

Neoliberal-Oriented Health Care System Answer to Global Competition or a Threat to Health Equality for People With Chronic Illness

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The aim of this article is to explore how a neoliberal-oriented health care system affects the experience of people living with chronic illness. We report findings from a critical hermeneutic phenomenological research study that explored how the social, economic, and political structures impinge on the lives of people with chronic illness. Research findings of this study show how the people with chronic illness in Colombia live through the effects and pressures of globalization and corporate agendas. Results also showed how the marked social inequities caused by the unequal distribution of power, services, and goods leads to health inequities and social exclusion of research participants. **Key words:** *access to health care, chronic illness, globalization, health equity, neoliberalism, nursing*

Washing one's hands of the conflict between the powerful and the powerless means to side with the powerful, not to be neutral.^{1(p206)}

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We thank the University of Alberta Faculty of Nursing Helen E. Penhale Graduate Research Travel Award for funding this study.

We express our sincere appreciation to the Dean of the Faculty of Nursing at the National University of Colombia Professor Natividad Pinto Afanador for her unconditional support. We thank the ongoing support of the Grupo de Cuidado al Paciente Crónico y su Familia associated with the Faculty of Nursing at the National University of Colombia. We are also very grateful for the generous support and engagement of Professor Lucy Barrera Ortiz and Professor Lorena Chaparro, members of the support group. Their collaboration was integral to the development of this research study.

We lack words to express our deepest and sincerest gratitude to our 5 participants in Colombia who generously consented to participate in this study and so enthusiastically and thoughtfully gave their time to engage with this study and offered without hesitation the hospitality of their homes. We will never be able to thank them

UNDERTAKING this study with people with chronic illness has meant being attentive to how 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.

enough. It is for them and others with chronic illness that we hope this research will have an impact on.

The authors have disclosed that they have no significant relationships with, or financial interest in, any commercial companies pertaining to this article.

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DOI: 10.1097/ANS.0b013e31825372a4

People with chronic illness have to strive to attune themselves not only to the complexities of their ill body but also to 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. Therefore, strong support from the health care system makes it easier to overcome the unexpected situations that come along with chronic illness. However, when the health care system's orientation does not support the needs of people with chronic illness or makes access to timely care difficult, life becomes overwhelming. In this article, we critically examine how a neoliberal-oriented health care system affects the experience of living with chronic illness. Throughout this article, we present findings from a doctoral research study² that explored the meaning of living with chronic illness in Colombia in the age of globalization. We end with a discussion and future research, practice, and education implications.

GLOBALIZATION AND NEOLIBERALISM

Globalization is a complex and disputed concept that presents itself as a new ethical challenge for the health care community.^{2,3} This force, ruled by capitalism and neoliberal policies, unifies as much as it divides human beings and nations. Globalization is understood as a more or less economic process characterized by increased deregulated trade, economic communication, and capital mobility. It encompasses not only economic, political, and technological forces, but also social, cultural, and environmental aspects.^{4,5} 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.⁵⁻⁷ Detractors 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.^{4,5}

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.^{5,8} 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.^{4,8} 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.^{8,9} Neoliberalism has brought devastating consequences, including the widening social disparities and the concentration of income and wealth among a few.^{2,3}

Neoliberalism 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.^{5,9} The core of a healthy and egalitarian society is an effective health care system. According to the Commission on Social Determinants of Health,¹⁰ to achieve national and international goals—including the Millennium Development Goals*—it is necessary to invest in health services and systems. Throughout the world, governments are seeking innovative ways to create innovative health care systems with the help of communities, non-governmental organizations, and the private sector. And yet, there is no guarantee the poor or marginalized will benefit from reforms unless they are carefully designed with this end in mind.⁵ Yet, neoliberalism perceives health care systems as commodities where productivity and economic growth are the sources of potential revenue.^{5,8} In neoliberalism, health care systems cannot be seen as public and social goods. Institutions like the World Bank promote health care systems

*Millennium Development Goals are goals adopted by world leaders in the year 2000 and set to be achieved by 2015. They provide strategies to tackle extreme poverty in its many dimensions.

