her past life. She is the only person responsible for her illness. Her brother does not bring any support to her.

> *I received a lot of support from my colleagues and friends. They knew about my situation because I had to pass my doctor's note to my boss. This first note I passed in said that I had a multiple myeloma. So they knew I had cancer. They called me a lot, asking how I was. Also, the hospital is near our office so during the time I stayed in the hospital some of my colleagues and friends came in the morning, others at lunch and others after work. I was never alone. My boss was a different story. He did not care. Despite all the work I did for him, he never came to visit me or talked to me again because the only thing he cares about is work, work and work. Several times I tried to call him but he did not answer me or return my calls. After a while I just decided I would never talk to him again. So now I just pass my doctor's notes to Human Resources. I also received a lot of support from people I just talked to on the phone. They were from other offices across the country. Once they knew about my condition, they phoned me to ask how I was. I am grateful for all that support. Sometimes I think that I don't deserve it. Many times my friends called me to say I was included in their chain of prayers. So I am really grateful for their kindness. When I told my brother about this, he just said, "Prayers are good but the real healing and the change must come first from you. You need to forgive all those people you have not forgiven yet. You need to talk things out. You need to let go of all those things that do not allow you to live. You need to let go all the rage and frustration you have inside." That is his theory. I agree with some of the things he says. He has been hard with me. But I don't care. I hope someday he will change his attitude for my sister because when I am gone she is going to*

> *need him. She is going to need a shoulder to cry on. Until now she has not found any support from him. It is sad and it hurts me because they are my family. They are the only ones who know about my situation. There should be more support from one another. On Saturdays we go to a prayer group and they see me with my cane but they don't know about my cancer.*

I am grateful for all that support. Different from Hannah, Camille has received a lot of support from her colleagues and friends. They go to the hospital when they have time. She is not alone. They even include her in their prayers. She receives all this support from unexpected people. Having support eases life when one is ill. The bond with God becomes stronger. Her support group has helped her to go through the process of disease. They have not judged her. Her condition has brought a new set of friends. Probably her cancer makes it easy to find friends in the same condition while for Hannah her autoimmune disease does not have any support group.

Not having a clear diagnosis makes things difficult to overcome. For Camille, the support group has opened a new world of possibilities. Life becomes easier when there are friends around the person with chronic illness. Friends and family bring company and support and they make things easier with the health changes that occur with chronic illness. They are the company that she needs at this point in her life. Even people that she barely knows call her to know how she is doing. And yet there is no need to explain to others outside of family about her situation. People in her prayer group do not know about her condition. The cane is the only knowledge they have about her limitation. She receives a lot of support because of her cane. Her condition has become apparent to the eyes of others and they come to help her. Limitations are not really important to her anymore. Her body has changed and the concern comes from her physicians. They worry that she is putting too much weight on her ill body. Camille decides to live life as it comes. She is in charge of her life. Her boss does not have any ownership in her body anymore. She does not need to be productive. She examines her past to attempt to change her present. There is less pressure in her life. She is oriented toward the present. Rather than tomorrow, today has meaningful connotations for her. She looks back to change her today.

For her brother, prayers are good as long as they are part of self-examination of her past decisions. He believes Camille's cancer is the result of abandoning herself. He thinks Camille has neglected herself and the consequence is her cancer. He put her feet on the ground again. It is not nice. It is tough for her because there are no words of encouragement from her brother. It opens her eyes and she needs to speak. She needs to know if her brother is right, if she has ghosts to fight. Eventually, she decides that her going to the psychiatrist is not a bad idea. She needs to talk and she is ready to talk. She suffers a transformation of her life, a new beginning. But a major concern is her sister's future when she is gone.

> *Before my situation I did not want to go anywhere; I was tired all the time. Now my interests have changed. My friends have changed. My sister used to invite me to a lot of conferences but I did not want to go. Now I am the one inviting her to everything. In October, 2007, I was invited to an event for the month of breast cancer awareness. It was nice because there were a lot of life testimonies. My cancer has opened a door for me. It has been a time to say, "I am going to do what I really like." The people I have met are different from my other friends because we share similar experiences. The level of understanding is similar. We all know what the real meaning of cancer is. Not long ago, I called a friend, who is 35 years old and had breast cancer, to say "Hi" for her birthday. The first thing she told me was, "My birthday was different this year because I was surrounded by my family but on another level more spiritual, calmer and more peaceful. There was no rush and gifts were not important." When you get ill you learn to live your life without any rush. When you are ill you learn how to respond sincerely to a simple question like, "How are you?" When we answer that question the answer comes truly from the heart. We understand the meaning of that question.*
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> *Another place I like to go is to the support groups of women with breast cancer. There you learn a lot of things about your disease. When I hear someone telling her story of cancer it is like that woman in front of me is talking about my life. It is like she is sharing my story with others. Sometimes through their testimonies I feel like they were giving me a warm hug. It is like someone saying, "Yes, we understand you. We are here for you." It is an immediate connection with their stories. I also like the group because we look after one another. Lately, one of my friends has this terrible pain in her knees and the painkillers were not working anymore. So the doctor told her she needed a procedure that is not covered by her health insurance company. So this morning when I woke up, I immediately began to call all the places where she could get the surgery done for less money. I asked in different places, not only trying to find the cheapest place but also the quickest because she needs that treatment right away. I did it simply because I understand what it is like to have an excruciating pain. I had had pain. I still remember the pain I had at the beginning of my disease. It was terrible. I could not think. I could not do anything. When you have pain, life goes away. Pain is something that drills your body deep inside. It takes your life. I used to think how terrible it would be to live with pain all the time because it was*

> *excruciating. I was scared of pain. Now that I don't have pain, my life is easy. I can live a normal life. We know the solution to pain cannot wait. I understand because I have been there. Once you go there you don't want the same situation neither for yourself nor for your family and friends. However, how you perceive your illness only depends on how you learn to understand life. As patients, sometimes we lock ourselves in our own worlds. Sometimes we don't share our feelings. Not long ago, in one of our support group meetings I met a bacteriologist. She was 45 and she was recently diagnosed with breast cancer. The first thing she said during the meeting was, "I don't want the pity of anybody. I don't want to read anything about this. I don't want to have any information. I don't want to hear any advice. I only want to receive the treatment and that's it." But we don't go to the support group to feel pity or sympathy from one another. We go to these meetings to support one another. We go there to have someone to rely on. And yet she kept saying, "The only thing I want to know is when I am going to lose my hair. When should I shave my head?" Another friend told her, "It all depends on the treatment you are going to receive. Although we all have breast cancer, the treatment for each one of us is different. Some have had radio and chemo, other just chemo and others just radio. We cannot generalize that all women with cancer lose their hair because the treatments are unique." You can tell she was new in this world of cancer mainly because she still had all that bitterness, pain and suffering people have when they learn about their diagnosis. She had not accepted her condition yet. She had this arrogant attitude. And yet we understood her because somehow we all have been there. It is a nicer journey when you are surrounded by people who understand you.*

My cancer has opened a door for me. For chronically ill people there can be many ups and downs. Nothing is as it once was, and normal no longer exists in their vocabulary. Normality changes its meaning and redefines itself once people with chronic illness learn to live with their illness as best as they can. Being chronically ill is like walking into the woods: one knows how varied the path can be—level areas covered with soft pine needles can give way to rocky descents or short climbs that require careful footing. Camille takes a different approach to her illness; instead of spending time feeling cheated, hurt or sad about her illness, Camille sees her life as a new opportunity. It does make her stop and think about things other people do not have to. She considers the pain of others. She has been there. She understands what it is like to suffer pain when you have cancer. She has learned the meaning of the unexpected good. There is a lot of determination to change. She does not give up; she keeps fighting to have a couple more years to live. The quality of her life improves and what seems important in the past lacks meaning today.

What seems important in the past becomes unimportant today. It is a new beginning that she takes advantage of. There are new friends and interests. The memories with past friends are blurred now. She does not share the same space as her old friends so the conversation is not the same. New friends fulfill the needs she has. They share a common circumstance: all of them have or have had cancer. The friendship is understood on another level full of solidarity and support. Material things are not important. There is an increased value to the spiritual world. The process of illness is a process of learning about oneself. Camille has learned what the meaning of solidarity is. She focuses on taking advantage of every minute in life. Being ill gives a sense of belonging to a special group of people that understands what one's problems and life are. This understanding is beyond pity. It seems like the need to be supportive of others prevails over everything and she shares her experience with others in the same condition. There is a mutual accomplishment overcoming a situation in some sense similar to one's own. Identification with others in the same condition awakens solidarity in Camille. For instance, she knows what pain is. She knows because she already had the experience of pain at the beginning of her disease. Sharing with other people in the same condition creates bonds and reassurance that one is not alone in this world. She has learned to understand people in the different stages of their disease. They are the mirror of the past and the future. However, difference is always preserved: despite all having the same condition they do not share the same feelings when they learn they have cancer.

> *I have not had any problem with my insurance company. They have given to me all the things that I need. Nurses and physicians have given me a lot of support. For instances, in my first hospitalization, I remember the afternoon the group of nurses were really nice to me. The head nurse put my name on a plaque. She also drew some flowers and hearts around my name. It was really nice. It made me feel special. Everybody who came to visit me asked me if I had drawn that, but it was not mine—it was drawn by the nurse. A few days later, it was my birthday so my sister bought a cake for me and came to my room to celebrate. My sister didn't say a word to the nurses. However, they showed up with balloons, confetti and streamers and they sang "Happy Birthday" for me. That simple detail really touched my heart. They were attentive to my needs all of the time. I was so grateful to know them. Also for my chemo I had to stay in a wheel chair for a while but my sister hired a nurse to be with me all the time. She was nice; she use to be my company for my chemo and radio. She stayed until 2008 when she couldn't come back for personal reasons. In terms of my physicians, my*

> *oncologist has been like my mom: she listens to what I have to say, she advises me, she has been there for me. She takes care of me. I think I've been blessed for being surrounded by nice people. I think all this support has influenced the good results in my treatments. My doctor once said, "That chemo has really done miracles on you." I haven't felt affected by disease because I did not have a mastectomy. I have new curly hair now and I love it. Indeed, I am taking the second advantage God has given to me. I think today that I am closer to God, my sister, my brother and my new friends.*

They were all the time attentive to my needs. The relationship between Camille and her nurses and physicians is different from Hannah's. Camille has received a lot of support from health care providers. What make her condition special to receive the attention of health care professionals? For instance, Hannah finds health care professionals dismissive, whereas Camille receives support and understanding from her nurses and physicians. They even try to make her feel good on the day of her birthday.

Nurses and physicians have been there for her, working with her. In nursing, caring for the other is a moment of mutual accomplishment between nurse and patient. It is a moment when care itself is the bridge between two worlds. It is a moment with one goal—the recognition of the other through the vicarious experience of illness. The recognition of the Other implies that you are part of the Other, share in the Other's world, with the possibility to know more about the universe of the Other, and in that way start a relationship of mutual interchange of experiences and interact in specific situations. There is a sense of solidarity. Being next to that human being ill means recognize the Other's situation without properness. In Camille's story we found how in nursing we approach our patients as a partner. That is our responsibility as nurses. At the end all our efforts are reduced to the fact of nursing that person. In those moments, approaching includes a feeling of unity as a human being.

Alfredo

> *It was hard for my little daughter. She was five when I got the news of my cancer. I could not explain anything to her at that time because she was already suffering from my divorce with her mother. I waited until she was older to explain to her about my situation. When she was nine or ten years old I gave her some hints that I was ill. Then one day I talked to her about my situation and what to expect in the future. She is 13 now. She has not been worried because my situation is stable right now. She assumes everything is okay right now. I have this special bond with her. We talk almost every day. She comes every Saturday. Sometimes she*

comes during the week and Sundays as well. When I was able to walk we used to go to the movies or outside to the park. Today, due to my limitation to walk we stay in and talk a lot. If I die I know she is going to be just fine. She is becoming a strong woman so I know she will overcome my death easily. I have another daughter, 25, that I do not have a good relationship. We are not really close. She knew I was ill only because one of my sisters told her. At that time we barely spoke. However, our relationship has improved since then. We talk more often. My cancer has helped me to improve the bonds with my family and friends.

I have received a lot of support from my colleagues and friends from the school where I used to teach. I have a friendship of 24 years with the principal so for him it was really difficult to learn about my cancer. I received a lot of support and love from all the people I used to work with. When I got sick my work was deeply affected. I loved to play soccer, basketball or mini soccer with my students. Also, I used to organized one day trips with my students; we used to go outside of Bogota. After my diagnosis I could not go back to any of these activities for the risk of a fracture. I had to refrain from all those risky activities. I never said a word about my disease to my students. They found out when I received my long term disability because I was not old enough to be retired. It was rare to see the teacher who used to play and travel with them retired. My home is close to the school so one day they came by to visit me and I told them. They continue coming to visit me. During the first two years of my disease I did not want to go anywhere. I was reluctant to go outside of my home. I was bitter and overwhelmed by my situation so I did not want to know anything about parties or gatherings with friends. I was sour. I used to watch a lot of TV until I met Maria who is my wife. Today with her I have become the old Alfredo again. My social life improved. I met new friends and new family. It was wonderful. Everything was okay until last November when the pain in my right leg began. I could not walk without the help of a cane or crutches. My life was limited again but this time it was my body not my mind. The pain in my leg is sometimes unbearable. I know this is a consequence of my disease. The pain in my leg does not allow me to move the way I used to. Yet, I do not consider the pain in my leg a problem because I have my wife. She is my company. I like to be with her. I like that we have some time to share, talk, read and hear some conferences on personal growing. Looking back in my life, I see a lot of goals reached, a lot of satisfaction experienced. I could work in my two careers: I was a lawyer from 8 to 12 and then I was a social science teacher in high school from 1 to 6. I left them both due to my fragile health. I have good memories of both but now I have to recognize that nobody is indispensable. Everybody could be replaced. I left law for two reasons. First, my nephews came to see me one day and persuaded me to leave my career as a lawyer. They were right; I was overwhelmed by stress from all of the cases I was handling. Second, due to my limitation in walking and my constant pain I could not go back to court anymore. I had to give all my cases to other friends. I needed to take things easy. I moved on with my life. My advantage was that my disease was not noticeable to the

> *eyes of strangers. So I kept my life as normal as possible. For example, the day of my chemo I did not go to work but the next day I was working as if nothing had happened. At first sight, people do not realize I have this disease. They may recognize that I have a limitation to walk because they see the cane or the crutches but that is it. What I missed the most is my athletics; with this illness I have become sedentary and I do not move enough. So I am getting fat, which is risky, putting weight on my hips and legs. I did lose my hair but I like that. Since I was a child I wanted to be bald and my disease gave me that opportunity so for me it was a blessing. I wore my baldness with pride. I think my life has continued the same, well, the same within the circumstances of my disease. I could continue working.*

I have received a lot of support from my colleagues and friends. Alfredo is worried about his daughter's learning that he has cancer. He does not want her to know he has cancer. He wants to protect her from the suffering the word cancer will bring to her daughter. His family has to accept the reality of cancer but worries about the easy way to break the news to a five year old. He does not know how so he waits until she grows up to tell her he has cancer. He is afraid his situation could traumatize his little daughter. His daughter is the most important person in his life. After the divorce she became the whole world for him. He waits until she is 13 to let her know what is happening to him. Little by little he explains to her. She sees that he is stable so she does not worry about his situation.

With his older daughter the situation is different as they do not have a very close relationship. They barely speak. His disease is the bridge that helps to re-build a deteriorated relationship. They talk more often today. There is something positive about cancer and it is the idea to create bonds with the people around one. His estranged daughter returns to re-build their relationship. He is happy. He has love around him. Life is easier when there is some company around you. It eases the load. He talks more often with his oldest daughter than before his disease. The disease has eased the communication between father and daughter. Both daughters have grown, thus he assumes they can live without him. He is not worried for them anymore knowing they can survive when he is gone.

Death is a permanent and silent threat. Sometimes it is not even implicit and yet in the way he speaks about his daughters it is easy to see he is saying good bye to them. However, it was not always easy and when he first received the diagnosis he was bitter. He did not want to go anywhere. His world is limited by his mind. He spent much of his time watching TV alone. He did not care because his marriage had ended and he has cancer. He did not know what to do. Everything seems blurry. He was alone until he met Maria who brings to his life a new beginning. His world improves by meeting new people and having a new family. Everything seemed okay until last November when his disease became apparent again. He cannot walk anymore without the help of a cane or crutches. He is limited but this time he describes his limitation as something that comes from his body. His mind wants to live as full as possible. He even plans a trip to a warmer place. His life continues and his wife is his reason to live. Maria is his caregiver. She was with him the last five years of his disease. They spend most of their time together.

Alfredo has a lot of friends in both the law and the social sciences. Knowing he is ill has not been an easy thing for his friends. They suffer for him. At the same time they give him support to go on. They are there for him. Initially, his students do not know their teacher is ill. He does not tell them. He just withdraws little by little from the activities that could cause any harm to his ill body. He has to take care of himself, to pay attention to his body So many activities such as mini soccer, soccer, and basketball are sacrificed to pursue well-being. When one is ill there needs to be a lot of sacrifice. The old life is sacrificed. Things that you like cannot be practiced anymore because the body is fragile. Alfredo has to look after his body. The silent partner needs constant attention and vigilance. He has to watch others from the outside playing and doing the things he cannot do anymore. He does not know how to explain to others about his disease. He keeps the information of his cancer to himself. Despite the friendship he has developed with his students, he keeps quiet and they only learn later when he receives his long term disability. It must be hard for these young people to know his teacher has cancer, but they come to visit him.

He continues working throughout most of his treatment until he receives his long term disability. He does not have to work anymore as a teacher. He realizes that nobody is indispensable. His school can survive without him. Life goes on. And he can live without working in both places. He continues working as a lawyer until his nephews asks him to leave the profession. He has to leave because his body does not allow him to deal with the stress of being a lawyer. Through time his space has been reduced but it brings calmness to his life. Like

Camille, Alfredo realizes his life has changed and the remaining time has to be used to be around people he loves. Family is important for him. What seemed important before lacks importance now and there is no more rush in his life. It is a time to heal. What kept his mind busy before is not important anymore. There are also negative connotations. His body is sedentary and his weight gain creates more risks for his hips and legs. However, there is no time to feel sorry. One must continue living. One must continue until the disease defeats the person. Cancer is the bridge that not only brought him to his wife but has brought other new reasons to live.

Alejandro

> *After my heart attack I became close to my home. I think I have become more tolerant now. My kids were worried about my situation. They came to the hospital and stayed with my wife the whole time. I have 12 siblings and we only gather at weddings and funerals. The last time we got together was at our dad's funeral. One of my sisters told them about my situation and since then they have called me a lot. Solidarity is what you need in these moments. It makes things easier to assimilate and overcome. I do not beg for money so the only thing I ask my family is for company and moral support. Fortunately, I do not have to beg for money; I have my pension and we live with little but without any problem. I also have my health insurance company. So I only need their solidarity and moral support, a shoulder to rely on.*
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> *With my friends and co-workers I did not expect anything, mainly because I never told them I was ill. I did not want their pity and I did not want to be bullied. They did not have any education to understand what diabetes is. I did not want to be called names by them or for them to laugh at my condition. So I kept my disease to myself because there is a saying, "If you tell a friend about your disease he may respond that that's none of his business." So I wanted to avoid their laughter. I try to take things easy. When I told one of my friends about my disease, he said, "You do not look sick," but he does not know that the process goes on inside. When I hear those comments I always try to relax and forget the words of those people who do not know what it is like to have diabetes. I try to stay calm. So we have kept knowledge of my disease within the family. My kids have not said too much about my condition. When everything began they were just children and now they are all married, so they have their own spouses and kids to be worried about. They come here to see me and sometimes they call and ask their mother how I am, but that is all.*
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> *My diseases have changed my social life. My feet do not have enough circulation so I live with a lot of pain--pain, torture and tiredness--so that I cannot go outside anymore. I do not see anything with my right eye. I have completely lost sight in my right eye. My left eye is becoming more blurred every day. However, I have taken insulin for a while so*

> *physicians say that insulin protects the eyes. I am expecting my surgery soon. I recognized that what I am living today is a consequence of wrong decisions in my past. I have to accept that. I don't feel anything; I just stay calm and keep to myself.*

My diseases have changed my social life. Alejandro has other priorities in life. He does not deal with his health issues because he feels his first need is to educate and feed his family. Consequently, today he faces death and he is afraid. His wife, who is his caregiver, prays for him. The only solution to control his disease falls in the hands of God. He has multiple chronic diseases with multiple complications, but still he has faith in God. Chronic illness improves bonds with family members and friends and it also brings closeness to God. The spiritual part of someone with chronic illness is developed. He needs to believe in something when the disease is advancing. His mother is the picture of his future, but for Alejandro there are more important priorities than his health and well-being.

During all this time of disease he has received support from his brothers and sisters. They call him to know how he is doing. However, it seems his condition does not alter the dynamic of his family. Like his daughters and sons, his sisters and brothers continue their life. They worry for him but from a distance. He is alone with his wife during the process of living with his disease. His wife is in charge of his care. Although she is his caregiver, he feels alone. He requires the solidarity of his family and they give him comfort when he is ill. The presence of the other is what makes it possible for him to ease the process of illness. He has economic means to survive, he also has health insurance but he does not have the company of former times. Friends and family move on with their lives and he stays relegated to living within the four walls of his apartment. He needs a shoulder to rely on. His kids have visited at the hospital but still they have their own families to take care of, so he understands that they have to make commitments. He likes to have company and he likes the moral support during the process of disease but when the crisis is over the company and the moral support are gone too.

With regard to his friends, he has a different story. They never knew about his disease. He kept the information of his disease to himself. He thinks they do not have the knowledge to understand what diabetes is. So he keeps the situation of his life to himself. In the first years of his retirement his friends call

all the time to invite him to work or to travel. He enjoys this life. For Alejandro, most of the time he worked outside of Bogota, and now being secluded in his apartment is one of the hardest things in his life. He wants to be free but he cannot. His body does not allow him to go further. His diabetic foot and his retinopathy in both eyes do not allow him to move outside of the four walls without someone accompanying him. His space has been reduced. It is different from Camille: what was broad in the past seems small in the present. His world has shrunk. Nobody understands him or what he is feeling. Knowledge of his being ill is restricted to the family; he does not want the rest of the world to know. Alejandro is afraid of being bullied by his coworkers or discriminated against so he hides all the suffering his condition brings to his life and he faces the future with resignation because he knows chronic illness cannot be cured.

Alejandro's social life has been circumscribed by the limitations of his body, especially his diseased foot. He cannot go outside because he barely walks. His foot hurts. He knows his condition in life today is the result of his decisions in the past. However, there are no regrets and he only revisits the past to recognize that he is the author of the situations in the present. Certainly, he misses his old life. From being active, he becomes sedentary. His world is limited by his situation, thus creating a lot of resignation in his story, unlike Camille who likes the freedom of her new situation. She has new friends. Her perspective is a positive one despite her prognosis. Alejandro, like Hannah and Alfredo, is suffering from isolation. His friends are gone. He cannot find new friends with the same condition because he does not belong to any support group. The difference is the support the person receives when they are ill. For Alejandro being alone when you are old is part of the reality of life. He is bored with his life because there is nothing new besides the daily schedule of TV and he cannot read because of the problem with his eyes.

Maria

> *One week after my breast surgery I met with my surgeon again. He prescribed some oral chemo. I was happy with this treatment. But later that year the government changed our health insurance again so I had to change my doctors. This time I met an oncologist who in our first appointment told me, "I don't think this is the best treatment for you. I am afraid we need a tougher treatment for your cancer. So I am going to schedule four rounds of chemo and 36 rounds of radio." I was not expecting that so when she saw my face she said, "Don't worry,*

everything is going to be alright." It was certainly an advantage to have her as my oncologist. First, she was a woman and as a woman she understood what I was going through. Second, she listened to me. She even looked at my face when we were talking. She was a really good support, something that is difficult to find at the medical level. She was nice but I was completely bewildered by the news. It hurt me to learn that I needed all those treatments. I thought I would not need more than the surgery and the oral chemo the other doctor prescribed to me.

Yet, to me IV chemo was another story. I knew all the side effects. I know how exhausting that treatment is for the person because I witnessed it with my husband. I still remember how exhausted he ended up after his rounds of chemo and radio. So to have that firsthand knowledge of the side effects of chemo and radio but that did not really help me at all. I was scared. It is hard to deal with all the aggressive treatments and especially all the sickness afterwards. Also, the idea of losing my hair mortifies me. I did not want to see me bald. I was worried because I did not want to worry my family. My husband and one of my sisters knew about my condition but I did not want my parents and other sisters and brothers to learn about it. I was especially worried for my parents; I wanted them to avoid this suffering. So when I began to picture me bald and I thought, "My parents are going to discover I am ill," I had this idea that the surgery and the oral chemo were enough treatments for me. I did plan to tell my family but only after the surgery. With the new change of events I decided to keep quiet. My parents are old but they are healthy. They do not even live here in Bogota. So what would be the point to scare them with such awful news? I did not see the point. I told my other brothers, sister, nephews and nieces. And we agreed not to say a word to my parents. Even today they do not have any idea about my situation. One day my dad asked one of my sisters what was happening to me. My sister told my dad I was receiving a treatment to prevent cancer. My dad did not say a word but I think he knows. He may feel something is wrong with me. Then, another day my dad said to my sister, "We respect Maria and we understand if she does not want to share with us what is happening to her. We are not going to pressure her to share her health issues with us." From my brothers and sisters I have received a lot of support. They are my shoulder to rely on. One of my brothers once told me, "Don't worry Maria, everyday there are new discoveries in medicine so you are going to be just fine." I am the oldest in my family so another brother said, "I don't want to see you defeated. I want to see you fighting this disease. You are our role model. We want to see you overcome this." They were the most wonderful support I have ever had. They were there for me. My nephews and nieces sent me boxes with drawings and letters. It was nice to receive that support.

From my friends and colleagues I have received a lot of support too. My dear friends in my job were the first ones to know about my condition. When I told them, I was calm, I did not cry. It was hard on them to know I was ill. They cried and hugged me. One of my best friends barely spoke to me afterwards, but wherever she saw me, she just hugged me. I understand her because sometimes there are no words for this situation. Later, my friends spread the news in the school to my other colleagues.

> *They all surrounded me with support and love. I was blessed to have them because I could not ask for any support from my husband due to his illness. The school is really close to our home so during my rounds of chemo my friends and colleagues came to visit us. During my chemo I continued working as a psychologist but I perceived a change. My colleagues and boss did not send me all the cases. They handled most of the situations in their classrooms. They sent me only the simple or the urgent cases, nothing else. They tried to alleviate my workload. After one round of chemo my leave finished so I had to go back to work. When the principal saw me he said, "Go home Maria, take one week more if you need it" He gave me one week more and the school paid for it. They were very nice to me. I was happy most of the time. I liked to be the centre of all the attention from my friends and colleagues. The year before my disease began, there was another colleague who died from cancer; however, she did not receive the same attention and support I received. So I felt blessed. My disease just gathered all these people around me. I cannot complain. I am still very grateful for their support and love. My cancer has strengthened the bonds with my friends and family. For sure this support has changed my whole perspective about this disease. I see my situation with other eyes.*

My parents are going to discover I am ill. After the surgery, her doctor prescribed oral chemo and she was happy with the treatment. However, the fate of her health is in the hands of the government and they change Maria's health care insurance. Her new doctor decides to increase Maria's treatment causing her disappointment because the idea of receiving chemo and radio were not considered before. She is pleased that her new doctor understands her condition and is attentive to her needs. But Maria feels anguish knowing she has to readapt to the new change in her life. Suddenly, she recalls how awful the side effects of an aggressive treatment for cancer are. Being Alfredo's caregiver during his time of treatment with chemo and radio reminds Maria what the difficulties of this new condition in her life are. She does not want to be bald. Baldness for her means others will discover what she has. Like Camille, Alfredo and Hannah, Maria keeps the information about her disease from her parents to prevent them from suffering for her.

Suffering is a key point in the experience of illness. The ill person wants to keep others from going through the process of acceptance of their chronic condition. It is hard, and sometimes like in Maria' story it is impossible to hide. She hides her disease from them mainly because they are old, they do not live in Bogota and they are still healthy. And yet her father perceives Maria is hiding something from them because parents sense what is happening to their children.

