

2017-04-17

The Embodied Experience of Pain: A Phenomenological Study of Pain in Adults Diagnosed with and Treated for Cancer

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UNIVERSITY OF MIAMI

THE EMBODIED EXPERIENCE OF PAIN: A PHENOMENOLOGICAL STUDY OF
PAIN IN ADULTS DIAGNOSED WITH AND TREATED FOR CANCER

By

Liza Hayes Mathias

A DISSERTATION

Submitted to the Faculty
of the University of Miami
in partial fulfillment of the requirements for
the degree of Doctor of Philosophy

Coral Gables, Florida

May 2017

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THE EMBODIED EXPERIENCE OF PAIN: A PHENOMENOLOGICAL STUDY OF
PAIN IN ADULTS DIAGNOSED WITH AND TREATED FOR CANCER

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The Embodied Experience of Pain: A
Phenomenological Study of Pain in Adults Diagnosed
with and Treated for Cancer.

(May 2017)

Abstract of a dissertation at the University of Miami.

Dissertation supervised by Professor Linda L. Belgrave.
No. of pages in text. (226)

The main goal of this dissertation project was to understand and explain the meaning of pain for adults who are diagnosed with and treated for cancer. Cancer diagnoses generate different responses and multiple life disturbances in most participants. In this context, the search for meaning of these experiences is fundamental, particularly understanding both physical and emotional pain. In order to comprehend how people diagnosed with and treated for cancer experience their pain, I used a phenomenological approach to interview 15 adults (13 women and 2 men) with a variety of cancer diagnoses. Although I approached these interviews as conversations, I utilized several subquestions to guide my interactions with the participants.

Based on this study, the meaning of pain is related to the process of making meaning. This process, although presented in a sequential form, is not strictly associated with the lifeworld in this manner. Rather, the process of meaning fluctuates from one stage to another and the boundaries of each stage overlap. The first stage corresponds to The Awakening of Pain. Pain disrupts the participants' temporality and everyday lives, pushing them to seek meaning within the biomedical field. The trauma and dramatic

intensity associated with the initial pain is now related to the shocking news of the diagnosis of the disease. This is quickly followed by the dawning awareness of multiple losses: the loss of function, of daily roles, and of taken-for-granted physical safety; these losses push individuals to retreat from the life they once lived. As the body is transformed due to the medical treatment, participants' lifeworlds are disrupted. This sudden disruption, for some participants, curtails their involvement in the world, resulting in a shrinking life. Other participants, meanwhile, struggle to keep the world unchanged so as not to be alienated from it. However, in either case, the normal flow of the self is interrupted as participants lose familiarity with the basic process of their identities, their bodies. In the third and final stage, making sense of pain, participants seek to reconcile themselves with their new reality. At this point, communication becomes the main source of meaning. By sharing and communicating their experiences of pain, participants acknowledge the significance of those experiences, and by listening to the communicated painful experiences of others, participants validate their own experiences.

The communicated pain is the public essence of the meaning-seeking process, while the search for meaning also has a private realm, explained in the triangle of meaning. This stage extends epistemology into a context of pain awakening, where genuine knowledge of pain is experienced and explained within the boundaries of science, spirituality, and the self. The self is the most important element of this triad, as it regulates and mediates the relationship between the scientific and spiritual meanings of pain. It is through the self that the person in pain becomes both subject and object of his or her experience and meaning, acquiring knowledge about his or her particular

experience of pain. In sum, it is through this process of self-reflection and reflection on the pain that each person comes to know what the essence and meaning of his or her experiences are. In some sense, by experiencing pain, participants are experiencing the essence of pain and of themselves. These findings support the claim of many sociologists and phenomenologists (see Kotarba, Charmaz, Zola, Frank, and Leder, among numerous others), physicians (see Biro, Morris), and anthropologists (see Jackson), who all state that pain is more than just a biological response. Pain is a lived experience that encompasses all aspects of a person's life: the body, self, emotions, and culture; therefore, studies should not try to explain the pain outside of these boundaries.

The result of this research project has substantial implications for understanding the complexity of how aspects of pain are interconnected and intertwined; each makes the experience meaningful, and none should be taken lightly in future research. The results, hopefully, will help improve the current biomedical understanding of cancer and pain, and promote a change in the way physicians understand and treat their patients, as well as promote a change in the policies of pain.

DEDICATION

I dedicate this dissertation work to my family. Simply stated, I could not have finished this project without their overwhelming support and encouragement, both of which have made the last five years less arduous and this accomplishment more enjoyable. I am especially grateful to my husband, Jones, for his endless prayers, motivation, and for providing a constant voice of peace and focus during times of frustration and uncertainty; I am forever thankful for my daughters, Liza and Tanisha, who sacrificed their time, allowed me to work, and were my number one cheerleaders. I know sometimes it was very hard for them both not having me home when they needed me the most, but they are my inspiration. I love both dearly. I also wish to express my thanks to my mother, Alicia, for her unconditional love and for having instilled in me a drive to succeed and to persevere. I also cannot forget my brothers, who are sources of inspiration for me.

ACKNOWLEDGMENTS

This dissertation represents five years of challenging, enlightening, sometimes frustrating and other times enjoyable and stimulating work. The completion of this dissertation would not have been possible without the help and support of numerous people, who have contributed to this work in multiple ways. Today, it is with pleasure and honor that I express my gratitude to each of them.

To my committee, I thank each for being part of my dissertation and their constant support. First of all, I would like to express special thanks to my academic advisor and committee chair, Dr. Linda L. Belgrave, for her continued support, wisdom, knowledge, and belief in me. Without her academic advice, this dissertation would have been impossible to complete. I would like to thank her for agreeing to be a part of my committee and for accepting the challenges and responsibility of being the chair and of working with me. From the beginning, she gave me the foundation to develop the topic and ignited in me the intellectual curiosity to pursue the research in the field. Although I did not always understand her methodology, I shall always be grateful to her for challenging and encouraging me to become a sociologist and, most importantly, leading me to the finish line.

Along with Dr. Belgrave, my three committee members always helped me. There was a time where I did not meet with each of them for more than a year. Nevertheless, they patiently understood my situation and supported me. I am truly grateful for that. I am particularly grateful for the emotional support of Dr. Marvin P. Dawkins, whose teaching on race and ethnic relationships taught me to see below the surface and consider other relevant aspects that encompass the complexity of racial and ethnic

interactions. He always listened to me carefully and nonjudgmentally when I was struggling and gave me wise words that encouraged me to do better. He prepared me for the task ahead and helped me to understand that I will always be tested. However, my moral duty is to boldly represent the community to which I belong, African-Caribbean women, and to then comprehend that there is a point in life when I will not need to prove myself anymore. I am very thankful for Dr. Dawkins' kind words and advice. He is indeed my mentor.

I am also grateful to Dr. John W. Murphy for his teaching and passion about sociological theories, which provided the inspiration and confidence I needed to consider the phenomenological approach. Even though this is my dissertation, many of the basic ideas and theoretical approaches are those I learned in his classes. Having an opportunity to learn phenomenology was one of the biggest fortunes of my life; he is the type of academic I dream of becoming, and this dream is the reason I am pursuing a doctoral education. I would like to thank him for always having a positive and relaxed mood that soothed my stressed feelings. In this sense, I simply owe him a lot.

I would like to also express my gratitude to my outsider member, Dr. Joseph A. Kotarba, whose research based on his lived experience of pain inspired me to pursue studying pain. As did my other committee members, Dr. Kotarba always helped me and pushed me to think more deeply, to move from the superficial to the most relevant aspect of pain: the meaning. There is no doubt his presence has made a difference in my dissertation. Thank you for being part of my committee and for your invaluable insight.

I am also grateful to the faculty, staff, and graduate students at the University of Miami. I am especially grateful to Dr. Roger G. Dunham and to Jeanine Ocon for being

constant sources of support throughout my graduate years. I am also indebted to Teresa Amador for her understanding, patience, support, and interest in me. I feel I owe a lot to a special friend, Ana Maria Lobos. She helped me vastly in the initial stage of my graduate life and continues to do so, as her friendship makes my journey through graduate school smooth and memorable. I also express my gratitude to my Pastor and his wife, Bob and Carmen Brumley. They helped me emotionally and spiritually. I would like to thank all the study's participants, who shared their intimate stories. Without their support, this dissertation would not have been possible. Lastly, I would like to thank my Lord and Savior Jesus Christ for sparing my life and for giving me the strength and clarity required to complete such an enormous task. **Thank you all!**

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CHAPTER ONE: INTRODUCTION

In this chapter, I introduce the reader to the main purpose of this dissertation, which is to explore the multiple aspects of experiential pain in adults diagnosed with and treated for cancer. I begin by providing a brief background and critique of the mechanical and biomedical understandings of pain, which then provide a basis for the proposed model to explain cancer and pain. I briefly introduce the reader to the sociological and phenomenological theories of pain (described in Chapter Two). I then proceed to state the problem of cancer and pain and clarify some of the terms I use in this dissertation project. Finally, I explain the organization of this dissertation.

Theories of pain have been dominated by a biomedical understanding of the body and concentrated on neurophysiological aspects of the body. Hence, biomedical theories reduce the experience of pain to an elaborate mechanistic view of signals and symptoms, regarding the living body as a machine (Leder 1990). René Descartes postulated that pain signals travel from the skin to pain receptors in the brain. The brain then interprets these signals and generates a mechanical reaction of the muscle; pain is the physiological response (Morris 1991). This approach ignores the person's emotional and social contexts and his or her cultural environment, favoring the physiology of the reacting human body. This unidimensional and simplistic understanding of pain has dominated the biomedical field for more than five centuries, focusing on the sensation. An example of this dualistic approach is the experience of cancer and pain. While a person with cancer and pain experiences pain as an aspect of his or her everyday life, inseparable from his or her humanity, physicians treat the body as a machine, monitoring blood pressure and the intensity of pain, exposing the 'body object' to

medical scrutiny (Leder 1992:34). The person in pain is then forced to recognize his or her own body outwardly as a perceptual object, distancing from his or her experiential pain.

However, the reality is different: people with cancer-related pain perceive their bodies inwardly and are limited by the experience of pain while simultaneously transcending their bodies in pain (Leder 1992). Pain, thus, for cancer sufferers, is an embodied experience, shaped and delineated through consciousness. The full significance of human pain necessarily eludes the model of the body-as-machine (Leder 1984).

The other approach to the study of pain is the biopsychosocial model of pain, formulated by George Engel [1913-1999]. Engel retained biomedical assumptions in his theory; his research acknowledges that pain is a sensation, and he expanded it to include the psychological, social, and cultural components of pain (Engel 1977). For Engel (1977, 1959), pain is an interrelationship between the body, the physiological processes that take place within the body, and the individual's interactions with his or her own social contexts. Because traditional medical practitioners ignored the emotional and psychological component of pain (Engel 1959), holistic biomedical practitioners advocate the biopsychosocial model as it banners the notion of "treating the whole person" (Leder 1992: 32). The vast majority of existing studies has unquestionably focused mainly on psychological correlates (Jackson 2011), placing this approach in a circular argument and not transcending biomedical reductionism (Leder 1992), instead presenting the Cartesian dualism in a complex way (Duncan 2000).

Although contemporary biomedical and biopsychosocial understandings of pain have evolved from initial postulations, there is still a lot to learn about cancer-related pain. As a matter of fact, physicians and psychologists know less about cancer and pain than people believe because there is no consensus about it; particularly, according to Morris (1991: 22), most biomedical specialists in oncology “don’t know anything about cancer and pain.” Therefore, this leads to an ineffective diagnosis and, with it, an increase in the incidence of cancer pain. The underdiagnosis of pain is attributed to the shallow understanding of experiential and lived pain (Morris 1991). The failure of orthodox biomedical and biopsychosocial approaches to pain follows from the assumption that all pain is similar and that people live and experience pain equally (Sheridan 1992). However, experiential cancer pain is neither uniform nor dualistic (neither a bodily real experience nor an imaginary mind creation), but rather are unique, greatly complex experiences (Kotarba 1983).

The lack of a proper theory of pain, which integrates the multiple dimensions of the experience, perpetuates the dualistic understanding of pain (Leder 1992). This dissertation project seeks not to formulate a theory of cancer pain, but to provide the framework for the study of pain by integrating both sociological and phenomenological approaches to study of cancer-related pain. A phenomenological approach to pain presents an understanding of the experiential pain that results from the intertwining of the personal, social and cultural meanings of pain (Biro 2010; Morris 1991) and of the body-object, the body-subject, and the lived-body (Leder 1992). From these approaches, the body in pain is both “subject and object” of cancer pain, moving beyond Cartesian

dualism (Leder 1992: 33), or the so-called ‘myth of the two pains: physical and subjective pain’ (Morris 1991).

Statement of Problem

I conducted a phenomenological study of the meanings and the narratives of cancer pain. Cancer-related pain is one of the most common experiences for the nearly two million Americans diagnosed with cancer (ACS 2007). Despite numerous technological and medical advances devoted to ameliorating cancer pain, in many cases, even when people survive the cancer, they still have to live with pain caused by the disease. The reason for this discrepancy is a poor understanding of experiential pain, which is a byproduct of the Cartesian dualism that prevails in biomedical theories of pain.