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, neoliberalism has been associated with the weakening of the health care systems in middle- and low-income countries.⁵ According to the World Health Organization,¹¹ health care systems in too many countries are on the point of collapse or are accessible only to particular groups in the population. Health reforms have systematically benefited some groups at the expense and detriment of others.^{10,11}

HEALTH REFORM IN COLOMBIA

Colombia is a middle-income country of 45 million people located in the Northwest side of South America. In 1993, Colombia's health care 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, such as the social determinants of health, that incorporate internal realities.¹² Under this reform, the State relinquish its role in delivering health care and the health care system must be self-sustainable by selling services.¹³ This health reform is based on 9 key principles: equity, universality, solidarity, efficiency, quality, responsibility, respect for cultural and ethnic diversity, community participation, and effective integration—all of them are considered important to pursue well-being.¹⁴ This reformed ruled (a) individual insurance as the only mechanism of affiliation to the system; (b) the health care system is composed of, first, the Contributory Subsystem, which covers employees and those who can afford to pay, and, second, the Subsidized Subsystem, which covers those who cannot afford health coverage; (c) services are provided in both subsystems by health insurance companies called *Empresas Promotoras de Salud*; (d) health insurance companies must cover a basic plan that includes medical procedures, hospitalization, and treatments (those medica-

tions and procedures not included in the basic plan must be bought in the market); (e) public hospitals and primary health centers before financed by the state must compete with private institutions for contracts with health insurance companies; and (f) primary health care must be provided by health insurance companies.¹⁵

Colombia's health reform has been widely criticized because the goal of universal coverage by the year 2001 was not achieved. Colombia's current health care system covers only 89% of the population.¹² Competition between the public and private sectors led some of the public hospitals into bankruptcy mostly due to old infrastructure and technology, lack of resources, and administrative preparation to face competition with private hospitals.¹²⁻¹⁴ Financing catastrophic or high-cost conditions such as organ transplants and chronic conditions have also threatened the financial stability of Colombia's health care system.¹⁵ Finally, insurance companies refused to fulfill their obligations in primary health care mainly because community work is not as profitable as hospital care.¹⁶ This health reform has only strengthened the private sector and increased social inequities in Colombia.

THE GLOBAL DIMENSION OF BEING CHRONICALLY ILL

Globally, chronic diseases are a major problem and they are a barrier to development and alleviating poverty.¹⁷ Chronic diseases, including cardiovascular diseases, 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.¹⁸ 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%.¹⁹ 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 global or country level.²⁰ For example, there is no pertinent representation of chronic diseases in the United Nations' Millennium Development Goals.³ Chronic diseases are being ignored by policy makers and development agencies, and limited funds mean limited action to address prevention and control.²¹

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.¹⁸ 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 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.²²

Studies, to date, in chronic illness have demonstrated that the economic cost and burden of chronicity threaten to overwhelm economies and health care systems worldwide.²³ Despite increasing attention to issues of health care for people with chronic illness, having no health insurance is significantly associated with health care access barriers in this population.^{24,25} There is 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.²⁶ For people with chronic illness, delayed or forgone care may represent missed opportunities to improve

functioning, provide preventive services, or delay disease progression.²⁷ In low- and middle-income countries, studies have widely described the main barriers to accessing health care,²⁸ the cost of chronic conditions, the difficulties to access medications in developing nations,²⁹ and the link between poverty and chronic illness in low- and middle-income countries.³⁰ In both developed and developing nations, studies in nursing care have 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 up of nurses' interventions, implementation of self-management programs, and shared decision-making programs to assist a decrease in debilitating behaviours.³¹⁻³³ As well, research has been focused on the cultural shift and the change in the cultural values that are required for initiatives of prevention to be successful in dealing with chronic illness.³⁴ A complicating factor is that, to date, little is known about how globalization forces come together and impinge on the body of a person with chronic illness and subsequently direct the care. The need for this specialized knowledge of subjective data is significant because it will assist us to improve our understanding and develop stronger nursing practices for people with chronic illness.

RESEARCH APPROACH

In what follows, we look at how the marked social inequities caused by the unequal distribution of power, services, and goods leads to unfairness in the immediate, visible circumstances of research participants in Colombia. Through 5 stories, we attempt to give voice to the experience of people with chronic illness and uncover the contextual factors that have an impact on individual-based risk factors, health, and health care. Our perspective entails a claim for social awareness of what chronic illness is and what the person with chronic illness requires. We present stories that come from a doctoral

research study involving the experience of living with chronic illness in light of globalization forces. The overall purpose of the doctoral study was to understand the effect globalization forces have on the personal experience of people living with chronic illnesses. Globalization forces, in this context, were the political, economical, and social effects that manifest themselves within the experience and the physical self of these people that affected their ability to live well and flourish. A small phase of the study was conducted in Canada and the major phase was undertaken in Colombia. In Colombia, participants were recruited through a support group for people with chronic illness and their families associated with the faculty of nursing of a public university in Bogotá, Colombia. In Canada, participants were recruited through a foundation that works with people with chronic illness. Ethics approval was granted by the University of Alberta research ethics board. In this article, we limit ourselves to report findings from the Colombia wing of the study including the scope of literature that informed the study due to space limitations.