Hannah's parents know as well when she is ill. It may be the bond between parents and children that make it easy to read when they are suffering. Different from Camille, Maria does have the unconditional support of her sister and brothers. In Camille's story the reaction of her brother is the result of the experience of his only son. For Maria, the responsibility of being a role model like Hannah has not finished, she has to fight against her cancer. Hannah does not want to be a role model. Maria, on the other hand, assumes with pride her position in her family as a role model. The support she receives prepares her to meet the new reality of her life. Also, Maria's brothers do not blame her for her condition. They know the reality and encourage Maria to fight against it. They do not want her defeated by the battle against cancer. They are there for her. Alfredo, as husband, needs to take a similar position but he cannot. He has his own problems with cancer. That is why Maria relies on others to overcome her condition. Other members of her family gather around her. She receives support and unconditional love from sisters, brothers, nieces and nephews. She is calm because she knows life is easier when you are given the support you need. The more support she has, the more hope she builds in her life. Bonds with others are always preserved. Maria's experience is unique. She sees life in a positive way. For her there are no final definitions of what living with cancer is. Everyone has a different one according to his or her experience. There is strong empathy felt by Maria's friends and she becomes the centre of attention in her job with everyone eager to help her, a situation that she likes. She needs the reassurance because she cannot rely on Alfredo. Despite the change in her social life, she does not consider it to be dramatic. Everything in her life seems to unfold naturally. The priorities and interests change their order, what seeming to be out of the question before becoming certain and a priority now. It is a time to be with Alfredo, wanting and needing to share the moments of illness with him. They need each other.

Maria tells her friends right away about her condition. They help her by trying to make things easier for her in her work as a school psychologist. Because they do not like to see her sick, there is a lot of support. There is a change in her life: before she was Alfredo's caregiver and now she is not only his caregiver but also a patient with cancer. She lives with both statuses. Even during the moments of crisis after chemo they have compassion for her, the same compassion and understanding Camille and Alfredo received. Her disease has caused her to gather a lot of people around her. Hannah has not had that luck. Her condition does not awaken any compassion and empathy in her friends. Maria, on the other hand, finds a door open for her when she is ill. They are there for her trying to handle the situation the best possible way, easing her workload and making it easier to receive the emergency treatments or the follow-ups.

> *For sure this support has changed my whole perspective about this disease. I see my situation with other eyes. I have pretty much learned to have a positive attitude toward my breast cancer. But this has not been well understood by some professionals. Sometimes I have been criticized and judged by professionals who think that having cancer is equal to sadness, frustration, rage, despair and death. If you as a patient with cancer do not behave the way all patients with cancer are expected to behave, you are criticized and judged. It happened to me during my first session of chemotherapy. During the treatment with chemo it is possible to meet people who are in different stages of treatment and disease; however, that day we were all new. So a psychologist came to support that first moment. I saw her talking to the patients and their families but I did not really pay attention to her. I brought a book to read during my session. I wanted to forget my arm and forget the chemo. I just wanted to be drawn away into my mind for a moment. I just wanted to forget I was there when suddenly and without previous introduction she asked me, "Do you know what is going to happen in your life from now on?" I was not expecting this kind of question, so I answered rudely, "Yes, I know what is going to happen to me at all levels: physical, psychological and emotional. So what?" I responded in that way because with this disease you need to be real. She was expecting another type of answer. She was expecting teary eyes and despair and I was not there at that point. She told me, "You should be more open." But I was concentrating on my reading when she rudely interrupted me. She kept arguing with me for a while. She continued with the same argument on and on and with the same question, "Why you are not crying? Why don't you display some emotion? The 'normal' behaviour for someone with cancer is to be emotional." So if I did not cry then I was not within the parameters of normality she was describing to me. She does not know about my situation. I did not have the need to cry at that specific moment. But she did not take a no for an answer, so she continued, "Look at that woman across the room, look at her family, all of them are crying. Why are they crying and you are not?" She does not know that I cried. I cried alone. I cried with my husband at home because I know how hard it is to go through this disease. I know because I was experiencing my husband's situation, I was his caregiver. And yet she judged me. She did not allow me to explain my position. How is she going to understand if she does not know who I am, my story, my life? And yet she was expecting tears when the first drop of chemo came into my body. My husband cried in all his treatments; therefore, he fit the normal behaviour of a patient with cancer. I did not see her again in my other sessions. But what I got from*

> *that day is that all patients with cancer have to feel the same, cry at the same time and for the same reasons. If one does not fit those expectations one is considered a stubborn person who does not want to face reality. At the end of the road, I do not really care what these people think about me. I have my own perspective. I know God gave me this disease for a reason to change my life, to be patient. After all the time I cared for my husband, now it is my time to be ill.*

How is she going to understand if she does not know who I am, my story, my life? Maria has understood her disease as part of her life. With her husband she has cried. She has received the support of her family and friends. She feels blessed to receive that support; however, during her first chemo a psychologist visits with her. Maria's perception of her illness is challenged by the psychologist on her first day of chemotherapy. Maria comes to the treatment with a book to read, wanting to forget her condition for a moment. She sees the psychologist working with families and patients with cancer, but Maria is focused on her book. Suddenly a question about her condition brings her back to her immediate reality of cancer. With Alfredo, Maria has learned the ups and downs of living with cancer.

Maria's experiences with cancer and her psychological state are invalidated by the psychologist. According to the psychologist, Maria needs to behave the way other patients with cancer are behaving during the first round of chemotherapy. Maria does not fit the parameters of normality defined by the levels of sadness and suffering someone has during the moment of chemotherapy. She is judged by the professional who is supposed to advise and help her through the first chemo. Like Camille and Alfredo, Maria's cancer has brought positive changes into her life. The possibility of death is there but they decide to live life as full as possible.

The Social Life of Chronic Illness

Our experience of the world includes and is dependent upon experience of the social world (Merleau-Ponty, 2005). As human beings, we are all part of a political, economical, cultural and social network that is impossible to ignore: all the external actions have an effect on our lives and especially on our health. To use van Manen's (1997) words, "As we meet the other, we approach the other in a corporeal way" (p. 105). Therefore, interaction implies being part of the other's world and the interchange of experience is always under parameters of mutual respect and recognition. It is through recognition that we perceive the other in a vocative way (Levinas, 1985, 2002). In fact, responsibility means that our life is tied to another human being's life in a way that is impossible to break and forget. As Dussel (1999) affirms, "The other presents itself as an anarchic being that slips into me *like a thief* through the outstretched nets of consciousness" (p. 131) Perhaps it is that as human beings we have a filial bond, a basic need to form relationships in order to survive. We have what Dussel calls sensibility, a pre-opening to the other's world. Who has not experienced some kind of identification with another's problems? It is as if I share this moment with that person as mine. Although it is not mine, I understand it. However, it is more than a physical encounter: it is the feeling of "I know, I understand you, and I am here with you." There is a sense of solidarity. I am an empathetic outsider, because as a human being I know what it is like to suffer.

What do you do when chronic illness sneaks into someone's house and robs from everyone who lives there? Living with someone who is chronically ill causes a disruptive change in the dynamics of the family. The healthy siblings are there for them, but what happens through time with the support offered to a chronically ill person? Do families, friends and colleagues get tired of the unpredictable changes associated with chronic illness? People chronically ill are never quite certain what lie ahead of them. The social life of people with chronic illness is both a complex and a subtle affair. Chronically ill people endure hardship. It seems like the illness controls the situation, as if the whole family were ill. However, to face the situation, a family as a whole develops strategies in order to preserve the unity among its members. It is difficult for family members to accept that the chronic illness may not go away.

Hannah's family swings back and forth between periods of overprotection when she has pain to periods of under-protection and abandonment, as she describes it, when her disease is controlled. In fact, caring for her means being responsible in order to handle the situation and in order to live with the fact that the spontaneity in the daily social life has to be exchanged for a planned one. Her family's life is on a roller coaster careening from hopeful when the situation is under control to hopeless when the situation is uncontrolled. Despite Alejandro's siblings knowing about his condition, he spends most of the time alone with his wife. Daughters, sons, sisters and brothers continue living their own lives. They call him but not with the frequency he expects. He feels alone. Maria and Alfredo have gathered their families around them. They have received a lot of support and love during the overwhelming process of disease. Camille finds support in her sister who is alone in the process of taking care of her. Meanwhile, Camille's brother blames her lack of forgiveness and careless behaviour as the culprits of her cancer. It hurts Camille to see her family split by her condition. Camille's brother wants her to reflect on the reasons behind her disease. Caring for a person with a chronic illness is a process which requires strength and willpower; it is an enduring battle against the characteristics of that particular situation. For Maria's, Camille's, Alfredo's and Hannah's families, chronic illness transcends their bodily experience or physical events; chronic illness has created bonds that have kept their families together. These bonds cannot be imposed; rather they emerge as a filial empathy with the affected person. There is a sense of solidarity, and perhaps more important, a feeling of filial love growing out of the family's need to be there with that person. Alejandro feels that solidarity from his relatives when he is in the hospital. For him it is really important; it is what keeps his moral up.

Living with chronic illness requires a delicate balance between what the chronically ill person can and cannot do. Hannah is young but due to her chronic pain she cannot participate in all the activities a person of her age does. For Hannah it is difficult to interact with friends, family and health care professionals the way Maria, Alfredo and Camille do. It seems that it is more difficult for young people to adapt to the circumstances of chronic illness. She has not found the support the others participants have found among family and friends. Is it because she does not have a diagnosis yet? Or is it related to her age? The diagnosis of cancer gathers a lot of solidarity for the people who live with it like in Maria's, Alfredo's and Camille's story. They have found unconditional love and support from people around them. Despite how difficult it is to interact with her brother, Camille has received a lot of support from her friends, sister, support group and health care professionals. Like Hannah, Alejandro's social life has decreased due to the pain in his foot and his retinopathy; he cannot socialize with his friends in the way he used to. Both miss the activities they used to do with their friends before the beginning of their diseases. In Alejandro's case he does not want to spread the news among his friends about his condition. He keeps quiet. He believes they are not educated enough to understand what diabetes is. Like Hanna, he is alone most of the time because of his physical limitations. Through time he has found his friends do not call him anymore. It seems that chronic illness builds barriers against relationships. There is this feeling of being afraid of a lack of understanding. Alejandro decides to keep information about his illness to himself. When he is with them, he forgets he is ill. He likes to be surrounded by healthy people because their company makes it easier for him to forget for a moment that he has diabetes. Chronic illness for Hannah and Alejandro has negatively affected the interaction with other human beings. For them the balance and harmony of their daily life has been threatened. On the other hand, Camille, Alfredo and Maria have striven to live as normally as their condition allows. For them, having cancer is a blessing that has strengthened the bonds with relatives and friends. It has also helped them to find new friends with the same condition. The old activities are not missed: for them this is a second chance in their lives and an opportunity to change old habits. They decide to take advantage of this second opportunity, in spite of the imminence of death for Camille and Alfredo. However, for all of them, there are times when they can do certain things and times when they have to cancel. In the moments of illness, knowing someone is with us can significantly influence the comfort we experience (Yorgason, Roper, Wheeler, Crane, Byron & Carpenter et al., 2010).

Being ill has a personal connotation. When we are ill, we never go to the street and tell others about our condition. We share with people close to us that we are ill. There is something about chronic illness that keeps it as a secret until the ill body becomes apparent to others. It is easy to hide when chronic illness is not obvious to the eyes of others. Camille shares her condition only with people close to her. Maria wants to keep her illness as a secret. Alfredo does not say any word of his disease to his daughters and students. Alejandro does not share with his friends his condition. Hannah shares but her friends do not believe her; they think her disease is the result of too much stress. But the side effects of their diseases and/or treatments will open their chronic condition to the world. Others will know about their secret. Mostly they keep quiet to avoid causing suffering for others. Illness is a moment of privacy.

Socially, the inadequate regard for chronic illness is an example of discrimination and indifference that occurs every day and everywhere. Through the years, society has looked for perfection that has tended to be defined in terms of success, beauty, intelligence, and wealth. If people are unable to achieve these standards, they sometimes face discrimination or oppression. As Kristeva (1991) writes, "Who is the foreigner? The one who does not belong to the group, who is not '*one of them,'* the *other*" (p. 95), when exploring the notion of the stranger—the foreigner or outsider in a society, Kristeva offers a reflection on foreignness and foreigners. Her writing sympathizes with the problems and thoughts of the foreigner as well as those of people who live with foreigners and even with the troublesome realization of finding the foreigner in oneself. Sometimes the foreigner is something hidden in ourselves, something with the potential to destroy what we know and something that is beyond understanding or relations with each other. The foreigner has a particular quality of otherness. Is chronic illness a foreigner for these participants? If so, is their foreignness the result of their illness or is the foreignness the result of exclusion by society. Many societies have granted rights for the foreigners (Kristeva, 1991) as rights have been established for people chronically ill. And yet, as we see in these stories people with chronic illness do not have the same rights as other citizens. Is possible to learn to love one's chronic conditions when there are barriers that prevent one to flourish in society? How could one tolerate a foreigner if one did not know one was a stranger oneself? (Kristeva, p.170).

Hannah's social life fits in what Kristeva describes as foreigner. She does not belong to the group. She cannot do what other healthy people of her age can do. Her foreignness comes from her impossibility to have free will to decide her life. Maria in her first session of chemo experiences foreignness as well. She does not fit the parameters of normality of patients with cancer established by the psychologist. Alejandro's disease has shaped his life as a foreigner. He does not belong to his group of friends anymore. At the beginning of his condition and despite that his social life is active, he keeps his disease a secret. Alfredo is not the active teacher anymore. He has to take care of his health so he decides to abandon his two careers and outdoor activities with his students. He has inflicted self-foreignness to avoid any setback in his health. Camille's brother has been hard on her. His way of seeing Camille's life burdens her and puts her in a position of foreignness with herself. At some point in their lives these five people have lived a state of not belongings to a group. Their condition has made them foreigners in their own country, community, family and with themselves. Chronic illness has excluded them from their social group. Through time Alfredo, Maria and Camille overcome their foreignness and adapt their lives to the new situation. The only thing that they ever learn is that the path they choose will influence the quality of their life. Thus, they must be wise and prudent in order to survive.

According to Arendt's totalitarianism ideologies are inextricable bound up with the problem of the foreigner in modern society (Kristeva, 1991). The appeal of totalitarian ideologies is the mobilization of populations to do their bidding and devastation of ordered and stable contexts in which people once lived (Arendt, 1994). We still live in a totalitarian world. Neoliberal polices drive the course of the world. As Arendt (1994) describes, "totalitarianism is used today to denote lust for power, the will to dominate, terror, and a so-called monolithic state structure" (p. 312). We live in a postcolonial world in which systems are structured in ways that have the potential to perpetuate inequities. In a world in which the politic of imposition and exclusion is the pattern of work, we need to take into account that otherness means being different, but not worthless.

Currently, in the world there is a trend to individualism. Human beings, consequently, are forced to compete in order to survive, originating what Taylor (1991) calls, "the dark side of individualism [or self-centrism], which both flattens and narrows our lives, makes them poorer in meaning, and less concerned with others or society" (p. 4). Indifference occurs when one knows of and disregards what is happening within other people's worlds. Closing one's eyes to reality does not make it disappear. This self-centrism is just one face of indifference; another face is portrayed in how priorities for policies and health systems are organized to run the world today. For the chronically ill, their world is surrounded with more indifference and less solidarity. Technological, economical, political, social and other forces have shaped the way societies work and the way individuals interact with one another. People are cured, disciplined and educated to follow this mandate and produce economic reward, while those who cannot fit into this capitalistic value of production are marginalized. In nursing, we talk about care as the opposite to indifference. Then, why do we not act against the exclusion of people who are chronically ill? For Hannah, indifference has been the rule during her moments of illness. She has not found compassion or solidarity from health care professionals. Most of her interactions with health professionals are focused on working on her body. She describes herself as an object, a table that needs to be cleaned. Hannah feels hurt when she is not treated with respect and not listened to by health care professionals. When one is hospitalized, one's needs, which are usually taken care of by oneself, are taken into the hands of others. Today, in this world of globalization, independence is highly valued and losing it can make you experience a feeling of unworthiness. For Hannah, at the end, achieving a balance between the need for care and the demand for dignity is part of caring for herself. Maria's oncologist has helped her through the process of disease. She has been friendly with her, something she describes as difficult to find at the health care level. Yet, she knows what imposition and generalization are. She faced indifference during her first session of chemotherapy. Camille, on the other hand, has a different experience; she has had very good experiences with health care professionals. Her nurses helped her during her first hospitalization. They made her feel comfortable, almost at home. When a nurse is with us, like in Camille's story, in the sense of being present, we feel the security of her protective gaze, we feel valued as a person in the focus of her attention. When the nurse is not with us, like in Hannah's story, illness becomes difficult to accept.

Today, we are facing an era of globalization and, "our presence in the world is not a neutral presence" (Freire, 2004 p. 7). It cannot be neutral because the changes in the world affect how we practice, educate, research and develop knowledge in nursing; then, the social mandate must be to look forward and deal not only with the individual but also with a more inclusive view of human beings. We cannot turn our backs when nursing, caring becomes difficult. In nursing, we cannot restrict our understanding of and caring for human beings to capitalistic terms of economic profit: we must neither forget nor forgo our purpose to treat each person as a unique human being with diverse needs. Thus, the impact of chronic illness in social life is something beyond commitment. It is loving without restrictions, with empathy at its core, and a battling everyday against challenges, living one day at time, elevated when the situation is hopeful and down when it appears hopeless. It can be a situation full of negative feelings, a trial which requires strength, determination and enduring heart. However, beyond the negative connotation of chronic illness dwells a special human being who needs attention, love, and care.

Attentive to the Space of Chronic Illness

Everywhere we go there is pressure to silence our voices, to co-opt and undermine them. Mostly, of course, we are not there. We never "arrive" or "can't stay." Back in those spaces where we come from, we kill ourselves in despair, drowning in nihilism, caught in poverty, in addiction, in every postmodern mode of dying that can be named (bell hooks, 1999 p.148).

Hannah

> *Last year, my doctor told me I needed surgery immediately to correct the malformation in my head. According to my doctor, without the surgery I could crash or die without any warning. I was very scared. So right away, I prepared everything and went to the authorizations office at my health insurance company. There I was told I had to wait fifteen days to get my authorization. Fifteen days later I came back, but instead of finding my authorization I was told my request needed to be studied further by the medical board of the insurance company. This medical board meets only once a month. So I had to wait one month for the meeting. One month later, I was called to be present at the medical board meeting to plead my case. During the meeting they quickly read my records and asked me how I was. Then a doctor told me, "Yeah. You need this surgery." In five minutes they gave me the authorization for my surgery. But I had to wait one month more to schedule the surgery. That's not fair. I had to wait six months for the surgery. Six months since the doctor gave me the diagnosis. The surgery was supposed to be a priority but it was not. During the waiting time I had three more episodes of paraplegia. My life was at stake and my insurance company did not care. I could have died waiting for my surgery.*

My life was at stake and my insurance company does not care. What is the space of chronic illness? Although Hannah's disease is a priority for her, her insurance company does not seem to care. For them it is not an emergency. Why? What prevents Hannah's insurance company from providing opportune care? She has to wait for authorizations, a meeting with the medical board, and scheduling of her surgery. Everything requires time and that is precisely what Hannah lacks. During the wait she has three more episodes of paraplegia and yet her insurance company does not respond. Hannah's freedom space has been violently modified by others. Her disease owns her space and time. Everything in her life has to be planned according to the needs of her ill body. Also, family and friends have been affected by the unexpected presence of her chronic illness. However, not only her disease controls her life but also her insurance company determines how, when and where her disease must be controlled. It is overwhelming for her because her health is at the stake. Others have the power to decide what medication she is going to take or what procedure she is going to have. There is no free will for Hannah; she waits.

Etymologically, the meaning of *to wait* is to watch, to guard (Skeat, 1963). As she waits, Hannah becomes bewildered and powerless. She keeps guard of her health but her guard is from the margins. In reality she does not have any control over which way to turn. She does not have any voice or vote in terms of her treatment. The power dwells in people who hardly know her. They are in charge of deciding what test, treatments or medications are suitable for her. Hannah's world crumbles. Thus, not only her disease governs her being and her relations but also the policies of her insurance company have a claim on her life and being.

> *My parents have invested more than $3 million pesos in my disease taking into account medications, procedures, diagnostic tests and private specialist that I have gone to. However, this estimate does not take into account all the extra money I have spent on doctor bills, medications, and diagnostic tests in my insurance company. Lately, I have been using homeopathic medicine which I consider very holistic but at the same time it is expensive. This kind of medicine is not covered by my insurance company so I have to pay out of my pocket for my visits to the doctor and the treatment he orders. I like to go there because the appointment lasts two hours while with my regular doctor it lasts only twenty minutes. My homeopathic doctor lets me talk not only about my affected organs or my pain but also about how I feel and what I think about my condition. My rheumatologist never asks how I am feelings or what I think. But it is expensive to use this medicine so I only go there twice per year or when I feel really burned by the physicians of my insurance company.*
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> *During the last ten years I have had a private rheumatologist, a neurosurgeon, a neurologist, a cardiologist and an orthopaedists but the visits are expensive. My parents paid for them. The fee for the first visit with a private specialist goes around 120,000 pesos*[1] *and the follow up 100,000 pesos every time. If you need a blood test or other medical test you have to pay for them, plus the medications. I can easily spend 500,000 or 600,000 pesos on private physicians without getting any answers about my condition. Everything is supposed to be covered by my insurance but, no, instead, I have had a lot of problems with them. According to my insurance company, users can go to the medical specialist only every third month. Then, for crisis the only place available for chronically ill people is Emergency. My insurance company is supposed to cover everything regarding my health, but it doesn't. One day, I had this terrible chest pain and my rheumatologist sent me for a*

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[1] On 15 Feb 2011, 1.00 Canadian dollar(s) = 1,926.78 Colombian peso(s), at an exchange rate of 1,926.78

> *special diagnostic test. He said it was a priority test but I have been waiting three months for the authorization to come out. If I need an authorization I always have to bring the summary of my records written by my doctor and a copy of my records and a summary written by me explaining my situation so in my insurance company they don't have any excuse to reject my request. During the last ten years of illness, I have had a lot of problems with this company.*
>
> *A few weeks ago, I had an excruciating pain in my joints again. For a couple of days I had to stay in the hospital. The painkillers did not work until the doctor sent me a new medication that is not covered by my insurance. It was the only thing that relieved my pain. The day of my discharge the doctor gave me the prescription in a special format for that painkiller with the justification and everything to be submitted to my insurance company. At my insurance company I was told that I had two more authorizations on hold so they could not process my request for the specific painkiller at that time. Authorization for the specialized tests could take more than two months because they have to be cleared by the medical board. If the other two requests are authorized I have to wait two more months to get the authorization for my painkiller. So what was I suppose to do? Hold the pain? It is hard because this medication is the only one that has calmed down my pain. But this medication is too expensive. I cannot afford it. I would buy it if the treatment was for no longer than five days. I would invest in it but it costs 80,000 pesos for enough medication that lasts only five days. I do not have that money. So I have to be patient with my request. I have to be resigned. When we have chronic illness we are relegated to a lower status. We have to wait more than twenty days for something. And the answer is always the same.*

For Hannah, being ill costs a lot of money. Her parents have assumed the cost of her disease and she has been able to go to private specialists looking for a diagnosis, but she has not received any positive answer: the puzzle of her illness has been difficult to solve. Without knowing what to do, Hannah tries alternative medicine. It seems to be an answer to her pleas because this type of medicine re-charges her energy and creates some peace in her life. However, it is a luxury she cannot afford all the time. A regular visit with her rheumatologist is focused on her body. He does not care what Hannah thinks and feels. Meanwhile, alternative medicine brings to her the possibility to share what her perspectives are about her illness and how she feels. It is not only the time spent with the health professional that makes a difference but also the quality of the time. But sometimes she cannot afford to go there. In fact, sometimes she cannot afford being ill. A medication that is not covered by her insurance company becomes a reason for distress in her life. Her ill body does not understand what the priorities for the insurance company are. She needs the medication immediately. The insurance company has a different order of priorities and all of them are against what Hannah needs to control her disease. And yet she tries to accommodate her body to the circumstances imposed by others. The doctor prescribes the medication and the insurance company wants her to wait until other exams are approved by the medical board. However, pain cannot be put on hold; pain arrests her dreams and life. Hannah cannot suspend her illness until the insurance company has time to attend to her pressing needs. According to her insurance company, Hannah has to wait three months to go to her specialist; if she gets ill in between she has to go to emergency. However, in emergency her condition is just one among many, not a priority. People with chronic illness learn to expect the unexpected in life.

It seems that the unexpected not only includes undesirable symptoms but also the perception and management others give to the situation of chronic illness. People in the insurance company do not know what Hannah is going through when she is ill. She suffers the dismissive attitude of the people in charge of her health and well-being. Her world has been limited by others. People in Hannah's insurance company do not know all of the vicissitudes she has to confront every day with her ill body. And yet they have the control over her. They have the power to dismiss her pain. In the end, Hannah is resigned to her fate. She waits and hopes her body does not betray her during the waiting time. Is there a way out of these situations? How long can she hold on?

> *In some ways I feel discriminated against. I feel the Colombian health system is designed only to care for acute or life threatening diseases but not chronic illnesses. When we have chronic illness we are put on hold. We have to wait more than twenty days for something. Many people in the support group have left their work and everything to take care of their relative with a chronic condition. They are a relief for the health system but the government does not recognize this. How many families are giving up their lives to care for someone with a chronic illness? There is no consideration for us. It does not matter, either, if someone has a physical disability; we all have to go through the same bureaucratic process to get our authorizations for procedures, medications and medical specialists. We all have to line up. There are no considerations. There is abandonment from a government which does not demand quality of service for us. There are some programs to prevent cancer or for people with HIV, but nothing for the rest of the community with chronic conditions. Nobody says, "Let's do something for them," or, "Let's facilitate full access to health care for them." That would be nice. It would ease our lives. It would be nice to be part of the health care system. But sadly, we don't have the same rights as other Colombians.*

> *A few years ago I wanted to change my insurance company due to all the difficulties I have been having with it. So I sent my records to the other insurance company to be studied. But when they learned I was chronically ill, they immediately rejected my application. They did not say, "No," to my face. But I could tell with all the obstacles they put in front of me what they were thinking. If another person wants to change insurance companies there is no problem. People can do it right away, but in my case I was rejected because we are expensive for them. They don't want us. I know I have a chronic condition but it does not mean I don't have a right to have access to health care or to change my insurance company. It is frustrating.*

There is abandonment from a government which does not demand quality of service for us. Hannah lives in Colombia but as a chronic patient she does not enjoy the same rights other Colombians enjoy. The unequal policies of her insurance company have positioned her on the periphery. She recognizes there is discrimination against chronically ill people in Colombia. Etymologically, *chronic* comes from the Greek *khronos, meaning* time, long-lasting, continuous (Skeat, 1963). Insurance companies with all their formalities put chronically ill people on hold, but, ironically and unfortunately, they do not have much time. Hannah tries to speed up the procedures to obtain prompt services but everything seems futile. She does not obtain what she needs. Hannah sees how caregivers alleviate the health system when they take care of a chronically ill relative. But they do not have the support and solidarity of the health system.

People like Hannah get used to the idea of being rejected because of their situation of chronicity. Many caregivers are giving up their lives to care for relatives with chronic illness but they do not receive the support they are supposed to receive. It is hard for someone to be a witness to injustice. Hannah questions how, despite all the suffering and bad things they have to face within the health system, they do not lose their hope. They keep their spirits up. She wonders how they keep smiling despite their being little to smile about. There are many support groups in Colombia for people who are chronically ill but Hannah's disease seems to be one of those diseases known as an orphan disease. For her it is more difficult to find the adequate support she requires to get through the moment of illness. This makes it harder to accept. Hannah feels there is no point to raise her voice because nobody cares about her health condition. She lives with the chronic illness, finding no empathy or sympathy because her illness does not have a name.

Somos un problema para el sistema de salud por todas las cosas que necesitamos. Chronic illness brings instability to people's worlds. There are a lot of struggles for the chronically ill, from the acceptance of the ill body to the difficulties of interacting with others. Chronic illness takes people into an unknown and unfriendly world, a world full of obstacles that are sometimes difficult to overcome. Hannah has experienced unpleasant restrictions in the provision of proper health care. She patiently waits until her insurance company decides what procedures and treatments should be followed. In fact, her insurance company decides the course of her disease. In the following passage, Maria describes how difficult it has been for her husband to obtain some attention from their insurance company. Maria and Alfredo want to know how advanced Alfredo's cancer is. They require knowledge about Alfredo's condition and yet they cannot get it. Different from Hannah, Maria and Alfredo do not wait patiently and they decide to take action to fight for their rights.