Pain can be present at any time during the course of the disease, but this pain varies mainly due to the type of cancer, the stage of the disease, and the treatment or tests being administered. Pain caused not by the disease itself, but by cancer treatments, like chemotherapy, radiotherapy, or surgery, affects 50-90% of people with cancer (Portenoy and Lesage 1999; Cleeland et al. 1994). Pain is more common in people with an advanced stage of cancer; 64% of adults in an advanced stage of cancer have been shown to experience significant pain (Cleeland et al. 1994; Portenoy and Lesage 1999). Despite the dissemination of several guidelines for cancer pain management by the World Health Organization, the Agency for Healthcare Policy and Research, and the Expert Working Group of the European Association for Palliative Care, cancer-related pain persists over time. Unfortunately, between 16% and 91% of people with cancer-related pain is undertreated (Cohen et al. 2003). Cancer pain is far more than a medical

problem; it is indeed a lived experience with social and personal implications (Morris 1991).

Cancer-related pain challenges the biomedical understanding of pain. Pain is far more than physiological; it is inherently social and personal. The non-Cartesian understanding of pain, thus, involves interpretation of the multiple narratives that provide the experience of meaning (Biro 2010). Meaning, therefore, remains open to impermanent social and personal interpretation (Morris 1991). An understanding of pain requires the convergence of multiple realities, particularly for those experiencing the pain. Therefore, in order to properly understand the pain sufferer's knowledge of his or her own pain experience, it is necessary to recognize pain as an embodied experience, an understanding that can be viewed through a sociological lens.

Although pain has recently generated some discussion within the social sciences, particularly within the sociology of health and illness, pain remains largely undertheorized and taken for granted as a solely biomedical phenomenon. The scarce sociological research on cancer-related pain provides very little insight into what it is like to experience cancer pain. Utilizing a phenomenological approach, this dissertation seeks to contribute to the existing literature by bringing forward the taken-for-granted knowledge of cancer pain and identifying any relevant social, cultural, and psychosocial factors that influence the experience of cancer-related pain and the elements that attribute meaning to this experience. To do so, I conversed with 15 adults, who come from different social and cultural backgrounds and who have all been diagnosed with and treated for cancer in South Florida.

Purpose of the Study

The overall purpose of this qualitative dissertation project was to explore the factors that provide the experience and meaning of pain in adults diagnosed with and treated for cancer. In order to obtain the essence of the experience of cancer-related pain, I utilized a phenomenological approach.

Research Questions

Through this project, I attempted to answer the following main research question: What is it like for women and men diagnosed with and treated for cancer to live with pain, and how do they experience their pain? Although both men and women were invited to participate in this study, the main purpose of this dissertation was not to compare how men and women experience cancer. Therefore, crucial to this central question are the following subquestions:

1. How do people diagnosed with and treated for cancer perceive their pain experiences? What are their pain experiences like?
2. How do these people's narratives unfold, and what is the effect of this unfolding on their experiences with pain?
3. Do people diagnosed with and treated for cancer from different cultural groups experience pain differently?

Terminology

I clarify the use of some terms. In this dissertation, to refer to people diagnosed with cancer, I use the expression 'people with cancer' instead of using 'cancer patients.' The label 'cancer patient' permanently invalidates the experiences of the person because it presents cancer as the master of the person's life. Instead, the expression 'people with

cancer' advocates for a more human-centered notion, where the person is in control of his or her life and the cancer and the experiences associated with it become the objects of scrutiny (Burrows 2010; Jackson 1994): A person with cancer is first a person.

Organization of Chapters

This dissertation is divided into five chapters and an Appendices section. In Chapter Two, I provide an overview of the different models of pain. The clinical understanding of pain and the biomedical and psychological models of pain are highlighted in the first part of the literature review, along with the limitations of extant work. In the next section of the second chapter, I provide an overview of the sociological and phenomenological models of pain. These two theories serve as the theoretical framework for this dissertation project. I also explain why phenomenology is an appropriate choice for this project.

In Chapter Three, I delineate the methods that I used to develop this dissertation. I used qualitative methods, specifically the phenomenological methodology. Clark Moustakas defines phenomenological methodology as “a return to experience in order to obtain far-reaching descriptions that provide the basis for a reflective structural analysis that portrays the essence of the experience” (1994:13). This descriptive study encompassed a three-level phenomenological research process. The first level involved obtaining data using open-ended questions to guide the conversation with each participant. The second level corresponded to data reduction using techniques of phenomenological reduction. The third level described experiences using reflections, analyses, and interpretations of the participants' lived experience of pain. The final product of this dissertation project is a document of the experiences of pain and of pain

sufferers' knowledge of cancer pain. Although medical and nursing approaches and understandings of pain are important, the scope of this study does not include them. In this chapter, I state the problem and research questions and I include details about methods, how cases were selected, how data were collected and analyzed, and any potential ethical issues associated with a phenomenological study of pain. In Chapter Four, I present the findings of the study. I describe each case in great detail, and I discuss the themes that emerged. Themes are accompanied by direct quotations from study participants. The results of the cross-analyses also are presented with quotations, representing different perspectives. The results of this study, the implications for theory development, practice, public policy, future research, and the study's strengths and limitations are discussed in Chapter Five. Lastly, the Appendices section includes copies of the internal review board approval from the University, the informed consent forms, the conversation protocols, and the demographic questionnaires.

CHAPTER TWO: THEORIES OF PAIN

During previous decades, there has been an explosion of studies regarding the physiological and psychological mechanisms underlying the complex experience of pain (Turk and Okifuji 2002). As a consequence, there has been a significant advance in medical and psychological treatments. As a matter of fact, as Dennis Turk and Akiko Okifuji have stated, the scientific research on pain of the last decade has been “not only evolutionary but revolutionary” (2002: 678). However, the level of knowledge about pain and the results of medical intervention have not been totally related since the biomedical interventions, in particular, have often been inadequate (Jensen and Turk 2014), seeking to cure the body-as-object (Bendelow and Williams 1995) while ignoring the multiple facets of the painful lived-body (Leder 1992; 1986; 1984; Morris 1991). Given the modest benefits of increased scientific knowledge about pain, the debate and concern regarding pain have increased and the interest of the scientific community has become more focused on the ontological understanding of pain: what is pain? Where is the pain located, in the mind or in the body? Who experiences pain, the body-as-object, the body-as-subject, or the lived-body? (Geniusas 2014). Until we clearly distinguish between these multiple bodies, “our understanding of pain will remain distorted” (Geniusas 2014: 391).

In this chapter, I briefly review the definition of pain. Next, I provide an overview of the biomedical and psychological understandings of pain, addressing the weaknesses of each school of thought. Then, I outline sociological principles for a study of pain. Finally, I explain the theoretical orientation of phenomenology.

Definition of Pain

Pain is an individual experience lived and felt in the body (Morris 1991; Kotarba 1983), conferred with social and cultural meanings that can be interpreted in multiple manners (Leder 1990; 1984), as a punishment from the gods or a call from the dysfunctional body, for example (Frank 1991). However, there is pressure within the biomedical field to adjust the experiential pain to fit the boundaries of the semantic dominion (Bendelow and Williams 1995). In an attempt to constrain pain within the boundaries of the semantic dimension, in 1939, Dallenbach devised a list of 44 words to define pain. These words were grouped in five categories according to the temporal course of pain, spatial distribution, fusion with pleasure, affective dimension, and qualitative attributes (Melzack 1975; Melzack and Torgerson 1971). Ronald Melzack and colleagues (Melzack 1975; Melzack and Torgerson 1971), thirty years later, modified Dallenbach's study, describing the experience according to three principal dimensions: 1) the sensory qualities in terms of temporal, spatial, pressure, thermal, and other properties; 2) words describing the affective qualities, in terms of tension, fear, and words that are part of the experience of pain; and 3) evaluative words that describe the subjective intensity of the experience of pain (Melzack 1975). With these changes, the words people used to describe their painful experiences became subject to objective mathematical procedures: of counting, grouping, measuring, and consequently scaling. Clear examples of the mathematical processes are the Brief Pain Inventory (BPI) and the McGill Pain Scale (Melzack 2005; 1975) – tools used to record and measure pain and thus to define pain in an objective manner. These measures are presented as a possible basis for a uniform method to acquire the information necessary for the study of pain

within the clinical setting (Melzack 1975). However, when it comes to pain, words are inadequate to capture the dimension of this subjective experience (Käll 2013).

Nevertheless, in the second half of the twentieth century, physicians came to understand that the responses or descriptions of pain prompted in sufferers varied and that neither a single definition, nor a list of words, nor a scale could capture what people knew about their own pain and how they experienced it. This inability to describe pain has serious consequences. Defining pain properly is necessary in order to obtain appropriate medical treatment and thus to alleviate pain (Käll 2013; Morris 1991).

In recent years, pain has come to be viewed as subjective, experiential, and an inseparable aspect of a person's life (Käll 2013) with emotional, social, and cultural connotations (Freund 1990). Attention to the emotional components of pain is not new. Price (2010), in his analysis of Plato [429-347BC] and Aristotle's [348-322BC] discussion of emotion, shows that emotion and pain are strongly related, as pain is described as an emotional experience of the soul, or *quale*. However, contemporary biomedical studies of pain have deliberately ignored the emotional dimension of pain, for many "physicians regard emotion as an epiphenomenal [or a secondary symptom or complication that arises during the course of a disease] state associated with mental activity, subjective in character, and largely irrelevant state of a patient's physical health" (Fishman et al. 2010: 376). In fact, emotion can affect a person's health, exacerbating certain pain states and with it other aspects of the person's life. Ignoring the emotional component of pain may cause major damage to the biomedical understanding of pain (Fishman et al. 2010). Aware of the consequences of a one-dimensional understanding of pain, which ignores the emotional and individual

relevance of the experiential pain, John J. Bonica, an American physician and anesthesiologist, wrote the *Management of Pain* in 1953 and founded the International Association for the Study of Pain (IASP) in 1973. Today, the IASP is the largest organization in the United States devoted to the study of pain. According to Fishman and colleagues (2010: 2), Bonica's work "was a Herculean endeavor and monumental achievement, as no one had ever attempted to comprehensively describe all that was known about pain and how to diagnose and treat it." In his book *The Management of Pain*, Bonica (1990) explains that pain is a complex dynamic between anatomy and physiology and emotion, and calls for a multidisciplinary approach. This understanding of pain marks a departure from the "nerve block" clinical view of pain (which focuses mainly on the symptomatic aspect of pain, diagnosing and relieving pain through biomedical intervention and management) to a more integrated understanding of pain (Vrancken 1989: 435). Bonica's (1990). This departure essentially splits the clinical understanding, conceptualization, and treatment of pain into two major groups: the biomedical, or "nerve block," group, and the multidisciplinary group, which combines the biomedical and sociocultural explanations of pain (Vrancken 1989). Similarly, Melzack and Wall's (1965) Gate Control Theory of Pain (explained in detail in the next section of this chapter) promoted a shift from the biomedical paradigm, a one-dimensional view, to a more integrated approach, emphasizing the sociocultural and psychological components of pain.

These shifts have caused a change in the collective understanding of pain, resulting in changes to treatment. In 1989, Mariet A. E. Vrancken examined how physicians in clinics in the Netherlands understood and treated pain. She identified five approaches:

the somatic-technical, the dualistic, the body oriented behaviorist, the phenomenological, and the consciousness. First, the somatic-technical approach defines pain in terms of physiology: pain originates in the body and can therefore be identified. Second, the dualistic, body-oriented approach conceives pain as the result of organic, psychological, and social interaction, where common medical practice focuses on the no-receptive, or sensory, aspect of pain. An example of this approach is the Gate Control Theory (Vrancken 1989). Third, the behaviorist approach deals exclusively with chronic pain (Vrancken 1989). This approach explains pain in neurophysiological terms only. Fourth is the phenomenological approach, which, views pain as a “mode of being” and the center of the life-world (Vrancken 1989: 438). Pain is seen as a complex reaction of the isolated body (Leder 1990), where the body becomes simultaneously the object and the subject of pain (Morris 1991). Fifth and finally, the consciousness approach considers that pain is a problem of consciousness, where the person has become aware of the body part in pain, disrupting his or her sense of space and time, as pain dissolves the sufferer’s ideas of past and future and focuses the entire subject’s attention on the present experience of pain (Frank 1991; Leder 1984). Although all of Vrancken’s definitions of pain incorporate, in some way or another, both emotional and sensory dimensions of pain, the physiological understanding of pain is most prominent in all of her approaches.

Bonica (1990) also changed the manner in which pain was defined. The actual definition of pain proposed by the IASP includes the emotional, physiological, and mental aspects of pain: “an unpleasant sensory and emotional experience associated with actual or potential tissue damage, or described in terms of such damage” (IASP 2016).

The IASP, in the previous definition, attempts to explain pain beyond the boundaries of the biomedical understanding. Pain, as defined by the Merriam-Webster Dictionary, is:

A state of physical, emotional, or mental lack of well-being or physical, emotional, or mental uneasiness that ranges from mild discomfort or dull distress to acute often unbearable agony, may be generalized or localized, and is the consequence of being injured or hurt physically or mentally or of some derangement of or lack of equilibrium in the physical or mental functions (as through disease), and that usually produces a reaction of wanting to avoid, escape, or destroy the causative factor and its effects. Or a basic bodily sensation that is induced by a noxious stimulus, is received by naked nerve endings, is characterized by physical discomfort (as pricking, throbbing, or aching), and typically leads to evasive action. (Hacker 2016)

Although both the IASP and the layperson understandings of pain contemplate the emotional or subjective aspects of pain, they actually perpetuate the dualistic understanding of pain (Bendelow and Williams 1995a; Morris 1991) by giving more importance to the sensory aspects of pain, silencing other narratives (Melzack and Wall 1983) and obscuring the experiential aspect of pain (Barsky and Borus 1995; Kotarba 1983). Emotion is a fundamental aspect of the pain experience; strong emotions can alter processes, perceptions, beliefs, attitudes, and pain experiences (Fishman et al. 2010). As Fishman and colleagues (2010: 375) state, “pain states never exist in isolation.” It is important to consider the emotional context of experiential pain, which is important for both assessment and biomedical intervention. The exclusion of the emotional context may lead, among other results, to a poor medical intervention, which is reflected in the high statistics of people with untreated cancer pain: indeed, more than half of people with cancer in the United States are in pain (Kohn and Portenoy 2009; ASC 2007; Van Den Beuken-van Everdingen 2007). There are many reasons for medicine’s failure to respond to the increased population of people with cancer in pain. They include inadequate training of physicians, disproportionately low funding for sociological

studies in pain research, and poor access to pain medication (Käll 2013; Morris 1991). But as many archeologists, biomedical, sociological, and phenomenological scholars (e.g. Jackson, Morris, Bendelow, and Leder) argue, the most important difficulty involved is an inappropriate definition of pain.