The method used in the doctoral research cited earlier involved a critical interpretive methodology, as informed by the works of Freire³⁵ and van Manen.³⁶ An interpretive approach facilitated the interpretation of the various dimensions of human experience in human situations such as embodiment, spatiality, relationality, and temporality. A critical approach was used to examine emerging findings in the context of globalization and resulting global inequities. As a research approach, interpretive inquiry evokes thoughtful questioning and understanding of human experiences. Hermeneutic and phenomenology are schools of thought positioned within the human science philosophical tradition, as portrayed in the writings of Heidegger, Gadamer, Merleau-Ponty, and others.³⁷ Hermeneutic phenomenology is concerned with the interpretation of the structures of experience and with how things are understood not only by people who live through them, but also by people who study them.³⁸ In nurs-

ing, hermeneutic phenomenology reveals the many possible ways we may experience, express, and understand the nursing world and the relations that comprise it.³⁹

Although hermeneutic phenomenology facilitated the understanding of human experiences of being chronically ill in Colombia and Canada, as stated earlier, the underpinnings of globalization required a critical approach to investigate the structures by which people with chronic illness are dominated and oppressed economically, politically, and socially. Moreover, a critical approach examines institutional and social practices and processes, identifies barriers and facilitators to change, and discovers the reasons for the success or failure of interventions. 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."^{40(p385)} Thus, critical approaches in nursing help to promote change and empower human beings by critically determining the social, political, and economic phenomena that place restraints on them.⁴¹

Through the philosophy of liberation by the Argentinean philosopher Dussel⁴² and the critical pedagogy approach by the Brazilian educator Freire,³⁵ this doctoral research critically explored the effects of globalization for the chronically ill. Their ideas are consistent with the doctoral research goals. Both Freire and Dussel thoughts emerged from South America, a continent that has been living under foreign imposed policies that 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. Dussel's philosophy of liberation informed our understanding of the experience of being chronically ill through his analysis of how society is organized using the concepts of the center and the periphery where the marginalized abide. And Freire's critical pedagogy helped us to explore emerging findings of that experience of chronic

illness in the context of global inequities. Both Freire and Dussel helped us 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 people with chronic illness are active participants.³

Using the critical hermeneutic phenomenological approach, data were gathered for the doctoral research study through conversations with 5 research participants. In Colombia, participants were accrued through faculty members in charge of the support group, as nurses, they were extremely careful and judicious at the moment of inviting a person to participate in the study. Potential participants received written and verbal information about the study, and prior to each conversation, they were contacted and explained the purpose of the study, given the choice of time and place of conversation. It was repeatedly stressed that participants had the right and opportunity to withdraw their consent at any time, although none did so. No individual information is reported here, and all names are pseudonyms. Conversations were conducted either at participants' home or at coffee shops. Participants were adults who at the time of joining the study were independent, able to communicate in Spanish, and relatively stable in terms of their illness presentation. Overall, participants were eager to contribute with their experiences to the study.

The conversation questions focused on the daily experience of living with chronic illness in Colombia; the emotional feelings associated with the disease; the experience of accessing health care services; the effects of chronicity on social life, work life, and family life; and the representation of chronic illness in society, state, health care system, advocacy groups. Conversations recorded and transcribed were not identified by name to ensure confidentiality. The data analysis of tran-

scripts followed van Manen's thematic analysis, in which transcriptions are read as a whole, then as sections of descriptions and stories, then as phrases and words in search of particularly revealing statements or themes.³⁶ Thematic moments was developed by reading and rereading the transcripts and also by replaying the audiotapes to ensure turning to the essence of lived experience. Emerging themes were further refined through conversation with participants until they evoked a particularly revealing understanding. This analysis aimed to reveal the complexity of the experience of living with chronic illness under the effects of global forces embedded in the rich descriptions. The analysis was done separately with each group of participants (Colombia and Canada) and written as findings of 2 groups. To maintain the rigor and credibility of this study, 8 criteria to work on culturally competent scholarship in nursing of Meleis⁴³ were used. The 8 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 participants were one of the most important priorities to get their trust during the whole process of research.

