Being Attentive to the Inquiry: Lifeworld Existentials to Understand Chronic Illness in the Age of Globalization

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Abstract: Hermeneutic phenomenology seeks to attain a deep understanding of human experience in the context of a particular situation. In this paper, we examine how lifeworld existentials as a thematic method of analysis us to gain understanding of the experience of living with chronic illness under the pressure of social, economic and political forces. Lifeworld existentials assisted us to reveal more clearly the resourcefulness and resilience of research participants and invalidated the stigmas and stereotypes that led to discriminatory and stigmatization practices that ultimately kept alive their exclusion from society. Through this subjective lens, illness reframes from being a simple matter of functional impairments and physical discomforts. This approach helps nurses to understand aspects of the illness-health continuum that cannot be accessed by observation alone and has implications for understanding patients’ unique issues and facilitating better clinical outcomes for patients and their families.

Keywords: Chronic Illness, Qualitative Research, Lifeworld Existentials, Phenomenology, Hermeneutic, Globalization

1 Introduction

To understand the effects of health inequities caused by global forces on people with chronic illness we sought a tradition of inquiry that would not misrepresent, add to, or mislead the experience. We encountered that tradition in van Manen’s (1997) interpretive work. As nurses, hermeneutic phenomenology facilitated a deeper understanding of the nature and meaning of living under the constant pressure by which people with chronic illness are dominated and oppressed economically, politically and socially (Camargo Plazas, Cameron & Smith, 2012). An interpretive approach gives voice to the human experience as it is (van Manen, 1997). Through interpretive methodologies, the objectives to explain, predict, and generalize 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, 2004). Interpretive methodology strives to be attentive to how things appear, to let things speak for themselves. The lifeworld has been used in the phenomenological tradition to explore the world of everyday existence (Rich, Graham, Take & Shelley, 2013). In his phenomenology of practice, van Manen (1997) has used the phenomenological notion of lifeworld existentials to explore and understand the world of the lived experience. These existential dimensions include lived time, lived space, lived body, and lived relation (van Manen, 1997). In this instance, we provide an account of these lived dimensions as people with chronic illness described them in light of social, economic and political forces that affect their everyday experience.

The study itself is not the focus of this paper; rather we are oriented to discuss how hermeneutic phenomenology assisted us to gain understanding of the experience of living with chronic illness in the age of globalization. In consequence, we will not be discussing the outcome of this doctoral research but rather reflecting on the theoretical-philosophical approach itself. The purpose of this article is to describe the process of undertaking an analysis of the four universal lifeworld existentials as explicated by van Manen (1997). In doing so, the applicability of the lifeworld existentials as a means of reflective inquiry will be discussed. Some important considerations in the use of the lifeworld existentials when
researching the effects of globalization forces on the body of people with chronic illness will also be presented.

2 Hermeneutic Phenomenology

The hermeneutic phenomenological tradition is developed from the philosophical work of Martin Heidegger and Hans-Georg Gadamer. In hermeneutic phenomenology knowledge is acquired through interpretation and understanding of the expressions of human life (van Manen, 1997). Phenomenology is a human science that attempts to describe and understand instead of observe and explain, as natural sciences normally do (Bergum, 1989). Phenomenology highlights the various dimensions of human experience that are possible, the contexts of these experiences, and how these experiences may be described (Van der Zalm & Bergum, 2000). For Heidegger (2002), humans are interpretive beings capable of finding meaning in their own lives; it means that the understanding of an individuals’ experience cannot happen in isolation of their cultural, social context or historical period in which they live. The aim of hermeneutic inquiry is to identify the participants’ meanings from the blend of the researcher’s understanding of the phenomenon, participant-generated knowledge, and data obtained from other relevant sources (Wojnar & Swanson, 2007 p. 175). The interpretation is open to re-interpretation and is dialectical in nature (Gadamer, 2006). There is a back and forth movement between the particular experience of a person and the larger themes of human experience such as illness, death, suffering. Yet our everyday way of being-in-the-world is not one of detachment, but one of engagement because sometimes the depth of human life may become flattened, simplified, and even polarized by traditional thinking (Bergum, 1989). For nursing, it means that in meaningful ways we may experience and understand the nursing world and the relations that comprise it (Cameron, 2004).