> *The only bad experience regarding my disease has been to find out how difficult the access to treatments, medications and medical specialists is for us. We have fought a lot to receive treatments. We have used a lot of resources to get whatever we need. For example, six months ago my husband went to the doctor for a follow up visit where we were expecting to find out how Alfredo's health was but the doctor limited the visit to re-filling Alfredo's prescription of Morphine and nothing else. During the visit he did not look at him or touch him; he just limited his task to transcribing what was written in his chart. So we wondered how my husband's cancer was doing. Another doctor told us we needed to go to this institute specialized in cancer to really know what to expect with Alfredo's cancer. With this information we went back to Alfredo's doctor to request a referral to this institute. Alfredo's doctor said he would do it and send it to the authorization office. The next three months we went back and forth asking for the permission but we always heard the same answer, "Your doctor has not sent us any referral" or "We have your referral but we cannot process your request right now. Come in two weeks to see if we have something ready for you" or "We are processing the referral in the institute but we have not had any answer yet." It was a simple referral to get another opinion and yet we were not allowed to have that opinion. They put a lot of barriers around something simple. Until one day we were so upset that we decided to take action. We went to the CEO's office of our insurance company and sat in his office. We were prepared for a long stay there so we had filled our backpacks with food, a blanket and our medications. We were prepared to stay there for several days until we obtained an answer to our situation. Some of our*

> *friends from the union called the media, so we did some interviews explaining our situation. But when the CEO saw the media, he granted us the referral to the institute right away. Also, the day of the exam the CEO sent exclusively to us six physicians and one ambulance to take my husband over to the institute. Something we were fighting for three months we obtained in three hours.*
>
> *The access to health care has not been easy for us. We have complained too much. We have noticed the discomfort our presence creates in our insurance company. They are not vocal but you perceive that they do not like us. In my case, I needed an ultrasound but all the time I heard, "We are not ready with the referral. Come in three weeks" or "The equipment in the hospital is not working. You have to wait." And I waited until I was tired so I filed a legal right of petition at the Minister of Social Protection and something that I did not get in four months I got it in 4 hours. Today they called me; I had my appointment for tomorrow at 7:30 AM. We still have to fight. We can move but what about the other people with cancer that cannot move or cannot speak out or do not have the knowledge to fight and defend their right to health? We have not received good attention without fighting. We do not know what that is yet.*

Alfredo is hardly acknowledged by the doctor and his actions are limited to re-filling the prescription of painkiller. Alfredo wants to know what is going on with his body. Since the previous November he has been having some recurring pain in his leg and he is also having difficulty walking. Despite this new set of symptoms, his doctor does not pay attention to him. It is difficult to fight against something unknown. Alfredo desperately needs to know what the progression of his disease is. When they do not find any support from his head doctor, another doctor tells them they should request an appointment at a specialized cancer centre. It is the only possibility for Alfredo to know what is happening inside of his body. When his doctor finally attended to Alfredo and Maria's request, the bureaucratic problems with the insurance company began. Their insurance company does not want to grant the authorization for this specialized evaluation. What is a priority for Alfredo and Maria is not for their insurance company. Like Hannah, Maria and Alfredo wait patiently to obtain the authorization. Three months later their patience has gone. They are tired of hearing evasive answers and they decide to take action. For them, this situation is disrespectful because their insurance company is questioning Alfredo's right to health. They are not asking for something extraordinary. They are asking for simple attention that is denied by people who do not know him. They prepare for a sit-in with medications, supplies and the heart to fight for something they are supposed to have as citizens. With the help of the teachers' union the media is called. Through the media they try to create an awareness of the day to day struggles of the chronically ill. They try to awaken solidarity but at the same time they try to intimidate the CEO of their insurance company. Nobody wants bad publicity in this competitive world. Then something that they have been trying to achieve for three months is granted in three hours. Alfredo obtains his referral to the specialized centre after all. The CEO sends an ambulance and six physicians to take Alfredo to the institute.

Maria needs an ultrasound, something simple; however, her insurance company does not grant the service. There are several, and, sometimes, contradictory, excuses. After 4 months of waiting for the service, Maria and Alfredo decide to complain to the Minister of Social Protection. Again, they get what they want through legal actions. What seemed impossible to grant before is readily provided when legal actions are taken to defend a basic human right to health. The battle against chronic illness is not only an internal one but also there are many external struggles that these people have to sort out. There are barriers for some, like Hannah's difficulties, and for others the battle never ends when life is at stake. Being chronically ill in a place in which the human values are not important is difficult and frustrating as Hannah, Maria and Alfredo know. It is overwhelming.

> *My husband had an IV catheter for his morphine which I was in charge of administering. He moved his arm the wrong way and the catheter was dislodged. I was upset because I did not feel comfortable giving him his medication without knowing if the catheter was positioned properly. So we called the insurance company and asked for assistance. They told us they would send us someone in two hours. After four hours a nurse came. Well, we think he was a nurse even though he never introduced himself. He did not bring anything to check on the catheter. Thank God we have some stuff in our home so he could verify the position of the catheter. Once he finished this, he said to me, "This time is free but next time you have to pay for the service." I would like to see a home care program implemented someday. It would be nice if physicians, nurses and even an auditor would come to our home to talk with us if we have questions about our disease, treatment and even if we have complains about the service. That would be great. That would be important for the recovery. Health professionals never have time. Nurses never have time to speak to you. They are always running from one place to another. They say "Hi" or "How are you?" but they barely stop to talk to you. During my chemo, a nurse was in charge of ten or fifteen patients so she was busy all the time. She did not speak to any of us. She was running*

> *connecting IVs, checking our blood pressure. If someone was sick she was right there helping the person. When she came to my stretcher, she asked me, "How is everything going on in here?" I would love to see more interaction but it was not possible because of all of her workload. Consequently, attention is reduced to the necessary. Whether I need to go to the oncologist or breast surgeon they always limit their time to write my prescriptions and say, "You are doing great" without even looking at me or touching me. How does he know? They never ask how I am feeling. They just limit their time to reading my ultrasound or my blood work and that's it.*
>
> *They also tell me to come to see them if I have any concern. Well, that is not true because one day a pimple grew on my breast and I was so concerned that I went to my oncologist's office. My appointment with him was in twenty days but I was worried so I couldn't wait. I went to his office to see him. I was following his advice; after all, that was a concern I had. So I came into his office and talked to his secretary who called him and explained my concern. He told her he would not see me until the day of my appointment. According to him, my request was not life threatening so I could wait. I was scared because it was on the same breast that has cancer. So I insisted but he refused mainly because the insurance company wouldn't pay for the visit. Desperate, I had to go to emergency. In emergency the doctor told me that it was simply a pimple but if the pimple didn't go away in three days I needed to come back. It went away. But they do not stop to consider the constant stress a person with cancer lives with. It is so hard to raise awareness about how you feel.*

Maria and Alfredo's insurance company does not provide home care visits. They have to struggle day to day with their diseases. Alfredo's health is a little more delicate and requires more vigilance of health care professionals; however, they do not have access to any kind of home service. Medication that requires being administrated by trained personnel is left in the hands of Maria. Maria is neither a physician nor a nurse. She is a school psychologist who has been in charge of Alfredo's care; however, there are some things she does not have the knowledge and experience to solve. As a caregiver, she requires a hand to help her through these moments when Alfredo requires professional care. Besides, she also has cancer and she needs someone to take care of her needs too. She does not have the knowledge to administer medications. When she calls the insurance company she is upset because she cannot provide the attention Alfredo needs. Alfredo needs his painkiller immediately but they have to wait four hours to get his catheter checked. The first comment they receive from the health care professional is not his name or who he is but the warning that next time the insurance company will charge for the home visit.

Maria is advised by her oncologist to call him if she has an unexpected symptom. One day a pimple appears on her breast and she is scared. It could be many things but she is worried that it could be the return of her disease. Living with cancer puts the person on guard and any symptom is interpreted as a threat to life. When Maria discovers her pimple, she visits her doctor immediately. When he hears her story, he does not respond to her request. For him this is not an emergency; he is going to see her in twenty days and feels no urgency. If he sees her now he will not be paid by the insurance company so Maria's concern is dismissed. Maria is afraid so she goes to emergency at which a physician assesses her condition. For someone who is chronically ill, every symptom is a threat. There could be more serious cases to attend to in emergency but when chronic illness is the threat, other people's problems seem insignificant and the victim feels that priority must be oriented toward the chronically ill.

Maria dreams of having a more humane service in the future. She recognizes how dehumanizing her insurance company is. Her oncologist limits the consultation to 20 minutes and limits his work to reading the results of her test and says that she is doing great. Without examining her, the physician determines that her condition has improved. How does he really know? Like Hannah, Maria and Alfredo recognize that twenty minutes is not sufficient time to socialize and get to know the health of the patient. The interaction is limited and only oriented toward curing the body.

> *When I was ill I wanted to be with my husband. Alfredo was at home alone and I wanted to be with him so I applied and got my long term disability. The process was quick because again we were changing our insurance company so they wanted to get rid of me. As patients with cancer, we are a problem for our health insurance companies for all the leaves, medications, treatments and specialized care we need. So they did not want to have me there anymore; thus, the best way to get rid of the problem is to approve the pension as soon as possible and pass the problem to the government which is in charge of paying our pensions.*
>
> *The attention in my insurance company is terrible. For me it is hard to understand how our insurance company avoids fulfilling what Law 100 says. I have seen how other people from other companies suffer in silence because they think there are no more options. Probably they do not have the money or the knowledge to fight for their rights. Poor medical attention is a trend being perpetuated among ill people. I have seen a lot of very ill people lining up when they can't even move. We do not receive the proper attention from the government and the insurance companies. The other day I heard in the news that the government is going to*

> *propose a new law that makes patients with my condition pay for their treatment. Insurance companies are not going to cover our treatments. It makes me sad to hear that. Nobody cares for our well being. There is nobody fighting for us. There was a senator who was proposing a law to protect the rights of people with cancer. She had cancer too. She called all the people with cancer to support her project. We tried to enrol ourselves in that project but we did not receive any answer. When she was planning to present it to the congress she died. The person who took her position did not do anything. There is nobody in the government or other institution fighting for us. There is a lot of dehumanization in the health system and the government does not care. We have this label that we are a burden to the health system because of the cost of our treatments. They may not care because cancer means death and we will die soon so why bother to fight for us. We are a waste of money for society. We are nobody. People do not say that out loud but you can feel it. I feel demoralized. Politicians do not speak about us in their political campaigns. They only say something when they have the situation in their lives or their family. It is not only the government or institutions but also places like the union; we worked really hard in our union when we were part of it. We never missed a meeting. We like to be politically involved. When we retired we were retired from the union as well. Being retired from the union means that the right to have protection, a voice or a vote is gone. We do not have any right. Our status with them changed. We go there sometimes for our friends but that is it. We have not received any support from them in our fight. Through time we have learned that our social life changed, our fiends changed. We now have other interests. We like other things. We prefer to be surrounded by people with our same condition. We are part of an association of people with cancer and their families. We love to go there. They have some conferences, they provide some legal advice, and they have some courses in acupuncture, cooking and exercise. It is a different place to meet new people with the same condition. At the end of the road, we are resigned to the situation of abandonment. We fight our battles alone. That is the reality of life; we just have to get used to it.*

There is nobody fighting for us. Like Hannah, Maria finds it hard to go against the flow. She knows there are no people fighting for her in the government. Maria, Alfredo and Hannah are alone in their fights against a health system oriented toward neoliberal policies of competence, individualism and consumerism. The only person in the government who would fight for people with cancer died of cancer. They seem to be alone despite that the number of people with chronic disease is increasing in the country. Maria likes to be politically active. And yet she has seen that once they received their pension the support of the union was gone. They are not protected by them anymore. It seems that they have lost their right to participate in society. Like Hannah, Maria and Alfredo are marginalized. Their space has been limited by others. Their bodies are not the able bodies anymore so the value of being productive is gone. However, Maria and Alfredo have found the association of cancer, a private institution, has helped them to overcome their marginalization. This place provides a new beginning for them, a wide horizon to look at. New friends in the same condition help them to overcome the marginalization they are suffering day to day.

Alfredo

> *My only complaint is with the health system. I think the health system is not prepared to attend to people with conditions like mine. The service in my insurance company is bad not only for people like me with cancer but with other conditions like diabetes, AIDS and hypertension. For our health insurance company we are high maintenance people. So they restraint us from receiving quality services such as referrals to medical specialists, treatments, procedures and diagnostic tests on time. Before my wife's diagnostic surgery we met with her doctor who suggested a specialized test called "localization of sentinel lumps." According to the physician, my wife needed this procedure to avoid a radical mastectomy. The doctor told us the procedure was not covered by our insurance company. In the anguish of the moment we did not stop to think about anything or question anything because her well being was at stake. We paid one million pesos to the doctor for that procedure. One day in our insurance company we talked with this woman who was going to have the same procedure. She told us she was waiting for her authorization. So we went right away to the authorization office in our insurance company and asked if the procedure was covered by the company. It was and the doctor did not say a word. We went to the doctor's office and talked to him about it. We were astonished by his answer, "Most of patients' insurance companies do not cover this procedure. So I thought your company was the same." We had to fight this legally and two years later we received our devaluated money back--but at least we got it. We always have to complain everywhere. At least we can guarantee our service but what happens with other people with cancer or other conditions who keep quiet? What if they do not have insurance? What would happen to them? They may die. What else would they do? If you do not have money or an insurance company, death becomes the only option for these people. We have seen people let insurance companies' employees or physicians take advantage of them or abuse them. What for? We are paying. It is our right. You hear them saying, "It is the way life is." With my wife we fight for our rights. We do not tolerate abuse because we are paying. We fight until we will be defeated on the battlefield. We love to be politically involved. We fight for good health and good services. We are fighting for our fundamental rights as citizens.*
>
> *Yet, my relationship with health personnel has been good. During these eight years with cancer I have found nice people. They are not the ones to blame for the policies of the health system. They are just employees of*

> *the place. I did have to fight for one of my physicians once when he had many problems with the administrative board in the insurance company and he even was almost suspended because he prescribed good, expensive medicine for me. He had a lot of issues for that. The board even considered replacing him. But I did not want to tolerate that so I wrote a support letter for him and he won. He is still working with the insurance company. I feel the insurance companies are merely businesses that do not really care about people. What to expect otherwise, though? If our government does not care for our well being either, what should we expect from other entities? There have not been any politicians ready to fight for our rights. We are alone. We knew about this woman, a senator fighting to create a law to protect our rights in the health system. She was calling people with cancer and their relatives to promote this law. We wanted to participate and we called but we received no answer; it must be when she got really ill and died.*

For our health insurance company we are high maintenance people. Maria and Alfredo work as a team. They know each other's issues with the health care system. Alfredo is a lawyer so for him it is easier to fight for his rights; he also knows what legal means are available for them. He has first-hand knowledge of how unfair the health care system is for people with chronic conditions. It is not easy to fulfill his needs in terms of health because a simple request for an exam, procedure or medication becomes complicated. Fighting against their insurance company takes time away from caring for their ill bodies.

Different from Hannah, Alfredo and Maria have no patience when it is necessary to take action against the marginalization and discrimination they are exposed to. They live on the margins but they fight fiercely to ensure that they get respect for their space as citizens. Alfredo knows it is unfair for health as a human right to be proclaimed when in reality they have been exposed to dehumanized services. He recognizes they are not alone in their fight: many people living with other chronic conditions have to face the same depersonalization. As a team, Maria and Alfredo live their stories together. They have each other but they wonder what happens when people do not fight or do not have the knowledge to fight. Hannah must be patience and resigned despite that her condition could kill her. It seems that resignation and passiveness only bring more devastating physical consequences for chronically ill people. Alfredo battles against time. He wants more time to be with his wife and daughters but it seems impossible when the answer to his pleas do not have the support the health system should guarantee.

When Maria and Alfredo learn she has cancer too, their world falls apart. They try to survive as a couple and handle the vicissitudes of day to day living. Maria's doctor tells them she needs to have a diagnostic test to guarantee she does not end up with a radical mastectomy. Her doctor tells them the procedure is not covered by the insurance company so they pay out of their own pocket in the attempt to save Maria's breast. They do not stop to think of the pros and cons of their situation. When life is threatened people do not stop to think if their actions or decisions are the right ones. Maria undergoes the test. Later, at their insurance company, they learn that the procedure is covered by the insurance and ultimately they are reimbursed. However, nothing has been easy for this couple. Besides living with the impact of being chronically ill, they also have to overcome the barriers to access services for them. How much do these fights affect their ill bodies? It is not easy for them. The pressures they have to endure everyday are undermining the vitality of their beings. They are tired of fighting. Things should be easy for people who are chronically ill. On the contrary, the place they are in is rough. Is it possible to heal the body inhabiting a marginalized space full of discrimination? How does one deal with that kind of situation?

Alfredo even has to defend one of his doctors against the insurance company. This doctor dares to prescribe expensive treatments for him. For Alfredo, insurance companies are profit driven businesses in which quality is sacrificed for quantity. For Hannah, Alfredo and Maria most of the fault falls into the hands of the government. The Colombian government has not paid any attention to the conditions of chronically ill people. There are neither politicians nor laws that protect them against the abuse inflicted by health insurance companies. Politicians only care when they are personally affected by chronicity; otherwise, the fight against injustice falls on each person affected by chronic illness. Maria and Alfredo belong to the cancer association; however, this group does not interfere in politics mainly because they receive money from outside of the country. They feel marginalized because there are no politicians, laws, associations or advocacy groups that represent their interests and urgent needs in society.

Alejandro

> *In December 2005, when I got my stroke, we went to the hospital. In the hospital my son-in-law and my son helped me to go to the bathroom.*

They lifted me up and carried me to the bathroom because in Emergency everything was a disaster, a complete mess. The attention was terrible for everybody. If I needed a bedpan the nurses responded, "Wait, wait I'm busy." If my IV was not working the nurses would say, "Wait, wait we are busy." Really there was nobody to help me with anything. For example, if I needed to go to the bathroom or anything I always had to wait for my family. I spent three days in emergency in a stretcher with no blanket. I was lucky because other people were in wheelchairs and you could tell they were really sick. It was uncomfortable. Sometimes I am scared to get sick and have to go back to that place. I don't even want to think about it. After three days of IV and some medications they sent me to another hospital for rehabilitation. They sent me to this place because the emergency doctors found in one of the tests a clot in my head. I was so worried. I didn't want to be crippled. I wanted my health back. I wanted to walk again. So I went to therapy where they taught me how to write, speak, read and walk again. With patience and dedication I improved day by day. Today, I still I have some problems with my leg but not as bad as that time.

After my stroke I had my heart attack. When my daughter saw me gasping for air, she said, "Dad, we are going to the hospital now." In emergency, my wife, who knows all about my medications and treatments, was left outside. I don't and didn't know what medications I am taking and was taking. When the doctor came and started to ask me about my medications I couldn't respond. He was mad at me. He said I should bring a prescription with me all the time. It was not a big deal because when my wife came in she gave him all the information. I cannot complain about the attention in the hospital because I had food, shelter and the nurses were good to me because I was a good patient. I never complained of anything. If you are not nice to doctors and nurses they are not going to be nice to you. So you have to behave in the hospital. Every day I greeted them all the time saying, "Good morning," or "Good afternoon," and they were really nice to me. They like me because I was nice to them.

During the time of this hospitalization, doctors did not pay attention to my sugar levels. I didn't ask either. I thought everything was okay. So when I went home I saw this brown scab under my foot. It was like a mole. My wife tried to cut it with a nail clipper but it was painful. So I went to the doctor because one of the things that I learned from my podologist was to take care of my feet. When the doctor saw me, he said, "It is nothing," and I believed him. Despite the pain I believed him. My brown scab didn't grow. But it became almost black, so I went to the doctor again, and again I was told it was fine. In my hospitalization my sugar level was never tested. When the black color advanced over my second toe I went to the doctor again and this time the doctor sent me for a sugar test that reported 400. My sugar was out of control. Immediately, she sent me for an X-ray which showed that my toe was dead. There was a lot of damage in my bone so there was nothing they could do to save my toe. The doctor told me, "If we don't amputate the toe now, later we will have to amputate your food. It is your call." I was in shock, astonished. Suddenly I had this cold feeling running all over my

> *body. I was feeling anguish but I know that I cannot cry over spilled milk so I decided to have my toe removed to save my foot. Before they cut my toe they sent me to this psychiatrist to talk to me and he asked me, "How do you feel?" "I feel calm because there is no easy solution for me now, cut the toe or not there is no easy way out. This could be God's test of my faith so there is no room for arrogance," I said. He did not say anything else. I have no feelings of rage for my fate. Really, I have not felt anything; I just stay calm and keep what I think to myself. Yeah. I miss many things of my past life, the freedom to move from one place to another. I miss my life of freedom but nobody knows about this because I have learnt to keep all this to myself. How many times have I told the doctor I could not sleep because of the pressure of the sheet and the blankets over my toe? How many times could I not walk and how many times did I have to wear flip flops because I could not wear shoes. Now, I continue with pain in my foot and I'm scared of losing my other toes or even my foot. I still cannot walk with shoes. At home I wear flip flops all the time but they are not good either. They are so thin that even the smallest pebble bothers my foot. I am so sensitive with my foot now. I wear shoes when I go to the physician's office. Those days I just tried to put away my pain.*

Clara's voice

> *We have had a lot of problems with the authorization of treatments. For example, after the amputation he was supposed to have a follow up with the surgeon but instead they sent him to the insurance company to be seen there by the doctors. In the insurance company they told me the doctors in the hospital were in charge of his follow up the first month. In the hospital they said they need a referral from the insurance company for the follow up. So I am the one going back and forth from the hospital to the insurance company trying to find a solution. The first month has long gone and nobody has seen him yet. I have to go again to talk to the nurse in the orthopaedics floor and see if she can help me. But that's not all. Before his surgery he needed to set a time with cardiology to see if he was okay to go through surgery. I passed the referral to authorizations but we got the appointment after his surgery. So I told the secretary, "My husband already had the surgery. We don't need this appointment now" and she said, "He was scheduled to see the cardiologist no matter what so he needs to go." They don't really get what is a priority for a patient. I am the one in charge of his medication and also to do all these errands but it is hard. It is hard to line up for hours to get an authorization. It is hard to go to the insurance company for medication and find out they have run out of it. It is hard to wait three months to get an exam. The priorities are the priorities of the company; my husband's priorities are not important.*

Alejandro's voice

> *As you can see, my wife is in charge of everything here. She knows the name of the medication I am taking. She has to go and line up for me. She has to set my appointments with my doctors. She has to do everything. To go to the doctor is expensive if you take into account all the money in transportation, plus, for example, going to pick up*

> *medication at the insurance company. It cost me around $35,000 pesos*[2] *including a round trip by taxi, and buying the medication. And sometimes if you are unlucky they run out of medications so you have to go back again, but if you go to the drugstore one block from here and pay out of your pocket the medication cost you $2,500 or $1,000 pesos. For me it is cheaper to go here and avoid the stress of going far away for the medication. Going to the doctor is expensive. Everything is expensive if you go to the Diabetics Association. The first visit costs $160,000 pesos, the follow up costs $20,000 pesos and the medication is expensive as well. And I am not including the expenses for transportation. I would like to be part of a cheaper program. I would like to be part of a Diabetic or Hypertension program but there is nothing in my insurance company. I am not begging for economic support. I just need a place to go and speak about my disease; I would love to receive some advice and talk to people with the same condition. I feel marginalized. But there is no one to give me any advice or help with my morale. I need someone to take care of me. Society doesn't give a damn for us, nobody really. If you want to have good attention you have to pay. For example, my doctor told me I needed someone to clean my foot after my surgery; he also said the nurse would explain to me how to do it. Later, when the nurse came, she took off the bandage, applied some petroleum jelly and then re-dressed it. That was my cleaning. When I was discharged, the same nurse explained to my wife that my wound only needed water and soap. We don't have the education but we thought she was wrong. After a while we have noticed my foot had not improved. Nobody really cares. The other day I went to the doctor's office and he said to me, "The partner does not look good." It was my other toe becoming brown. He did the cleaning this time and he put some Iodine on it. That was it. So I might lose my other toe. I would like to have a place to go to and I don't even care how much I spend on taxis, just a place where someone can help me save my foot, but there is nobody for me.*

Society doesn't give a damn for us. Alejandro tries to be a good patient; he greets his health care professionals and follows all the rules and recommendations given to him. And yet he receives poor attention during his hospitalizations. Sadly, this strategy of being a good patient does not seem to work, especially when he tries to survive the advances of his diseases. Physicians and nurses do not pay attention to his claims but he does not complain. He keeps quite because he does not want to jeopardize his treatment. He waits for his sons to help him to go to the bathroom or to cover all his needs. Emergency is in chaos. There is nobody to ask for help. Alejandro has to wait until someone compassionate decides to help him. Alejandro has relegated his care and responsibility of his treatment to his wife. He does not know what medication he

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[2] On 15 Feb 2011, 1.00 Canadian dollar(s) = 1,926.78 Colombian peso(s), at an exchange rate of 1,926.78

is taking. So when the doctor asks him, he cannot respond. The doctor is mad at him but as always Alejandro keeps a calm attitude. He is trying to be polite, to be a good patient. He needs the attention of nurses and doctors but he does not want them to be mad at him because he needs them.

Despite his paying for his health care Alejandro considers it a favour he has to earn. He wants his doctors and nurses to like him so he behaves well and greets them when it is necessary. Being ill, he needs the care and attention of others. Consequently, there is submission in Alejandro's voice. He wants the best for him and the best for him perhaps means tolerating and accepting the dismissive treatment by health care professionals. Different from Alfredo and Maria, Alejandro gives up his space to others. He does not fight because fighting to him means not to have care.

Alejandro does not complain and the results are disastrous for his health. His sugar levels are not evaluated and he loses one of his toes. When he went to the doctor to check his feet he was told that everything was okay. He trusts them. Something that could be prevented has not received the proper attention and now he has to live with the consequences. He is sad thinking about how much time he has lost going to the doctor without receiving adequate care. He does not pay attention to his body, and, having faith in his doctors, he believes what they say to him. Alejandro keeps his suffering and pain to himself and despite his apparent calmness he is scared he could lose his foot. Thus, being a docile and compliant patient has not helped him. It would seem that when life is at stake there is no room for politeness.

Alejandro's wife, his caregiver, has another perspective on his disease. She recognizes that the treatment she is receiving from the insurance company and the hospital is unfair. It is difficult to see how paper work affects the quality of life and health of Alejandro. There is no one who can properly take care of his wound. She is worried. She lines up for him. She waits for him. She fights for him. Time is passing by and neither the insurance nor the hospital has taken care of Alejandro's follow up. As caregiver, she knows it is not right to let patients wait one month for an appointment. She is the one who has to face the negatives and the vicissitudes of his disease. Like Hannah, she cannot do anything; she just waits until others define which institution is in charge of Alejandro's health.

He recognizes that he does not have any knowledge about his condition, but, like Hannah, he is very aware of how expensive it is to be chronically ill. Being a part of an association or group costs a lot for him. He needs something affordable. Alejandro wants to belong to a group in which he could share with others with the same condition. Hannah's disease does not have a name so she does not have any group to be part of. Alejandro has diabetes and hypertension and yet for him it is absolutely impossible to find a place where he can go to share his problems with others. He remains in solitude. He struggles to socialize with other people because of his illness but also he struggles because others do not understand his problems. It does not help that he is incommunicative. Like Hannah and Maria and Alfredo, Alejandro dreams of a place where he can go and share his story. He likes to share with other people. In fact, socializing with others is one of the things chronic illness has taken away from his life. He stays at home waiting for someone to help him and keeps all of his suffering to himself. There is no place for him in society and he feels marginalized. He is alone and in a situation that is out of control. Hannah, Maria, Alfredo and Alejandro claim their position in society. Alejandro needs someone to take care of him. He is at risk to lose his other toes. His wife does not receive adequate information about how to take care of his wound. He is neglected by the health system and health care professionals. His strategy of being a good patient has not helped him at all. He is afraid for his health and, despite the urgency of his situation; attention to his needs is always delayed. Like the others, his health does not seem to be important to his insurance company. He has to accommodate his disease and symptoms to the schedules of his insurance company.

Camille

> *The change has been radical. For example, every day I wake up at 10:00 AM, have breakfast, feed my sister's cat and dog, take a shower, clean the bathroom and then I go out to the terrace and stay there watching the green of the mountains or on a windy day I like to watch how the trees move with the wind and when I hear the birds I feel free. In those moments I like to take a deep breath and enjoy the place where I am. Sometimes I look at my watch and think that at this time in the office I would be running from one side to the other trying to finish most of my work. In the office, I was always in a rush. Now I have a space; my space is bigger and it is just for me. In the office my space was limited by four walls. Here there is no limit. At 10:00 AM I can be in any place. It is wonderful to have this freedom. The meaning of life changed. What seemed important in the past takes a second or third place. For my job I*

> *used to buy a lot of clothes, jewellery, scarves and shoes. They were filling the three rooms I have in my house. When my sister moved in, she put all these things in boxes in one room and told me, "You should choose what you want to keep and what you want to donate." For a long time I was not able to open that room or those boxes. I did not want to look back at my old life, so I told her, "Choose for me please. The only things I want to keep are the three scarves my mother left me before she died. You can do whatever you want with the other stuff." So she did; she donated almost everything. My jewellery was the only thing she did not donate but I don't want it. I don't need them. The only rings I like to use are these two, one I found on the street one day while I was coming home and the other one was a birthday gift. I liked them because they are neither expensive nor fancy. They are simple.*

My space is bigger and it is just for me. Cancer has brought a drastic change in Camille's life. She does not live in a rush anymore. She feels free. Before her disease, she was controlled by many rules. Camille was living under the pressures of the modern world. Her work was the most important thing in her life. She now has the freedom to stay in any place at any time. This is the time to look after herself. There is limit in neither her space nor her time. Her disease has lifted her up and taken away the burden of work. Despite her disease, her life has lightened in important ways. This is the time to understand and take advantage of this second opportunity in life. Once the priorities of life change, Camille becomes owner of her space and time. She does not need to work more overtime to fulfill the requirements of her demanding boss. Her space becomes peaceful, a space that satisfies the demands of her ill body. Camille's space in the office is limited by four walls; in that place there is no time to waste or take a breath. The only time available is to produce. Once Camille recovers the ownership of her space what seems important before lost its meaning.