FINDINGS

The Colombian participants gave vivid accounts of how the unequal distribution of health care services affected them and how it leads to their social exclusion. The lack of appropriate and equal access to health care services had a significant effect on every aspect of their lives. These effects were exposed through the analysis of transcripts in which the following 5 themes were identified: (1) "My life was at stake and my insurance company does not care"; (2) "We have not received good attention without fighting"; (3) "For our health insurance company we are high maintenance people"; (4) "Society

doesn't give a damn for us"; and (5) "I experience preferential treatment in my insurance company." The principle of the health reform stated earlier that they need to approach health care through their insurance companies had imposed a very heavy burden on their ability to live with their chronic illness. Each one of the participants had a different insurance company.

My life was at stake and my insurance company does not care

Hannah was living with chronic illness for more than 10 years. Her condition began when she was in her last year of high 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. The pain, which had become part of her life for a long time, was what defined and oriented her rhythm of life. The whole experience was 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 had not been an answer; her illness had continued its violent course while not giving her or her doctors any clue to what it was. She had not come to terms with this part of her condition; it was hard for her to fight against something unknown. In what follows, we present how she experienced access to health services in her insurance company:

My insurance company is supposed to cover everything regarding my health, but it doesn't. 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.

Etymologically, the meaning of *to wait* is to watch, to guard.⁴⁴ As she waited, Hannah became bewildered and powerless. She kept guard of her health but her guard was from the margins. In reality, she did not have any control over which way to turn. She did not have any voice or vote in terms of her treatment. The power dwelled in people who hardly knew her. They were in charge of deciding what test, treatments, or medications were suitable for her. It was overwhelming for her because her health was at the stake. Others had the power to decide what medication she was going to take or what procedure she was going to have. There was no free will for Hannah; she waited.

For Hannah, being ill cost a lot of money. In fact, sometimes she could not afford being ill. A medication that was not covered by her insurance company became a reason for distress in her life. Her ill body did not understand what the priorities for the insurance company were. She needed the medication immediately. The insurance company had a different order of priorities and all of them were against what Hannah needed to control her disease. And yet, pain could not be put

[‡]On October 13, 2011, 80 000 COP (Colombian Peso) = US\$42.01 at an exchange rate of US\$1 = 1904 COP.

on hold; pain arrested her dreams and life. Hannah could not suspend her illness until the insurance company had time to attend to her pressing needs. 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 did not know what Hannah was going through when she was ill. She suffered the dismissive attitude of the people in charge of her health and well-being. Her world was limited by others. People in Hannah's insurance company did not know all of the vicissitudes she had to confront everyday with her ill body. And yet, they had the control over her. They had the power to dismiss her pain. In the end, Hannah was resigned to her fate. She waited and hoped her body did not betray her during the waiting time. How long could she hold on?

We have not received good attention without fighting

Maria was in her late 40s. She worked for a long time until she was forced to retire due to cancer. Her breast cancer was discovered by accident. In her first visit to her new doctor, a mammogram was requested, although her last one was done just 11 months before. During a mammogram, 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. Through a biopsy, Maria confirmed she had cancer. At first, she did not say anything to Alfredo her husband because he had cancer too. The moment she disclosed to Alfredo the news was really hard for both of them. The following anecdote describes her struggles in accessing procedures to control her disease:

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 ultrasonography 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.

Maria needed an ultrasonography, something simple; however, her insurance company did not grant the service. There are several, and, sometimes, contradictory excuses. After 4 months of waiting for the service, Maria and Alfredo decided to complain to the Minister of Health. They got what they wanted through legal actions. What seemed impossible to grant before was readily provided when legal actions were taken to defend a basic human right to health. The battle against chronic illness was not only an internal one but also there were many external struggles that these people had to sort out. There were barriers for some, like Hannah's difficulties, and for others, the battle never ended 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 knew. It is overwhelming. In the next anecdote, Maria recalled what happened when Alfredo's intravenous catheter was dislodged:

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 complaints 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 ultrasonography or my blood work and that's it.