2.1 The Lifeworld Existentials

The main focus of hermeneutic phenomenological inquiry is the relation of human beings with their lifeworld. For Heidegger (2002) the term lifeworld expressed how individuals’ realities are constantly influenced by the world in which they live. To reflect on the world of lived experience or lifeworld van Manen (1997) builds on an understanding of the four lifeworld existentials which are: lived body, lived human relations, lived space and lived time. For example, when as a researcher you are given a description of a particular experience of how a person suffered and you are investigating suffering, you might begin with a consideration of these life existentials that are present in every human experience. You would contemplate how these existentials, an integral part of the lifeworld, show themselves within the direct description of the experience. Lived body refers to how through our own bodies we experience our everyday lives, including all that we feel, reveal, conceal and share through our lived body. When people encounter one another in the lifeworld, they do so in a sensorial way, through sight, touch, smell and so forth. In the lived body the physical body and soul are integrated as one (Merleau-Ponty, 2005). Lived body is the experience of one’s own body. It is our way of being in the world (Heidegger, 2002; Merleau-Ponty, 2005). Lived human relations refers to the lived relation we maintain with others in the interpersonal space we share with them. Our experience of the world includes and is dependent upon experience of the social world (Merleau-Ponty, 2005). 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 (van Manen, 1997). According to Merleau-Ponty (2005), being in the world means existing in a reciprocal and communicative relationship with the world. Lived time is different from our perception of clock time or objective time (Le Poidevin, 2007). It is our temporal way of being in the world. Past, present and future together shape our
temporal landscapes (van Manen, 1997). These existentials let the researcher access the lived experience of human beings and develop a deeper understanding of the nature and meaning of everyday experience. Therefore, spatiality, corporeality, temporality, and relationality are productive categories for the process of phenomenological questioning, reflecting and writing in phenomenological research.

3 Globalization forces and the lived experiences of people with chronic illnesses

Throughout the world a rising number of people are increasingly becoming marginalized at an alarming rate due to complex and rapid global changes that inevitably lead to deleterious effects on their health and social status (Camargo Plazas, et al., 2012). Economic, social, and political forces have shaped the conditions in which people live, work and age (Reutter & Kushner 2010). In this paper we refer to these as globalization forces. As a result, injustice impinges on people’s lives and 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 (Camargo Plazas et al., 2012). The inadequate regard for chronic illness is an example of discrimination and indifference that occurs worldwide (Camargo Plazas et al., 2012). Chronic diseases are the major disease problem facing the world as they are a barrier to development and to alleviating poverty (WHO, 2013). According to the WHO (2013), 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. Yet chronic illness has not had the necessary attention to prevent or control it. 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. Heads of state, private foundations, regional and international agencies, banks, and NGOs have mobilized resources and attention mainly towards infectious diseases in low- and middle-income nations while ignoring chronic diseases (Colagiuri, Colagiuri, Yach & Pramming, 2006). Thus, chronic conditions are prevalent and solutions cannot wait.

Studies to date in chronic disease have demonstrated that the economic cost and burden of chronicity threaten to overwhelm economies and health care systems worldwide (Huckabee, 2006). Other studies support the creation of self-management programs for people with chronic disease to help them change risky behaviors that only worsen the condition of chronicity (Boldy & Silfo, 2006). As well, research has focused on the cultural shift and the change in cultural values that are required for initiatives of prevention to be successful in dealing with chronic disease (Astin, Closs & Lascelles, 2005). There also are those studies that have explored how some barriers in the health system prevent many individuals from accessing health care professionals, thus developing vulnerabilities, especially within minority populations. Such barriers are responsible for the presence of disparities (Valverde et al., 2006). Research, however, is limited about the effects of social, economic, and political structures on the lives of people with chronic illness. And, also, we know little about the effects that these forces produce on the body of someone with chronic illness (Camargo Plazas, 2011). Such experiential knowledge is needed to provide effective interventions for people with chronic illness.

3.1 Research Study

The purpose of the doctoral research was to understand the experience of living with chronic illness in the age of globalization. In this study we followed a unique way to understand the effects of global forces in the lives of eight people with chronic illness in Colombia and Canada, an approach, to our knowledge, not previously found in the literature. In Colombia five participants were recruited. In Canada, three participants were accrued. All participants were adults between 25 and 75 years old.
The chronic conditions that participants had were cancer, diabetes, cardiovascular diseases, autoimmune disease and chronic kidney diseases. This sample included women and men living for more than 2 years with chronic diseases, a period chosen to avoid potential distress that may result from participants talking about their chronic illness too soon after initial diagnosis. Income was not considered as an inclusion criterion to achieve a representative mix of social, political, and economic backgrounds. The doctoral research study presented in this article was carried out over the course of 2008-2011. Ethics approval was granted by the University of Alberta Health Ethics Board. The method used in the doctoral research work included a combination of critical pedagogy and hermeneutic phenomenology, as informed by the works of Freire (2002) and van Manen (1997) respectively. Hermeneutic phenomenology was used to guide the researchers in drawing forth meaning from the participants’ views of their lived experiences, therefore, enabling a deeper understanding of how social, economic and political forces affect the experience of living with chronic illness. Through participants’ experiential stories, we witnessed how the distribution, availability and provision of health care and social services, stability of employment, and financial stability profoundly affect health. Hermeneutic phenomenology provided a base for exploring the complexities of these peoples’ lived experiences and understandings of chronic illness in a world influenced by global forces and resulting global inequities. By addressing the influence of external forces on the personal experience of people with chronic illness, we encourage in nursing practice the need to advocate and change the reality of alienation for people with chronic illness. And yet, this approach was not enough to understand the complexity of the predicament of the being chronically ill under the context of globalization and resulting global inequities. We wanted to more deeply probe how the effects of social, economic and political forces imposed by globalization affected the experience. We used a critical approach that assisted us to examine institutional and social practices and processes, and identify barriers and facilitators to change published somewhere else (Camargo Plazas & Cameron, 2015).