> *I experience preferential treatment when I go to request authorizations for medications, treatments and specialists. For example, the other day one of my authorizations for a test expired and I did not want to go to the doctor again to ask for a new one. So I went to the authorization office and explained to the clerk. She responded nicely, "Normally we don't do that but I see this is really important for you, so I will grant the test for you. But don't tell anybody about it." Wherever I go people are always nice to me. Probably my attitude helps me to receive that kind of attention all the time. So for me I am really grateful for my health insurance company. They have helped me a lot. They also have a support group for people with breast cancer. If I need special tests or medication they go through the normal process of being authorized by the medical board but the wait it is never long. My requests are granted right away. But nobody knows how expensive my illness is. My only concern is*

> *economic. I do have a lot of economic issues. I have not received my long term disability yet so I am still receiving half of my wage every month. The money I receive does not help me with anything extra. I am still paying the mortgage of my house; also, I have to consider transportation and the extra I have to spend going to the doctor, specialists, and tests or to get medications. I have a lot of expenses to cover; my financial situation is upside down. A few months ago I applied for my long term disability. They ranked my disability at 60 percent so I may receive only 60 percent of my pension. I have to wait one year to get it. At least that's something because what I am receiving right now does not cover all my expenses. So it does produce a little anguish and despair. In the end, I leave everything in God's hands. I cannot speed the process so what is the point of worrying about it? My other expenses are covered by my sister so I don't have anything to call mine until I receive my long term disability. Thank God my insurance company covers absolutely everything in terms of treatments and specialists. When I had my fracture in my ribs they covered the corset I needed to use. I passed my authorization into the medical board of my health insurance company and the corset was granted in one week. Perhaps I have not had any problems with my insurance company because I am a palliative patient; I am dying so for me everything has to be done quickly.*

Camille likes her insurance company because she has not had any problems with them. They have given her preferential treatment, treatment that is different from the other participants. She is happy with the attention she has been receiving and she has a support group she loves to be involved in. She does not experience the same rejection as Hannah, Maria, Alfredo and Alejandro. On the contrary, kindness was shown when her authorization expired and she did not need to go back to the doctor. What seems impossible for the others, for her is easier. She attributes her preferential treatment to her condition but Alfredo, Maria, Hannah and Alejandro also have conditions threatening their lives. Her not having to wait makes it easier for her to live with cancer. However, despite that her insurance company covers most of her treatments; cancer is still an expensive situation for her. Camille does not have the means to survive alone. Right now she is receiving half of her wage and she has to use all of that money to pay for her mortgage and her illness, causing many difficulties for her. Camille's sister is in charge of assisting her with the house's expenses. She needs to receive her long term disability but, unlike Alfredo and Maria, she has not received it yet. She has to wait one year to obtain it and despite her disability she may receive only sixty percent. For her, it does not do much but at least it will bring some relief for her. Her financial condition creates a little anguish and despair but there is little she can do. It is hard but Camille is not overwhelmed by the situation. She leaves her fate in God hands.

> *In the end people in the government don't care about us. The only person who cared was this senator. She had breast cancer as well, but she died and her replacement did not do anything for us; that person doesn't have the motivation that someone with cancer has. The intention of the senator was to create a law that protects the rights of people with cancer, to defend our rights and to be considered as human beings in the health care system. She wanted to guarantee access to medications and treatment and medical specialists for us. She wanted to give us back our position in society. Sometimes if you have cancer you cannot access bank credit, or even if you are in remission, like one of my friends, you cannot adopt a child. The attitude is that if you have cancer you are going to die soon, so there is no point in helping someone who is dying. There is a lot of stigmatization and this senator was fighting against that but when she died that was the end of her proposal. It is understandable that there is a difference between going through the whole experience like we do and just being aware of it. The replacement senator and the nurses are outside of the cancer experiences. I recognize how much knowledge nurses have about cancer, how much experience they have with the disease, but that is not even close to what we are going through. Nobody knows what it is to live with cancer until he or she has it.*

In Camille's space there is hope but also there is concern about what the future holds for her. Her concern is rooted in the idea that the government does not care about people with cancer. For her there are no politicians fighting for people with cancer. They are alone in their battle and they have to live from day to day in solitude. For her, the journey has not been difficult because she has the support of her insurance company, family and friends. Despite her cancer, her life has opened a new world of opportunities to her. She feels the conditions for people with cancer are not good in Colombia. For her the only person fighting for their right was a Senator who died from breast cancer. For a brief moment this Senator turned the eyes of society to the lack of rights and to the discrimination of people with cancer. When she died her ideas and political projects died with her. Camille feels that this is normal, because most people outside the condition of cancer do not really understand what living with cancer is for a human being. The comprehension of this condition comes when one lives the situation. To understand the space of chronic illness it is necessary to inhabit that space.

There is a lot of stigmatization for people with cancer. One of Camille's friends could not adopt a baby because she had cancer. As well, once one has cancer the stigma prevails. The stigma is always there even when the situation has been long gone. Camille feels that society thinks there is no point in easing the life of someone who lives with a chronic condition. Life has changed and now productivity has to be preserved: there is no space for someone who does not fulfill the requirements of productivity. They do not have social participation; they have to live on the margins of society, trying to survive. It is hard to be alone or to have nobody fighting to obtain the urgent needs of people with chronic illness.

The Space of Chronic Illness

Lived space is the place in which human beings move and find themselves at home. Space is more than the geographical and mathematical place we find ourselves in. According to Merleau-Ponty (2005), being in the world means existing in a reciprocal and communicative relationship with the world. We become the space we are in (van Manen, 1997 p.102). What is the space of someone who is chronically ill? Who is in charge of defining the space of chronic illness? Is it possible to own one's space when access to treatments, specialists and medications is restrained? Chronic illness has a profound impact on people's lives and creates much grief in response to the losses it imposes. Sometimes with chronic illness there is a great variety of life interruptions and changes. Illness is erratic and unpredictable and requires constant readjusting to the unexpected changes in personal, professional and social lives. Visits to doctors and having tests to guide treatments are frequently part of what it takes to live with chronic illness. Therefore, a stronger support from the health care system makes it easier to overcome the unexpected situations that come along with chronic illness. However, when the health system's orientation is not supporting the needs of chronically ill people, life becomes overwhelming.

By acting upon reality, human beings seek to improve their lives to "become more fully human" (Freire, 2002, p.41) and flourish. However, for Freire, not all people are free to pursue their "ontological vocation" (Freire, 1973, p. ix), and for oppressed people, freedom in the sense of a human being's ability to choose a course of actions toward happiness is hardly an option. For instance, Hannah, Maria, Alfredo, Camille and Alejandro do not have an opportunity to control their access to health care, and the only thing that can be controlled in chronic illness falls in the hands of the employees of their insurance company.

They do not have freedom to select the courses of treatment for their illnesses and the health care system constrains their ability to pursue happiness. According to Freire (1973), human beings are free "in theory" but in reality society excludes them from realizing their freedom. Then, for the participants, being chronically ill positions them on the margins of society. It is a place where they have very little voice and no vote; they just try to fit within society with the small resources they have. It is hard and requires time and courage to regain some of their freedom. Maria and Alfredo have developed survival strategies to recover their freedom. They may also have personal characteristics that enhance their chances of successful development, health maintenance and recovery despite all of the constraints of the health care system (Hall et al., 1994). They have integrated into society. For Freire, integration requires not only the ability to adapt oneself to reality but also it involves the critical capacity to make choices and transform reality. Maria and Alfredo have integrated into society by fighting through legal means. They are politically active. Camille at this point in her illness trajectory does not have to do anything: she has not had any problems integrating herself into society. Alejandro and Hannah do not have the same resilience. Despite Alejandro's playing the good patient to avoid upsetting health care professionals, his strategy leaves him with a lot of health care problems. He is at risk to lose his foot, but he does not complain. The quality of attention depends on the roles people with chronic illness take during the course of treatment. Hannah and Alejandro have adapted their chronic condition to the schedules for treatments and procedures given by their health insurance company. They do not fight back even when their health and well being are at stake. Hannah and Alejandro have always attempted to overcome the factors which constantly oppress their full humanity. Camille feels the economic pressure her condition creates. Despite her insurance company's covering everything for her, there are other expenses that she needs to meet but cannot because she is receiving only half of her wage. Life becomes hard when the financially independent woman needs the economic support of her sister in order to survive. Maria, Alfredo and Alejandro do not have economic constrains; they live without restrictions with their pension. Hannah's parents are in charge of subsidizing her chronic condition. She feels the financial pressure her condition has imposed on her parents. She deals with the fact that alternative treatments for her pain are expensive and cannot be constantly provided. On the other hand, politically, none of them feels represented in the government. There are no laws to protect them against the abuse inflicted by the insurance companies. Colombian society has not been friendly toward them.

Having chronic illnesses restrains their lives; there are no politicians, associations or advocates to support their urgent needs; they are fighting alone to obtain access to health care that should be considered as a basic human right. These economic, social, political, and cultural norms, structures and institutions shape their human existence. Health insurance companies in Colombia and the government have shaped and perpetuated the marginalization of chronically ill people. Structures of certain societies are founded on relations of exploitation of certain groups of individuals by others. Freire calls this adaptation, which implies the loss of the ability to make choices. When adapted people are subjected to others' decisions, their will is not their own because it is the result of external prescriptions and structures. Adapted people like Hannah and Alejandro are no longer integrated into society: they adapt their lives to the impositions of their insurance company. The integrated person is a person as subject. In contrast, the adaptive person is person as object (Freire, 1973). Thus, participants swing back and forth between integration and adaptation to society. Being chronically ill does not make it easy for them to be active participants in society. Why? Perhaps it is because sometimes people do not have the confidence to "reflect upon the world" (Freire, 2002, p.83) and develop their own agenda for change. Or it is because the health system approaches chronic illnesses as catastrophic conditions. Etymologically, the word catastrophe has the meaning of an overturning event or sudden disaster (Skeat, 1963). Being chronically ill, then, carries the perception of a close world, a limiting situation impossible to live with and in which death is the only possibility. This perception of chronic illness as catastrophic or a tragic event has kept people like Hannah, Alejandro, Alfredo, Maria and Camille in the periphery of the Colombian society. A being from the periphery described by the center becomes nonbeing with a catastrophic condition (Dussel, 1980). The inability of people to participate in societal decision making is called massification (Freire, 1973). According to Freire, a massified society leads to dehumanization and keeps groups of people in society unthinking and unreflective of their conditions. Massification is the opposite of conscientizacao, which is the process of acquiring critical thinking. People like Hannah, Camille, Alfredo, Alejandro and Maria may be unaware that despite that their health condition is permanent, realities such as discrimination, oppression and health illiteracy are not permanent facts, but results, rather, from the operation of unjust structures and mechanisms in society which, once understood, can be changed. Should we as health care professionals allow the exclusion of the chronically ill from policies, health systems and society? Is the indifference toward the chronically ill ethically correct?

The Colombian health care system promotes universality; under this principle, all citizens are provided with preventive and curative care. Universality is an admirable principle; however, in reality, people like Hannah, Maria, Alfredo and Alejandro have to face restrictions and sometimes a lack of access to health care. For the chronically ill, the Colombian health systems is a mirror of how as human beings we reduce one another to numbers, statistics, body assessments, evaluations, registers and pathologies, all of which affect the social body for the sake of economic profit. Hannah, Alejandro, Alfredo, Maria and Camille share the commonality of marginalization and stigmatization. As well, their chronic illnesses bring social, financial and political instability into their lives. The rigid policies and structures of the health care system have violently transgressed the space of Hannah, Alejandro, Maria and Alfredo. The restriction is felt deeply when other people are in charge of defining what a priority in chronic illness is. The authorization of tests, medications, treatments and access to specialist are left in the hands of rigid structures which dehumanize and depersonalize them as human beings. The way the health system is organized promotes efficiency only, leaving outside the other eight principles the law promotes. Based on the experiences of people from this study we can say that the Colombian government does not provide equal access to health care for chronically ill people. For Maria, Hannah, Alfredo, Alejandro and Camille, home becomes the only space in which they can freely reflect on the unfair treatment they receive on a daily basis. Home represents a “site of resistance” (Hooks, 1990, p42) in which they can freely confront indifference imposed by a health system. Home is the place to learn about dignity of person, integrity of being and value of faith. With their family they find the comfort and support necessary to overcome the difficulties and indifference imposed by a neoliberal driven health care system.

Why do people like Hannah, Alejandro, Alfredo, Maria and Camille have to face indifference within the health care system? Is it because the financial investment from the government on health is not enough? According to Browne and Tarlier (2008), it does not matter how much a country invests in health, the overall health of a population will not change if the root causes of health are unattended. In Colombia, the expenditure for health has increased through time. For example, in 1999 the general expenditure on health was 6.1%. In 2003, the general government expenditure on health accounted for 18% of total government expenditures and for 85% of total health expenditures. Total expenditures on health were 7.8% of gross domestic product or US$ 13.4 billion, in which 4.7% corresponded to the private sector and 3.1% to the public sector (Ministerio de Proteccion Social, 2008). Financially, health has received more attention from the government; however, despite the amount of resources for health, indicators of inequity have not really changed. For instances, the Gini coefficient which refers to equality in which 0 represents absolute equality and 1 absolute inequality (UN, 2009), in 1999, it was 0.53, followed by 0.55 in 2006 and 0.58 in 2009. In terms of life expectancy at birth, in 1999, it was 70.4, and infant mortality was 25 per 1,000 live births (UN, 1999). In 2009, life expectancy was 72.7 years, and infant mortality was 17.5 per 1,000 live births (UN, 2009). The indicators show there has been some improvement; however, these are not mere neutral indicators of health and well-being for any population (Browne *et al.,* 2008). Rather they are a reflection of how the social determinants of health such as education, employment status, income level, housing, nutrition and access to health services affect the ability of people to live well and flourish (Raphael, 2006).

Acting on social health inequalities is a difficult task. There are good reasons to consider why much of the debate over health care justice around the world remains focused on the lack of access to health care services, inadequate health insurance coverage, and shortage of health care professionals in rural areas. Health, as a part of economic, social and political forces, is not only a benefit of development but also plays a key role in achieving development. Due to the establishment of global markets and global trading systems, the provision of proper health care has been involved in serious implications for its participation in world trade (Ollila, 2005). Health care has been seriously changed by capitalism and exhibits some of its characteristics such as being asymmetrical, competitive, dehumanized and profit seeking. If health and life are human rights, why are human beings worldwide exposed to disparities that affect their rights to health, life and well-being? An awareness of and sensitivity to social conditions are crucial to understanding the health status of populations (Dahlgren & Whitehead, 2006). Health status follows a gradient in which people with lower socio-economic circumstances are more likely to have poorer physical and mental health outcomes than those at higher socio-economic levels (Butler-Jones, 2008). However, the unequal distribution of health care resources affects people's lives and their freedom. Reducing health inequities is a matter of fairness and social justice (Marmot, 2010). To deal with unfairness and injustice, it is necessary to attend to the underlying societal causes of disparities. Hence, national responses toward social determinants of health must be rooted in ethical values and principles to avoid exploitation and marginalization of vulnerable people. Social justice affects the way people live, as well as their risks for illness and premature death (CSDH, 2008).

Today, not only globalization exists as a threat for the health of those for whom nurses care, but also it is a threat to nursing as a profession itself. Due to the implementation of the health reform, Colombia has moved its health care system from promotion and prevention to institutional services—that is, hospital based care. In the last 20 years little involvement has been seen in primary health care. Despite that Law 100 encourages the promotion and prevention of health through the Basic Care Plan, private providers of health care do not promote those values, mainly because community work is not as profitable as hospital care (Malvárez & Castrillon, 2005). Today, private investors in charge of primary health care have denied the home care visits, and the alliances between health care professionals and community groups have been reduced to only epidemiological surveillance. Nevertheless, primary health nurses claim more professional autonomy than clinical nurses. Through establishment of education, nursing care and nursing programs create bonds and interaction with the people they care for. Different from primary health care, hospital based care has imposed on nursing professionals new responsibilities in service and cost management. It means that nursing care has been relegated to administrative and clerical tasks and the responsibility for nursing care has been delegated to less prepared and less trained personnel (Jaramillo Echeverry et al., 2004; Pico Merchan et al., 2005). Due to the reduction of costs, nurses have been forced to undertake more work with less auxiliary staff. Work in hospital settings is recognized as demanding both physically and mentally. Shortages in human resources, supplies and equipment in the old public hospitals only increase the exposure to emotional stress and fatigue for nurses. Nurses also perceive that the social value of the profession is less appreciated and recognized by society, a situation that has caused many nurses to resign.

Before the health reform, the Nation was the main employer in public institutions. Nurses were well paid. But after the health reform, a movement of nurses toward the private sector began (Guevara & Mendias, 2002). Today, in Colombia, nurses need to be more productive with less salary. Work conditions are not the best for them: the average salary is US $400-700 per month plus social and salary benefits, while it is 30% less for nursing auxiliaries (Malvárez & Castrillón, 2005). However, there has been a proliferation of temporary positions with low salaries and intermittent social security. These temporary positions have obliged nurses to hold two or three different jobs at the same time. Also, newly graduated professionals were forced to join employment agencies as intermediaries of employment with the health care institutions. These agencies were highly criticized mainly because reducing costs for health care institutions brought exploitation of health care professionals. Most of these agencies kept their employees without legal benefits and with lower salaries than the minimum wage permitted by the government. In Colombia, quality has been exchanged for quantity and the eventual result is a health care system that is seen as a market with goals that focus on supply, demand and competition, thereby reducing the patient to being a mere consumer. Today, worldwide, we dehumanize and exploit each other for the sake of economic profit and technological advantage. In some sense, there is no place for respect or ethical values, neither for self nor for the other. Both respect and ethical values are treated with indifference.

Health must be considered as a matter of social justice because health and the social determinants are issues of human rights; consequently, equitable distribution of resources is thought to be the best approach for good health care (Kelly, *et al.*, 2006; WHO, 2007). Justice in health requires societies to provide individuals with the necessary conditions to reach the goal of health. A world in which human beings suffer and die unnecessarily when it is possible to provide a solution is unfair and unjust (Ruger, 2006; WHO, 2007b). To deal with unfairness and injustice it is necessary to attend to the underlying societal causes of disparities (WHO, 2007). The aim of governments is not to eliminate all health differences, but rather to decrease to the lowest level possible or eliminate those which result from factors avoidable and unfair (Whitehead, 1992; WHO, 2003). In theory this aim is a good one; however, in reality, minorities have to face restrictions and the governments are controlled by external forces that make it impossible to control the widening gap. Thus, instead of well-being for all, market competence becomes the priority for governments and, coupled with globalization, has direct and indirect effects on health. The direct effects of globalization on health are related to the impact on health systems, health policies and the exposure to hazards such as tobacco marketing. The indirect effects are related to trade liberalization and the availability of resources for public expenditure on health with its resulting effects on living conditions and household income (Labonte *et al.*, 2006; Navarro & Shi, 2001). Meanwhile, minorities continue to expose themselves to risky behaviours and struggle with a lack of continuing treatments, lack of money to pay for care and, as a consequence, live with uncontrolled illnesses and functional limitations. States need to look for quality of attention toward human beings, need to change the concept in capitalism of the creation of wealth as equivalent to eliminating inequality and to understand that health inequities always have moral and ethical dimensions (Kawachi, Subramanian & Almeida-Filho, 2002; Whitehead, 1992). Health systems need to become more humane, exemplifying equality and real commitment according to the universal principles that they promote. As nurses and members of the Colombian health care system, our responsibility is to be an advocate for our patients. However, our advocacy in this world of inequalities must take into account that self-determination and freedom are the most significant and priceless human rights (Gadow, 1990). It means engagement with the other through actions with the recognition that the person who is vulnerable requires our best performance. According to Cameron (2004), "...for an understanding of ethical practices in health care situations, our challenge is always both to recognize and respond to the call of this moment while much vies for our attention elsewhere. The address of the other makes a claim on us" (p.

54). So, regarding chronic disease, nursing needs to be socially and politically active to defend the rights of our chronic patients, taking into account that the problem does not have an easy answer. The situation requires commitment and concrete solutions. Therefore, our priority is to prevent and manage chronicity, handle policies of the health system and follow the essence of our profession by trying to provide quality of care.

El Significado de Tiempo en la Enfermedad Crónica

We comfort ourselves by reliving memories of protection. Something closed must retain our memories, while leaving them their original value as images. Memories of the outside world will never have the same tonality as those of home and, by recalling these memories, we add to our store of dreams; we are never real historians, but always near poets, and our emotion is perhaps nothing but an expression of a poetry that was lost (Bachelard, 1994 p.6).

Hannah

> *As a patient I have seen and suffered a lot of indifference that encouraged me to become a nurse. As a nurse, I wanted to alleviate other people's pain. I wanted to take some steps against that indifference. But the physicians of the medical centre at the university and my doctors discouraged me from pursuing nursing. They said I would not be able to work in nursing due to my joint pain. Also, they said I would be burned out. They said that nursing would debilitate my body and produce more pain. But I was stubborn so I always thought, "I can do it." I did have a lot of setbacks in my health during the four years of study. In my first year, for example, I had surgery on my knee. In my second year, my hands were so swollen that in the practical nursing exams I could not handle a syringe; however, my teacher allowed me to tell her the theory while one of my classmates did the procedure over the mannequin. In fact, many practical exams were oral for me. Despite that I came to many practices with canes or crutches, I became a nurse. But after I finished nursing, I had the worst pain I ever had in my whole life. My whole body was swollen so I had to stay in bed for three weeks. In bed I realized that I could not work in a hospital setting. I couldn't force my body to the daily rush of emergency or ICU. So I gave up my dream of becoming a clinical nurse and I began to consider occupational health nursing. It was my best option for work. This area demands little physical exercise so it really fits my needs.*
>
> *Two years ago, I began my master degree in occupational health and safety. I have always considered myself a good student but due to my joint pain the last couple of months I have not been able to attend most of my classes. The joint pain has been so severe that I am at risk to fail my semester. My doctor's notes don't cover all my absences and the absences are kept in my record no matter what, so with five absences I could easily fail my semester. Thus, to avoid failure and despite my pain I have been obliged to go to class. Besides, it was my investment. I cannot throw away 4 million pesos just because I am in pain. I have to work because I am finishing. My thesis needs a lot of my attention but sometimes I cannot do anything because I am in pain. I try to fulfill all my obligations, I really try, but it takes a lot of time to do so when I am sick. When the moment of threat is gone I like to go to the hair dresser and get a new hair cut and I like to wear makeup. It is kind of my way to say my illness is gone and I am over it again.*

It is like seeing the bullfight from outside. Hannah perceives a lot a suffering around her when she is in pain. She decides to be a nurse, to be an active participant to alleviate the suffering of people with chronic conditions. However, things are not easy for her; during the time of her study she has to face setbacks with her health. She goes to class with a cane and sometimes with crutches. Hannah does not want to give up.

She wants to finish her dream to become a nurse. Her life spins around the idea of what she can and cannot do. Despite the advice of her doctors Hannah continues studying nursing. Once her career is finished she suffers a terrible pain that obliges her to stay in bed for a long time. She has to face the reality that her life must be organized around her illness. Hannah has had to battle not only her disease but the stigma that chronic illness carries for others in society. She knows in her own flesh what it is like to live with chronic pain. She is tired of the dismissive care so she decides to take action. Being a nurse is part of the solution to that dismissive care she has perceived during her life with chronicity. She endures a challenge of going to practical examinations when she is in pain. However, she finds support in her teachers and classmates. They help her through the process of becoming a nurse. After many setbacks, she manages to finish nursing. However, after her last year of studies she has the worst pain she has ever had in her life. It seems that nursing after all serves only to aggravate her chronic condition. Nursing places too many demands on her body. Her soul wants something but her body refuses to obey. It cannot. It is tied to her chronic condition. After three months of being secluded in bed Hannah decides to give up her dream to be a clinician nurse. She has to adapt her life to the demands and needs of her body. She goes for a side of nursing that does not demand too much of her physically. Hannah's decisions and world have to fit the requirements imposed by the ill body. Every day is a new challenge for her. She has to live one day at the time. She keeps dreaming. Her goals include working with people with chronic conditions in work settings. She is attached to her roots. Chronic illness has shaped the pathway of her life. What would be different in her life if she never had chronic illness? We do not know the answer to that question but for Hannah her life has taken another course, a course dictated by her condition.

> *Some of my bosses worry about my situation and others don't really care. For those who care there are a lot of considerations and support when I am sick. But for those who don't care there are a lot of demands. For example, they demand I have to be working at all times even when I am on leave because the work cannot be postponed. If at least my pain*

> *were easier to control, my life would be different. Some people I work with don't know I'm ill and I don't want them to know because I don't want to be stigmatized by them. I am not "a poor thing" for anybody. I have learned to keep my illness to myself because being ill is something personal. I know someday I won't be able to hide my disease but for now I can hide it so I don't like my illness to be a public concern. When I have opened my mouth and told others my story I have to hear, "poor thing," "courage" or "you can do it." I know I can do it. I have been dealing with this situation for ten years. I recognize there is no bad intention in their words but I don't like to hear them, especially when I am in pain. It is not a good idea. During this time those words lose their meaning, they just create a lot of revulsion in me. It is like seeing the bullfight from outside. These words upset me mainly because my body is the one in pain. I am the one who cannot breathe or I am the one who has to walk barefoot on the street because of the burning sensation in my feet. I am the one everybody is looking at. So don't tell me, "Don't worry, nobody cares." Because I see how people look at me in the street for walking barefoot. That comment just makes me mad. I'm the one everybody is looking at as the crazy woman walking in the middle of the street barefoot. I don't have many friends but the few I have are the unconditional ones.*

As with her family and friends, Hannah's bosses are divided by her condition. Those who support her are nice with her. Others do not care and try to make things harder for her. She has no option when she is ill—she has to go to work. Her doctor's note does not help her to stay at home. There is no time to be ill when someone is working. There is another group of people Hannah works with who she does not want to know about her condition. Her condition is not apparent in her body yet, so she wants to hide her situation from them. She does not want to deal with the pity her condition would awake in other people. She keeps quite when it is necessary to stay quite. Being ill is something private that only is shared with the people close to oneself. She has had bad experiences when she has shared her condition with others. Sometimes she finds support but other times she finds words inadequate when she is in pain; it is hard for her to hear encouraging words that have lost their meaning. Hearing words of compassion makes Hannah mad. Why? To use Cameron's (2002) words, "Being vulnerable is difficult to manage" (p.17), and people like Hannah try to live as normal a life as is possible. They do not want to be treated differently because of their health condition. Hannah feels vulnerable when she shares her condition with others. She feels that she is at a disadvantage when she exposes her being to the other. Hannah wants to keep control of her life. She does not want to be vulnerable in front of others. She needs to be like other people. Being barefoot in the middle of the street only exposes her vulnerability, her illness more. It is difficult to assume how the symptoms impose a burden on her.