Contemporary sociologists are striving to make evident the impossibility of defining pain within the boundaries of a scientific semantic (e.g. Leder 1990). Firstly, the multidimensionality of the experience makes it difficult to adjust a theory to properly contemplate the entire spectrum of the complex experience of pain (Leder 1992). Additionally, no definition is adequate to overcome the well-established Cartesian dualism. On the contrary, the definitions tend to perpetuate the hegemonic view of pain of the biomedical field, where the brain is privileged above the body and experiential pain is totally ignored (Leder 1992). The English semantic structure is, in many cases, poor when it comes to describing the uncertainty of pain (Käll 2013); when describing pain, “language easily goes wrong” (Franz 1991: 30), and sufferers neither adjust their experience to a list of words, nor conform to the biomedical semantic definition of pain, but instead create new forms of narrative, which in many cases involve the creation of metaphors and art, such as painting or writing poems (Käll 2013; Frank 1991).

Medical sociologists such as Gillian Bendelow, Joseph Kotarba, and Drew Leder, among many others, are proposing a model of pain whose aim is not to develop a definition of pain, but rather to contemplate the multiple definitions of pain, since each of them incorporates life experience, means of communication, and the dynamic of the interaction between the pain sufferer and his or her social and cultural environment (Duncan 2000). This new approach to pain gives way to other narratives, particularly to

the worldview of the pain sufferer (Morris 1991), placing the person and the interaction with his or her environment — not with the mind, not with the brain — as the solemn source of knowledge, since the body, mind, emotions, and social and cultural understandings are all intertwined (Bendelow and Williams 1995).

As mentioned previously, the inability of pain sufferers to express pain within the boundaries of the biomedical semantic has serious consequences. Physicians rely on the manner in which people (in particular, their own patients) express their pain. The better a person is at describing his or her pain, using a limited number of words, “the better physicians are at pointing to the source of pain and prescribing the appropriate treatment” (Käll 2013: 14). But pain goes beyond words (Scarry 1985), and physicians are unable to help those in pain (Käll 2013; Morris 1991).

What We Know About Cancer Pain

Pain is one of the most terrifying and prevailing symptoms of cancer (ACS 2007; Winslow, Seymour, and Clark 2005). According to the American Cancer Society (ACS), in 2014, there were an estimated 14 million people with cancer diagnosed in the United States, out of whom 11.9 million experienced severe pain, and less than half of whom received proper medical pain treatment (Fisch et al 2012; ACS 2007; Cohen et al. 2003). The poor medical treatment during this era of high levels of technological advancement is contradictory. However, this is the reality that many cancer pain sufferers live with everyday, and it happens more commonly than we might imagine (Käll 2013). There are many reasons for this, which include, among many other aspects and as mentioned previously, the difficulty to define and, consequently, to classify pain within the boundaries of the scientific interest.

Traditionally, the cancer scientific community differentiates between pain associated with therapies and pain caused by the disease itself (Chan and De Leon-Casasola 2009). The two most common types of pain associated with the cancer itself (that is, not caused by the treatment) are spinal cord compression and bone pain. Spinal cord compression is pain caused by a tumor on the spinal cord, which mainly generates back and neck pain. Bone pain is caused when cancer spreads to the bones.

Although many cancers are incurable, medical, pharmaceutical, and technological advances have allowed people with cancer to live with the disease. However, for some, the pain becomes unbearable (Kohn and Portenoy 2009). Cancer-related pain is more severe than any other type of pain because it endures and, in some cases, intensifies over time (Chan and De Leon-Casasola 2009).

The most common type of pain caused by surgery is known as phantom limb pain. Phantom limb pain, which can worsen over time, is a long-lasting pain caused by surgical removal of certain body parts that gets worse with time, 5%-10% of amputees experience pain six months after the surgery and 60% of amputees experience pain two years after the surgery (Fisch et al. 2012). Another example of cancer-related surgical pain is post-mastectomy pain, which occurs after any breast procedure and can manifest itself many months after the surgery, affecting about 20% of women (Stevens, Dibble, and Miaskowski 1995). Another example of pain that can persist for years after surgery is post-thoracotomy. This very painful experience occurs after a thoracotomy or incision to the chest, which involves multiple layers of chest muscle and rib section; between 50%-80% of thoracotomy survivors experience pain, 19%-30% of them for up to five years after surgery (Portenoy and Lesage 1999). Among adults undergoing cancer

treatment, 50%-90% report moderate to severe pain caused by therapeutic interventions, mainly chemotherapy and radiation (Portenoy and Lesage 1999; Lesage and Portenoy 1999).

As mentioned previously in this chapter, the ravages of pain vary with time. Time also plays a role in determining or classifying cancer pain: acute, subacute, chronic, and breakthrough. According to the clinical approach, the only difference between chronic and acute pain is the duration of the pain. Acute pain is short-lived (lasting no more than six months) and can be caused by physical disruptions, such as a broken bone or surgery. In people with cancer, acute pain is frequently associated with emotional distress experienced at the onset or recurrence of the disease (Chan and De Leon-Casasola 2009). Subacute pain is experienced for four to six weeks after a major surgery or procedure. This type of pain becomes disruptive, affecting mainly the person with cancer daily activities (Burry 1982). Chronic pain recurs over time (more than three months) and is generally caused by a disease or by abnormal psychological conditions. Although both acute and chronic pain have an impact on a person's mental and psychological well-being, psychological distress is also a determinant of cancer-related pain.

As cancer progresses, the once-clear distinction between acute and chronic pain becomes blurred; at this juncture, acute pain and chronic pain intermingle to form a new type of pain known as breakthrough pain (Chan and De Leon-Casasola 2009). Breakthrough pain is chronic pain with episodes of acute pain that occur even though the person is taking pain medication. As Arthur W. Frank (1991) explains it, breakthrough pain is the pain that breaks through the sedative. This type of cancer-related pain is very

aggressive, and although it is shorter in duration, it can last as long as an hour and can happen even when chronic pain is clinically controlled (Chan and De Leon-Casasola 2009).

These aspects make pain one of the most horrifying and frightening experiences of the disease (Winslow, Seymour, and Clark 2005), which intensifies with time as the disease progresses. These alarming facts have highlighted the importance of understanding cancer pain properly to provide better medical treatment.

In order to improve the treatment of cancer pain, the World Health Organization (WHO), the Agency for Health Care Policy and Research (AHCPR), and the Expert Working Group of the European Association for Palliative Care have developed a methodological process to mitigate cancer-related pain. The most commonly used part of this process is the WHO guidelines, developed in 1986, which consist of a three-step process designed to standardize the treatment of pain by administering opioids increasingly as pain intensifies, estimated by means of a 1 to 10 numeric rating scale. The WHO's 3-step guidelines determine that for mild pain at Step I, non-opioids (e.g. analgesics, including acetylsalicylic acid (ASA) and nonsteroidal anti-inflammatory drugs NSAIDs) are administered. For moderate pain at Step II, Codeine and Tramadol are used, and for severe pain at Step III, narcotic analgesics or opioids are utilized (WHO 1996). NSAIDs are effective in treating pain associated with inflammation (Melzack and Wall 1965), while opioids are considered to be the most effective therapeutic option for moderate and severe cancer pain (McQuay 1999; WHO 1996). Opioid pain treatment is considered to improve occupational and social functioning of the person in pain while minimizing physical damages (Jacox et al. 1994).

Unfortunately, the WHO's ladder approach has developed other social problems, such as addiction or the development of physiologic tolerance (Jacox et al. 1994).

Ten years after the adoption of the WHO's guidelines, this methodology has provided good to satisfactory pain relief in about 88% of people with cancer (Zech et al. 1995), failing to provide sufficient pain relief to 10% to 20% of people with cancer in pain (Ahmedzai 1997). The WHO guidelines were revised and a fourth ladder, the international nerve blocks, was later added (Miguel 2000). However, these modifications to the ladder have proven insufficient, since the WHO stepladder approach is no longer accepted as the best approach to the alleviation of cancer pain (McQuay 1999). Studies show that approximately 25% of cancer patients died with pain, 10-20% of patients in advanced stages of cancer did not experience relief of their pain, and only 13% of patients who had severe pain were being treated with opioids (Fisch et al. 2012). Regardless of which WHO ladder is used, opioids are the drug of choice for unrelenting, intense pain. The use of opioids is associated with the development of physical dependence and tolerance (WHO 1996). This last resort, however, is becoming increasingly unavailable, due to political, medical, and law enforcement efforts to restrict opioids, based on concerns about both addiction and the misuse of these drugs when prescribed (Pear 2016; WHO 1996).

Today, cancer pain treatment strategies are questionable and urgently need to be improved, as an increased need for pain medication may be indicative of an exacerbation of the underlying cancer process causing the pain (Jacox et al. 1994). According to Jacox and colleagues (1994) more than 90% of cancer pain can be treated. Unfortunately, the inappropriateness of clinical treatments is mainly due to four

significant barriers or impediments to cancer pain relief (ACS 2007; Paice, Toy, and Shott 1998; WHO 1996). The first barrier is grounded in the lack of understanding people with cancer have of their disease and of their experiential pain. People with cancer tend not to communicate about their painful experience since they believe it will interfere with their treatment and will make them look like they are not fulfilling their role of being good patients (ACS 2007). The second barrier is created by health care professionals. This barrier is present mainly due to inadequate education in the areas of pain assessment and management (WHO 1996; Morris 1991). A third factor is the restrictive laws and regulations controlling the use of opioids (ACS 2007) and the “absence of national policies on cancer pain relief” (WHO 1996: 42). Finally, there is the inadequacy of the WHO orthodox approach to pain, which relies on the assumption that all pain patients follow a similar course (Sheridan 1992). This failure, according to Sheridan (1992), is not accidental, but, on the contrary, is the result of the intentional effort of those who favor the biomedical approach to emphasize the standardized measurement of pain. To overcome these barriers and to improve the quality of life of the people with cancer pain “efforts must be made to ... obtain patient reactions to their experience” (Paice et al. 1998: 1).

Pain is a subjective experience, impossible to quantify universally (Noble et al. 2005; Morris 1991; Bendelow and Williams 1995; Leder 1986; 1984). Each person with a similar type of cancer may experience it differently and thus may respond to the same medical treatment in different ways (Randall and Cleeland 2006). As noted by Hoffman (2016), “the dynamics of pain are complex and also highly individual,” and the solutions to cancer pain treatment are more complex than simply changing the WHO analgesic

ladder strategy. Strategies to alleviate cancer pain should incorporate non-medical therapies and the meaningful knowledge of the person experiencing pain (Hoffman 2016; Winslow, Seymour, and Clark 2005; Morris 1991), targeting the person in pain rather than the objective body source of pain (Randall and Cleeland 2006; Morris 1991). The problem with this approach, as described by Frank (1991), is that pain is the most difficult aspect of the cancer experience to describe. However, individuals have endeavored to communicate their experiences of cancer pain (Winslow et al. 2005), and this dissertation project considered individual experiences of cancer pain by exploring these verbal narratives.

Medical Models of Pain

Although there are multiple models by which pain is explained, only the most well-known biomedical models of pain are explained in this section. After, the sociological and the phenomenological understanding of pain are reviewed in this section.

Biomedical Theories of Pain

According to multiple authors (e.g. Gillian Bendelow, David Morris, and Ronald Melzack, and Patrick D. Wall, among many others) the biomedical understanding of pain is based on Descartes' dualistic approach. In 1644, Rene Descartes postulated that pain signals, or "animal spirits," travel through hollow tubes, which convey both sensory and motor information from the skin to a specialized brain center where a sensory cord pulls on the tube, thereby opening the gate between the brain and the tube (Bendelow 2006; 1993; Bendelow and Williams 2002; Sheridan 1992; Melzack and Wall 1965). Once the gate opens, the "animal spirit" flows through the tubes to the muscles, causing a body movement (Figure 1).

Figure 1 illustrates Descartes' mechanics of pain. The heat activates the nerve that traverses up the leg to the spinal cord, and finally, to the brain. Descartes compared the nerve tubule to a cord attached to a bell: pulling the rope will cause the bell to ring. Ergo, pain will cause the body to move. Pain, in mechanical terms, is both a warning that prevents further injuries and a punishment for ignoring the warning signal (Sheridan 1992; Morris 1991).

Figure 1. Descartes' Illustration of the Pain Pathway (1664)



Source: Melzack and Wall 1965: 972

Although contemporary understandings of pain have evolved beyond Descartes' initial postulation, the basic assumptions of his theory are still relevant today. For example, contemporary biomedical theories of pain have rejected the notion of the "animal spirit" and replaced it with the nervous system (Sheridan 1992). This change has elevated Descartes' theory to a more sophisticated understanding of pain. As a matter of fact, this approach evolved to determine the presence of specific nerves, specialized in detecting pain. This new theory, known as the specificity theory of pain, determines that pain is the result of the quality of a physical sensation on a particular nerve receptor, or *nocioceptor* (Sheridan 1992; Melzack and Wall 1983). The specificity theory hypothesizes that nociceptors conduct pain impulses through the spinal cord to

the pain center in the brain. The brain, in return, sends a message in the form of a reflex or sensation to the part of the body experiencing pain (Melzack 1996).