3.2 The Interpretation Process

As a methodology, hermeneutical analysis guides the interpretation of the phenomenological written description or text of human experience in order to further unravel the meaning of the experience (van Manen, 1997). Interpretation requires the right language if the interpreter truly wants the text to speak (Gadamer, 2006). The dialogue with the text is not mutual. In fact, “The interpreter acts upon the text” (Smith 1997, p. 439). This means 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). We come to a conversation with the text with our own views and personal vantage point. In fact, the researcher’s personal viewpoint with which the chronic illness is approached necessarily carries its own assumptions, biases, and theoretical knowledge. Identifying pre-understandings or prejudices are essential to interpretation (Gadamer, 2006). This means that the researchers must reflect on what particular preunderstandings they hold, for example, do they believe that funding should not be given to chronic illness? Or do they think that chronic illness is a very neglected area of disease? To ignore the identification of preunderstandings would to then engage in a discussion of opinions applied to the text rather than openness to what the text is revealing. According to Gadamer (2006), understanding takes place when the horizon of the other blends with our own horizon and changes our perception of the world. Through reading and re-reading and writing and re-writing our interpretation of the effects of social, political and economic forces on the world of people with chronic illness increased. Our horizon was expanded when things that we could not see before around the experience of chronic illness became more apparent.
Thematic analysis and lifeworld existentials. Once the conversation was completed, the audio-tapes were played and re-played and the conversations were transcribed. 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. Thematic moments were developed reading and re-reading the transcripts and also re-playing the digital recordings to ensure turning to the essence of lived experience. Then, there was a reflection 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. To develop those themes, we used the four existentials lived body, lived relations, lived space and lived time to explore the structures of human lifeworld, the lived world as it was experienced by people with chronic illness in Colombia and Canada. Below, we present an explanation with examples of each one of these existentials.

Lived body (Corporeality). This existential helped us to discover how participants perceived their bodies through the process of illness and the limitations or demands the illness might bring. Also how others in society perceived their body ill. There were many examples of how lived body is understood under economic, social and political forces. 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. 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. The following is an example of how lived body helped us to interpret the experience of Camille a participant with chronic illness:

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. 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 my health at stake and he did not care. The only thing he cared about was to complete our work in time (Camille).

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. A simple neuralgia, they call it. Through time, Camille grows even weaker and she is diagnosed with metastatic cancer. In a world oriented by productivity the demands of society surpass the claims of the body ill. Everybody dismisses what she is feeling. 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). Lived body existential assisted us to understand the changes experienced by research participants. 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 health 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 bring the body into view and disrupt this taken for granted state (Gadow, 1994). Then, through illness our unnoticed partner draws our attention to itself. In chronic illness often the exacerbation of symptoms comes on suddenly and the person needs immediate treatment. Yet political, social, and economic forces may prevent that access.

Lived human relations (Relationality). As human beings, we are all part of a political, economic, cultural and social network that is impossible to ignore: all the external actions have an effect on our lives and
especially on our health. In our study we found how the social life of people with chronic illness is both a complex and a subtle affair. Alejandro’s story clearly portrays the effects of chronic illness in his social life:

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 bebullied. 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. 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 just stay calm and keep to myself (Alejandro)

In Alejandro’s story we explored how the existential lived human relations intertwines with the other existentials lived body, lived time and lived space. 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. His space has been reduced. Time runs slowly. His world has shrunk. Nobody understands him or what he is feeling. For Alejandro, friends 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 (Camargo Plazas, 2011). Here we see how the life existentials converge at the same time even though for interpretation we look at them separately at first to understand them and then the interplay among the existentials.

Lived Space (Spatiality). 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. In this study, 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 (Camargo Plazas, et al., 2012).