> *Living with chronic illness is like riding on a roller coaster: one day I'm fine, the next I'm in pain; one day I am independent and the next I'm completely dependent. Back and forth periods of being in control and being out of control of the disease. It really exhausts me. You are aware of death in those moments. I'm living with the unexpected--I never know what I am going to feel and how my illness is going to go. Sometimes when I am in pain I ask myself if life is worth fighting for. In those periods you walk side by side with your death. I feel that death is always stalking me in those moments. I would love to get out of my body and not feel any pain. And yet it is during this time that you learn to appreciate the moments when the body is healthy, when there are days free of pain. Those moments are priceless. In those days of calm I like to go out to see the sun, to look at the sky and to breathe the air and admire my surroundings. You learn to love the simple things. I take advantage of these moments because I don't know how much longer they will last. For sure I know I'm here for a reason. When I had my head surgery I met another two young girls with the same procedure. Before surgery we laughed and shared our stories but I was the only survivor. One died in surgery and the other one in ICU. She never woke up. She was my mirror of what could be my future. But it was not my time to go. I believe firmly my time here is not over. Due to my illness my dreams have changed many times but I'm still dreaming. They are shaped by my disease but this situation has never broken my desire to live, love, work and study. My dreams are my north. They give me the necessary direction and strength I need to keep living.*

Living with chronic illness has been difficult for Hannah; she feels her life sometimes is out of control. It is really tiresome the swing back and forth between independence and dependence. Her life is at the will of her ill body and she cannot do anything to stop the way her life unfolds. Time plays a key role in her life. For instance, periods out of pain are treasures to enjoy as full as possible. She likes to take advantage of those days because she does not know how long they will last. Like riding on the roller coaster, Hannah does not know what to expect. Some days Hannah finds herself at the top of her life; during these days optimism invades her and she enjoys life. These are her sunny days and life is simple. But during the down days Hannah finds a lot of pain and suffering that is difficult to control. During the uncontrolled moments of illness Hannah finds herself dealing with the company of death. Death stalks her. Death accompanies her during the moments of illness; she can feel its threat. Her optimism and morale increase and decrease according to the state of health she is in. Then, Hannah goes to her spiritual path. She feels she is in this world for a reason. It is not her time to go yet. Before her surgery she met two other girls with the same condition. She was the only survivor. They were a mirror of what her future could be. Hannah's dreams and life are shaped according to her condition. She has hope in her future and her hope in the future changes every time she has a setback in her health. Her dreams and plans for the future change with her illness. Her time with chronic illness is oriented toward projects and dreams that from time to time change and reshape due to her ill body. She has not lost her capacity to live her life as full as possible.

Camille

> *Before my disease, I was excessively responsible and very quiet; I would say I almost was a workaholic. I had all my life this picture of me being the only one capable of doing things at work. So I ended up with a workload that I did not need because there were other people I could delegate my responsibilities to but I did not. Also, I was obsessive with exercise. I loved to ride bicycle. The gym was like my second home. Now I barely move. I do other stuff but I cannot exercise. I go out because I have a lot of errands to do but not with the same rush as before. So when I received my diagnosis of cancer I did have this feeling of relief. Something that I never felt before like a big load was taken away from my whole body. It was like I had this huge pile of bricks all over my chest and I could not breathe. Now I can breathe. With my cancer I was free. I did not feel anger, despair or rage as other people with cancer do when they learned they have cancer. No, I kept thinking, "This is a second chance. It is a time to worry about me, to be with me and to move on with my life. I just need to figure out how to get out of this new challenge in my life." What else can I do? So it was the rebirth of a new Camille. The old Camille died. The obsessive compulsive, perfectionist died and the new Camille decided to take advantage of this second opportunity in life.*
>
> *I never had a social life before. Now my social life is different and better. Before, I was looking impatiently at my watch all the time, thinking about my work. Now I have time for me. With my cancer my life has recovered its peacefulness and calmness. Sometimes it is too much calm and yet I love it. I have learned to take advantage of my time. I learned that from my sessions of chemo. During this time we never look at our watches. Our time was determined by the slow fall of the drops of chemo coming into our bodies. We used to chat a lot when the chemo therapy sessions allowed it. We just sat there and shared our stories. If someone was new, we used to write down our phone numbers to keep in touch before the next session.*
>
> *Cancer really changes your life. Through this experience I have learned to take advantage of and enjoy each minute as if it were the last. Also, I have learned the meaning of solidarity. In fact, I have seen a lot of solidarity around me. When I take the bus, people see me walking with my cane and immediately they give me their seats, or if I am lining up*

> *people help me to go to the top of the line without my even asking. I like that. Pity is what I don't like because I am not "a poor thing." Fortunately, that's not happening often. What I have found is that there are a lot of people with my condition and even in the oddest places. It was late at night when I got off the bus with a woman. I did not know her but she approached me and asked me if we could cross the dark park together. I said, yes. While we were crossing she told me she was buying some bread from the bakery for her nephew who came from Germany to visit her only son who was diagnosed with lung cancer not long ago. I told her, "Tell your son that he needs to take things easy. Tell him to enjoy life. Tell him to have faith in God because He is the only one who can help him." Then, I continued, "Do you know why I am telling you this?" She said "No" by shaking her head. "I know because I have cancer too. I am in the final stage of my disease." When you have cancer, you know what it is like. You know how hard it is. You understand. That is solidarity.*

Living with cancer has really changed my life. Before her illness, Camille had her whole life planned, professionally and personally. She believed she was the only one trained to do certain jobs in her office. She imposed on herself an excessive amount of work, but when she learned about her cancer what seemed to be important lost its meaning. She learned that in the hardest way possible. Cancer brought to her life a new breath in which work, exercise and shopping are completely forgotten. Life prevails over shallow living. She can breathe freely. Her life is not tightened up by her job and past life anymore. She takes time to live each moment as it comes. Looking at the birds, trees and mountains occupies most of her time. She does not live in the rush of the present. Her freedom comes with a reward—another chance to live. She does not have much time though. She does not feel what other people feel when they learn about cancer; she thinks this second chance will provide her with enough time to move on with her life. Her space and time have improved due to her condition, and her ill body adapts to this new set of changes in her life. Before her illness, Camille did not have a social life; her life was driven by the rules of today's market.

She was trained to compete and produce, but cancer has carried her away from patterns of the market. New friendships and interests have been born from her encounter with cancer. As she continues living she integrates cancer into her life in a positive way. Her positive way has helped to develop solidarity toward others in the same condition. Camille worries about others when they are suffering. Different from Hannah, Camille likes to share her experience of illness with others in the same condition, for her cancer develops solidarity. Etymologically, solidarity comes from the French word *solide* which means fellowship in good times and bad (Skeat, 1963). Camille practices this fellowship with the mother she met getting off the bus. Camille learns this mother is preparing her home for the arrival of a nephew who is coming to visit her only son who is affected by cancer. Even in the oddest places it is easy to know someone who knows or is affected by cancer. However, others discover about her condition through various kinds of encounters. Walking with a cane makes public her disability, but not her cancer. Yet, people are moved by her disability, and for Camille it is easy to find solidarity everywhere when she uses public transportation or public institutions. Like Hannah, Camille does not share her story with everybody, only opening up to others who are in the same situation as her. She does that to show others that despite how devastating her condition is there is time for hope.

> *My metastases are coming back again. After my chemo and radio my doctors were surprised. All my metastases were controlled but now my disease is not under control anymore. It is not only me but also my friends. Today I see my friends with cancer and one by one they are getting ill again after being okay for some time. Some are dying. Sometimes I wonder when my turn will be. I am not afraid of death. I know that is my future and yet I try to enjoy each moment and each person I have met. I will die happy because this last two years I have been happy. Death will come when it is my time. Before my cancer I was anxious to finish everything I started. Now I don't have that rush. I am grateful to enjoy a second opportunity. I am not attached to anything or anybody. Other people think they are going to live until 70 or 80. When you have cancer you learn to live one day at a time. I don't plan long term goals. There is no time to plan. With this disease you learn to be short of time. I know I am running out of days. My time is limited now. I could die tonight tomorrow or the day after tomorrow so let's give importance to what really matters. My family is what really matters to me right now. I love the weekends I spent with my sister. Lately, she complains she is not at home all the time because of her work. I don't feel alone. I know the weekends are for us. Sometimes we rent some movies and stay in. Other times we just stay up late in our pyjamas and talk to each other. We like to talk. Other times we go to the mall to buy our groceries. In the last few months my brother has been worried. He has been there with me all the time if I need to go to the doctor. He has changed a lot lately. But I have changed too; I don't care about shallow things anymore. God gave me this second chance to be close to him, my sister and my new friends. Before my cancer I was hungry for success. I was so focused on getting what I wanted then, my whole life was planned. I was full of objectives and goals. Now I try not to plan my life*

> *too much. Now I tell my sister, "Enjoy your life. Life is short. Enjoy what I cannot enjoy anymore." That is living with cancer to me.*

My time is limited now. Through time Camille has learned how her life is coming to an end. She is running out of time. The meaning of time for her is different from Hannah; Camille is not thinking of projects or dreams for the future anymore—she is thinking of her farewell. She is dying. Her metastases are coming back. Her illness is taking advantage of her weak body. But she also knows she is running out of days and death will come soon. She feels it in her body and yet she is not afraid of death. She sees in her ill friends the mirror of her future when one by one they become sicker. She wonders if her end is close. During this period of her life time seems to fly. Despite that her cancer is taking advantage of her body, having two years of freedom makes her happy. Through this period of time she has met new friends, she has changed her perspective of life, she has learned how important it is to fully enjoy each moment of life. For the first time she does not have the compulsion to finish everything she plans to. She does not have the need to rush that she felt in the past. There are other things more important in life like sharing with her family and friends. She does not have attachments to material things or success; she finds this second chance an opportunity to enjoy a full life. Even the issues with her brother seem to be in the past. Keeping her family together is her priority now. She spends most of her time with them enjoying their company; her plans are not year oriented, they are day oriented. After all, her time is precious and she needs not only to be watchful with the advance of her disease but also to relate with the people she loves. Her legacy for her sisters is to enjoy life, enjoy for her the things Camille will not be able to enjoy anymore. For her, having cancer has given her the opportunity to explore a side of her life she did not know. That is what it is like to live with chronic illness--to let the negative outside and take advantage of the positive side of her condition. Chronic illness has brought to Camille a new beginning. Her experience of living with chronic illness is full of life changes, rewards and farewells. Chronic illness has opened for her a door to a world she had never been to, a world in which her time available is enough when she is able to cultivate her relationships with loved ones.

Alfredo and Maria

> *I met with my friends when my body allowed me to do so. I did not have to face surgery, and I was not confined to bed or had to stay in the hospital because my disease was not as severe in the beginning. I did not have all the physical limitations I have right now. Despite my limitations I still had a trip with my wife and sister-in-law to Santa Marta two months ago. My limitations become visible when people invite me to conferences or meetings and I have to say, "Thanks, but I prefer to stay in; I am too tired." With this disease I have learned to see society with other eyes. I know I am not the only one with cancer. I know everyday many people learn they have cancer. In the association, I have met people living with cancer for 15-20 years. There are a lot of people who are living a normal life with cancer. I wish I could have that. My life is fading. People do not understand the reasons we have to be attached to life. They do not understand what keeps us fighting. Once a doctor asked me, "Alfredo, how long have you been ill?" "Eight years," I said. He said almost in disbelief, "That much?" his comment was like a slap in my face. I do not know if he was joking or what, but according to his answer I should be dead a long time ago. I don't like that because people always link cancer with death. Maybe they think because I have cancer I do not have the right to live more than their medical books say or what they learn in the university. Through time I have learned to take things easy. However, my cancer has not taken away my desire to live. My dreams to keep learning, studying and reading are the only things this disease has not taken away from me.*

Cancer has not taken away my desire to live. Alfredo knows his condition does not define his being. Cancer is part of his life and despite his condition he tries to accommodate friendships and gatherings. It has been difficult but not impossible; however, sometimes he prefers to stay in at home with Maria. Since last November he has experienced limitations with walking. He tries to forget about this new physical limitation and live his life the best possible way. He has plans to go with his wife and sister-in-law to the beach. He knows there will be some difficulties but he wants to go. His limitation becomes visible to others when his social life is reduced due to his disability. And yet he sees other people with cancer living a full life. Living with cancer is not necessarily a death threat for people anymore; he knows there are a lot of survivors of cancer. He wishes he could be one of them, but he recognizes his life is coming to an end. Other people wonder what keeps Alfredo alive, what his motivation is. For others, eight years seem a lot of time; for him, it is just the beginning. His doctor's comment makes him mad because there are many reasons that have kept him fighting for his life. He fights to subdue his disease because he needs more time to spend with his wife, daughters, family and friends. Cancer cannot be defined by books: according to Alfredo the experience and uniqueness of being alive enables him to persevere despite all medical predictions. As Alfredo says, cancer has not robbed his desire to be a full human being. Like Hannah, he has dreams to fulfill but at the same time, as with Camille, he knows his time is running out.

> *The hardest thing in my life is to experience my wife's disease, especially because she was dealing with my situation as well. I say everyday to her that I love her. I ask her to be patient with me because I understand how hard it must be to bother someone with simple things like a glass of water. Things that I used to do, now because of my limited ability to move I cannot do anymore. Since last November I have had to bother her with my needs. They are simple needs but accumulated they become a big deal. Being limited to these four walls on the second floor of my home and seeing myself confined to bed produces in me a lot of sadness, demoralization, melancholy, powerlessness, anger and at other times resignation. It is difficult to depend on someone when all your life you were independent. I feel bad when we are talking and I have to bother her with, "Could you please bring me a glass of water," especially when she comes from a whole day doing errands for both of us. All of those things taken together create a lot of inconvenience. Being close to someone with cancer carries a lot of sacrifice, love and, yet, it is too hard for me to be a burden for someone I love. God will be the only one to take away this suffering from me. I was not a good Catholic before my disease but through time I have learned to be close to God. He is the only one who can help me as King of kings. I know he can do it. I have my last hope on Him. My family taught me to believe in God again. They taught me to have faith, to think of the possibility of a cure: a miracle. That's why my family prays every day for me. With my disease my faith has grown. With my wife we pray for my recovery every day. I am not alone. They are here with me.*
>
> *It is hard to recognize that I am losing my battle against this disease but that is a reality I have to assume. Every day my disease becomes stronger and stronger and I cannot do anything to stop it. It is nerve racking. Pain is the most difficult thing to handle and lately there has been a lot of pain in my life. During this time of pain absurd thoughts come to my mind. One of them is suicide as the result of hopelessness, despair and suffering but thanks to God I have my daughters, family and wife that help me to get rid of those thoughts. However, when I have pain I cannot help but to feel the closeness of death. Every day I have this sensation that my end is close. I do not want to. Last week I had this excruciating crisis of pain in my leg. The medication did not work so I had to go to emergency. In emergency I had to wait from 8 pm to 12 am to be seen by a doctor. Meanwhile, I had this awful nausea, was vomiting and endured pain. I felt so close to dying. I was in bad shape so they kept me in the hospital for two days until the painkillers really worked. Death is like a threat that I can feel close when I am in pain. I can even touch it. I am scared of death. I do not want to die. I want to live. So with my wife we took a decision for a radical procedure to take away the pain of my leg. I know that would be a provisional cure before*

> *the disease shows up in another side of my body. It is hard to be in pain all the time despite the medication I am taking. Before my disease I used to be a workaholic; I did not have time for anything but work. Now I try to make it up to my wife. I say to her everyday that I love her, that I am happy to have her in my life. This disease has united us. Before, I was worried for my little daughter; now I am worried to die and leave my wife alone. We have lived through beautiful, marvellous and even bad times but overall we love and respect each other. I want to fight for her to be with her. I know she is suffering a lot because of me. Since the last couple of months when my health has deteriorated she has been so worried she does not sleep very well. She does not complain to me. She says she is fine but I know she is suffering. At night I can hear her when she gets up and lifts the sheet and blankets delicately to check if am still breathing, if I am still here. She does that every night. Also, I have heard her sobbing, putting the blanket in her mouth to avoid any noise. I know she is crying for me, she knows my end is close. My life is fading away. She is the only motivation that keeps me alive. I have not thanked her enough for being part of my life. I'll always love her.*

I am losing my battle against this disease. The hardest thing in Alfredo's life is to face Maria's disease. It is especially difficult, a couple suffering from the same condition at the same time. Alfredo knows the burden he is imposing on Maria's life. Alfredo's ill body has brought his life to the point of partial dependence on Maria's help. This is the point at which their stories come together. Maria has been Alfredo's caregiver for a long time; she knows Alfredo is losing the battle against cancer. Her disease and health conditions take a second place in her life.

For now, she is a devoted wife taking care of her husband. She worries for him and is suffering the repercussions her distress is causing. Meanwhile, all that Alfredo can do is ask for patience, knowing how difficult it must be for Maria to deal with not only her condition but Alfredo's as well. Before the last setback of his illness, Alfredo was living an independent life. Now he has to depend on Maria's care and compassion. Being limited to the second floor of his home has not been easy to accept. For him, living with someone with cancer carries a lot of sacrifice and work. He has found in Maria companionship and support during the moments of crisis. Maria is his companion during the moments of solitude on the second floor. She is there for him and suffering in silence with him. She and his family have taught him to have patience and faith in God. With the new setbacks of his disease a miracle is the only chance Alfredo has to survive. During the moments of illness Alfredo has found in his faith the comfort to face his condition. The love of his family and his faith keep him alive.

At this point in his story, Alfredo acknowledges he is dying. He is losing the battle against cancer; however, the hardest part is not the recognition of what is happening to him but how the course of events shackles his life and he cannot do anything to stop it. He resists to the end and he fights back, but his condition has regained a lot of terrain. Death is there besides him, especially lately when he is in pain. As with Hannah, Alfredo sees pain as a difficult thing to handle. Pain overshadows and overwhelms his life. When he is in pain, suicidal thoughts came to his mind; however, thinking of his wife, daughters and family helps him to overcome the negativity of pain. Life prevails over death. But pain is the constant remainder of his close end. As with Camille, Alfredo's life is coming to an end. His pain is becoming more difficult to handle. Painkillers that used to help him are not working anymore. He needs four hours in emergency and two days in the hospital to control his pain. Alfredo is afraid of death. He does not want to die; he wants to live because he does not want to leave Maria alone. He loves her. They decide on a radical decision to control the pain in his leg. For Alfredo, this is a temporary solution before his illness shows up in another part of his body but at least it will give him a little more time to share with the people he loves. Like Hannah and Camille, Alfredo finds pain difficult to overcome. He requires more time to be with Maria. Before his illness, Alfredo was focused on his two careers; with the advancing of his disease, he finds himself really close to Maria. His illness has made them close to each other. He knows Maria suffers in silence because of his illness, alone with the burden of his condition. She suffers with Alfredo's setbacks. She has seen how illness is taking advantage of his life. She is afraid of his dying when she sleeps. Thus, she is watchful of Alfredo's breath. Despite Alfredo's desire to live, his cancer is causing his life to fade away. They know it. They do not say it aloud to each other but they recognize he is dying. They do not want to confront the inevitable. As human beings, we are born, grow up and organize ourselves to live. We are afraid of death because we do not know what happens after death. But at the end, death is the only thing definite for all human beings. Although we are mortals and we are aware that death is one of the things in our life that we cannot control. To recognize the face of death in someone else is to recognize our own mortality. We think that we are prepared for everything. But life changes the rules of the game all the time. Now we are here. The next minute we do not know what has happened to us. As with Camille, Alfredo finds himself saying good bye to his beloved Maria. She is the only motivation that keeps him alive. He is grateful for being part of her life. At the end, Alfredo acknowledges death as a hard reality, part of our existence and part of our life.

Alejandro

> *Eventually, I have become more limited due to the pain in my foot. I used to go out with my friends and meet with them, talked to them about other things except my disease. But now I spend days and nights within these four walls just watching TV because I cannot read either. If you are ill sometimes you need to go out to see other faces. I am not going to drink anything. I just want to forget for a moment that I am ill. When you see other people socially the disease gets away from your head. You forget for a short period of time that you are ill. It was like taking off my coat on a warm day. With them, I took my diabetes off my mind for a moment. I mean the illness does not go away forever but for a moment it does. But being here at home, without being able to walk, it's just a continual reminder of my situation. Indeed, my social life has been affected by my diabetes and all the other diseases I have. Before the problem in my foot I used to go to other cities and worked with my friends. I used to receive 8 or 10 calls for me saying, "Hey! How are you? We have this or that to do, are you in?" During this time it was easy to forget my disease. Today my phone does not ring for me anymore. Nobody calls me mainly because most of my friends are gone or move on with their lives. It has been hard to learn that. My friends do not call me because I cannot go outside anymore. It is hard to be restrained. It is hard to be alone. I miss the chit chat with my friends. Here nobody talks to me. That is the reality of life, the reality of getting old. My life now is boring. A day for me is to wake up early in the morning, then my wife gives me my insulin, then I have breakfast, take a bath, watch TV, then lunch, more TV, dinner, more TV and go to bed and that's it. I have to take things easy. I'm bored most of the time but there is no short or long term solution for me so I have to be patient. However, nobody knows about my needs. I always keep them to myself. I see myself as a bird in cage. My wife says to me all the time "Don't be sad, stay in bed. You don't need to be walking all the time." But I like to walk. I miss many things of my past life like the freedom to move from one place to another; I miss the travel and having fun with my friends; and I miss my old life. In the end, it doesn't matter if the cage is made of gold because a cage is always a cage.*

It doesn't matter if the cage is made in gold: A cage is always a cage. Alejandro knows what it is like to live in a cage; he has been living in one for the past few years. It is dramatic for him to see how his life has been limited by his condition. Before his limitations affecting his moving or reading, he used to live a different life surrounded by friends and work. Now his world is restricted to the four walls of his small apartment. Different from Camille's, Alejandro's world has shrunk. He needs to see other faces and talk to other people but going out is an impossible task for him. In his desperation, Alejandro longs for the freedom to go out because he needs to forget his diseases for a moment. As with Alfredo, with the advances of chronic illness in his life Alejandro sees how everyday his world is restricted. Nobody goes in or out, nobody calls. He knows his diseases are not going away but wishes that at least he could go out and see other people. It would be good for his mental health. But he cannot. The transformation is dramatic from being a dynamic and independent person to becoming a solitary and dependent human being. Alejandro misses his old life. Time seems endless with the same routine every day. It is frustrating for him to be secluded within four walls. Despite that he has everything inside his home; he wants the freedom that exists outside of his window. He wants the freedom to walk and go out with his friends as he used to. He wants to be with other people besides his wife. Like his birds, he has many things, but lacks freedom. Camille's disease brought her a bigger space and more time for herself. Alfredo and Maria have little time to enjoy each other. Alejandro does not enjoy his time. He is captive in the cage of his apartment.

The Time of Chronic Illness

Lived time is different from our perception of clock time or objective time. It is our temporal way of being in the world. Past, present and future together shape our temporal landscapes (Van Manen, 1997). According to Van Manen, our lived past creates bonds with our memories and our memories leave traces in our being. Is it possible to perceive time through our senses? Through our senses we have such perceptions as sounds, textures and colours (Le Poidevin, 2009). However, time cannot be linked to a particular sense. As human beings, we cannot feel time passing, and yet we still notice how time passes through the changing pattern of our thought (Le Poidevin, 2009). How do people with chronic illnesses perceive and understand time? The word chronicity implies the persistence of symptoms over the temporal course of a disease. Time in chronic illness needs to be understood as an extended field, being linked to performed activities. For chronically ill people there is no need to pay attention to time in its objective flow as measured by the clock because chronically ill people must always be concerned with the evolution of their illness and their treatments or procedures. Alfredo's personal clock is his body's need for the next dose of morphine; for Hannah, steroids and ASA mark the hours of her daily life; Alejandro's glycaemia times his next shot of insulin; and Maria's and Camille's regimens of oral chemo set the pace of time in their lives. People in this study are caught in their personal time lines that keep them in the routine of the next scheduled dose or treatment. Chronic conditions restrict people's freedom to move and organize their lives according to their free will. Hannah sets aside her dream to become a clinical nurse because of her joint pain, Alfredo, Camille and Maria leave their careers to take care of their ill bodies, and Alejandro is forced to abandon his social life due to his mobility limitation.

Lived time is a specific form of lived experiences, and is integral to how chronically ill people experience, understand and are reconciled to their illnesses. Chronic illness interrupts the linear flow of time and, thus, shapes their relationships with time as a temporal continuum (Morris, 2008). Time for the chronically ill, then, is not determined by its linear flow; it is shaped by the revision of life's priorities in accordance with their perception of the value of family obligations in the Colombian context. Living with chronic illness brings a new perspective to life and death, which facilitates their reflection on time and selves. For some participants, the process of living with chronic illness is perceived as a process of living and growing, rather than a process of dying and deteriorating. To this end, making sense of time helps them to regain control over their lives and, in turn, improve their sense of normality that has been commitmentd by their diseases (Ohman *et al.,* 2003)

The perception of time in chronic illness is affected by the inability to receive a permanent cure; that is, time is not seen as an open-ended linear flow. The disruptive nature of chronic illness disturbs the ability to improvise with time. All their lives are focused on the requirements and needs of the body. Perhaps with chronic illness the most difficult change is the loss of the identity each held before becoming ill. Participants mention a complete restructuring of the way they define themselves and the ways in which they interact with the world. Sometimes, as with Hannah and Alejandro, it is difficult to feel good about themselves as the chronic illness is incorporated into a new self-image. The work of rebuilding their lives and identities can be further complicated by the loss of friends or other supportive relationships that sometimes follow the onset of serious illness. Also, family members are likely to experience the same feelings as the chronically ill as along with their own feelings relating to how the illness is impacting on their lives. For instance, Maria forgets her own health problems when Alfredo has health setbacks, and she is quiet about her own illness, speaking only about his suffering. Despite that Alejandro's wife suffers from chronic conditions, her health and well-being are secondary when, for example, she has to go back and forth to the insurance company to get the authorization for Alejandro's follow up with the orthopaedists. Hannah's parents and sisters suffer in silence during the whole process of her disease. They try to conceal their feelings, not showing the full extent of their concern for her. Camille's family tries to be with her as the end approaches. Her brother stops judging her and her sister complains for not having enough time to spend with her. Changes in the roles in family, work and social life can create additional adjustment problems for everyone involved. Being chronically ill also creates the very real possibility of relinquishing hopes and dreams while having to face the fear of more ongoing losses.

Despite the variations in their illness and health status, all participants appeared certain about the closeness of death. But overall they do not conceive of their end is near. When they are in uncontrolled periods of their diseases, death becomes more palpable and feels closer. It is like death is breathing down their necks. They cannot avoid feeling afraid of death. On a daily basis people are unaware of death, but when chronic illness appears, the threat is imminent, especially during the moments of crisis. Pain is the main source of the awareness of death. When they are in pain, they become aware of their own humanity. They do not want to die. Dramatic descriptions of the immanent end of life are common in their stories. The inevitability of death was perceived by some participants as unbearable to think of, especially when its impact on their loved ones was taken into account. The possibility of premature death creates a strong sense of despair among the participants because it means they might be unable to fulfill family obligations.

The sense of imminent death discourages Alfredo, Maria and Camille from making commitments to the future. Feeling uncertain about how much time he has left to live is frustrating for Alfredo who often feels upset about his lack of control over his health. Meanwhile, Maria waits and carefully watches Alfredo's breathing at night. He does not want to leave yet. He has many things to fight for. He does not want to leave Maria alone. They are partners in their fight against their illnesses and the health care system. He wonders what is going to happen to Maria when he is gone. Maria suffers in silence, not wanting to say a word to Alfredo about her fears. When I interview them, she tells me how scared she is of seeing Alfredo dying. She tells me that she feels in her body the pressure of the moment, and feels a lot of stress, especially in her neck and shoulders. And she cannot sleep well anymore. They cry when they talk to me about their situation. With the last words of the interview, Maria stands up and leaves the room. The stress on both of them has negative effects on their relationship. Camille, in our first meeting, is waiting to receive her long term disability, but two months later with the appearance of new metastasis she knows there will not be much more time for her. She does not feel conflicted about the new set of events; she just wants more time to have a detailed plan to maximize the relationship with her beloved family and friends. Other things seem unimportant to her anymore; she does not plan long term goals, perceiving the futility of doing so. Camille has given up some objectives and ambitions that she used to prize. Hannah has learned through time how to schedule her life according to her condition. And yet there are some days when her illness is out of control and she feels death walking next to her. However, she feels her end is not close yet because there are many projects in her life that she needs to take care of. For Alejandro, time goes slowly because of his being isolated within the four walls of his apartment; he describes his continuous internal struggles and his solitude due to his physical inability to walk again. He withdrew from his social life, because the interaction with his healthy friends reminded him of the sharp contrast between their futures and his future.

Participants struggle to come to terms with the reality of their condition. Hannah, Camille, Alfredo, Alejandro and Maria swing back and forth between periods in which the desire to live a long life is interwoven with the deep pain of being unable to do so. As human beings, we live as a part of groups; we spent a lot of time in groups such as our families and friends. However, the most important instances of life are lived in complete solitude: one of those moments is our birth and the other is our death. Despite that in both birth and death people are surrounded by family or friends, the specific moment is not shared because nobody can share the experience of his or her first breath or last. It seems that our own humanity is resistant to being a social being in those moments of life and death. Perhaps we are selfish and we do not want to share our most intimate moments. As Derrida (1995) says, I can share my life, my dreams, my grief and all the things that join me with another person, but the moment of death is a moment to be alone, a moment when the word "share" is left behind.