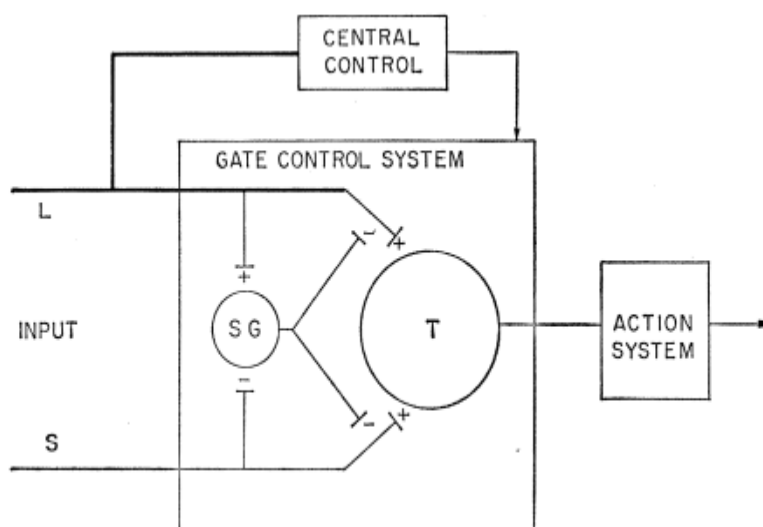
Clinically, the importance of Descartes' model of pain is invaluable; however, his approach is grounded in erroneous assumptions. First, Descartes' theory suggests a mechanical and a unidirectional understanding of pain; pain is caused by factors external to the body. In many cases, however, pain is caused by an internal stimulus not always easily identifiable, such as pain caused by damage to internal organs or by emotional distress (Bolger 1999, Von Baeyer, Johnson, and McMillan 1984). This leads to Descartes' second flawed assumption: he assumes that people always respond or react to pain. Some people live in pain but do not always react to it because pain is neither a consequence nor a cause – it is a lived experience. Studies show that pain is an individual experience, and people do not similarly respond to or react to the experience of pain (Scarry 1985; Kotarba 1983), specifically because different people attach different meanings to the experience of pain. Third, Descartes' approach, by assuming that all humans will react in the same way to the same external stimuli, completely ignores the social contexts and the unique features that comprise people's lives.

Melzack and Wall write that pain “does not consist of a single ring of the appropriate central bell, but is an ongoing process” (1965: 976). In an attempt to overcome the downfall of, and to add complexity to the medical model of pain, as well as to maintain pain as a subject of scientific research, Melzack and Wall introduced the Gate Control Theory in 1965. This theory, based on the authors' arguments, accounts for a number of facts that previous biomedical theories could not explain, such as the following:

(1) The variable relationship between injury and pain; (2) non-noxious stimuli can sometimes produce pain; (3) the location of pain and tissue damage is sometimes different; (4) pain can persist long after tissue healing; (5) the nature of pain and sometimes the location can change over time; (6) pain is a multi-dimensional experience; and (7) there is a lack of adequate pain treatments. (Melzack and Wall 1983: 165)

Melzack and Wall's theory was the first to integrate the physiological and psychological aspects of pain. Pain is a physiological and psychological response to peripheral noxious signals. The peripheral noxious signals enter the spinal cord and are then processed in the brain (Figure 2).

Figure 2. Melzack and Wall's Gate Control Theory



Source: Melzack and Wall 1965: 975

Figure 2 depicts pain signals entering the spinal cord until a neural mechanism in the dorsal horns area of the spinal cord acts like a gate, increasing or decreasing the impulses of pain from the peripheral nerve endings to the central nervous system, located in the brain. The gates, located in the central nervous system, then modulate the peripheral input before the brain evokes a response to and a perception of pain stimuli. The extent to which the gates modulate the pain signal is determined by the activity of

the nerve fibers and by descending fluids from the brain, which at the same time are modified by persons' psychological and cognitive understandings of pain, their past experiences with pain, their sociocultural learning, and their level of mental distress [anxiety or anticipation, for instance] (Melzack 1996; Melzack and Wall 1983; 1965). In short, emotions and culture can either amplify or minimize experiential pain. The region labeled "Central Control" in Figure 2 is where all previous experiences of pain are stored.

This theory enables the interpretation of pain in terms of a nerve impulse (Melzack 1996; Melzack and Wall 1983). The target of pain is often thought of as a 'thing' that can be measured, observed, and inspected (Barry et al. 2001; Morris 1991; Scarry 1985). The vast majority of biomedical studies on pain not only define pain in terms of intensity and severity, but also push the sufferer to describe their lived experiences in these terms (Althus et al. 2013; Morris 1991).

The Gate Control Theory constitutes one of the first medical approaches to viewing pain beyond its physiology; as Mary S. Sheridan writes, the Gate Control Theory "opens the gate to the consideration of pain as an interactive phenomenon" (1992: 8). Despite its widespread nature, the Gate Control Theory is strongly criticized. Bendelow and Williams (2002; 1995), for example, explain that although the Gate Control Theory takes into account the emotional aspect of pain, the biological understanding of pain still prevails over the social. The Gate Control Theory has provided, as Robert Kugelmann writes, a "new metaphor" of the Cartesian body-mind dualism, where pain is defined in a very complex and technical manner, but as chiefly a bodily process (1998: 194).

Despite technological and scientific advances, biomedical approaches to pain have their limitations, such as the following: the intensity of cancer pain, in many cases, is not proportional to bodily damage or disruption; physiological recovery does not necessarily ensure alleviation of pain; and, finally, biomedical models do not account for the emotional and sociocultural components of pain. In 1959, the biopsychosocial model was introduced.

Biopsychosocial Model of Pain

George L. Engel formulated the biopsychosocial model, in which the author expanded the anatomical understanding of pain to include psychological and social components of pain (Engel 1977; 1959). As stated by Grant Duncan:

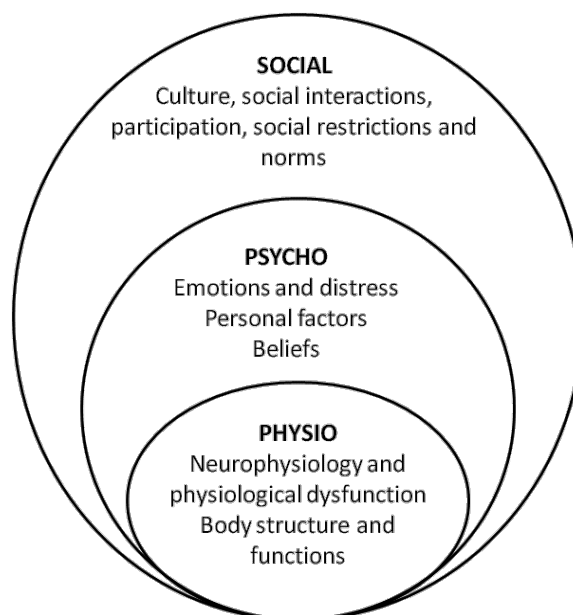
The biopsychological model [of pain] broadens the definition of pain beyond the raw sensation to include higher-order perception, enabling scientists to account for the influence of the central processes of emotion and learning of pain. This model allows a clear distinction between the neural signal (nociception) and the complexity of emotions. (Duncan 2000: 494)

Engel's model departs from a critique of the Cartesian dualistic understanding of pain, arguing that both mind and body function in conjunction with the social and cultural environment to define the experience of pain. To state it another way, neither the experience of pain caused by a bodily disruption, nor a mental understanding define an event as painful (Duncan 2000; Bury 1982). Conversely, personal attitudes, beliefs, and expectations, as well as social and cultural factors, do shape a person's understanding of a life experience as painful (Duncan 2000).

Figure 3 describes the Biopsychosocial Model of Pain. Each component of pain - the psychological, the biological, and the social - interacts with the others and together they

constitute a unique understanding of pain. In other words, each component influences and is influenced by the person's social and cultural meanings of pain.

Figure 3. The Biopsychosocial Model



This model of pain was widely accepted by psychologists, due in part to the Gate Control Theory of Pain becoming the most utilized model to explain and treat pain, and particularly to treat chronic pain, “to the point of becoming a kind of catechism in medical education” (Morris 1991: 1).

The conceptual framework engendered by the biopsychosocial model of pain reminds scholars that these two components, the social and the psychological, are also relevant components of experiential pain. For example, Chandler’s (2013) study supports this view: using narratives, the author explores the life stories of self-injured adults, illustrating that adults who inflict injuries upon themselves see physical pain as a means of alleviating psychological pain. For this particular social group, bodily pain works as a placebo, obscuring the real source of pain that resides outside of the body and that has a more profound emotional impact (Chandler 2013).

Engel's model broadens the definition of pain to a "higher-order perception" (Duncan 2000: 494) to explain how previous experiences influence later pain behavior (Syrjala and Chapko 1995). Research shows that cancer pain is associated with depression and distress (Breitbart et al. 2009), and with distress prior to the onset of the disease (Novy and Aigner 2014; Syrjala and Chapko 1995).

The biopsychosocial approach to pain has broadened the knowledge related to the conceptualization and treatment of pain, but it also presents a static view of pain (Freund 1990). The Biopsychosocial Model of Pain is not as inclusive as it is portrayed to be because it does not incorporate enough motivational, behavioral, or social aspects of pain (Jackson 2011; Duncan 2000). Instead, this model is caught in a circular argument, ratifying the Cartesian body-mind dualism in a complex way (Duncan 2000), and fragmenting experiential pain (Jackson 2011; Barsky and Borus 1995; Kotarba 1983). The biopsychosocial model ignores the uniqueness of the pain experience and it masks ethical imperatives in the guise of scientific findings about the nature of pain (Duncan 2000).

The biopsychosocial model, as described by Gillian Bendelow (2006) and Irving Zola (1972), is a powerful and deceptive metaphor that converts a non-scientific, non-technological, subjective, and meaningful experience into a technical, objective, and insignificant experience owned by biomedical professionals, explained in biomedical words, and treated by the medicalization of the body, particularly within the clinical treatment and understanding of cancer pain, and with the perpetuation of biomedical control and domain over the body (Conrad 1992; Zola 1972).

The Challenges of the Biomedical Understanding of Cancer Pain

Pain is a subjective experience with multiple emotional factors and sociocultural meanings (Maxwell 2012); it is not an objective thing that can simply be measured and treated (Morris 1991). The biomedical understanding of pain ignores the relationship the person in pain has with his or her environment and how this relationship determines how people live, perceive, and experience pain. According to sociologists, the main challenge to the biomedical field lies in the ontological presumption of the biomedical field that pain is interpreted in the brain (Maxwell 2012). The complexity of cancer pain can only be properly understood and interpreted through a real dialogue and not through the process of the gold standard of self-reported pain, where a physician focuses on achieving objective measures or indicators of pain, such as temporal features, location, severity, and quality (Maxwell (2012). As Leder (1992) notes, pain cannot be reduced simply to indicators of sensory qualities; rather, pain is a manner of being in the world.

It is this contradictory behavior, to measure the immeasurable, that leads to the misrecognition of the real dimensions of pain and, thus, to its poor medical treatment (Käll 2013; Bendelow 2006; Bendelow and Williams 1995). As Gillian A. Bendelow writes: “Biomedicine, in particular, is characterized by this process of rationalization and over-simplification which suppresses the ‘voice of the lifeworld’ and subjective experience in favor of evidence-based criteria and tangible pathology which upholds the risk discourse” (2006: 59).

Biomedicine strives to enclose the subjective experience of pain within the boundaries of uniform and universal description. The unpredictability of pain has become one of the greatest challenges and is of paramount significance within the

biomedical field, as pain can neither be described universally nor objectively. As a matter of fact, the assumptions that all pain follows a similar course, that all people live and experience pain similarly (Sheridan 1992), and that all pain can be measured and interpreted in the same manner are why pain prevails and why biomedicine has failed. This approach, according to Sheridan (1992), is not accidental; on the contrary, it is the result of an overemphasis on the biomedical understanding of the body and the perpetual underestimation of the emotional and social connotations of pain. Biomedical studies of cancer pain should, therefore, contemplate the meaning of pain in different cultural settings and among different cultural groups (Leder 1984).

With the Gate Control Theory of Pain, new medical narratives are presented which are portrayed as being inclusive and integrative. However, as Vrancken (1989) shows, these new medical models and narratives locate the mind as the center of the pain experience, suppressing and fragmenting the lifeworld (Barry et al 2001). Or, as stated by Christine A. Barry and colleagues, in these models the mind/body dualism is often employed in its strongest form (Barry et al. 2001) and the lived body is treated as a corpse (Leder 1992). The “epistemological primacy of the corpse” has shaped the medical understanding of pain from the beginning (Leder 1992: 22). Medical and clinical understandings of pain begin with the education of the dead body (*körper*) and culminate in the treatment of the living patient as cadaverous or as a machine (Leder 1992). This disappearance of the lived body tends to be profoundly disruptive within the context of pain (Leder 1992), particularly of cancer pain, where the lived body becomes a central aspect of the experience (Frank 1991).