I feel the health 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 (Alfredo).

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. Besides living with the impact of being chronically ill, they also have to overcome the barriers to access services for them. 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 these research participants with chronic conditions (Camargo Plazas et al., 2012).

Lived Time (Temporality). Time in chronic illness needs to be understood as an extended field, being linked to performed activities. For people with chronic illness 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. In the following story Camille describes the meaning of time:

*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. 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. We used to chat a lot when the chemo therapy sessions allowed it. We just sat there and shared our stories. 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 (Camille).*

Before her illness, Camille had her whole life planned, professionally and personally. 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 takes time to live each moment as it comes. 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. 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 (Camargo Plazas, 2011).

*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 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 (Hannah).*

Like riding on the roller coaster, Hannah does not know what to expect. Death accompanies her during the moments of illness; she can feel its threat. Time in chronic illness needs to be understood as an extended field, being linked to performed activities. 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 loses 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.

### 4 Lifeworld Existentials as a Reflective Method to Explore Chronic Illness

The use of van Manen’s (1997) lifeworld existentials proved an extremely helpful approach through which to gain a deeper insight into the phenomenon of chronic illness. By undertaking an analysis of the four existentials as explicated by van Manen (1997) we are not trying to create a set of rigorous steps to be followed by other researchers rather we attempt to describe our own experience. The lifeworld existentials assisted us to understand abstract components of living with chronic illness under
the influence of social, economic and political forces. These four existentials did not impose a set of predetermined themes or categories upon the data but rather they provided guidance in our understanding of the phenomenon under investigation. This was particularly important in staying true to the interpretive nature of interpretive inquiry and in supporting methodological trustworthiness. Furthermore, as researchers these four existentials helped us to gain deep insights related to the experience of living with chronic illness in the context of contemporary globalization forces and how these forces affect the body of research participants.

For nursing research is important to explore the layers within which people create meaning from the experience of chronic illness as it becomes apparent that chronic illness is powerfully shaped and influenced by the social, economic, cultural and political context in which it occurs (Camargo Plazas, 2011). Human beings are complex and that complexity needs to be addressed in an integral way. Within this current context in which people with chronic illness live through the effects and pressures of globalization and corporate agendas, as nurses we cannot restrict ourselves to traditional approaches. To do so limit our imaginative ability to produce questions, and further, limits the answers we can generate for the questions that we pose (Leonard, 1989). Therefore, there must be in nursing a return to things themselves to find out the wisdom, frustration, puzzles, dilemmas, and knowledge of health, illness, and suffering embedded in the daily practice (Benner, 1985). A great need for nurses and healthcare professionals is to educate themselves in the direct effects that globalization forces have on the ill body, i.e., no access to emergency care due to policies regarding chronic illness.

The lifeworld existentials offers nurse scholars and clinicians an approach to inquiry that has a good fit with nursing’s philosophy. The lifeworld existentials are consistent with the values of nursing practice such as recognizing the uniqueness of the person, the potential for professional and personal growth, and the importance of working with people in an open dialogue in which both nurse and person nourishes each other with experience and help instead of working without commitment on the person (Rapport & Wainwright, 2006). Nursing requires a phenomenological sensitivity to lived experience, and it also requires a hermeneutic ability to make interpretative sense of the phenomena of the lifeworld in order to see the significance of situations and relations of nursing with human beings. This approach presents to nursing the opportunity to understand the meaningfully rich and complex lifeworld of those human beings for whom nurses care (Edward, 2006). Thus, interpretive approaches reveal the depth and diversity of nursing knowledge: they allow for research which is conducted in a natural, uncontrolled setting and for research which utilizes the knowledge embedded in the experience (Van der Zalm & Bergum, 2000).

The four existentials are clearly useful to comprehend how context influences structures and upholds experiences such as the meanings and understandings that are articulated by the researcher and the participants. Health professionals must not forget that the aim of research cannot be merely to answer a question. In the race for scientific pursuits, researchers should not objectify their participants and define them in the generalization of diseases or problems to solve. Hermeneutic phenomenology attempts to describe and interpret phenomena of the lived experience, for nurses this attempt creates new ways to comprehend phenomena such as the experience of living with chronic illness in the age of globalization as experienced by individuals who have lived through it. The culture of scientific endeavors makes it easy to dehumanize and depersonalize for the sake of progress, production and economic profits.

In closing it is important to recognize that through an examination of one’s preunderstandings and prejudices prior to interpreting the experience described in the text, allows the researcher to not just apply preconceived theories and conceptualizations. The researcher then turns toward questioning the text as to how does this person live through this experience, what does this show in terms of understanding the phenomenon, not classifying it.
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