The disruptive nature of chronic illness not only truncates the lifespan of people who live daily under its shadow but also produces a deep pain when they understand they may be unable to live a long, healthy life. For the participants of this study, chronic illness brings a more present-oriented rather than future-oriented life. For instance, Camille is not thinking of her future anymore. Her present life is only about today, given that thinking of tomorrow is not secure. Time for Hannah has a different meaning: she is focused on following her dreams no matter how many times her illness changes them—she keeps dreaming as her illness progresses. Alfredo and Maria know death is close and the future is uncertain so they keep their minds in the painful present while trying to survive. Alejandro cannot help but relinquish his desire to dream of a secure future; he has created a routine that assists him to survive in the present. In chronic illness, the security of today is based on the idea to survive today or to go through one day at a time without a health problem. Also, time does not only include a subjective perception, but also it brings about substantial changes in their bodies that affect their freedom to move in their space and their interactions with others. Alejandro has voluntarily decided to withdraw from his social life, because his healthy friends do not have the education to understand his disease. And yet he misses them, in part because they helped him to forget his disease for a couple of hours. But they have moved on with their lives, as did he. Like Alejandro, Alfredo knows his future does not hold any hope. He keeps all his suffering to himself. Their inability to move has constrained their expectations and imaginings of the future, and changed their views about the relationship between present efforts and future rewards. Alejandro's and Alfredo's diseases have alienated them from a safe future that often motivates people to move forward. Such deterioration has made the time they spend at home unbearable, especially when sitting and watching TV for long periods are the only activities they have. The meaning and significance of time change for someone suffering a chronic illness.

Lived time for the participants involves not only the physical experiences of being chronically ill but also the influence of social, economic, cultural and political forces that have shaped their perception of what it is like to live with chronic illness. These participants do not rush with their lives. There are serious difficulties that they have to face, like the lack of access to health care, lack of political representation, lack of economic means to survive and social isolation, but still they find the best possible way to live given their circumstances. Their approach toward time is a different one; they have learned to take things easy and to be focused on the spiritual side of their lives. Plans and life change according to the will of the ill body and what seemed to be important in the past losses its meaning when life is at stake. It seems that a serious illness is a journey with an unknown destination. In chronic illness the dichotomies are vivid. To hope in chronic illness is to learn how to wait for test results, for appointments, for the body to heal, for the spirit to lift up. “Through hopes and expectations we have a perspective on life to come, or through desperation and lack of will to live we may have lost such perspective” (Van Manen, 1997, p. 104). In chronic illness hope is the wrestling match between science and compassion, between body and being, and between pain and relief. Illness dramatizes for people the fragility of life. As well fragility is revealed when participants are exposed to discriminatory and dehumanized aspects of the society they live in.

How is time experienced in a globalized world? In globalization, time is oriented toward long term goals. While for these participants living one day at time is the way to go. They do not rush things. In globalization’s discourses, space and time have a different meaning: space, for instance, explores the effects of spatial change like changes in the shape, scale and extension of social processes, and time explores the effects and, in particular, changes to or away from, modernity (Oke, 2009). Life and, especially, health in globalization is understood in monetary terms of productivity. People are dehumanized for the sake of economic profit. Throughout the world, the transformation and extension of capitalist exchange relationships create unequal relations within and among countries. This activity also creates new venues for exploitation, control and competence among nations, societies and individuals (McMurtry, 2002). In this trend, capitalism influences all aspects of society, including health, health care systems and health care professions. Rather than continuing the pursuit of quantity, health systems and, especially, health professionals should look for quality of attention toward human beings. However, dehumanization is not a cause for despair; rather, it can inspire hope. As Freire (2002) points out, “As long as I fight, I am moved by hope; and if I fight with hope, then I can wait” (p.92). Hope does not emerge by crossing one’s arms and waiting; rather, it grows out of a conscious, thoughtful struggle.

Freire’s fight involves critical thinking, using the perception of reality as a process, as transformation, rather than as an unchanging entity. It is an evolving entity that does not separate itself from action, but constantly immerses itself in temporality without fear of the risks. Critical thinking differs from naive thinking, which aims to hold time and adjust to it. Critical thinking relies on historical time as a way to understand the past and change the reality of today (Freire, 2002). Critical thinking acts as a transformer of reality to pursue humanization. Human beings exist in time. They own time. They embody and incorporate time as a way to perceive the world (Freire, 1973, 1998). When time is embedded in humanity, human beings are not imprisoned within a permanent today; they emerge, and become temporalized. But is it through critical perception that human beings find their own temporality? A world instilled with critical thinking is a world with consequence, a world in which human beings discover their own temporality. To use Freire’s (1973) words, “Transcending a single dimension, humans reach back to yesterday, recognize today, and come upon tomorrow” (p. 3). According to Freire (1973, 1985), passiveness is not the role that human beings must have *in* and *with* the world because we are not limited to the biological sphere; as human beings, we must participate in the creative dimension as well; we need to intervene in reality in order to change it.

Yet, we live in a world where power affects all human values, reducing everything to merchandise for trade. Power does not exclude; it invades everything and everybody. Social, economical, and political patterns set us over or under others, but the way we handle that power makes the difference. Since power is not always a negative force, its authority and influence must be addressed to develop strategies against disparities and marginalization. For example, in nursing, we have power over our patients and others, such as administrators and health systems have power over us. Our duty is to advocate and exert that power for the well-being and health of our patients. And our other duty is to develop social and political strategies against those who marginalize nursing. Nowadays, worldwide, human beings dehumanize and exploit each other for the sake of economical, technological, and individual profit. In some sense, there is no place for respect or ethical values, neither for the self nor for the other. Both respect and ethical values throughout the world are traded with indifference. Nurses, as human beings, need to be conscious of the fact that globalization is happening right now; and, being aware of that reality, must act against it by caring deeply and advocating for the other. Ethical action in a world of globalization includes being there unconditionally and free of judgment towards the other. It is being an advocate for the other to make possible the creation of an intercultural dialogue, where no one imposes on the other. It is being *with* the other instead of *for* the other and creating real bonds and commitment toward the other. Thus, as human beings we have the ability to transform globalization so that knowledge, power and ethics are used to create equality. One small step that we, as nurses, can take in the transformation is to advocate for and care for our patients in an equal way.

Chapter VI Reading the Word and the World: Engaging in Dialogue about Chronic Illness

Looking at the past must only be a means of understanding more clearly what and who they are so that they can more wisely build the future (Freire, 2002 p. 84).

Dialogue is an encounter with the world that is mediated with words (Freire, 2002). It implies a horizontal relationship among participants. Dialogue is an existential necessity. It cannot be the mere deposit of ideas in one person, nor can it be a simple exchange of ideas by the participants. It is an encounter in which people name or rename their world. No one can name on behalf of another. Dialogue is an act of mutual growing; it is not a tool for the domination of one person by another. Dialogue is nourished by love, humility, hope, faith, trust and critical reflection. Each of these elements brings the possibility to build a better reality, a better world for the oppressed (Freire, 1973). Through dialogue, oppression becomes an object of reflection by the oppressed and out of that reflection comes engagement for their liberation (Freire, 2004). To use Freire's words, "Liberation is thus a child birth, and a painful one" (p.49) and yet through liberation human beings emerge as a new people. Dialogue creates the possibility to critically disclose the manifestations of dehumanization (Freire, 2002).

Freire's greatest contribution has been to emphasize the process of humanization rather than the techniques of imparting ready-made knowledge. Literacy is not a set of technical rules or skills to be transferred to a learner; it is viewed as a key element of liberation intended to provoke a new sense of self and creative orientation toward external realities that surround and threaten to submerge us. To use Freire's (2002) words, "If dialoguers expect nothing to come of their efforts, their encounter will be empty and sterile, bureaucratic and tedious" (p.80); therefore, no dialogue can exist without hope. Dialogue is critical thinking about human beings and their roles in the world. This thinking does not separate itself from action in which reality is a process of becoming rather than a predetermined state of being. Critical thinking requires a rigorous analysis of the existing reality and the means by which it may be transformed. Dialogue draws out the creative potentialities innate in people; it is not a process to fill them with the ideologies of manipulators (Freire, 2004). For Freire (2002), dialogue is education; he makes this explicit in the statement, “Without dialogue there is no communication and without communication there can be no true education” (p.81). Dialogue and reflection are tools to understand politics, economics and history. Through dialogue participants benefit in an exchange of ideas. Freire (1973, 2002) believed that if a person listens to the other, really listens, she or he may be able to understand the difficult social conditions other human beings face. Social reality is the result of human action and not the result of transformation by chance (Freire, 2002). The dialogue must bring a change in the attitude of the oppressed, a change that must be the result of the oppressed *conscientizacao* (Blackburn, 2000). It also involves an epistemological perspective that requires an engagement with and understanding of knowable objects. Dialogue presupposes curiosity or the desire to understand the world around us. Such curiosity embodies the ability to engage in a search for meaning of an object and to encompass the full meaning. Curiosity evokes the exploration of the object of knowledge. And without curiosity, the development of superficial understandings of the subjects and problems occur (Freire, 1973).

The goal of the dialogue with the participants is to enable them to accomplish critical consciousness. Through dialogue it is possible to achieve liberation. Making a dialogue about chronic illness can be meaningful only when it constitutes a stage in the process of *conscientizacao*. Only then will the knowledge that emerges in the group enable participants to develop a fuller sense of their humanity. In this context, the person with the greatest store of sheer knowledge is not basically different from someone who is illiterate about health issues. Knowledge about health is nothing but a technical instrument. It is like the alphabet, a mere tool to read the world. The main issue for a person is how to perceive and use this instrument as an aid to his liberation, to pass from a stage of primary consciousness to one of *conscientizacao*. It is through dialogue that the participants of this study, as knowing subjects, accomplish deeper understanding of the socio-economic and socio-political reality in which their lives are built, and enhance their ability to transform that reality. A participatory educational method leads people to be aware of their context and their conditions as human beings as subjects (Freire, 1973). Thus, pedagogy of action must not reduce consciousness to a mere reflection of reality; it needs to produce recognition of the world not as a given but as a world dynamically in the making (Freire, 1985).

In the next section I am presenting the transcription of the group activity with participants in Colombia:

> ***Pilar:*** *Thanks a lot for being part of this study. I would like to start our conversation by asking, "What is chronic illness?"*
>
> ***Alejandro:*** *For me, chronic illness does not have a cure, so it is something you cannot run away from. Also, we have to be real and recognize how with these conditions we don't have any chance to recover. We need to learn how to deal with and care for our sick bodies. One of my doctors used to say, "Accept your illness as a part of your life. Love your body the way it is. Love it, don't despise it." So from him I learned to respect my disease. Some people see their diseases as a test from God or, worse, a punishment from God. But I don't think so. I think the best way to deal with a chronic disease is by taking things easy. We need a lot of patience. For example, if you can't have eggs or sugar or whatever, the solution is simple--don't eat them. If there is a delicious piece of cake and you are diabetic, don't eat it. But at the same time, don't restrain yourself from everything all the time. Sometimes it is good for the body to eat a small piece of candy because a small piece is not going to kill you. However, the most important thing is to love and embrace your illness. That's what we have to do. I don't like to despise my disease. I just have to live with it.*
>
> ***Pilar:*** *Doña Clara, you were saying something about illness as the end?*
>
> ***Clara:*** *Yes, I know these diseases are going to be with me for the rest of my life. There are no short or long term solutions so our only possibility is to live life as it comes. We have to take care of our illness to prevent setbacks. Also, we have to wait patiently to see how everything unfolds around us. We have to wait for God's will because we don't die until He says so.*
>
> ***Alejandro:*** *We have to coexist with our conditions; we have to live in harmony with our symptoms. We cannot lose our good mood. We have to practice a lot keeping our patience because cursing or blaming God for our luck is not going to resolve the whole situation. Our condition is not a punishment from God, and thinking in that way is not going to help us. But we have to recognize that we are ill for a reason.*
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> ***Maria:*** *With our conditions we have learned a lot. But the most important is to understand the reasons why we are ill. In our case, this disease has brought to Alfredo and me many positive changes. We share the same condition, so overall we consider our condition a blessing that has served to strengthen our marriage. We have had many satisfactions. We share a lot of time together. We share the same doctors. So cancer is something that has brought both good and bad moments for us. Our experience is like any other experience in human life. Sometimes it is hard, especially when we are really sick; we think, "This is it. I am going to die soon." Even in those moments we have realised this has happened*

to us for a reason. Through this time I have found the support of family and friends. They have always been there for me. At the beginning it was not easy because I hid my condition from them. I was trying to prevent them from suffering. I wanted to go through this process alone but that's impossible. We always need the company, support and love of someone. So later I had to disclose my condition to my loved ones. Nevertheless, having this condition has been rewarding for us, even with all of the anguish I have been feeling lately due to Alfredo's setbacks. In the last couple of weeks, I have felt the stress and pressure of his deterioration in my own body. I have been having muscle spasms in my neck and back.

Hannah: *To me, chronic illness is something you have to learn how to deal with for the rest of your life. So it is like a partner that you have to look after. It is something that needs all your attention and dedication. Even something simple like taking your medication on time is important because if you fail to do so it could have serious consequences for your health. Dealing with all this has been a difficult process to digest for me because at this age you are not supposed to be ill. Overall, I see my illness as my partner. I brainwash my head with the idea that this is part of my life from now on. This is now my normal life. Our illness is something we have to take seriously because if we take our off eyes it, later we will have to deal with the consequences of our reckless decisions.*

Alejandro: *Yeah, we have learned to coexist with our worse enemy; an enemy living under our own roof.*

Pilar: *Do you consider your chronic condition an enemy?*

Alejandro: *Well, it is an enemy but we are not afraid of it or at least we have to learn not to be afraid of it because our disease shares our own space. In my case, I have tried to coexist with my disease because I have learned the hard way how dangerous my disease is if I don't pay attention to. Well, probably dangerous is not a good word here.*

Hannah: *But we need to be careful.*

Alejandro: *Keep your friends close and your enemies closer, people say, and in our case this is really true. So we need to learn how to love and be patient with our condition. Overall, we cannot crumble; we need to take things easy and with humility. Even I have heard some people say, "My disease is God's punishment." And I don't think so because God does not punish anybody. He gives the disease and later the relief. Yeah, God is not going to leave us suffering forever. We are not going to live more than 100 years. So we have to learn how to live with our disease close to us.*

Clara: *Indulging our disease.*

Hannah: *Sure*

Pilar: *What is it like to live with chronic illness in Colombia?*

Alejandro: *We are an imposition on society. For us, it is sometimes impossible to find immediate attention or good medication. If you have money, finding good medications is not a problem. You can do it right away. But for the rest of us, good medications are not available so we have to accommodate our illness to the treatment available. We are fine* *when there is some treatment available for us and when we have the money to pay for it. However, when there is no money, you have to get used to this idea because you cannot spend money you don't have. So we always need to have a lot of patience when the medical resources are not available or your financial resources are not enough. There are many things that we need to consider when we talk about what it means to live with chronic illness in Colombia.*

Maria: *Our health insurance companies think that all the money they invest in us is a waste of time.*

Alejandro: *At 50 it is easier to receive any treatment available; for example, if you have surgery at 50 and you are healthy you have an option in life.*

Maria: *Yeah, you are going to live longer.*

Alejandro: *At 50 there is a bigger chance for you to recover from surgery than at 60 or 70. Doctors don't want to waste their time with people in their 60s or 70s because the recovery is slower. After 60, nobody wants to look at you. If you have a chronic disease your situation is worse.*

Pilar: *Chronic illnesses are called high cost conditions by insurance companies*

Hannah: *Sure, we are a burden for our insurance companies. They really do not know what to do with us.*

Maria: *We are a problem for them. We are the most expensive people in the health care system. For example, educators have a different health plan in Colombia but the government wanted to end our plan so they were going to put us with the elderly, but they couldn't. They don't want us close to them. Alfredo and I have received attention but only by fighting through legal and non legal means. Fighting is how we get things from our health insurance company. Alfredo is a lawyer but still we don't receive the attention we deserve. Last year we had a problem with a referral he urgently needed for an excruciating pain in his leg. The answer was always, "Go to the radiologist;" then, the radiologist, "Go to your oncologist" and the oncologist, "No, this is not my concern. I did what I had to do. Go to the Pain Clinic." And at the pain clinic they said, "We have done what we had to do." It was overwhelming to receive those words, especially when you are facing an agonizing pain. At some point, we got tired of hearing again and again the same negative answer so right there was when we thought the only solution was to take action. We did it and something we didn't get in three months we got in three hours. The next day my husband went to [name of institution A] and the orthopaedist saw him and helped him to alleviate his pain. We have had to push a lot for everything. We are relegated to a lower status in Colombia and everyday things are getting worse for us because these diseases are not only part of becoming old, but also there are children and young people suffering from them. We have heard how children affected by chronic conditions suffer from our insurance company's lack of attention. We have a limit; once we reach that limit of services the insurance company does not do anything for us. We can have a positive* *attitude toward our conditions but without the support of the health system our world just crumbles. Our conditions become almost impossible to overcome.*

Alejandro: *In the hospital the father of [Colombian actress] was in dialysis. He was in dialysis almost every day. One day I was talking to my doctor about the cost of my disease when he pointed to this guy and said, "Do you know how much the insurance company is spending for dialysis for him?" I got it. We are expensive for our insurance companies and if you do not receive the support from them the only alternative for us is to die.*

Maria: *If we die, probably they will be happy.*

Hannah: *A relief.*

Alejandro: *I don't like to talk bad about my insurance company but I think our death would be a relief for them. Some of our diseases are really expensive for them. They are greedy people. I heard the other day on TV how the wealthiest companies in Colombia are the health insurance companies. They are so wealthy that even they are the ones investing in the construction of the new airport in Bogota and other investments outside of the country. They really don't know what to do with their money.*

Pilar: *According to your experience with chronic illness, do you think health is considered a human right in Colombia?*

Alejandro: *According to this TV show I watched, health is a right for each one of us. As Colombians, we have the right to be seen by doctors or receive treatment, and yet our right to health is violated by insurance companies when we do not receive the attention we deserve. They really do not want to invest in us because someone with cancer or AIDS is expensive so what is the point to help us.*

Maria: *I agree with Don Alejandro. The health system is not good. You can see how in other countries the attention for palliative patients is good. It is a right we have but unfortunately, in reality, we don't receive the service. We have to fight for everything but also we have to speak out because if we keep quiet they do not pay attention to us. In other countries, the attention is free, and for people who are chronically ill it is a priority. In Colombia, we have to pay for a very expensive service that lacks in quality. Health care in Colombia is really expensive because we have to pay a lot of money, whereas in other countries health is a responsibility of the State. But here we are marginalized.*

Hannah: *I agree with your comment. We have to fight a lot for a basic right that is supposed to give you some relief from all the anguish we have to deal with regarding our diseases. Health is not really a right here because we have to pay for it; we have to pay out of our pocket for medications not included in the Compulsory Health Plan which is in charge of deciding what medications are covered by our insurance companies and which are not. It is unfair because despite that I have to pay monthly for insurance, I don't receive the coverage I deserve. Nobody in the government stops to consider how expensive some medications are for us and how our health is going to be affected if we* *don't receive those medications. The government is getting wealthy with our contributions. It is just unfair. In the end, we have to pay for medications or tests not contemplated under the Compulsory Health Plan. And if we don't fight through legal means we have to buy the medication or pay for the service we need. So I wonder when health becomes a right? Probably it is a right but we have to do too much to get it.*

Alejandro: *For example, I am taking some pills for my heart; do you know how much they are? 7,500 pesos for each box. And do you know how much the bonus is that I have to pay for in order to receive this medication from my insurance company? I have to spend another 7,500 pesos out of my pocket.*

Maria: *Everything costs 15,000 pesos. So it sounds to me that it is better for you to buy the medication outside of the drugstore of your insurance company.*

Clara: *The other day I needed to buy a prescription the doctor gave to me. With the doctor we talked and decided not to go for the medication in the drugstore of my insurance company because it was more expensive than buying it in the drugstore close to my home.*

Maria: *Sure, everything is business in those insurance companies. They don't care about us because health is a business for them.*

Alejandro: *It is a profitable business. The other day my doctor asked me, "Alejandro why are you not coming more often to see me." They don't really get how expensive is to go to their offices. To go to see my doctor I need to take two buses to go to my insurance company to set a time with my doctor. We cannot set a time by phone or even the doctor is not going to see you the same day so we need to go there twice. If I have blood work I have to consider that too. We try to do all these errands together but sometimes we waste a lot of time lining up. Then, when we want to go to the blood work often the lab is closed. So again we have to plan another day to go to the blood work. Approximately, I spend more than 15,000 pesos in transportation alone and this is just a rough estimated because there are other expenses we have to take into account such as the 2,500 pesos bonus we need to pay for every time we go to the doctor. And then the medication is another 2,500 pesos per box and normally he sends me 90 pills so that would be 6,000 pesos. Sometimes due to my inability to walk I have to take a taxi so my expenses go up. They don't consider the money we expend to go there. They don't consider that I live in the south of the city and to move to downtown or to the north for medications, appointments and blood work is not easy.*

Clara: *Sometimes, after all these processes we have found out the insurance company is running out of our medication. They waste our time. It is really sad.*

Alejandro: *Yeah, it has happened. Sometimes after spending more than 30,000 pesos in commuting and other expenses and after we waste hours lining up we have found out the insurance company is running out of the medication. To me it is better to walk one block to the nearest drugstore and buy the medication for only 2,500 pesos. I always go for* *the cheapest option. That's what I explained to my doctor that going there is really expensive for me. I have my glucometer at home so I just need to poke my finger to know what the level of my blood sugar is. I have learned what kind of diet I must follow so if I am in charge of everything, the cost goes down.*

Hannah: *So far to go for just one box of pills.*

Alejandro: *Yeah, it is not only the cost of the medication but also the other expenses such as the buses or taxies to go there, and then the bonus to be seen by the doctor or to buy medications.*

Clara: *Sure, we need to pay every time because if we don't pay they are not going to give us any attention.*

Alejandro: *Sometimes we have to pay double or triple and more and if they don't have the medication available we lose our money.*

Clara: *Yeah, if you pay for the bonus and they don't have the medication you lose the money because they don't give back the money, so everything gets expensive.*

Pilar: *In summary, to access health care in Colombia it is expensive. There is neither protection nor consideration for chronically ill people. Also, health that is supposed to be a human right is not. There is no quality of attention and services do not provide the quality they are supposed to. Therefore, do you think people with chronic illnesses are discriminated against by the fact of living with a long-lasting condition?*

Alejandro: *Let's say the insurance companies are the ones to blame. In fact, the administrators of those companies are the culprits because they are the ones practicing these policies of exclusion.*

Maria: *Health is a huge business in Colombia.*

Alejandro: *Sometimes it is not even the insurance company that is the one to blame. In my case, they have helped me a lot with all my health problems. They have helped me a lot. They helped me to overcome my stroke and my heart attack.*

Clara: *Yeah, he has received good attention.*

Alejandro: *I don't have any complain but I am surprised how insurance companies deny a box of medication that costs 7,500 pesos while other treatments such as catheterizing are covered. For this test they don't hesitate to send you by ambulance to the hospital. What about the food they provide in the hospital? All these are covered by the insurance company. All these services are not denied, but when it is time to pay for a simple box of medication that costs 7,500 pesos they refuse to pay it. I still wonder why.*

Pilar: *Hannah, what do you think about this?*

Hannah: *We are discriminated against. Many times in Emergency I have heard doctors saying to me, "You are a chronic patient. You have to wait" or "You need to go to your specialist because he is the one that can give you a solution." This situation makes me wonder why I have a health service if I have my appointments with the specialist every third* *month, or why I have a health service if I always get sick the week after my specialist sees me and why I have to wait another three months. Being ill upset the balance of our lives physically and mentally. When I am sick I become depressed, anxious and I always need emotional support. Instead of support what I have found in our health system is just dismissive care. When I see this I always think, "Why didn't I stay at home? Sometimes I prefer to stay at home with my pain rather than go to a place where I will be mistreated. Why should I go to a place where I have a long wait for attention only to receive the same answer? Sometimes I prefer to stay at home rather than go to Emergency to receive half measures such as, "Okay, I will give you something but you need to go back to your doctor." Every time it is the same. At least for me it is always the same. As Doña Maria, my orthopaedist, has said many times, my pain is not part of his area of expertise so his recommendation is always to go back to my rheumatologist and if I go to my other specialists they send me to the rheumatologist and so on. Nowadays I have five specialists; of those five, four send me all the time to my rheumatologist. They don't know how to handle my pain, so they just throw me like a ball from one side to another. So I wonder who is in charge of my care or who is going to say what I should do or where to go. I don't know yet. They don't even agree on what is suitable for my treatment, and the best option of treatment for one is not for the others. In the end, I don't know if I should stop my medications or continue them or what to do.*

Alejandro: *Sorry to interrupt you, but your story reminds me of something I heard last night in the news. In Armenia a patient gathered 3,000 acetaminophen pills, all those prescribed by his doctors. Right there you can see doctors never talk to each other so they continue prescribing the same again and again. It was for the pain but this person ended up with 3,000 pills of painkiller and the insurance company gave away all this medication without even looking at his records.*

Pilar: *Maria what do you think?*

Maria: *Our situation is terrible. We suffer from discrimination because we are labelled as problems. We are a problem for our insurance companies. We are a pain for them. As Hannah said, we have to go from one place to another and we cannot do anything. The only thing we hear constantly is, "We have done everything we can do to help you." In reality we don't receive good attention. One said that all people who need medical attention must receive it but in reality we don't. We should be a priority but we are not. It would be nice to have doctors specialize in this field of chronic illness. I bet that would decrease the inhumane treatment we receive every time we go for attention. In our health insurance companies they see us as nobodies. It has not only happened to me, I have talked to other people with the same condition and they have gone through the same. For example, if we are receiving chemotherapy it would be nice to hear, "With this treatment expect this or that" but they don't really seem to care. They don't really understand our suffering. After the sessions of chemo we used to go through eight days with side effects and we never ever received a follow up call from any health care professionals to see how we were doing. Not even our* *doctor who is my husband's doctor has called us. And yet, it seems so simple and basic to do, just pick up the phone and call to find out how his patients are doing. That's so simple to do but they don't do it. We are always waiting for that call from our specialist or a nurse asking us how we are doing. My husband had a procedure to reduce his pain last Tuesday and today I went to see our doctor and he did not ask me about Alfredo. Indeed, nobody asked me how he was feeling after the procedure. They told me they will call the same Tuesday but until now we have not received any call. Since last Tuesday not even out of curiosity has our doctor asked anything. He just prescribed my prescription and that was it. We worry because it is an experimental procedure and there is no evidence this procedure is going to be effective for people with cancer so it is really hard to see that nobody seems to care. We are abandoned by them.*

***Pilar**: How can we change this indifference? What solution do you propose to change the fact of being excluded or discriminated against by the health care system?*

***Alejandro:** The insurance companies do not want to lose money, so they are not going to waste money improving a service.*

***Clara:** Better if we die quickly.*

***Alejandro:** Another thing I have noticed is how people with diabetes, hypertension or other problems receive the same treatment. Always the same which makes me wonder if all the treatments for all the diseases are the same.*

***Pilar:** What would be the solution for all that? As a group what would be the solution for those issues?*

***Alejandro:** A first step would be to improve the quality of medication. It would be better to receive a pill that costs 20 or 50 pesos rather than one that costs cents or 2 pesos which is not going to improve our health. I believe our situation would improve if we receive good medicine.*

***Clara:** To me it would be nice if they improved the service we receive. The medication is also important; they should take into account that each one of us has a different disease. I think it would be nice if each one of our prescriptions were focused on our personal needs. But in reality if you have a headache, stomach ache or backache we always receive the same acetaminophen. It seems doctors use this medication for everything. For instance, when our kids go to the doctor they all receive the same acetaminophen. One of my daughters suffers from migraine and she always receives the same prescription of acetaminophen. There must be something else besides acetaminophen.*

***Pilar:** One of the proposals is to improve the quality of medication and, second, to receive personalized or individualized attention of which the most important is to understand the person's needs.*

***Alejandro:** Yeah, we need that. If you go to the drugstore in any insurance company and ask people what their prescriptions are, I think most of them would say it is acetaminophen. I wonder if there is no other* *medication for everything or at least something better to alleviate our symptoms.*

Hannah: *I agree with Don Alejandro. In my case, one of my doctors prescribed Aspirin for me which I have to take daily to avoid the formation of clots in my blood. While my doctor was writing the prescription, he said to me, "Don't buy the Colombian version because that one is not coming with the enteric coat to protect your stomach. Buy the American one." Right now I have the means and the people to bring the American Aspirin but what would I do if I were not working. Something simple like an enteric coated medication makes the difference in what would be my quality of life. So I wonder why we cannot access medication that would improve our health and well-being. If I were taking the Colombian version for sure I would be suffering from gastritis. How something simple affects the quality of life of someone chronically ill.*

Clara: *The question is, why don't we have access to those medications in Colombia?*

Hannah: *Maybe it is because of the cost of those medications.*

Maria: *The cost would be one reason because, as I said before, health here is a huge business that, unfortunately, we don't know anything about. To me one of the solutions would be to humanize health care and health care professionals. The quality of attention would improve greatly with humanization not only at the administrative level in our insurance companies but also at the State level. If there is a little of humanity and understanding then we would not be experiencing what we are experiencing right now. Regarding Hannah's topic I think we can produce those medications here in Colombia, and even cheaper, but when people are driven by ulterior motives like business and bureaucracy everything becomes complicated.*