Once the biomedical field comes to realize that cancer-related pain has an existential dimension no less important than its physiology, the understanding of cancer pain, as well as methods of treatment, will shift and will improve the quality of life for the person in pain (Leder 1992). The biomedical field will then allow the lived body to speak of its pain, and of its experience (Leder 1992), giving the person in pain a voice which will interact with the voice of the medicine (Bendelow and Williams 1995; Morris 1991). According to Drew Leder (1990), only by giving voice to the lived body will the full significance and etiology of pain emerge.

The study of cancer pain calls for a new model (Kohn and Portenoy 2009; Bendelow and Williams 1995). I suggest an approach that includes a meaningful knowledge of the lifeworld (see Winslow et al. 2005; Bendelow and Williams 1995; Leder 1992; Schutz 1967). This is no easy task; as the sociologist and cancer patient Arthur Frank says of the cancer experience, pain is the most difficult aspect to describe (Frank 1991). However, sociological and phenomenological approaches to cancer pain are the only two approaches with the ontological capacity to overcome the dualistic understanding of pain, refocusing the attention on the interrelationship between body-subject and body-object, to the lived body, where the many facets of pain are intertwined. In the following section, I will illustrate how and why sociological and phenomenological approaches are the best theoretical framework for the study of cancer pain. These approaches illuminate the complexity and multidimensionality of the lifeworld and of the subjective experience of pain, overcoming the limitations of the biomedical approach (Bendelow 2006; 1993; Kotarba 1983).

Sociological Understandings of Pain

The general acceptance of Cartesian dualism, as described in previous models of pain or at the extreme margins of other pain models (Jackson 2011), has resulted in a neglect of the emotional and cultural components of pain (Bendelow 1995), rendering experiential pain meaningless outside the biomedical spectrum (Morris 1991; Zola 1966). Today, however, there is a latent need to draw attention to experiential or subjective pain. In this respect, both the sociological and phenomenological approaches offer the following: 1) a rich framework within which to understand the multiplicity and complexity of the lived pain; 2) a unique scenery in which experiential pain becomes meaningful; and 3) a theoretical setting in which to overcome the so-called myth of the two pains: physical or objective and mental or subjective (Morris1991).

The aims of this section are twofold. First, I will explore the insights of an integrated sociological theory of pain, which is grounded in the sociological understanding of culture and emotions and in how these aspects determine experiential pain. The development of an integrated sociological theory of pain, however, is quite challenging (Jackson 2011). According to Jackson (2011), the main reasons that pain presents such a formidable challenge and makes the development of a theory so difficult are the subjective and individual natures of pain, the silent feature of the experience, and the emotional and sociocultural meanings attached to pain. These elements make pain a difficult terrain upon which to develop a theory, but also fertile ground for comprehending the magnitude and importance of the lived body in people's understandings of their daily lives. Second, I will describe the phenomenological

understanding of pain, in which culture and meaning contribute to a unique understanding of the pain lived and experienced by the lived body.

Culture and Pain

In order to develop a more sophisticated medical-sociological model of pain, it is necessary to locate the individual's pain within his or her social and cultural contexts (Leder 1990). The understanding of how culture interacts with the everyday life experience of pain is not new in the sociological approach to health and illness. However, it is a topic that has not been studied exhaustively (Bolger 1999, Bendelow and Williams 1995, 1995a, Freund 1990). Indeed, pain remains poorly defined until it is located within the sociocultural context (Jackson 2011; Bendelow 2006). Culture not only shapes the interpretations and responses attributed to pain, but also is shaped by pain (Morris 1991). Before progressing in the arguments about the relevance of culture to pain, it is important to clarify the notion of culture. The meaning of the word *culture* varies across disciplines. Although the sociologist Talcott Parsons has been strongly criticized, the definition of culture proposed by Parsons is a first approach to the social dimension of culture, which goes beyond mere symbols to the understanding and interpretation of the symbols for members of a social group (Parsons 1951). The shared symbols, for Parsons (1951), work as social norms that guide an individual's interactions and that represent society's core values or cultural traditions.

Culture is much more than a mere common set of symbols (Robbins 1999). The sociological understanding of culture emphasizes the study of a complex system of meaning that structures experiences and sees culture as the mechanism through which the meaning and structure in social life is generated (Bendelow and Williams 2002). In

this way, “culture is seen to mediate social processes and is construed as the source of real phenomena, that is, as determining the very structure and substance of human existence” (Bendelow and Williams 2002: 40).

Within the cultural approach, pain and the manner in which we experience pain are primarily determined by the society in which we live (Bendelow and Williams 2002). Culture not only shapes the interpretation of pain, but also is the only sphere where body and mind interact; society and persona amalgamate, providing the experience of pain with meaning, breaking with the classical Cartesian dualism that splits the mind and the body (Freund 1990; Leder 1990). From this perspective, culture is seen as the primary source and the locus, in sociological terms, of an internalized set of norms, values, and rules (Bendelow and Williams 2002). In this respect, Freidson (1988) observed that people are different in the way they respond to pain; however, social groups ascribe meanings to pain that are socially shared. The way a person makes meaning of and experiences pain varies culturally and socially (Freund 1990). Meanings of pain are derived from the individual’s past experiences, culture, and social norms; in fact, pain is an inter-subjective experience, as it includes the individual’s everyday life experiences (Jackson 2011). Pain, therefore, can only be understood within the social and cultural norms and practices in which the experience of and response to pain are legitimized (Jackson 2011; Helman 2007; Zola 1966). Helman (2007), for example, shows that not all cultural groups respond to pain in the same way; the manner in which people perceive, respond to, and communicate their own pain is influenced by their cultural norms.

Some social groups, due to behavioral norms considered proper within their culture, prefer to keep their pain private, while others make it a public matter. One of the most notorious examples of this phenomenon is Henry Beecher's report on wounded soldiers during the Second World War. He found that soldiers, despite the seriousness of their traumas and the subsequent severity of their pain, requested pain medication less often than was expected. Beecher (1956) concluded that in general, these soldiers preferred to keep their pain experiences private, as going home honorably was a shared cultural value among these soldiers.

In his book, *People in Pain*, Zborowski (1952) provides an influential perspective on the relationship between culture and pain. The conclusion of his study revealed that there is a marked behavioral response to the experience of pain based on ethnicity or cultural background. Italians and Jews, for instance, focus mainly on the immediacy of the pain experience, forgetting their past experiences and disclosing their pain openly and loudly. Irish Americans, on the other hand, generally tend to hide their pain, engaging in strategies of denial and presenting themselves stoically. What Zborowski (1952) discovered, then, is that pain encompasses cultural norms as people respond to their pain not only as individuals, but also as members of sociocultural groups. Thus, pain tends to take on the meaning that social groups assign to it.

Likewise, Zola (1966) examined the influence of culture on pain. Zola sampled patients seen in various outpatient clinics at Massachusetts General Hospital, specifically 63 Italians and 81 Irish people. The results of the study illustrate that these cultural groups have different strategies to communicate pain and that they experience pain differently because of their different ethnic backgrounds. The Irish patients, for

example, located their pain in a very specific part of the body, such as eyes, nose, or throat. However, the Irish patients also obscured their pain, ignoring the real magnitude of their experiences and referring to their pain using phrases like “It was more a throbbing than a pain” (Zola 1966: 623). The Italian patients, however, were more diffuse in identifying a specific pain location in the body, instead locating pain in multiple areas of the body, and were more prone to highlight their pain entirely. Zola (1966) concluded that the different ways social groups experience, attach meaning to, and communicate their pain may reflect major sociocultural values and behavioral norms unique to a particular culture.

The lack of a social group or subculture, according to Bolger (1999), is characterized essentially by a sense of brokenness and isolation that increases the feeling of low self-esteem, loss of self, victimization, depression, and low self-worth, all of which increase pain levels. This sentiment of isolation produced feelings of alienation from the body, the experiential pain, and the subculture (Leder 1990).

Although culture defines behavioral norms, members of a particular cultural group are adept at developing new social norms with shared meanings in which the experience of pain is normalized, generating what is known as a pain subculture. Kotarba (1983) explored the meaning of pain between two subcultures: professional athletes and manual laborers. The author found that within the athletic subculture, pain is a familiar and expected feature of their everyday lives and that networks were crucial in circulating information about methods to overcome and disguise pain. The athletic subculture defines when to conceal or disclose the experience of pain, which depends on the potential social and emotional costs (Kotarba 1983). For some athletes,

The benefits of pain disclosure include access to health care, sympathy for one's suffering, and help in adjusting to everyday contingencies affected by the pain. But the cost of pain disclosure, as learned through experience, can be perceived as overwhelming. Certain reactions of critical audiences may elicit feelings of shame and guilt. (Kotarba 1983: 134-135)

Although manual workers faced the essentially same problem as the professional athletes there is a certain audience from which pain should be either totally concealed or presented in certain favorable ways (Kotarba 1983). The disclosure of pain takes place most of the time within a tavern, which Kotarba defines as the "tavern subculture" (1983: 169). The conversation of pain, as described by Kotarba (1983), that takes place within the tavern subculture is usually conducted in a very humorous manner. As manual workers presented to others an image of competence, which is achieved by showing emotional control over the pain, they also disclose their experiential pain with humor. Through humorous conversation, manual workers gain access to medical knowledge and thus the "manual laborer has in general, less reason to conceal nonvisible... pain problems... and the material benefits of disclosing ... pain problems may either be irrelevant or secondary to the symbolic cost of disclosure" (Kotarba 1983:168). In either case, the author concluded, "[the] pain-afflicted person may decide to conceal the experience of pain from a potentially critical audience if the social and emotional cost resulting from disclosure far outweighed the perceived benefits" (Kotarba 1983: 134)

Kotarba (1983) and Zola (1966) highlighted the relevance of cultural norms in defining people's behaviors towards pain. In both cases, some sociocultural groups adopted a stoic attitude. Hilbert (1984) believes many sociocultural groups are stoic about their pain, which in many cases results in minimizing experiential pain in order for

their pain to be recognized by others as normal pain. As a matter of fact, normal pain determines that nothing is wrong with experiential pain; it is an expected event, and therefore the sufferer should not be experiencing pain as problematic, but rather as a daily life event, which is one of the greatest ironies of pain (Hilbert 1984). However, people who have persistent pain, according to Hilbert (1984), are not complying with the social norms and are therefore violating the cultural ideologies of their particular sociocultural group. As Edrington and colleagues state: “culture can dictate one’s personal adjustment to an illness or its symptoms” (2007: 341).

In spite of the importance of studies in drawing attention to the significance of sociocultural dimensions in shaping pain, these studies have been criticized. Baszanger (1989) acknowledged the potential of Kotarba’s approach, but he also criticized the idea that experiential pain defines the person, rather than the other way around. Baszanger noticed that sociological studies are moving beyond the concept of living with pain to the notion of experiencing pain. Experiential pain is influenced by an individual’s perception and emotional understanding of pain, a group’s cultural beliefs regarding the experience of pain, and the social norms regarding the manner in which the sufferer should behave (Thoits 1989; Zola 1966).

Experiences of pain are only significant within the boundaries of a particular sociocultural environment and the emotional manifestation of the perception of pain proper to the individual interpretation of the painful experiences (Leder 1984; Schutz 1967). Leder (1984) suggests that cultural and social conditions influenced how the body expresses, communicates, or responds to pain. Culture influences the social understanding of pain, where some cultural groups expect an extravagant display of

emotions (Zborowski 1952; Zola 1966), but others value stoicism, restraining emotional expressions of pain (Shilling and Mellor 2010; Edrington et al. 2007; Juarez et al. 1998). Lastly, pain is considered a part of life and enduring pain is thus an indication of personal strength and an acceptance of cultural norms (Shilling and Mellor 2010). Some cultural groups expect an extravagant display of emotion in the presence of pain, but others value stoicism, restraint and downplaying the pain.

For example, a study shows that Chinese adults suffering cancer pain were less expressive because it is their cultural norm to be less vocal and more stoic in their expressions of pain (Edrington et al. 2007). Likewise, a qualitative study of 17 Hispanic adults with cancer pain reported that the cultural norm is to live pain stoically. One of the participants pointed out that:

At home, I saw my father die of the same illness [cancer], and it became engraved in my mind forever that I never, never saw him complain, nor cry out, nor ask for medication. And that's how I am. I endure it alone until I can't stand it [cancer pain] any more. (Juarez et al. 1998: 264)

The lack of verbal or behavioral expressions of pain should not be equated with the absence of pain (Juarez et al. 1998), or the exaggeration associated with high levels of pain (Zborowski 1952; Zola 1966). In sum, culture impinges at many points on the manner in which people experience pain emotionally (Bendelow and Williams 2002).

Emotion and Pain

Both contemporary and traditional medical theories ignore the emotional aspect of pain. The main reason given for the exclusion of emotion in biomedical studies of pain is the lack of scientific rigor regarding emotion; emotion cannot be explained, described, or measured objectively (Jackson 2011). Neglecting the emotional realm of pain has created a serious schism in pain research (Melzack and Wall 1983), and contemporary

studies of pain, particularly sociological ones, must take this schism into account. The sociology of emotion looks at the social context of pain (Bendelow and Williams 2002). As an emotion, pain lies at the intersection between mind and body, between culture and biology; it breaks from the prevailing biomedical understanding of pain, claiming the terrain for a more integrated view of pain (Bendelow and Williams 2002).

Emotion is one of the most complex and subjective human experiences. In fact, emotion is a fusion of “mutually modulating cognitive-physiological and behavioral aspects” (Freund 1990: 269). Emotions, as Bendelow and Williams (1995) argue, “lie at the juncture between mind and body, culture and biology” (1995: 90). It is with emotion, not with the lack of especially scientific rigor, that the complexity of understanding pain lies.