Maria and Alfredo's insurance company did not provide home care visits. As well under neoliberal policies, health care professionals often became disengaged because of having to neglect some things and pay attention to others. This created ethical dilemmas and often an erosion of their caring practices. This added to the day-to-day struggle to treat the ups and downs of chronic illness. Alfredo's health was a little more delicate and required more vigilance of health care professionals; however, they did not have access to any kind of home service. Medication that required being administered by trained personnel was left in the hands of Maria. Maria was neither a physician nor a nurse. She was a school psychologist who was in charge of Alfredo's care;

however, there were some things she did not have the knowledge and experience to solve. As a caregiver, she required a hand to help her through those moments when Alfredo required professional care. Besides, she also had cancer and she needed someone to take care of her needs too. She did not have the knowledge to administer medications. When she called the insurance company, she was upset because she could not provide the attention Alfredo needed. Alfredo needed his painkillers immediately but they had to wait 4 hours to get his catheter checked. The first comment they received from the health care professional was not his name or who he was but the warning that next time the insurance company would charge for the home visit. Maria dreamed of having a more humane service in the future. She recognized how dehumanizing her insurance company was. Without examining her, the physician determined that her condition had improved. How did he really know?

We do not receive the proper attention from the government and the insurance companies. 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.

Like Hannah, Maria found it hard to go against the flow. She knew there were no people fighting for her in the government. Maria, Alfredo, and Hannah remained alone in their fight for care against a health care 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 seemed to be alone despite that the number of people with chronic disease was increasing in the country. Maria liked to be politically active. And yet, she had seen that once they received their pension, the support of the union was gone. They were not protected by them anymore. It seemed that they had lost their right to participate in society. Her space was limited by others. Her body was not the able body anymore so the value of being productive was gone.

For our health insurance company, we are high-maintenance people

Alfredo is in his 50s. He loved to practice several sports. He had 2 daughters. The youngest one was 5 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. The news of cancer was another desolating moment that, added to his divorce and his work overload, resulted in his depression. There was no motivation for him. During this time, he met Maria; they were working together. She was his company during chemotherapy and radiation treatments. After 5 years in the rela-

tionship, they decided to get married. His life changed with Maria. She gave him a new beginning, another reason to fight. This is what he said about his experience accessing health services:

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. For example, six months ago we went to the doctor for a follow up visit where we were expecting to find out how my health was but the doctor limited the visit to refilling my prescription of Morphine and nothing else. So we wondered how my cancer was doing. Another doctor told us we needed to go to this institute specialized in cancer to really know what to expect with my cancer. With this information we went back to my doctor to request a referral to this institute. My 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 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 me over to the institute. Something we were fighting for three months we obtained in three hours.

Maria and Alfredo worked as a team. They knew each other's issues with the health care system. Alfredo was a lawyer, so, for him, it was easier to fight for his rights; he also knew what legal means were available for them.

He had first-hand knowledge of how unfair the health care system was for people with chronic conditions. It was not easy to fulfill his needs in terms of health because a simple request for an examination, procedure, or medication became complicated. Fighting against their insurance company took time away from caring for their ill bodies. They prepared for a sit-in with medications, supplies, and the heart to fight for something they were supposed to have as citizens. Through the media, they tried to create awareness of their day-to-day struggles with chronic illness. They tried to awaken solidarity but, at the same time, they tried to intimidate the chief executive officer of their insurance company. Nobody wanted bad publicity in this competitive world. Then something that they were trying to achieve for 3 months was granted in 3 hours.

Society does not give a damn for us

Alejandro was in his 70s. He was retired at the time of our conversation. 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 diagnosed with diabetes. When Alejandro was young, he did not care too much about his health. He took his medications but he did not follow his diet. Today he is living with the consequences of his lack of care. He had a myocardial infarction, a stroke, and 2 retinopathies; moreover, 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 missed his old life. This is what he said:

To go to the doctor is expensive. For example, going to pick up medication at the insurance company including a round trip by taxi, and buying the medication cost a lot of money. And sometimes if you are unlucky they run out of medications. Everything is expensive. 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 with some Iodine. That was it. So I might lose my other toe. I would like to have a place where 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.