Alejandro: *Yeah, by improving the quality of medication any patient can overcome any circumstance. Probably in the insurance companies they would not see too many people lining up for medications.*

Clara: *It is hard to watch how the elderly are mistreated when they line up for medication. There is no consideration for them; they have to wait many hours to receive attention and sometimes they receive nothing.*

Alejandro: *In one of the branches of our insurance company I saw an 80 years old woman lining up for hours to receive attention. She could not see, walk, write, read or hear. She was alone. She did not remember her phone number, address or the number of her ID. But we all have to fill out a paper with our name, address, phone number, ID number, age and birth date. I saw her struggling with all this information. She missed her appointments that day because nobody in the insurance company had patience with her. Nobody helped her to fill out these forms. Sometimes people lining up help them but the elderly normally show up there alone and they don't remember anything. That's unfair that an 80 year old person does not get any access to the service because nobody cares about them. It is unfair to see someone suffering without any protection.*

Maria: *Why do they have to fill out all these forms if each insurance company has all the information in computers?*

Clara: *There should be someone for the elderly. Someone that explains to them with patience what to do or where to go but, no, the attention is terrible. People in those clerk positions are rude; they don't even say "Hi", and right away they ask you, "What are you doing here?" Or, "Did you bring the referral? If you don't have a referral, you don't receive any attention." They don't seem to care how old we are, they make us come back and line up again. It happened to me with some authorizations I needed for my husband. In the hospital they told me they won't see Alejandro without a referral so I had to go back to the insurance company to set my appointment there. In my insurance company after three hours lining up they told me Alejandro needed to go back to the hospital because after surgery the hospital is in charge of the follow up for one month. In the end, he was not seen by anybody.*

Alejandro: *It was an appointment to see my podologist.*

Clara: *They don't consider us; we had to go back and forth in taxies from one side to the city to the other and in the end, he did not receive any attention.*

Alejandro: *All that travel just to hear, "Go set another time with the doctor." How long to get an appointment? 15 days.*

Pilar: *What would be your recommendation to health care professionals to improve the situation of people with chronic illness in Colombia?*

Maria: *It would be nice to teach them how to treat human beings correctly. We need more humaneness in the service. To me it is essential to have compassion and humanity for us. Also, it would be nice if they have more time to talk to us. As health care professionals you have more knowledge about our diseases so it would be nice to see more dedication, more commitment toward our needs. For example, if someone has breast cancer it would be reassuring to receive all the attention she needs. If the person has a cardiac disease, then her needs are going to be different. Look after someone in a real way. In reality the approach for everybody is the same. They decide what the best is for all of us; we don't have any say in our treatment. Alfredo, for example, is receiving morphine and we know this medication is controlled so we know we are not going to find it in a regular drugstore. Then, to access this medication we need to go downtown, but normally morphine is out of stock there so we have to go by bus to another drugstore in the north of the city. From our home to downtown is almost a one hour trip and to go to the north is almost two hours but people in our insurance company do not stop to consider that. In that drugstore we have to line up for hours without any consideration of our condition. It has happened to us many times. In the end, it would be nice if people were more aware of what chronic illness is and what our needs are. It would be nice to have specialists working in this area. I think that would improve our quality of life.*

Alejandro: *You see the same attitude everywhere. I have seen people in wheelchairs or with oxygen lining up in the banks to claim their pensions from 3:00 AM and coming out at 2:00 PM.*

Hannah: *To me a key element of change is education. We need more health care professionals prepared to take care of the increasing number of people with chronic illnesses. It is not the same to learn how to take care of someone with an acute disease and someone with a chronic condition. Chronic illness needs a different approach. Also, health care professionals should take into account the knowledge we have about our condition because we know better what is happening in our bodies. If we are in pain we know where it hurts. It would be nice if they take into account the knowledge we have about our condition. It would be nice just to find that support because as part of our care it is so important, especially when we go to Emergency--that makes us feel comfortable. We are not asking for some extreme measures, we are asking for simple gestures like a smile or a simple pat in our back or just something simple that makes us feel we are important. Doing this will calm us and it will decrease our level of anxiety when we are in pain. But in reality, they push us away because we are chronic people; then everything becomes frustrating and it creates the opposite reaction in us. That's why humanity and compassion are really basic for health care professionals to practice. Also, I think health professionals must be politically involved.*

Alejandro: *Yeah, we need a little bit of humanity and consideration toward our condition.*

Maria: *That's really important to have someone with knowledge in this area.*

Pilar: *Are there any programs in your insurance companies for your condition?*

Alejandro: *In my insurance company there are no programs for diabetes or hypertension. So there is nobody who can call you and tell you what precautions you need to take into account to keep you healthy. They don't have those programs now. They had them before the restructuring of our insurance company.*

Hannah: *Sure*

Maria: *Yes, that would be wonderful.*

Alejandro: *If you are pleased with the attention, you stay calm and the result will be better health.*

Clara: *Yeah, it is nice when you have someone touching your hand and making you feel that everything is going to be okay. It really helps to know we are not alone.*

Hannah: *Sure*

Alejandro: *It is so simple, and that simple gesture or encouraging words is something that makes us feel worthy, but it is hard to find physicians with that attitude. We need doctors telling us how to handle our condition in a personalized way. If I have diabetes, give me the medication I need for my condition independent of the cost.*

Pilar: *Hannah, have you found any support for your condition in your insurance company?*

Hannah: *No, there are some associations for some diseases. However, I have organized a group of people on the internet for my Arnold Chiari condition. It has been a positive experience because I have met people from all over the world with the same disease. One friend from Sweden is coming soon. So I think it has changed a little bit what I feel about my disease. I don't feel alone anymore. In Colombia, there is nothing, mainly because my condition is still an enigma. So everything is harder for me because there are no programs for people like me. Even if you are diabetic or have hypertension there is no orientation on how to take the medication or what to do. In general, I think insurance companies have not organized anything. We do not really know if it is better to take our pills with breakfast or if we need to fast or what kind of food we need to avoid. We don't receive that information on how to deal with our conditions. For example, despite my background in nursing, sometimes I don't understand what my doctors are talking about because I do not understand the jargon they use to talk to me. I can imagine how difficult it must be for someone without a background in health sciences. So it would be nice if they took some time to explain to us in plain Spanish what is happening to us or what the plan to follow is. In the end, my body is the one that is sick so why don't they include me in the process of treatment.*

Alejandro: *In my insurance company they have a program for the elderly. It is a program that includes only exercise and, look, I know my diabetes is not going away just with going to the park and do some exercise. It would improve my health a little bit but it does not cover all of my body's needs. All the aspects of our diseases need to be covered.*

Hannah: *I think there is a lack of knowledge of what the insurance companies and doctors must know about our conditions. They don't really know how to approach our conditions. There are a lot of people with chronic illnesses and a lot of chronic diseases but it would be nice if the insurance companies develop more programs for us. We need guidance, orientation. If I am taking a treatment it would be nice to receive a call asking how I am doing. Also, it would be better if there is a place I can call and receive advice. Also, we need some advice on when we should go to Emergency or when we should stay at home but we have none. So, if I go to Emergency I have to wait eight hours of my life by sitting in a waiting room to receive dismissive treatment. It would be nice to have someone to ask what to do if have this or that symptom.*

Pilar: *But according to Law 100, insurance companies must include programs oriented to prevention and promotion of health care. Does your insurance company provide these services?*

Maria: *Our insurance company does not provide those services.*

Alejandro: *My insurance company used to have some programs but after the restructuring those programs are gone. They did have home care and palliative care but now we don't have anything.*

Maria: *A follow-up program?*

Alejandro: *Yes, but now there is no one who explains to us where to go, what to do or how to take our medications. For us, knowing that is really important because we need to know what the goal of our treatment is and what the side effects of the medication we are taking are.*

Clara: *Even the pharmacist does not say anything. They tell you how many we need to take but they don't say with what or how we should take them.*

Maria: *Yeah, our doctors do not say a word either. What Doña Clara says is true, physicians just say, "Take this pill every this or that hour" but nobody says if we need to take them with water, milk, juice or coffee.*

Clara: *For example, I've been using inhalators for a long time but nobody really explained to me how they work until one day a nurse told me how to put my mouth and what to do. Before that I was wrong blowing the inhalator like a balloon so all the medication was out of my mouth.*

Alejandro: *We always ask innocently because we don't know, for example, how to take our medications.*

Pilar: *We are going back to the point of how important it is to personalize the attention in the health care system. The quality of medical attention has a deep impact on the way you understand how to handle symptoms and medications. You must be active participants when the goals for treatments are set. Therefore, you are key participants in the attention, attention that needs to be individualized according to your specific needs.*

Maria: *It does not take too much time to explain what to do. Doctors can tell us what to do when they are writing our prescription. But without information we may be perpetuating side effects or not having the expected results from the medications.*

Alejandro: *If you go to the doctor with a headache they prescribe a painkiller and if you ask how you should take those pills the doctor will answer, "Whatever you want. Don't make a big deal of that." So you came out of that office thinking that coffee, beer or milk are good alternatives to take your medication because the doctor does not take a moment to explain. Most of the physicians look down upon us.*

Pilar: *Let's move to the representation in politics for chronically ill people. In the conversation I had with each one of you there was a consensus that there are no politicians or people in the State representing the needs of people with chronic illness. How can we change that?*

Alejandro: *There are a lot of suggestions. We can suggest many things for our treatments. Indeed, we can be a fundamental part of our care. The treatment must be team work in which we are active participants. We can contribute with our thoughts, ideas and knowledge about our condition. There is a saying, "There is no one from whom I have not learned anything;" so, we can contribute with our experience and our age to solve the puzzle of our illness.*

Maria: *I think we should be represented by the physicians because they know more about our diseases.*

Hannah: *I don't think it should be only one profession. I don't think a physician has all the knowledge--a nurse, an administrator, an economist or a lawyer can bring knowledge to the table. So I believe the group must be interdisciplinary with representatives of the health professions, administration of the health insurance companies, law and someone with chronic illness because we know more about our disease. We know how much we have to expend on it and we know the social implications of our condition. Then, when people get together to discuss about us we need to be there. It is, like, to make clear to the State that we exist.*

Clara: *I think we should have a representative in the Senate. Senators never talk about health. They fight about many things but not health; thus, there is no support for any issue that involves health.*

Alejandro: *To me the solution is to listen to the people with chronic illnesses. Being attentive to their needs will help them to improve their quality of life. If the person thinks a certain medication is going to help, why not to take into account the request of that person? But in regards of our treatment, we don't have any say. There is no discussion there. Doctors have the last say.*

Pilar: *All good points, so let me summarize: the solution involves respecting the experience and knowledge chronically ill people have regarding their condition. Second, it is also important to organize an interdisciplinary group with representatives of all sectors to make visible to society and the State the situation of chronic illness. Most important is that this group must include someone chronically ill because it is really by involving them that changes in the health system will happen. You are calling for inclusion of chronically ill people in our society and also inclusion to have a voice and a vote in decisions that affect your life and well-being.*

Alejandro: *Yeah, it's making us participants of the process.*

Pilar: *To conclude the dialogue, I would like to hear what you are going to take with you from this gathering.*

Hannah: *I keep the support with me. I am really young so this encounter has reassured my idea that I am not alone. It has been a relief to find people sharing the same struggles with the health care system. It affirms that I am not alone, that outside there are many people fighting with their insurance companies, Emergencies or their physicians. Unfortunately, it makes me realize how the lack of attention to us is a common experience. Activities like this give us the opportunity to generate proposals to change our situation because only complaining does not do any good for our situation. We need to be part of the solution because when we are ill we know what triggers our symptoms. We need to value and make others value that knowledge about our ill body. Yeah, we have to fight a lot in the health care system but it is from us that the solution must come. We have to reach the point in which we don't have to fight to receive good attention. It is our right so we need to be involved.*

The how is the difficult part but not an impossible one. If we don't act we are perpetuating the lack of attention to us.

Maria: *To me it has been a wonderful afternoon. As Hannah says, we are the ones suffering the pain so we know what we are talking about. It is wonderful to create this kind of activity because we can share in small groups how we feel. It was also interesting to learn about other conditions. Before this meeting I was only concerned about breast or prostatic cancer. We were living in this circle of cancer forgetting that there are other people with other conditions out there. So I think today my world has opened to other situations and other experiences.*

Clara: *It was nice to gather with other people because there are no spaces to share how we feel. So today I am taking this awareness with me about other peoples' conditions. It was nice to share with other people our experiences and how we deal with our illnesses.*

Alejandro: *I take with me the key role we play in the attention we receive. We are the main actors in the process of attention because we have the knowledge. With our input we can contribute to our process of recovery. Our suggestions must be validated by the doctors because, despite that they have the knowledge, we have firsthand experience of what our illness is about. Listening to us is really important if doctors really want to help us. At the end of the route I think the doctor benefits from the patient. It is team work.*

Pilar: *Thanks a lot for your wonderful participation. Today I have learned a lot as a nurse and as a person. It has been an honour to be here and learn more about the experience of living with chronic illness.*

Chapter VII Attending to the Claims of People Chronically Ill in Colombia and Canada

Washing one's hands off the conflict between the powerful and the powerless means to side with the powerful, not to be neutral (Freire, 1985 p.206)

Globalization as a major driving force presents itself as a new ethical challenge for the health care community. This force, ruled by capitalism and neoliberal policies, unifies as much as divides human beings and nations. Economical, social, and political forces have shaped the way societies work and the way human beings interact with one another. Unfortunately, worldwide the major interest is monetary, then, societies, policies, and economies are organized with the desire to control the market or respond to market activity no matter what. In the end, it is an unfair situation, which produces inequalities among people. Life and especially health in capitalism is understood in monetary terms of productivity. The important principle is the production of a workforce to compete in the global market. In health, it means exchanging quality for quantity and the eventual result is a health care system that is seen as a market with goals that focus on supply, demand and competition, thereby reducing the patient to being a mere consumer. Under these tenets people are cured, disciplined and educated to follow these mandates and produce economic reward while those who cannot fit into this capitalistic value of production are marginalized (Dussel, 2000; Freire, 2002, 2004).

Throughout the world, we know that the gap between the worst off and the best off groups is growing in all nations. Wealthier groups are increasingly healthier and living longer, whereas poorer groups have higher rates of illness and are dying at a younger age. The conditions, then, in which people live and die, are shaped by social, political and economic forces. The health of the poor, the social gradient of health within countries, and the marked health inequalities between countries lead to unequal distribution of power, goods, income, and services. As a result of injustice in the immediate, visible circumstances of people's lives, in their access to health services and education, and in their conditions of work and leisure, their chances to flourish will not occur. Today, the health of individuals, communities and populations need more than the availability of medical care (Labonte & Schrecker, 2007).

The inadequate regard for chronic illness is an example of discrimination and indifference that occurs worldwide. Through participants' accounts, we have seen how the distribution, availability and provision of health care and social services, stability of employment, and financial stability profoundly influence health. This work has been an effort to explore the experience of living with chronic illness. In particular, it has been an attempt to show the impact of global forces in people chronically ill. This study shows the lived experience of eight chronically ill people in Colombia and Canada. Through their accounts, we have seen how the distribution, availability and provision of health care and social services, stability of employment, and financial stability profoundly influence health. In Canada and Colombia, the implementation policies of competence, consumerism and individualism have deeply threatened the quality of life and well-being of these participants. The results of this study establish a powerful and credible voice that cannot be ignored. Below I present a compilation of the claims participants share through this dissertation. Their claims are based on their personal experiences with illness, interactions with others in society, health care systems and health care professionals. They want to be heard. There is a claim for understanding, access to health care, compassion, social inclusion and political inclusion. Following this, I present reflections on the group activity I did in Colombia. This activity followed Freire's tenets on conscientization. Through this experience, we created an atmosphere of mutual transformation and understanding. It is through our understanding of the world that the transformation of unequal social relations may be effectively exposed (Dale & Hyslop-Margison, 2010). Indeed, conscientization offers another approach to reality, one that comes from the people affected by chronic illness. Through our dialogue, we became agents for re-invigorating discussion on the dominant discourses in the political, social and economic systems.

Claim for Understanding

Chronic illness has brought in a big change in participants' lives. From being active sociable people, they have been confined to a different world, the world of chronic illness. Chronic illness has disrupted their very way of being. Their lives have to be adjusted to compensate the changes in their bodies. The shift is traumatic because chronic illness never sleeps. But chronic illness invisible or not, does not occur in a vacuum. Through these stories we have seen how chronic illness and its management can and often does deeply affect the lives of the ill and their families—financially, emotionally, socially, and in the running in the household or the raising of children. Consequently, the needs of these people and their families require more than merely medical attention, even when an illness appears to be stable. Being ill upset the flow of their lives making impossible to move forward until they deal with the situation around them. Sometimes the news of illness crumbles the world of the person. Therefore, they do not require more barriers to stop their way forward. They claim for understanding from their physicians, families, friends and society in general. Understanding of someone chronically ill requires adjustments of the rigid structures that govern Colombian and Canadian societies. Then, schools, offices, societies, health insurances companies, health care professionals, and health care services must be prepared to deal with their situation, but in reality they are not. Understanding Hannah Arendt (1994) tells us is never finished. And when one cannot understand the person must make bridges to understanding through imagination, through putting oneself in the person's place. Surely those in power must realize these hardships at some level.

Claim for Access to Health Care and Services

In 2006, the World Bank presented a report on the high proportion of medical expenses paid out of pocket in the poorest nations of the world. This report argued that limited health care access for populations is the result of governments' reliance on public sectors and institutions. Therefore, to solve the problem of limited access to health care the World Bank recommended the organization of private health insurance in those countries (Waitzkin, Jasso-Aguilar & Iriart, 2007). Privatization of health services in Latin America often has happened as part of policies referred to as "market-based reforms" which for the most part are the result of economic globalization. But is it ethically correct for external agencies worldwide such as the World Bank or the IMF to impose on countries consumerism, competence, individualism and unhealthy life styles through neoliberal policies and then demand actions to deal with the situation they created? The Colombian and Chilean health reforms have been sold to the world as examples of success of privatization of services in Latin America (Homedes & Ugalde, 2005). How can the Colombian health care system be called the best example for other nations when chronically ill people are exposed to inequities in access to health care? In Colombia, we have been obedient to the demands of external agencies. Sadly, our health system has been portrayed as a role model of efficiency to be followed by other nations. We have learned to work under the Western standard viewpoint in which all countries ideally would be open to free flow of investment and trade without even taking into account the consequences for human health. As we have seen through this dissertation, states built under neoliberal polices abuse, exploit, and relegate their citizens without any regard of human rights or ethical values.

For some participants in both Colombia and Canada access to health care is not a problem. For others, not only their disease controls their lives but also their health insurance companies determine how, when and where their diseases must be controlled. Then, people who do not know them and their needs have the power to decide what medication they are going to take or what procedure they are going to have. There is no free will for them. It is overwhelming to be exposed to these bureaucratic agendas that only threaten their health and well-being. Then, people chronically ill not only face internal battles but also there are many external struggles that these people must sort out. Authorizations to obtain procedures, medications or treatments require time and that is precisely what they lack. During the wait they have to face setbacks in their health and yet their insurance companies do not respond. They neither have voice nor vote. For some, it is a matter of leaving their situation to fate or they simply try to be a good patient to obtain services. Despite their paying for their health care these participants consider it a favour they have to earn. This strategy does not work, especially when they try to survive the advances of their diseases. But for others it is a matter to defend their right to health. They fight alone to reach a basic level of well-being. When talking about access to health care, participants of this study feel that they inhabit the margins of Colombian society. Nevertheless, they fight fiercely through legal means and thrive to ensure that they get respect for their space as citizens. Their stories are a dramatic example of how the expansion of private insurance services in Colombia has not improved health services for vulnerable populations. Instead of reducing out of pocket expenditures, these policy shifts often have raised such expenditures and have exacerbated barriers to access for these populations (Waitzkin *et al.*, 2007). As I mention in the first chapter, health has been conceptualized as a resource of everyday life and the main determinant of socioeconomic and political development for a country. Despite these declarations, health is far from being considered a basic human right accessible to all because economic growth does not bring greater health outcomes or social equity in accessing health care. Health and social inequities and disparities are the result of the imposition of neoliberal policies worldwide (Hanefeld, 2008). Neoliberal policies have brought about a massive deterioration of living standards, growing income disparities, environmental destruction, an erosion of national sovereignty and the undermining of the development of equity-producing policies (Nef & Robles, 2000). Stories from this study have shown how the chronically ill live under the pressure of corporate agendas and rigid neoliberal structures that serve to dehumanize their condition. This is their claim for better access to health care.

Claim for Compassion

Participants request programs that help them to achieve stability in their lives. Stability in chronic illness is the goal. Much of that work is not clinically based. Since they are the central actors, why not take their role seriously and make them active participants in their health care, not mere spectators? Participants want to have a voice in their treatments. People with transplants are capable of being in charge of their care. And, yet, even Canadian participants perceive that their voices are not heard when suggestions about prevention or alternative therapies are proposed to their physicians. Chronic illness requires new approaches in which both the need for effective health care and the realities of dealing with and living with chronic illness are taken into consideration by health care professionals, insurance companies, society and the state. Participants claim to be the central agents of management of their care. Their main task is, usually, with the assistance of elements of the health care system, to prevent further complications of their illness and to maintain as much stability as possible. These stories address the urgency to create strategies to alleviate the alienation and oppression these people face every day.

Neoliberalism has changed the attitudes of health care professionals toward chronically ill people. The chronically ill ask for solidarity and compassion from the health care system but on their pathway to recovery and control of illness they have found injustice. They experience abandonment from health care professionals who do not appreciate the constraints placed on people suffering from chronic illnesses. There is little compassion in the attention these people receive. For instance, in Colombia, participants claim the current state of the health care system is inadequate to attend to their needs. They believe health care professionals are not trained to deal with unexpected states of chronicity. They claim respect.

Respect for the other means to be focused on the whole person. To respect someone is to recognize the other's place in the world. Respect also requires consideration and believing that the other human being is worthy of our attention and treatment (Dillon, 1992). It is not mere action but, rather, a real commitment toward that other. As health professionals, we must act with normative and ethical values, but within a context that implies understanding of our world and the world of the other (Bergum & Dossetor, 2005). Respect has different dimensions that we cannot deny: it implies emotion, reason, attitude, and values that we use to perceive another person (Dillon, 1992). Respect involves appreciation and understanding of other human beings. Today, the world is contaminated by dehumanization for the sake of economical reward, and health care is not the exception to this rule. Yet, we live in a world where technology and knowledge change every day, a world where those with the knowledge have the power and dominate the world. Therefore, as health professionals we need to make some choices in which common welfare, equality and justice are in an equal balance for each one of our patients (Bergum et la., 2005). To recognize the other as a human being, we need to see beyond the body as an object, beyond the body used for practice. In the stories, health care professionals did not look beyond the physical body of these participants. Sometimes they forgot that these people were not objects of their practice to be acted upon according to written policies, but rather, they were human beings, alive. Participants claim for compassion. They have the same right to be treated with respect. Disengagement toward the vulnerable only perpetuates disparities and inequities in society. As health care professionals, we need to understand that being chronically ill is just a little piece of their lives. It does not define who these people are.

Claim for Social Inclusion

Despite participants in both Colombia and Canada faced their experience with resilience and optimism. Other people and institutions in society have shifted their position from being subjects to being mere objects. Why do the people in this study not find the necessary support from society, the health care system and the state to flourish? We have seen throughout the accounts the damage individualism and disengagement produces in the most vulnerable. Merleau-Ponty (2005), states that the existential structure of human beings is "being in the world" (p.437); but how is it to be "in the world" when the world is mostly driven by competitiveness, consumerist, and individualistic principles? For Freire (2002, 1973), human beings are not only present *in* the world but also they are *with* the world. The world is an objective reality that is independent of humanity and capable of being known. However, how we perceive the world is not merely through associations of images. Being with the world involves, above all, thought and language, not only as a means to collect information and experiences but also as a means to act and change reality (Freire, 1973, 1998). At exploring layers within which people make meaning of chronic illness, it becomes apparent that chronic illness is powerfully shaped and influenced by the social, economic, cultural and political context in which it occurs.

In Canada, participants have described the impact that discrimination from financial institutions and insurance companies have had in their lives. Despite Canadians' positive outlook toward their illness rigid structures in society become obstacles that affect profoundly their well-being and health. There is a lot of stigmatization for participants in both countries. Societies do not ease the life of someone who lives with a chronic illness. In Canada, a transplant society keeps labelling them as sick even when they do not feel that way. Their transplants do not change their health status for insurance companies but payment must increase. It is unfair. Their inclusion in society is difficult. They have to live on the margins of society, trying to survive. It is hard to be alone or to have nobody fighting for their urgent needs. They feel discriminated against. And yet, they do not feel overwhelmed by this discrimination because there is little they can do to fight against policies of private and public institutions.

In Canada, participants manifest how important is to be productive. After their transplants they want to go back and do something in society. Sometimes they find some barriers and they have to demonstrate to their bosses and colleagues what they are capable of. It is hard task. In Colombia, at the time of the study, one participant was retired, two received long-term disability pensions, one was on permanent leave and receiving only 50% of her wage and died while waiting for her long-term disability, and the last one had a casual job. Due to the severity of their illness these participants did not consider going back to work. But at the beginning of their illness some participants had to postpone visits to the doctors or therapies to fulfill the requirements of production that their jobs and schools required. Bosses, principal, teachers did not care the health of these people was at the stake. But for some participants it was too late when they paid attention to their symptoms. Once the body fails to fulfill the requirements of society, the human being is excluded from society. Why? Perhaps it is because under neoliberalism socially, health and illness are the responsibility of each individual. According to Galvin (2002), chronic illness causes changes in lifestyle, behaviour and choice, and places the responsibility for illness on the shoulders of the individual. This notion of individualism has a deep impact not only with respect to how chronically ill people perceive themselves and are perceived by others, but also in relation to how they are expected to interact with the state, health system and the market place. For them, their world is surrounded with more indifference and less solidarity. It is difficult to overstate the effect of indifference on the health, life and well-being of people, especially for these people chronically ill. Neoliberal policies serve to jeopardize democracy, human rights and freedom for communities (Hanefeld, 2008). Neoliberalism has intruded on the analysis of political and social terrain as an effort to justify the superiority of the market as the major guarantor of both economic and social welfare, with minimum government involvement (Oke, 2009). Neoliberal polices do not reflect any voice from people chronically ill. They are only created to produce economic profit and social advantages for few privileged groups in society. The way the world is organized today does not allow people to live with chronic conditions because "... it clashes too uncomfortably with the image of the 'good citizen' as someone who actively participates in social and economic life, makes rational choices and is independent, self-reliant and responsible" (Galvin, 2002 p. 108). For some participants there is a chance to adapt their lives to their conditions imposed socially but for others it is a time to fight back.

Claim for Political Inclusion

Despite that chronic illness is the first cause of death in Colombia and Canada, politicians do not include chronic illness in their campaigns, and the states, through rigid policies of competence, have closed the door on chronically ill people. Indeed, it is overwhelming how the lack of commitment and commitment from the state has kept this group of people oppressed. To be chronically ill in Colombia and Canada is not just to be an individual struggling against fate; it is a societal condition that affects the lives of these participants. According to the participants' accounts, policy strategy in both countries fails to face up to the implications of the prevalence of chronic illness. It prevents a full facing of the responsibilities of a genuinely humane society. This study shows how the marked social inequities caused by the unequal distribution of power, services and goods leads to unfairness in the immediate, visible circumstances of peoples' lives—their access to health care, their conditions of life and their chances of leading a flourishing life. Politicians should pay more attention to what these chronically ill people have to say. Participants have firsthand knowledge of how polices personally affect their lives. Participants with chronic illness do not have ulterior motives or hidden agendas—they simply want to recover their well-being to be equals, as the law promotes in both countries. Their conditions cause them despair and desolation but their emotional realities only worsen when society does not support them and meet their needs. Their stories address the urgency to create strategies to alleviate the alienation and oppression they face every day.

Moving from Claims to Action: Conscientization as a Process of Mutual Transformation

In the current context, prevailing market practices are sustained by ideological forces that marginalize antagonistic discourses while at the same time operate through their imposition in society to legitimize their own beliefs and behaviour. In Freire's work, the needs of the individual learner are placed ahead of corporate political agendas and encourage social reconstruction to achieve social justice (Dale & Hyslop-Margison, 2010). Freire viewed education as a means of conscientization in which knowledge is power, and freedom comes into possession by conquest, never by gift (Freire, 2002). Indeed, education is a key component of any cultural project; it creates the conditions that would ease community and political participation by those traditionally excluded (Blackburn, 2000). Thus, through education, oppressed people transform their lives for the better. To overcome the situation of oppression, people must first critically distinguish its causes, but it is through action that they can create a new situation, one in which it is possible for the oppressed to pursue fuller humanity (Freire, 2002). And, yet, as Freire points out, "Political action on the side of the oppressed must be pedagogical action in the authentic sense of the word, and, therefore, action with the oppressed" (p.66). Therefore, the liberation of the oppressed must be the liberation of human beings, not things.