What is emotion and is pain an emotion? This is a central question, one that many traditional sociologists (such as Hume and Locke) have struggled with in their philosophical reflections and in answer to which they offered significantly different responses (Deigh 2010). However, the understanding of pain as a “substantial emotional component” can be traced to Plato and Aristotle (Bendelow and Williams 2002: 250). The Greeks, as stated by Price (2010: 121), “had no word equivalent to our Latinate ‘emotion.’ The term they commonly use in its place, *pathos*, had the most general meaning ‘*that which happens to a person.*’” The word “pain” comes from the Greek words *akos*, meaning *psychic pain* (the English word “ache” also derives from *akos*), and *poena*, meaning *punishment*. As described by Price (2010), Plato defines pain in terms of a dynamic of opposite sides resulting from the corrupted interaction between the heart, *phaedo*, and the head. Aristotle [384-322 BC], Plato’s student, defined

emotion as a mixture of pain and pleasure. Pain then arises from a disruption of the soul. Pain is more than “the perceptual and desirous” of the head because of consciousness; it is also a sensory experience for it is closely connected within sense-perception and imagination spectrum of the person (Price 2010: 133). Emotion, therefore, encompasses multiple responses to life events.

The complexity of pain is constantly evoked and reinforced, as is noticeable in the definition of pain given by Peter Goldie, a British philosopher. For Goldie, emotion is a:

Relatively complex state, involving past and present episodes of thought, feelings, and bodily changes, dynamically related to a narrative part of a person’s life, together with dispositions to experience further emotional episodes, and to act out of the emotion and to express that emotion. (2000: 144)

However, it is the complexity of emotion which makes it a difficult feature to classify; emotion is the main aspect that threatens the dualistic worldview or, in sociological terms, challenges Cartesian dualism (Bendelow and Williams 2002; 1995; Freund 1990; Thoits 1989). “The profound complexity which characterizes human life in the world is reflected in the broad and subtle universe of emotions” (Bericat 2016:492). I am not going to dig deep into the philosophical discussion about what emotion is, and instead move into the sociological understanding of emotion. The sociologist Norman K. Denzin defines emotion as a:

Lived, believed-in, situated, temporally embodied experience that radiates through a person’s stream of consciousness, is felt in and runs through his body, and, in the process of being lived, plunges the person and his associates into a wholly new and transformed reality – the reality of a world that is being constituted by emotional experiences. (2009: 66)

In short, Denzin’s definition incorporates the multiplicity and embodiment of emotion. Bericat (2016) defines emotions in terms of social and cultural responses to or manifestations of a lived experience. These responses determine how important an event

is for a person: “Emotion is a bodily consciousness that signals and indicates this importance, regulating in this way the relationships that a specific subject has with the world” (Bericat 2016: 493). Emotion is not an innate biophysiological phenomenon; rather, it is a complex sociocultural experience that centers attention on the self, or the “feeling subject” (Bericat 2016: 493). In essence, emotions involve four elements, as described by Thoits (1989): (a) the assessment or appraisal of situational events in the world that stimulate (b) changes in the physiological or bodily sensations, which in turn produce (c) the free and uninhibited display of expressive gestures, with great (d) social and cultural significance. According to Thoits (1989), when experiencing emotions, all four components are present simultaneously.

Emotion is therefore socially constructed and the link between emotion and the self is present essentially in the socially constructed meaning attributed to an event (Thoits 1989). The subject of emotion is not by any means an isolated body alienated from the social and cultural environment, but rather it is a human quality that exists within a community and is in a permanent relationship with its environment (Freund 1990). Freund (1990) describes emotion as a mode of being that involves a fusion of the physical and the psychological with the social and cultural environment and is manifested, in many cases, through the meaning of an event. The meaning of emotions, therefore, arises from the embodied experience.

Emotion, as Freund (1990) argues, integrates three bodies that constitute the body-subject: the lived body that suffers and experiences pain; the social body, where meaning is attached; and the behavioral body, which reacts and responds to physical pain according to social and cultural norms. All three bodies encompass the lived body.

Unfortunately, until now, within the vast majority of sociological studies of pain, the emotional aspect of the lived body has been under researched. However, within the biomedical field, studies of cancer pain have highlighted the importance of emotions as they relate to the body as an object of research. For example, in the case of adults with cancer, biomedical research shows that negative emotional experiences, particularly stressful life events, fear, depression, anxiety, and past experiences, increase the experiences of pain (Althus et al. 2013; Zaza and Baine 2002; Koopman et al. 1998). In contrast, positive emotional states generally reduce experiential pain among adults with cancer (Spiegel et al. 1994). Although biomedical studies of cancer pain address, to a certain extent, the relationship between pain and emotion, this research limits the understanding of a lived body (Morris 1991; Freund 1990; Scarry 1985).

Sociological and phenomenological studies of pain, on the other hand, take into consideration not objective pain (Morris 1991), but the voice of the sufferer of cancer-related pain, and these studies interpret pain from the perception of those experiencing it. Morris writes: “the meanings of pain are sometimes so deeply bound up with the historical culture within which it occurs that an outsider may find them utterly incomprehensible” (1991:41). Hence, others, as outsiders, may find the experience - and therefore the meaning attached to it - incomprehensible.

To explore the multiple meanings of pain, it is important to consider and disclose the social meaning created via interactions with others (Shilling 2007, 2001, 1997, Kotarba 1983a). Kotarba (1983a; 1983) conducted important sociological research on pain, which highlighted the importance of social interaction in the construction of meaning within social groups. In his study, Kotarba (1983) found that the self-awareness of pain

and the emotional meaning of pain emerged from the social interactions among peers of a particular subculture. Pain, in many cases, is an emotional state experienced in the lived body, or, as Turner states, pain is “an emotional state” of the embodied individual (Turner 1992:169).

Pain has both emotional (Chandler 2013, Chapple and Ziebland 2002, Bolger 1999, Johansson et al. 1999, Freund 1990) and sociocultural (Encandela 1997; Zborowski 1952) meanings attached to it. For example, Ha’elyon and Gross (2011), in their study of women undergoing painful in-vitro insemination treatments, showed that the women involved tolerated the physical pain because the emotional long-term benefit of their pain (that is, becoming pregnant and giving birth to healthy babies) overcame the temporality of the experiential pain. This, the temporal aspect of pain, according to Leder (1990), is one of the main characteristics that make pain a disruptive event affecting people’s everyday lives.

The emotional meaning of pain and the subsequent results of the experience have the ability to overcome the disruptive aspect of pain. The emotional connotation of experiential pain, however, is only relevant when the emotional interpretation of pain is shared, which rests upon relationships and interactions with others who are undergoing similar pain and in some way or another constitute a social group (Bolger 1999). Studies of emotional pain explore the role of narratives of pain and how emotion is manifested in the manner people express their experiential pain, conferring major prominence to the agency and autonomy of the persons in pain as they narrate their experiences; this construct is referred to as heroic narrative (Burrows 2010; Frank 1990). This narrative

structure provides insights into how people perceive and interpret their lived experiences as they shape their bodies and redefine their self-concepts and identities (Frank 1990).

Sociological scholars demand the incorporation of emotion into studies of health and illness (Bericat 2016, Bendelow and Williams 1995, Frank 1990, Kotarba 1983). In the particular case of pain, when the absent body becomes visible and present, disrupting the everyday life of those experiencing it (Leder 1990), emotion, then, becomes a way through which the self exteriorizes the experience of pain (Bericat 2016). Pain is not an emotion; rather, pain is a “feeling-sensation” (*gefühlsempfindung*): “There is no pain that I cannot sense just as there is no pain that is not painful” (Geniusas 2014a: 5). Pain is intrinsically marked by emotion (Geniusas 2014a). Therefore, incorporating emotions into the sociological study of cancer pain becomes fundamentally relevant to the understanding of such pain, which is only meaningful within the sociocultural context, expressed through emotion (Bericat 2016). Thus, there are evidently two sides of the experiences of cancer pain, as nicely expressed by Geniusas:

It suffices to get rid of one of these dimensions to transform [cancer] pain into something other than it is. For instance, if the experience [of cancer pain] has an affective dimension, which we in common language identify as ‘painfulness,’ but if the ‘pain’ in question cannot be sensed (that, is located in the body), we are not living through pain, but rather through an emotion. (2014a: 5)

Consequently, it is important to incorporate into the study of cancer pain, both sides: the emotional and the experiential dimension of cancer pain. As Freund (1990) argues, pain is a lived and embodied experience that is culturally and socially meaningful and emotionally manifested. Yet, in order to properly incorporate both aspects it is necessary to have a clear understanding of the subject of pain. This is a central issue that underlies

the analysis of pain in phenomenology. The following section explains the substantive phenomenological principles that sustain the need for a phenomenological study of pain.

Phenomenology of Pain

Phenomenology derives from Greek *phainomenon*, meaning *appearance*, and *logos*, which means *word* or *reason*. Phenomenology, according to Crossley (1995), is a descriptive study of existential beginnings, which are located in the world of the embodied subject. Merleau-Ponty defines phenomenology as “a study of essences,” of what makes a thing or an experience what it is (1962: vii). The study of phenomenology focuses mainly on the nature and meaning of human experience (Leder 1990; Crossley 1995). Geniusas (2014a) determines that the phenomenological understanding of the emotional component of pain can be traced to the Austrian psychologist and philosopher, Franz Brentano [1838-1917] whose ideas of object directedness of the mind influenced the German philosopher Edmund Husserl’s [1859-1938] notion of intentionality (Geniusas 2014a; McIntyre and Smith 1989).

Intentionality derives from the Latin word *intendere*, which means to point to or to aim at, and is a central concept in Husserl’s phenomenology, which stands for the mental states and experiences of being conscious or aware (McIntyre and Smith 1989). Consciousness is always consciousness of something. McIntyre and Smith (1989) stated that “as conscious beings, or persons, we are not merely affected by the things in our environment; we are also conscious of these things” (1989: 147). In particular, the person in pain is not merely affected by the painful experience, but they are also conscious of the things that are causing pain, and both the pain and the object of consciousness are intricately connected. As a matter of fact, the meaning people attach

to their experiential pain depends on the content of the experiential pain, or what makes a pain sufferer's description a representation of his or her pain (McIntyre and Smith 1989).

Cancer pain is only meaningful, as Merleau-Ponty (1962) puts it, within *dasein* or being-in-the-world, which calls for the understanding of pain, among many other human experiences, as an embodied experience from which knowledge is acquired and understanding of cancer pain is necessary:

To return to things themselves is to return to that world which precedes knowledge, of which knowledge always speaks, and in relation to which every scientific schematization is an abstract and derivative sign-language, as a geography in relation to the countryside in which we have learned beforehand what a forest, a prairie or a river is. (Merleau-Ponty 1962: ix)

A phenomenological exploration of people's taken-for-granted knowledge of cancer pain will disclose a mixture of assumptions, beliefs, social norms, and expectations (Toombs 2001). To bring forward such assumptions is to make it known that the person in pain is taking knowledge or perception of his or her experiential pain for granted (Toombs 2001). Perception, in this case, is a reflective and active thought of the world that bestows meaning on an experience of the lived-body that occurs in the world; it is the human being as a whole (mind and body) who perceives the lived world, making perceptions and interpretations unique to each individual (Toombs 2001). The situated meanings or experiences that are meaningful only within a specific sociocultural context must also be taken into account when studying pain. The knowledge and understanding of cancer pain are acquired from the intersubjective understanding of cancer pain (Edrington et al. 2007; Kleinman 1988). A phenomenological study of cancer pain combines the subjective and the social understandings of pain, understanding pain in its

most fundamental form of intersubjectivity (Jackson 1994), which represents a plurality of people suffering from cancer-related pain who seek answers to the following fundamental questions: “Why me? Why does it have to hurt so much? How do I handle the pain and the fear that comes with it?” And, for some people, “How do I live a life in pain?” (Toombs 2001: 268).

The experience of pain reorganizes the lived space of the sufferers, once “directed ecstatically upon the world,” to focus on the actual inward pain (Leder 1986: 255). As Leder (1986:255) describes it: “We no longer see, hear, feel the world through our bodies: instead the body itself becomes what we feel, the center or axis of thematic attention...we feel the pain inside.” Leder (1986) defines this aspect of pain as the centripetal mode. Pain sufferers adopt coping mechanisms that give meaning to the pain and the painful experiences. These mechanisms make it possible for sufferers to rationalize their pain and to therefore understand each behavior and action that constitutes their experience of pain (Schutz 1967). As Frank explains it: “I confess that I did ask myself how they [the tumors and pain] had gotten there [in his body]” (1991: 86). However, as Leder defines it, meaning arises when the sufferer goes beyond the hurt and he/she is forced to come face-to-face with their “vulnerability and finitude, and thus, ultimately, [their] death” (1986: 259).

The previous questions, “Why me? Why does it have to hurt so much?” (Toombs 2001:268) and also “What are the reasons for such suffering? What purpose does it serve?” (Leder 1986:261) reflect the embodied nature of pain that can only be addressed with a philosophical and sociological approach (Toombs 2001; Leder 1986), as a usual scientific approach does not address the question of how the meaning of an experience is

constituted in consciousness (Schutz 1967). A science which aspires to give a universal description of a phenomenon of meaning is unsuccessful. The scientific method removes individual meaning and decontextualizes the experience of cancer pain. On the contrary, the search for meaning should focus the understanding of the pain experience on the context of the lifeworld. The lifeworld is not a system of mathematical models; it is a world of perception, of meaning deeply rooted in action and communication (Merleau-Ponty 1962). Meaning is derived from the sociocultural environment and is inextricably connected in the world: “Because we are in the world, we are condemned to meaning” (Merleau-Ponty 1962: xix).