Alejandro had diabetes and hypertension and yet, for him, it was absolutely impossible to find a program in his insurance company to share his problems and concerns with others. If he wanted to be part of an association or private group, he had to pay. He needed something affordable. He remained in solitude. He liked to share with other people. In fact, socializing with others was one of the things that chronic illness had taken away from his life. He stayed at home waiting for someone to help him and kept all of his suffering to himself. There was no place for him in society and he felt marginalized. He was alone and in a situation that was out of control. He was neglected by the health care system and health care professionals. He was afraid for his health and, despite the urgency of his situation, attention to his needs was always delayed. Like others, his health did not seem to be important to his insurance company. He had to accommodate his disease and symptoms to the schedules and constraints of his insurance company.

I experience preferential treatment in my insurance company

Camille is in her middle 50s. As a mathematician, she worked in a private company 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 a therapy that 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 6 months. When the pain became unbearable in December, she went to emergency department. The discovery of her disease was accidental. Her doctor checked the box for a computed axial tomographic scan instead of radiography; during this examination, multiple metastases were found. Camille portrayed an image of calmness and peace with her diagnosis. She kept a positive outlook during our encounters. She recognized that she was a “palliative patient” as she called herself but she was fine with that. This is her story:

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. 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, spe-

cialists, 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.

Camille liked her insurance company because she did not have any problems with them. She was happy with the attention she was receiving and she had a support group she loved to be involved in. She did 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 seemed impossible for the others, for her was easier. She attributed her preferential treatment to her condition but Alfredo, Maria, Hannah, and Alejandro also had conditions threatening their lives. Her not having to wait made it easier for her to live with cancer. However, despite that her insurance company covered most of her treatments; cancer was still an expensive situation for her. Camille did not have the means to survive alone. At that time, she was receiving half of her wage and she had to use all of that money to pay for her mortgage and her illness, causing many difficulties for her. Camille’s sister was in charge of assisting her with the house’s expenses. Her financial condition created a little anguish and despair but there was little she could do. It was hard but Camille was not overwhelmed by the situation. She left her fate in God’s hands.

Not much later Camille died. The health reform listed earlier restricted the amount of disability pension she can receive. She remained in financial difficulties until she died without ever receiving the pension.

ATTENTIVE TO THE SPACE OF CHRONIC ILLNESS

On the basis of the experiences of people from this study, we can say that the Colombian government does not provide equal

access to health care for people with chronic illness. In reality, participants have to accommodate their diseases to what is imposed by the policies of insurance companies. The right to health has been disregarded by health insurance companies for the sake of economic profit. Participants feel relegated in status not only by the health care system but also by the state: Neither of them has given 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. Then, people with chronic illness 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.

According to Freire,³⁵ human beings are free "in theory" but, in reality, society excludes them from realizing their freedom. 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 people with chronic illness. Alejandro is patient when medical resources are not available or when the financial resources are not enough. Maria, on the contrary, 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.

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 people with chronic illness. They want a supportive health care 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 Colombian health care system, chronic illness is approached as a catastrophic condition as we mentioned earlier. Etymologically, the word catastrophe has the meaning of an overturning event or sudden disaster.⁴⁴ Living with chronic illness, then, carries the perception of a closed 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 participants in the periphery of the Colombian society. A human being from the periphery described by the center becomes a nonbeing with a catastrophic condition.⁴²

Participants 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.

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.^{11,45} 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.^{46,47} Regarding chronic disease, nurses need to be socially and politically active to defend the rights of people with chronic illness, taking into account that the problem does not have an easy answer. The situation requires compromise and concrete solutions. Therefore, the priority is to prevent and manage chronicity, handle policies of the health care system and follow the essence of nursing by trying to provide quality of care.

IMPLICATIONS AND FUTURE DIRECTIONS

The results of this research enhance nursing practices with people with chronic illness

in Colombia through a number of ways. First, by incorporating the findings from this study into the current understanding of the experience of people living with chronic illness, we strengthen clinical practices that respond sensitively to the needs of people with chronic illness. 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 improving the delivery of safe, appropriate, and culturally sensitive care.

Second, in Colombia 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 care system that have mobilized resources and attention only toward communicable diseases while ignoring chronic illness. Stronger and broader alliances of major health professional bodies, academic groups, people with chronic illness, 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 with chronic illness, we call those in nursing practice to advocate and change the reality of alienation for people with chronic illness. Nurses as a global body understand that people with chronic illness have intermittent exacerbations and remissions of their disease and that health care system must be responsive to their needs.

Third, 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 with chronic illness 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 with chronic illness and their caregivers is also needed. There is a continuing need for studies to provide a solid mapping

of the problem of chronic illness worldwide 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 the world 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 health care 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.

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