Conscientization is the ability to analyze, pose questions and affect the socio-political, economic and cultural realities that surround and shape our lives (Leistyna, 2004). It is much more than a mere intellectual process. On the contrary, it is a dynamic or dialectical process in which action is an equally important component (Blackburn, 2000). According to Freire (1973), to achieve conscientization, first, participants must start describing their habits, routines and traditions which need to be critically understood and transformed, if necessary. This process of transformation involves praxis and dialogue. Praxis is an ongoing relationship between theoretical understanding and critique of society that leads to action and transformation of human beings and their environments. For Freire, people cannot simply change a given situation through mere consciousness or the best of intentions, or through unguided actions; he argues that we, as active participants, must unceasingly move from action to reflection and from reflection upon action to a new reflection (Leistyna, 2004).

Following Freire's understandings of conscientization we started our dialogue by describing what the meaning of chronic illness is. In this first part of the dialogue, participants describe their beliefs, values and knowledge about chronic illness. Their descriptions show that they do accept their conditions as a part of their lives. Being chronically ill for them is something that they have learned to deal with. When they describe their conditions, they indicate an acceptance of the reality that their long lasting illness brings to their lives. There is neither fatalism nor drama, just adaptation to the process of being ill. Chronic illness is described as something that one cannot avoid or recover from. Being ill is a process of continued learning and understanding about the ill body. Sometimes they see their illness as a partner and on other occasions as an enemy that they need to keep close in order to control. For some participants, being ill has brought positive changes, mainly because it has improved the bonds with family and friends. Being chronically ill is to be exposed to swings between controlled and uncontrolled periods of their diseases. However, when they are going through uncontrolled periods their lives become overwhelming, mainly because they perceive and feel death as a possible outcome. Chronic illness is a pathway that cannot be walked alone. Support, love and company are fundamental elements needed by the participants. Even in the moments of anguish there is a reward waiting for them. Chronic illness is in their lives for a reason and in the journey to discover the purpose of it they change their lives. Faith and God are important in their lives. For them, God is not responsible for their diseases but is the only one that can take the pain and suffering away. With faith in God they learn to be patient. But also, they know that moderation and caring for the ill body are the ways to deal with their situation. In the end, chronic illness entails a process of recognition of and reconnection with the ill body in which the most important thing to do is to embrace their illnesses. They do not have anything to be ashamed of. Being chronically ill is a process of learning about themselves. It is a learning that entails living in harmony with their body and with their condition.

After the beliefs, thoughts and ideas about chronic illness were explored, we continue discussing chronic illness in the Colombian context. According to Freire (2002), the process of conscientization must lead participants to find out the main difference between nature and culture. By distinguishing themselves from nature and recognizing themselves as subjects, they discover themselves as creators of culture. For Freire (1973), people affected by oppression must be the ones to determine, based on their reality, what their problems are. They must determine what the top priority is in order to make the change relevant and accessible. In our dialogue, participants bring up and discuss a list of issues they perceive as the main causes of discrimination and exclusion for them in Colombia. First, participants find it difficult to access good medications and attention. More money means they would have better medications available and less money means they need to accommodate their illness to the treatment available. Alejandro reflects on how economic means will determine the quality of life of chronically ill people. Alejandro is patience when medical resources are not available or when the financial resources are not enough. Maria, on the other hand, identifies how the higher cost of her condition limits access to health care. She and Alfredo have to struggle the whole time with their access to health services. Like the other participants, they do not receive the support they deserve when it is needed. Hannah finds the attention she received frustrating; she perceives herself as a burden for her insurance company. Participants feel their diseases have lowered their position within the Colombian society. They perceive chronic illness as an advancing threat that not only affects elderly people but also children and adults. For them, insurance companies are seen as greedy corporations with a lot of money ready to invest in other projects rather than to improve services and attention for chronically ill people. They want a supportive health system because without it, life becomes difficult. The neoliberal policies practiced by health insurance companies are responsible for their exclusion. Thus, according to participants, a health care system organized under these policies of exclusion keeps them without a voice and on the outskirts of Colombian society.

In the third part of the dialogue, we discuss health as a human right as it is contemplated in the 1991 Colombian Constitution. They know that health is considered by the Colombian state to be a basic human right. For them, it sounds nice because the right to health entails receiving the best attention by health care professionals, medications and treatments available to cover the needs of all members of a given community. But in reality, participants have to accommodate their diseases to what is imposed by the policies of insurance companies. They wonder why health in Colombia is considered to be a right when they have to pay extra costs to receive attention or to accommodate their symptoms to the rigid structures of the health care system. According to participants, the right to health has been disregarded by health insurance companies for the sake of economic profit. From the health insurance companies' points of view, it would seem that there is no point to invest a lot of money in people who are never going to recover their health completely. Participants feel relegated in status not only by the health system but also by the state: neither of them has given the proper attention to their urgent needs. Accessing health care in Colombia is expensive because there is neither protection nor consideration for people who are chronically ill. For them, health is a huge business that is not easy or cheap to access. Sometimes they have to travel long distances in the city only to discover that they cannot get the attention or medication they require. Some participants prefer to purchase medication in drugstores close to their homes; although it is a personal expense, it can be cheaper than the cost of travel. They are forced to find ways to meet their needs as economically as possible, and if they have conditions that can be monitored at home, they try to care for themselves. However, this does not guarantee complete control of their diseases as with Alejandro's inadequate monitoring of his diabetes, resulting in the amputation of one of his toes.

Although participants have to deal with these issues every day, their physicians seem to be largely unaware of their struggles. It is as if their physicians were living in a bubble where there is no real engagement and interaction with their patients. The medical model to take care of the ill body is the only approach that their doctors know to try to deal with their conditions. There is disengagement in their actions toward these participants. In general, this approach to disease could be related to the Cartesian philosophy of dualism in that the mind is active, un-extended thinking and the body is a passive, unthinking extension (Audi, 2001). The body is a separated entity from the whole and disease is something that invades it, the object (Brody, 2003). This approach to disease reduces participants' identity to a medical term in which they become the diabetes or the breast cancer in need of prescriptions. The experience of illness for participants of this study has been confined to the organic level. Physicians do not pay attention to the daily suffering and struggles participants have to deal with. There is a lack of understanding of the experience outside of the doctor's office. There are no follow up calls to know how patients are during moments of crisis, and, yet, phone calls are a simple and basic a way to find out about their patients. On the other hand, the complexity of chronic illness makes it impossible to be handled by only one medical specialist. Indeed, participants of this study have more than one specialist in charge of their treatment; however, it would be very beneficial for the participants if their specialists met to define what the best option or treatment to follow is. But in reality their specialists do not communicate among themselves. Then, most of the time participants find themselves following contradictory treatments. As a consequence, five or six physicians do not relieve the impact of chronic illness in their lives; on the contrary, it heavily impacts on the well-being of participants. Being ill and not receiving the proper attention upsets the lives of these people. Not having the best attention increases their chances to become depressed and anxious in uncontrolled periods of their disease.

The participants gradually perceive their personal and social situation more clearly, and by critically discerning its contradictions, by discovering its causes and foreseeing its consequences, they become capable of transforming these facts into actions. Through reflection, the transformation of existential reality happens. Reflection leads to a praxis which is action for freedom provoked by reflection; this action will evoke new reflection and so on (Freire, 1973). At the end, this whole process leads to conscientization which according to Freire is the development of critical reflection or the critical insertion of a human being into history and culture. In this part of our dialogue participants analyse problems without allowing them to be blinded by passion. In their diagnosis, as well as in their search for solutions through dialogue, they keep a critical consciousness. One of their solutions to the indifference within the Colombian health care system and to improve their quality of life is to organize an interdisciplinary group with representatives of all sectors to make visible to society and the state the situation of chronically ill people. Most important is that this group must include someone who is chronically ill because it is really by involving them that changes in the health system will happen. Also, the chronically ill know how much they have to expend on their health and what the social implications of their conditions are. As said in one comment, “When people get together to discuss about us we need to be there.” They are calling for their inclusion to have a voice in the Colombian society in decisions that affect their lives and well-being. For participants, it brings out the possibility to overcome indifference with action and participation. Another proposal is to improve the quality of medication: treatment must be addressed according to personal needs not by generic approaches to their diseases. By improving the quality of medication, patients may overcome their circumstances.

They need people with commitment working with them. Chronic illness needs a different approach from those actually provided. They need physicians who take into account the knowledge ill people have about their condition because they have a better understanding of some aspects of what is happening in their bodies. They must be active participants when the goals for treatments are set. They need health professionals who are capable of understanding the fluctuations of chronic illness. They need health care professionals and specialty physicians with the ability to give comfort during the moments of crisis. They need a health care system that is people-oriented, not profit-driven. They demand humane treatment not only at the administrative level of their insurance companies but also at the state level. With a little show of humanity and understanding from these entities, they will not be subjected to the social exclusion they are experiencing. For participants, it is important to teach people from insurance companies how to treat human beings correctly. There should be more compassion, humaneness and consideration, and less indifference for the chronically ill. A simple gesture or encouraging word would help to make them feel more worthy. The health professionals need social awareness of what chronic illness is and what the chronically ill requires. The attitude of disengagement pervades society; for example, Alejandro has seen people in wheelchairs or with oxygen lining up in the banks for hours. They are not asking for extreme measures, just basic changes that make them feel that they are important, that will calm them down and decrease their levels of stress especially during their uncontrolled periods of illness.

To finish the dialogue, the participants share what of value has emerged from the process. For Hannah, the youngest participant of this study, the encounter has reassured her that she is not alone. The dialogue gives her the opportunity to generate proposals to change their situation in society. She is aware of her important role in the solution. She demands recognition of her knowledge, based on her experience, about her ill body and her illness. Hannah does not want to be silent anymore; she thinks the solution to the problems discussed must come from a dialogue between people from the health care system and people who are chronically ill. It is their right, she thinks, but they have to fight for it, a difficult, but not impossible task. Maria gains a new perspective on the others' conditions. She and Alfredo were centred in their own health issues but being in the dialogue has opened up to other experiences and other situations. Clara feels good to have a space to share with others about how she feels and what she thinks. It is an enlightening opportunity to learn about other illnesses besides hers. Alejandro had a fatalistic view of being ill in our first conversation, as the dialogue develops, however, his fatalistic perception changes. For Alejandro, the knowledge the patient has must always be taken into account by physicians. The patients' input can contribute to the process of recovery. They must be included because the work is a team effort.

There is a lot of transformation for all the participants. They feel reassured about their faith and hope for a change. Through reflection, participants have critically placed themselves in their context to describe what the reasons of their oppression are and what the solutions could be. There is no fatalism as the dialogue develops. They want to be active participants; they have moved to a more proactive position. As Freire (2002) points out, critical consciousness has made the world a place full of possibilities. Critical consciousness has helped them to switch from being passive to becoming active. In nursing, conscientization helps us to recognize and attend to the call of the vulnerable, in this case people who are chronically ill. Hence, our responses as health professionals toward the situation of the chronically ill, for example, must be rooted in ethical values and participatory action to avoid exploitation of the vulnerable. Instead of working without commitment *on* people who are chronically ill, it would be better to work *with* them in an open dialogue in with both health professional and patient nourish each other with experience and help. It is the ability to respond in a situation, an ability that cannot be acquired with technology. As a nurse, I have learned how each person has something to teach me. We need to be open to learn, to gain wisdom.

Reflections on the Research Writing Process and Future Directions

Chronic disease is a serious threat to health worldwide and deserves to be treated as a global health priority. This threat has been described extensively by the WHO; however, there is a persistent gap between what is known at the global level, and what is implemented at country level. The impact of globalization over chronic diseases is increasing. However, the prospects for chronic disease prevention and control are only slowly improving. Sustained progress will occur when states, relevant international agencies, non-governmental agencies, and society in general acknowledge that public health, health policies and health systems must include chronic diseases and their risk factors. The challenges are enormous and the progress will remain slow until the response to chronic disease epidemics is scaled up in a manner commensurable with their burden. Through this study I proposed a unique understanding of how globalization forces affect the lives of eight people chronically ill, an approach not previously found in the literature. It clearly reaffirms the importance of family support and positive outlook to overcome chronic illness; however, when the state, health system and society do not support the needs of these chronically ill people, life becomes overwhelming. Such knowledge is needed to provide effective interventions for people chronically ill in Colombia and Canada.

In fact, the results of this research enhance nursing practices with people chronically ill in Colombia and Canada through a number of ways. First, by incorporating the findings from this study into our current understanding of the experience of people living with chronic illness, we strengthen clinical practices that respond sensitively to the needs of people chronically ill. Health care providers can use these descriptive findings to guide them to be more sensitive and tactful in health care situations so they can work toward the improve the delivery of safe, appropriate, and culturally sensitive care. For example, interventions for education and support for people chronically ill are necessary to decrease the risk factors and complications of chronic conditions. These interventions must be oriented to provide adequate acute and long-term management of chronic illness.

Second, the results of this study will be used to create a day of knowledge exchange where researchers, nursing professors, health care professionals, people chronically ill and their caregivers, will meet and discuss these findings and plan ways of addressing their health needs and the effects of globalization. This encounter will provide a venue to articulate the moral and ethical urgency for policy and program development necessary for legitimate reform to reduce health disparities and promote equity for people chronically ill in Colombia and Canada.

Third, in Colombia and Canada advocacy for chronic illness tends to be fragmented and risk-factor or disease specific. This lack of advocacy for health promotion, prevention, management and control of chronic illness contrasts with the growing dominance of commercial and consumer oriented policies of the health system that have mobilized resources and attention only towards communicable diseases while ignoring chronic illness. Stronger and broader alliances of major health professional bodies, academic groups, people chronically ill, policy makers are needed to effectively prioritize prevention, control and management of chronic illnesses. By addressing the influence of external forces on the personal experience of people chronically ill, we encourage in nursing practice the need to advocate and change the reality of alienation for people with chronic illness. As nurses, our responsibility is to be an advocate for our patients. However, our advocacy in this world of inequalities must take into account that self-determination and freedom are the most significant and priceless human rights (Gadow, 1990). Our advocacy is based on recognizing that all human beings, despite their social and economic conditions or their political orientation, have the right to life, health and well-being (Kishore, 2006; Ruger, 2006; Austin, 2004). We must help to alleviate the impact of inequalities and abuse in our own settings; that would be a first step to deal with marginalization and disparities for the chronically ill. It seems that the responsibility for and the ethical treatment of the other human being never comes to an end. Critical education must be incorporated into health professionals' curricula. Human beings are complex and that complexity needs to be addressed in an integral way.

Fourth, once the context, extent, and contributing factors of those inequities are understood, the next level includes policy analysis and policy advocacy (Reutter et al., 2010). Participants in both countries gave to me their life-time, time abbreviated for most of them and I now must move forward to concrete work discovering how the policies that put them in these positions. Then, my next step is to proceed in a policy direction to collate these accounts with a robust analysis of policy documents from Colombian State, Canadian State, the World Health Organization and the World Bank to explain how ideologies of governing parties shape the quality of social determinants for people chronically ill. According to Spenceley, Reutter and Allen (2006), "As a profession we have knowledge that is crucial to intelligent and humane policy discourse; however, we also have a strategic “blind spot” when it comes to bringing that knowledge to the policy table” (p. 190). Nurses cannot be remain in the background or added as an afterthought to the policy arenas (Abood, 2007). Today, we must be aware of how health care is influenced by the asymmetrical, unequal, competitive and consumerist politics of globalization and we should address nursing research toward political advocacy. Political advocacy is the knowledge based action aimed to improve health by influencing system-level decisions (Spenceley *et al.*, 1995; Abood, 2007). According to Dussel (1980), the world needs a new system, one that brings together not only those who control the world today or those who work, but also those whom economists call externalities (Dussel et al., 2006). Dussel et al say, “These individuals [externalities] must be allowed to participate with symmetry in the decision-making of the organization because it affects the development of their lives” (p. 502); thus, social change does not diminish its participants because each one has something important to say. This change must be feasible, entailing what is economically, socially, technically and psychologically possible in each community.

And fifth, in writing and listening to their stories I often became so angry when I see the injustices and the improbability of how an agency can ask a person to come all this way to just make an appointment and then have to come back. My attempt through this study was to give voice to people chronically ill and uncovered the contextual factors that impact individual-based risk factors, health, and health care. This perspective revealed more clearly the resourcefulness and resilience of these participants and invalidated the stigmas and stereotypes that led to discriminatory and stigmatization practices that ultimately kept alive their exclusion from society. This study provided a foundation from which additional research can build and focus on gaps of knowledge in this area. Future research should examine how globalization forces affect the lives of people chronically ill and their caregivers through concentrating on the specific conditions of how policies and practices position those with chronic illness. Research exploring the effects of the current economic *meltdown* in people chronically ill and their caregivers is also needed. There is a continuing need for studies to provide a solid mapping of the problem of chronic illness in Colombia and Canada to guide preventive interventions and strategies to control the setbacks of these conditions. Finally, research exploring the effects of globalization forces in the practice of nursing and its ethical implication are also needed. The already high and still increasing burden of chronic illness in Colombia and Canada requires a concerted and comprehensive response. This response should involve governments, non-governmental organizations, academic and research institutions, and the general public. Actions must be rooted at all levels of healthcare provision, from health care promotion to primary, secondary and tertiary care. The way the world is run today there is no place for many who live in poverty, are unemployed or chronically ill.

To end

These participants have taught us that in health care professionals cannot work with indifference or concentrate on physical things, or work as separate entities, forgetting the patient and leaving behind their humanity. These people's stories taught us that each part is nothing without its counterpart. In nursing we are nothing without our patients: they are the reason for our work, they are our complement, and we cannot do our work effectively if we do not look beyond our own world. However, sometimes we build an invisible border and in that way we live behind walls. Those walls are created by our mind through biases, culture, and ignorance. They are walls which do not allow us to see what happens outside in another's world. Breaking down those walls makes it possible to open the way to understand and tolerate others, and, of course, it is a way to acquire new knowledge and other ways to perceive the world. In nursing we learn how to face everyday illness, suffering and death, learn how to deal with each as a part of our profession. Nothing is permanent; we need only to enjoy the good or endure the bad because from both we can gain valuable experiences. That is the wisdom of nursing: recognize first the imperfection and then continue growing from that.

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Appendix 1 Information Letter Canada
Information Letter for People Chronically Ill in Canada

Study Title:	Understanding the Experience of Chronic Illness in the Age of Globalization	
Investigators:	Maria del Pilar Camargo P. RN, MN PhD Candidate Faculty of Nursing University of Alberta	Brenda L. Cameron, RN, PhD Doctoral Supervisor Professor Faculty of Nursing University of Alberta

Why we are doing the study: Many studies about chronic illness have been conducted. However, we still know little about how people chronically ill experiences their lives. Your participation will help us to improve our understanding and attention to people chronically ill.

Purpose: Your participation will help us to understand what it is like for you to live with chronic illness. This study is part of doctoral work in the Faculty of Nursing at the University of Alberta.

What will happen if you take part in this study:

1. As participant, you will have interviews with Maria del Pilar Camargo Plazas. She will invite you to talk about your experience with chronic illness. You may wish to talk about particular experiences you have had. During the conversations Maria del Pilar will ask you the following questions:
    - How is your everyday life with chronic illness?
    - How do you feel about that?
    - How your family and friends respond to your experience?
2. Interviews will take place at your home or any place at your convenience. They will take place often at a time appropriate for you and for as long as you wish. We will record and type your interviews.
3. Later on Maria del Pilar will invite you to participate in a group activity with other participants. We will talk about general concerns in chronic illness. However, we will not discuss there your interview.
4. This meeting will take place in a community place close to your home. The group will not have more than five participants.
5. We will record the group activity.

What are the benefits for you: There may be no benefits to you personally. However, through interviews and your participation in the group activity you may gain new insights about your illness and your life. The results of this study may help us to provide more sensitive care to the chronically ill.

What are the possible risks for you: There are no major risks involved related to this study, but answering some questions may make you feel upset. You may also get upset about the ideas being expressed by others in the group activity. If this happens, please tell the persons in charge of the group activity. We do not know of any other risk of taking part of this study.

How we will maintain your privacy: All information gathered in this study will be stored in a locked cabinet. We will keep all the information from the study for at least seven years. We will store consent forms and study information separately to protect your identity. Only the researchers will have access to your information. We will not write or disclose your name in the information collected. We will only use your initials and coded number. Reports published as a result of this study will not identify you by name.

We need to tell you that in the group activity we may not be able to keep confidential what was said in the group. This is because in the group we will be talking about stories of what it is like to be chronically ill. We will ask people to keep what is said in the group as confidential.

Voluntary Participation: Your participation in this study is completely voluntary. If at any time you wish to withdraw from the study, you are completely free to do so. In the interviews and in the group activity you do not have to answer all the questions or discuss all the topics if you do not want to.

If you have any concerns about the study: please feel free to contact Dr. Christine Newburn-Cook, Associate Dean Research in the Faculty of Nursing University of Alberta, at (780)492-6764. She is not connected with the study.

Please contact any of the individuals identified below if you have any questions or concerns:

Maria del Pilar Camargo P (492-8185) or Dr. Brenda Cameron (492-6412).

If you agree to take part in this study, please sign the consent form attached to this letter.

Appendix 2 Consent Form Canada

Study Title: Understanding the Experience of Chronic Illness in the Age of Globalization

Investigator(s): Maria del Pilar Camargo Plazas PhD (c), Faculty of Nursing, University of Alberta, phone (780) 492-8185

Dr. Brenda Cameron, RN, PhD, Professor, Faculty of Nursing, University of Alberta, phone (780) 492-6412

Participants: Please circle your answer to each question. If you do not understand a question, or you answer "No" to any of the questions, please speak with the person who explained the study to you for more information

Do you understand that you have been asked to be in a research study?	Yes	No
Have you read and received a copy of the attached Information Sheet?	Yes	No
Do you understand the benefits and risks involved in taking part in this research study?	Yes	No
Have you had an opportunity to ask questions and discuss this study?	Yes	No
Do you understand that you are free to withdraw from the study at any time, without having to give reason and without affecting your future medical care?	Yes	No
Has the issue of confidentiality been explained to you?	Yes	No
Do you understand who will have access to the research data?	Yes	No
I agree to take part in this study	Yes	No

This study was explained to me by:
__________________________on________________ (Date)

By signing this consent form, I agree to participate in this study

Participant (Printed Name) ______________________ Signature

I believe that the person signing this form understands what is involved in the study and voluntarily agrees to participate

Researcher (Printed Name) ______________________ Signature

Appendix 3 Information Letter Colombia
Carta de Información para Personas con Enfermedad Crónica en Colombia

Titulo del Estudio:	Entendiendo la experiencia de vivir con enfermedad crónica en la era de globalización	
Investigadores:	Maria del Pilar Camargo P. MN PhD Candidata Facultad de Enfermería Universidad de Alberta	Brenda L. Cameron, RN, PhD Supervisora de Doctorado Profesor Facultad de Enfermería Universidad de Alberta

Porque estamos realizando este estudio: Diferentes estudios se han realizado sobre la enfermedad crónica. Sin embargo, poco conocimiento se tiene sobre la forma en que las personas con enfermedad crónica experimentan esa situación en sus vidas. Su participación en este estudio nos ayudara a mejorar la comprensión y atención brindada a las personas con enfermedad crónica.

Propósito: Su participación nos ayudara a entender que es para usted vivir con enfermedad crónica. Este estudio es parte de un trabajo de doctorado de la Facultad de Enfermería de la Universidad de Alberta.

Que pasara una vez usted tome parte de este estudio:

1. Como participante usted tendrá conversaciones con Maria del Pilar Camargo Plazas. Ella lo invitara a hablar acerca de su experiencia con la enfermedad crónica. Quizás usted desee hablar de experiencias particulares que usted haya tenido. Durante las conversaciones Maria del Pilar quizás le haga las siguientes preguntas:
    - ¿Cómo es su diario vivir con una enfermedad crónica?
    - ¿Cómo se siento con ello?
    - ¿Cómo su familia y amigos han respondido a esta experiencia?
2. Las conversaciones tendrán lugar en su casa o en otro lugar de su conveniencia. La programación y duración de estas se hará de acuerdo a su conveniencia. Cada uno de los encuentros será grabado y transcrito.
3. Más tarde Maria del Pilar lo invitara a participar con otras personas enfermas crónica a una actividad de grupo para discutir aspectos generales de la enfermedad crónica. El grupo solo se reunirá una vez. Los tópicos para el grupo saldrán de las preocupaciones en general de los participantes en el estudio. Sin embargo su historia personal no será discutida allí.
4. Estos grupos de discusión se harán en un lugar cercano a su casa. El número de participantes no sobrepasara de cinco personas.
5. Durante la reunión usted y los otros participantes discutirán aspectos generales de la enfermedad crónica. En la reunión Maria del Pilar los animara para participar y desarrollar los temas.
6. La sesión será grabada.

Cuales son los beneficios para usted: Quizás no haya beneficios directos por su participación. Sin embargo, a través de las conversaciones y su participación con el grupo usted obtendrá una mejor comprensión de su enfermedad y de su vida. Los resultados de este estudio nos brindaran un punto de partida para mejorar nuestra atención y cuidado hacia las personas con enfermedad crónica.

Cuale son los posibles riesgos para usted: No hay riesgos conocidos en este estudio, sin embargo contestando algunas preguntas quizás usted se sienta incomodo. Quizás usted también se sienta incomodo con las ideas expresadas por otros durante la actividad en grupo. Nosotros no conocemos de otros riesgos al hacer parte de este estudio.

Como se mantendrá su privacidad: Toda información reunida en este estudio será guardada bajo llave. Nosotros mantendremos toda la información sobre este estudio por lo menos durante siete años. Nosotros mantendremos los consentimientos firmados separados para proteger su identidad. Solamente los investigadores tendrán acceso a su información. Cualquier información recogida durante este estudio no tendrá su nombre, solo se identificara con sus iníciales y un numero. Su nombre no será publicado. Cualquier reporte publicado como resultado de este estudio no lo identificara a usted con su nombre.

Participación Voluntaria: Su participación en este estudio es completamente voluntaria. En cualquier momento que lo desee se puede retirar. En las conversaciones usted no tiene que responder todas las preguntas o discutir todos los temas si usted no quiere.

Si usted tiene alguna pregunta o queja relacionada a este estudio: por favor siéntase libre de llamar a Clara Virginia Caro Castillo Coordinadora Posgrados en Enfermería teléfono 316-5000 ext. 10326 o 10333 en la Facultad de Enfermería de la Universidad Nacional. Ella no está asociada a este estudio.

Si tiene alguna duda o preocupación puede contactar a las personas identificadas abajo:

Maria del Pilar Camargo P en Colombia 222-7914 en Bogotá o 1(780)492-8185 en Canadá
Dr. Brenda Cameron 1(780)492-6412 en Canadá.

Si usted está de acuerdo en participar en este estudio, por favor firme el consentimiento informado de este estudio que se encuentra adicionado a esta carta.

Appendix 4 Consent Form Colombia

Titulo del Estudio: Entendiendo la experiencia de vivir con enfermedad crónica en la era de la globalización

Investigadores: Maria del Pilar Camargo Plazas PhD (c), Facultad de Enfermería, Universidad de Alberta, teléfono 222-7914 Bogotá o 1(780) 492-8185 Canadá

Dr. Brenda Cameron, RN, PhD, Profesor, Facultad de Enfermería, Universidad de Alberta teléfono Canadá 1(780) 492-6412

Participantes: Por favor conteste cada pregunta. Si usted no entiende una pregunta o su repuesta es "No" a alguna de las preguntas, por favor hable con la persona que le explico el estudio para que le de mas información.		
¿Usted entiende que le han preguntado si desea ser parte de una investigación?	Si	No
¿Ha leído y recibido una copia de la hoja de información incluida aquí?	Si	No
¿Usted ha entendido los beneficios u riesgos envueltos al tomar parte de este estudio?	Si	No
¿Ha tenido la oportunidad de preguntar y discutir el estudio?	Si	No
¿Usted entiende que es libre de retirarse del estudio cuando lo desee sin tener que explicar y sin que esto vaya a afectar su futura atención medica?	Si	No
¿Le han explicado el tema de confidencialidad a usted?	Si	No
¿Usted entiende quien será la persona que tendrá acceso a su información?	Si	No
Yo estoy de acuerdo en hacer parte de este estudio	Si	No

Este estudio me fue explicado por______________________ el día ______________________

Firmando este consentimiento yo estoy de acuerdo en participar en este estudio

______________________________ ______________________

Nombre Participante Firma

Yo creo que la persona que está firmando esta forma entiende que está haciendo parte del estudio y voluntariamente participa.

______________________________ ______________________

Nombre Investigador Firma