Cancer Pain as an Embodied Experience

“The essential quality of all pain is its embodied painfulness. This is at once self-evident and yet, for some reason, obscure” (Toombs 2001: 268). In everyday life, the physical body often goes unnoticed, and the subsequent relationships between people and their bodies are largely unproblematic (Leder 1990). But with pain, the absent and recessive body suddenly becomes evident and problematic (Bendelow and Williams 2002; Frank 1991; Leder 1990) and the bodily state of disappearance is substituted by a negative state of disappearance and betrayal (Leder 1990). In other words, in the continuity of our daily lives, “the fidelity of our bodies is so basic that we never think of it” and pain is thus a betrayal of the fundamental trust we have in our body (Kleinman 1988: 45). Some may conclude that pain is an indubitable and bodily localizable experience (Genusas 2014). A good case to mention is Frank, a cancer pain sufferer, who objectifies his body and his pain as a thing that can be controlled and yet also has the power to control his life (Frank 1991; 1990). Alternatively, people in pain may seek

relief by moving toward the opposite pole of increased subjectification of their painful experiences. In this sense, as Jackson (1994) suggests, pain confounds the subject-object dichotomy: while the subject can be conscious of having an object body and an objective pain, it is also true that the subject can merge with his or her pain, becoming the pain-full person, the person full of pain. However, as Geniusas (2014) describes it, these two characteristics of pain (indubitable and bodily) are ontologically incompatible, as one answers the experiences of pain – the self-consciousness — while the other refers to the recognition of the body as an object that responds to painful experiences – consciousness. Who, then, is the real subject of pain? Is it consciousness, or is it the body?

It is not difficult to see how proponents of the biomedical field would answer this question. Proponents of the biomedical approach would say that the subject of cancer pain is the body-as-object; Leder (1984) would refer to it as the dead-body. The objectification of the body, also known as body-as-object, allows the biomedical field to understand the body in purely mechanistic terms, as with any other object (Morris 1991; 1944), thus reducing the complexity of pain to a mere physiological dysfunction (Leder 1984), while ignoring the temporal dimension of the body and of the experiences of pain (Toombs 2001).

Proponents of the biopsychosocial approach would argue that the subject of pain is the body-subject, which integrates both the physical and psychological components of pain. However, anyone who has ever experienced pain would argue that “the body in pain cannot be reduced to its physical properties, and the mind cannot be considered a separate inner subjective sphere of pain” (Käll 2013:29). A phenomenological view of

pain, by contrast, can make it clear that pain simultaneously is affected by and affects consciousness and the body (Geniusas 2014). Both the body (body-object) and the brain (body-subject) exemplify the consciousness of the real subject of pain (Geniusas 2014), as the body-subject and the body-object are in a dialectical relationship with each other. In fact, mind and body are interfused with pain, albeit in a problematic way, pointing to a fundamental issue raised earlier: pain is inseparable from its cognitive and emotional significances (Bendelow and Williams 1995a). As I argued earlier in this chapter, the study of pain requires the inclusion of emotions and the conception of the human body as a lived structure. As Turner writes, “If we recognize pain as an emotional state, then we immediately begin considering the idea of the person as an embodied agent with strong affective, emotional and social responses to the state of being in pain” (1992: 169).

The study of cancer pain requires a conception of the mindful and emotional body, one which oscillates between and intertwines with subject and object, unity and dissolution, and presence and absence (Bendelow and Williams 1995a). Awareness and consciousness, of course, are crucial here. In the absence of pain, the body falls back from the aware and conscious perception of the person into a “background disappearance” state, as the person’s attention is on the lifeworld and not on the body (Leder 1990: 29). As Leder states:

While in one sense the body is the most abiding and inescapable presence in our lives, it is also essentially characterized by absence. That is, one’s own body is rarely the thematic object of experience... I experientially dwell in a world of ideas, paying little heed to my physical sensations or posture. (Leder 1990: 1)

When a person is in pain, his or her sensory stimuli intensify, increasing the “episodic structure,” or times of unusual stress and trauma produced by painful experiences (Leder 1984: 72), and making visible the once invisible body organ in pain. As a result, the disappearance state of the body is substituted for a sense of bodily dys-appearance (Leder 1990). In his work, Leder differentiates bodily disappearance and dys-appearance. In the first, the person is not aware of his or her body, while in the second, the person is. The bodily dys-appearance takes place, particularly during painful experiences, when the body becomes a thematic object of attention as something ill (Leder 1990). During the bodily dys-appearance, sufferers’ perceptions of their pain are anchored to the specific spatial and temporal moment of the experience of pain, eliminating any prospect of the future and dissipating the past (Leder 1990), becoming self-conscious of the body organ in pain. Mead (1934) differentiates between consciousness and self-consciousness:

There is, of course, a current distinction between consciousness and self-consciousness: consciousness answering to certain experiences such as those of pain or pleasure, self consciousness referring to recognition or the appearance of a self as an object. (1934: 78)

The body then becomes the center of the attentive consciousness, or self-consciousness (Frank 1991; Leder 1986), and an intentional object of the disruptive experiences of pain (Leder 1990). This process is defined as focalization. The focalization, or concentration of all attention on a particular organ in pain, is always accompanied by the disappearance or absence of the corporeal background (Leder 1990). The body then becomes an absent-present. Leder (1990) defines this paradoxical condition of the present-absent as the *ecstatic body*. This term *ecstatic*, derived from the Greek words *ek*, meaning *out*, and *statis*, meaning *to stand*. Hence, *ecstasis* means “that

which stands out” (Leder 1990: 21). The *ecstatic body* is the body that projects outward from its place of standing, from its here and now. In pain, all attention of the *ecstatic body* is oriented towards the organ(s) in pain (Käll 2013; Leder 1990) and the once-invisible organs (or, as Leder [1990] defines it, the disappeared body part that went unnoticed until the pain) are transformed into the “dys-appearing body” organs (Leder 1990: 71). The ecstatic body, aware of itself through constant feedback between the person and his or her environment, is in a continuous state of flux, shifting from foreground to background (Leder 1990).

The changing status of the body from disappearance to dys-appearance, and from the background to foreground in Leder’s (1990) terms, implies a change from unnoticed to consciousness that evidences a tension between an absolute own-ness and an equally absolute otherness, presented as either the body-subject in or the body-object of pain (Käll 2013). It is in the midst of this paradoxical experience of pain, considering the body simultaneously as object and subject of its own interpretation (Geniusas 2014), that pain sufferers’ bodies are tricked by a force that threatens to make them alien to their own experiences, bodies and selves (Käll 2013; Bendelow and Williams 2002). The dys-appearing body demands attention, alienating the person from his- or herself and from other spatio-temporal dimensions (Leder 1986; 1984).

Jackson (1984), in her ethnographic study in New England, has shown how people with chronic pain tend to fall into a stage of self-reflection and isolation, which affects the spatial and temporal modes of pain. Pain has modified the world of the person experiencing it, limiting both space and time (Leder 1986), as “the expanse of the distant senses is replaced by the oppressive nearness ... We are no longer dispersed out there in

the world, but suddenly congeal right here” (Leder 1990: 75). Pain seizes the sufferer, bringing him or her back to the present, demanding all the attention to the *here* of the body part in pain, while time is pulled to the *now* of the moment of pain (Leder 1990). The very nature of the body in pain is to project outward from *here*, from which a perceptual world of nearness and distance from the pain arises. From the *now*, the person in pain inhabits a meaningful past and a future (Leder 1990), while pain exerts a centripetal force, directing the entire person’s attention, space, and time inwardly to the particular moment in pain (Leder 1990; Leder 1984). The body, which was once the source through which the world was experienced, becomes the main source of the painful experience (Leder 1984). Leder writes:

We feel the pain inside; the outward turning senses of hearing and vision, nutritive taste and smell are overwhelmed by this hegemony coenesthesia. We have difficulty admiring a landscape, enjoying a symphony, as our toe excruciatingly throbs. Our interest, attention and very possibilities of perception are redirected by a centripetal force. ... As pain calls us incessantly back to the here, so we are drawn to the now by an aching tooth, a cramping stomach. (Leder 1984: 255)

As is described above, pain becomes our main object of perception and an element of distance is introduced (Leder 1990; 1986): “I no longer simply ‘am’ my body... Now I ‘have’ a body, a perceived object in the world” (Leder 1990: 77). The body emerges, then, as an estranged thing that isolates the person and exerts a *telic* demand upon the sufferer (Frank 1991; Leder 1990; 1986). Pain’s telic demand forces sufferers to search for interpretation and understanding of their painful experiences, capturing the attention of the person in pain (Leder 1990; 1986). When pain sharply disrupts the sufferer’s daily life, it captures and holds his or her conscious attention (Leder 1990; 1986). As Frank describes it, when cancer pain strikes, all of the sufferer’s attention is on the body in

pain (Frank 1991). For instance, they may describe their pain as a god that is victimizing them, as an enemy that needs to be conquered, as a demon that needs to be cast out of the body, or as an object that is instigating harm, disturbing their daily life, and separating them from themselves, from the world in which they live, and from people around them (Jackson 1994; Frank 1992; Leder 1990; 1986; 1984). As Toombs (2001) stated “for the person experiencing it [cancer pain], pain is not something out there, it occupies a space within the very fibers of one’s body and makes it inseparable from the essential self” (268).

The increased consciousness of pain seems to follow an initial increase in the objectification of the body: “after imagining the pain as something entirely separate from the body and self, one makes some kind of identification with the pain” (Jackson 1994: 205). The search for interpretation ultimately involves mastery over or elimination of suffering. A clear example is given by Frank, who, while experiencing pain as a result of pressure exerted by tumors on his back, came to realize that his body was the object not only of perception and interpretation, but also of action.

The Lived Body in Pain

The lived body refers to the person, in the flesh, who has full consciousness of the experience of having cancer and pain and is thus the embodied consciousness of being in pain within a particular social and cultural environment (Leder 1984). The lived body is neither a passive receiver nor an object of transformation (Merleau-Ponty 1962), but is instead an engaging body that interacts with its environment, interrogating the world according to the acquired “stock of cultural skills and techniques” (Crossley 1995: 48).

The lived body is the ultimate “vehicle of being in the world” (Merleau-Ponty 1962: 82), and it is through the lived body that meaning and knowledge in and of the world are acquired. In the particular case of cancer pain, the lived body is experienced by way of the sentient embodiment of consciousness, where the body is a form of being in the world and experiencing it (Frank 1990; Merleau-Ponty 1962). Merleau-Ponty (1962) and Leder (1984) point to the experience of pain not as something that happens outside the body, but rather as something that occupies a space within the sufferer’s body (Toombs 2001). As Merleau-Ponty stated:

For if I say that my foot hurts, I do not simply mean that it is a cause of pain in the same way as the nail which is cutting into it ... I do not mean that it is the last of the objects in the external world ... I mean that the pain reveals itself as localized, that it is constitutive of ‘a pain-infested space.’ (1962: 93)

Pain challenges the taken-for-granted body, the structures of everyday life, and the uniqueness of people’s perceptions of their own bodies and selves (Toombs 2001). However, in clinical settings, sufferers may experience a sentiment of detachment from their pain, which at first serves as a strategy. This detachment involves a decreased sense of individuality. However, sufferers can regain a sense of wholeness. As Frank observes, the subject of pain is the lived body:

I could never split my body into two warring camps: the bad guy tumors opposed to the naturally healthy body. There was only one me, one body, tumors and all. Accepting that I was still one body brought me a great sense of relief. (1991: 84)

Pain is experienced in the lived body and the understanding of this reality brings a sense of coherence to the person, as it is through the body that a person simultaneously experiences, acts in, and knows the world, as it exhibits general understanding of their painful experience (Leder 1984). According to Nick Crossley, the lived body “sees and can be seen, hears and can be heard, touches and can be touched” (1995: 46); I will take

this further and add that it shapes and can be shaped, and transforms and can be transformed by pain. Maurice Merleau-Ponty describes the lived body as a place from which to view, perceive, experience, and describe the world. The person in pain is one with his or her pain and his or her body: “I am not in front of my body, I am in it, or rather I am it” (Merleau-Ponty 1962: 150). The lived body is then placed where pain is lived and experienced as “an intentional entity always directed toward an object pole, the world” (Leder 1984: 31).

As the person acquires knowledge through the lived body and its interaction with its environments, the lived body becomes an “embodied consciousness” (Geniusas 2014: 6). The embodied consciousness is an ongoing structure of the lived body, which dynamically incorporates all dimensions of the sufferer’s life, where meaning and interpretation happen. It is through the body that the world affects the person in pain, and it is by means of the body and the externalization of the emotions that the person in pain shares the perception of his or her experiential pain (Bendelow 1993; Merleau-Ponty 1962). As stated by Drew Leder, through its embodied character and through the thematization of the body, pain radically changes the sufferer’s life and the modes of being in the world, dislocating and disrupting the intentional life, transforming the spatial-temporal horizon, and exerting a teleological demand upon the sufferer (Leder 1990).

Summary

In the first section, I reviewed the relevant literature related to the biomedical understanding of pain. An historical review highlighted the origins of the conceptualization of pain, which have had great impact on contemporary understandings

of pain. The biomedical approach grounded its understanding of pain in the dualism of body and mind that comes from Descartes' model of pain (known as the Cartesian model). Descartes' theory has held domain for many centuries over medical teaching and over the day-to-day understanding of pain, so much so that it is viewed as a fact rather than as a theory (Melzack and Wall 1983). Contemporary medical theories, however, have deviated from Descartes' dualistic understanding of pain to encompass a more integrated theory of pain. However, these theories have neglected to take into account experiential pain, the emotional connotations of pain, and the culture in which painful experiences occur (Leder 1990), and this has in fact perpetuated the Cartesian dualistic understanding of pain that splits the mind and the body. The biomedical understanding of pain fails to include the self and focuses mainly on the body.

However, a review of recent sociological studies of pain has pointed to the growing interest in understanding the complexity of pain and the need for this knowledge to be incorporated into all the spheres of the understanding of pain, but particularly the emotional and cultural understandings of pain. The importance of the emergence of a sociology of pain that incorporates emotions and culture is partially emphasized by sociologists (Bendelow 1993), who maintain that a proper understanding of pain calls for a phenomenological perspective which emphasizes subjectivity and lived body experiences of pain (Freund 1990). In classical phenomenological literature, pain has always been on the margin (Geniusas 2014). However, contemporary theorists and sociologists, particularly Leder (1986), call for the incorporation of the multiplicity of experiential pain, and particularly for the inclusion of the lived-body and the consciousness.

CHAPTER THREE: RESEARCH METHODS

The previous chapter outlined the major tenets of pain and considered the potential implications that exist when locating the understanding of the experience of pain within the body, ignoring the other components of the experience. In this chapter, I will explain the specific methodology proposed for the data collection and analysis of this dissertation project, which will bring into account the two pains: physiological and emotional. As highlighted in the introduction, my primary research question is, “What is it like for women and men diagnosed with and treated for cancer to live with pain, and how do they experience this pain?” To address the main research question and the guiding research questions detailed below, I propose using a qualitative study, specifically with phenomenological theory methods. The guiding research questions are:

1. How do people diagnosed with and treated for cancer perceive their pain experiences? What are their pain experiences like?
2. How do these people’s narratives unfold, and what is the effect of this unfolding on their experiences with pain?
3. Do people diagnosed with and treated for cancer from different cultural groups experience pain differently?

Because these questions seek to understand what it means for a person with cancer to be in pain, the proposed methodology will facilitate understanding and uncover the multiple dimensions of the pain experience. For this dissertation project, phenomenological methodology is the appropriate strategy because it gives considerable relevance to an individual’s understanding, interpretation, and knowledge of his or her own experiences. Knowledge and meaning of cancer pain can only come out of those

individuals living with it. This viewpoint highlights the invaluable source of knowledge present in the 'subjective' interpretation of an experience, while devaluing the constant foundation of an 'objective' truth. Pain is also a social experience, and phenomenology provides an effective means of capturing the dimensions of the 'lifeworld,' or *lebenswelt*. This refers to socially transmitted and linguistically organized interpretative patterns that encompass a person's intangible lived experience of pain. Furthermore, phenomenology emphasizes the importance of language and the role of the researcher in the interpretation of a subjective experience shared through interaction, as posited by Shulant Reinhartz: "the researcher transforms what s/he sees or hears into an understanding of the original experience" (1983:78). This transformation makes the private understanding public and renders the intangible experience tangible. The knowledge of cancer pain is thus a product of the interaction between the person living with cancer pain and me, a complete human-being-mediated process. In this dissertation, I documented, in writing, how adults diagnosed with and treated for cancer understood and experienced their pain. In order to provide evidence of the pertinence of the study and the proposed methodology, I outline both the reason why I am interested in the study of pain and the philosophical assumptions (Creswell 2013; Moustakas 1994)

Why Study Pain?

Similar to many other scholars (see, for example, Zola and Katarba) this study stemmed partly from deep reflections on my personal experiences and academic interests. My encounter with pain began five years ago. In 2010, I underwent a right-

parietal craniotomy¹ as a product of a gunshot to my head. Contrary to expectations, I had no pain, as I was prescribed the highest doses of pain medicine, anti-depressive, anti-inflammatory, and anti-convulsive medications. These medications kept me free from pain, but as I begin my recovery, my body started to resist them, generating Stevens-Johnson Syndrome (SJS). SJS is a rare but serious and painful allergic reaction to certain medications that causes the skin to blister [from inside and outside] and to peel off, affecting the mucus membranes, making it painful and difficult to eat, swallow, urinate, talk, and even to sleep. As the allergy progressed, so did my pain. In an effort to avoid my experiential pain, I adopted a hero-self (Burrows 2010). However, as my body was all blistered and the pain had taken its toll on me, I could no longer keep up with the false image I had created. Then I succumbed completely to the pain. Neither reasoning nor rationalization could explain why I was suffering from such pain. At this point, pain lacked its intentionality (Biro 2010), for I could no longer explain the reason of my pain. Pain, then, became my everyday life experience (Biro 2010; Berger and Luckmann 1990), my ultimate reality, and with sufficient power to destroy my world and myself (Biro 2010; Scarry 1985). Pain forced on me a new quotidian existence, the one of a person in pain. I was no longer the happy person everyone knew, but rather a person in much pain.

The experience of pain I was living could not be described objectively in terms of ‘right’ and ‘wrong,’ nor as ‘black’ or ‘white,’ but rather it was filled with the colors of

¹ A craniotomy is the surgical removal of part of the bone from the skull to alliviate the brain’s blood pressure. In my case, this surgery was done because the bone was totally destroyed by the bullet, increasing my brain’s blood presure. Once the bone is removed, the brain is exposed and unprotected. To correct this, three months after the surgery, I underwent a second surgery, known as a cranioplasty. This time, the surgery was to correct the deformity of my skull and to protect my brain using prosthetic material.

the multiple meanings that pain had for me at that particular time of my life. This deteriorated my health. Doctors could not understand what was taking place, so in order to preserve my life they increased the doses of medication and even formulated new ones. Thus, my health got worse. The biomedical field had no answer to why my body was reacting in such a painful manner to the medication. This was a source of dispute among my doctors. The neurologists, on one hand, wanted to keep me on medication, completely ignoring the warning signs of my body, for their goal was to preserve the integrity of my brain. The internists, on the other hand, wanted to take me off all the medications, as they were seeking to protect my heart, my life, and myself along the way. The pain medication was also increasing my heart rate, complicating my preexisting heart condition, Wolff-Parkinson-White syndrome, which had been diagnosed a couple of years before the gunshot to my head. The 'Me' (in Meads' understanding) as mother, sister, wife, patient, but most of all as the subject of the experiential pain with full consciousness of the situation, was at the center of the medical and personal disputes: to be off pain medication was to take away my physical pain but probably cause brain damage. To be in physical pain was to preserve my brain, but complicate my heart condition and destroy me. Either decision had the potential to change the course of my physical and emotional pain, but most of all, to change my life.

My fascination with and interest in the topic of pain grew after the pain had invaded my entire body. I became aware of the literature on the sociology of pain (Bendelow and Williams 1995; Kotarba 1983), the experiential pain of many sociologists (e.g. Kotarba, Zola, and Frank, to mention a few) and the phenomenology of pain (Leder 1986), and I could not understand why or how others, particularly cancer survivors, could live with

their pain so bravely. Many questions came to mind: How does a person with cancer experience his or her pain? What makes their experience of pain different from mine? And what role does culture play in the way people experience their pain? These questions have driven my research on pain and this dissertation project.

Philosophical Assumptions

Phenomenology is more than a philosophy; it is a style of thinking that takes into consideration the complexity of lived experience and of situated meaning while simultaneously remaining truthful to the lived experience, also known as *Erlebnis* (Merleau-Ponty 1962). *Erlebnis* has the connotation of an experience lived through a conscious state, which, translated into English, means a lived experience.

Phenomenology emphasizes that knowledge comes from the lived experience of the individual. This assumption breaks away from the untenable dualism of objective versus subjective or impersonal versus personal knowledge, which has plagued science since the Renaissance and legitimized the autonomy of the biomedical field.

For classic sociological theorists, knowledge is an uncontaminated and “unadulterated truth” that researchers can access through appropriate objective techniques and theories (Murphy 1989:19). In order to determine the truth, consequently, it is necessary to remove the interpretative capacity of human beings from the generation of this objective and pristine knowledge. Consistent with this paradigm, knowledge is acquired when individuals transcend their own subjectivity or contingent nature (Murphy 1989).

While classical theorists seek knowledge outside of people, contemporary theorists understand knowledge to be grounded in the epistemological recognition that all reality

is ultimately tied to human interventions. Dualism, for contemporary theorists, is now passé and a mythical invention. People participate in the construction of their own realities and knowledge. The foundation of truth and reality is in language. This epistemological maneuver, known as the linguistic turn, sets language at the heart of contemporary theories. Language, for postmodernists, does not serve as a mere tool used to point to pure vision or to reality; rather, language has the capacity to create and recreate the lived world (Murphy 1989). A contemporary theorist, Martin Heidegger proclaimed in 1947 (as cited by Murphy 1989) that language is the house of being, meaning that humans embody understanding of their own experiences or situations and consequently reproduce and recreate their realities through the use of language. Language is central in the construction of the self; through language, the multiple facets of a person's experience and reality are exposed. The fundamental ontology of contemporary theorists is that nothing is outside of language (Murphy 1989).

Knowledge of everyday life is filled with subjective interpretation that varies as meaning is shared. This realization has prompted a new form of science, known as non-referential science (Murphy 1989), which searches for knowledge with the being and fully mediated by 'the flesh' (Merleau-Ponty 1964). Merleau-Ponty (1962) believes that knowledge is built upon the world of the one who is experiencing and living the phenomenon in his or her body, and meaning can only be grasped within the social and cultural contexts in which the experience exists. These contexts are often referred to as a *lebenswelt*, or 'lifeworld.' The idea of the lifeworld, as mentioned previously, refers to the protective world, that is, linking phenomenon and being (Murphy 2012; 1989). Cancer pain, consequently, is not an object that can be described or measured. Instead,

cancer pain is a phenomenon that is humanly inspired and is a result of consciousness. Consciousness alters the manner in which a person in pain understands his or her relationship to the world, transforming cancer pain into a cultural object with social meaning. Consciousness through intentionality attributes meaning to experiences (Sadala and Adorno 2001) of cancer pain.

Cancer-related pain is intentional; as Maria L. Sadala and Rubens Adorno wrote: “there is a phenomenon only when there is a subject who experiences the phenomenon” (2002: 282). Meaning, in this sense, is influenced by how an experience is socially and culturally interpreted (Murphy 1989; 2012). Accordingly, to understand the meaning of cancer pain, it is important to become familiar with the everyday experiences within which this meaning is constructed. This task involves communication through language because it makes available the stock of shared meanings, thereby becoming the instrument of knowledge. Language makes available the multiple narratives of pain and, with them, the complexity of the experience. Knowledge of cancer pain is thus translated from the subjectivity of the individual in pain to an intersubjective and shared understanding, yet is still subject to interpretation (Leder 1984).

Based on these philosophical assumptions, phenomenological methodology is the best methodological strategy for this dissertation project.

Sampling and Recruiting

Unlike quantitative studies, qualitative approaches do not aim for a statistically representative sample, but instead seek to obtain a sample relevant to the research question. Phenomenological studies use a narrow range of sampling strategies (Creswell 2013). I used both criterion and purposive sampling, making sure that all participants

have had both cancer and pain. For this study, I used purposive sampling, from which rich information can be learned (Patton 1990). I sought individuals who had been diagnosed with cancer, had undergone (or were undergoing) treatment for cancer, and were currently suffering from pain due to the disease and/or treatment. There are several different strategies for purposive selection of participants, described in-depth in Patton's (1990) book. While the homogeneous sample describes a phenomenon of a particular group, the purposive sample allows the researcher to guarantee the credibility of the phenomenon, removing the attention from how representative the sample is in order to obtain an "excellent or rich" group of participants with "the phenomenon of interest" (Patton 1990: 171). Patton (1990: 1982) defines "rich" groups as "cases from which one can learn a great deal about matters of importance. They are cases worthy of in depth study."

Both strategies address the specific nature of the research questions of this project. By targeting both approaches, I guaranteed that all the participants had experienced circumstances that pushed them to live with and experience pain and to be able to relate their experiences. The themes that emerged cut across the understanding and experience of pain of a great deal of participants. The recruitment strategy was as follows:

1. I posted recruitment flyers, both in English and Spanish, on approved bulletin boards and/or in designated areas of the University Medical Campus, the Sylvester Cancer Center, and the University of Miami campus in Coral Gables.
2. Interested prospective participants voluntarily contacted me via phone and/or email.

3. I contacted all the potential participants to set up a time to discuss the study's purpose and procedure, and to go over alternatives to participation.
4. I then proceeded with the conversations, which took, on average, between 45 and 120 minutes each. I audio recorded all conversations. Each participant selected an alias (or pseudonym) to ensure confidentiality.

Not all processes of investigation are easy or straightforward. During the recruitment process, few people contacted me, forcing me to reevaluate my recruitment strategy. As a result, I contacted the leaders of cancer support groups. Cancer support groups are small groups that meet outside clinical settings to focus on coping and adaptation to the physical, emotional, and psychological changes caused by the illness. Some groups include participants with metastatic cancer and address the fears associated with terminal illness. Others are designed for participants with primary cancer with a supportive-expressive orientation. In either case, support groups are characterized by voluntary participation and the provision of emotional support. Contacting the Cancer Support Group, which is a purposive sampling strategy, increased the number of people interested in participating. The following describes the recruitment strategy I used.

1. I sent a recruitment letter to various leaders of cancer support groups, explaining the purpose of the study and requesting permission to attend one of their meetings.
2. If the leader agreed, I then arranged a time, date, and place to present the research project to the members of the group.
3. At the support group meeting, I did a verbal overview of the research, in which I explained the purpose, what the participation would be like, the risks and

benefits associated with participating, and whether any compensation would be offered. I also reinforced the fact that participation was completely voluntary and would not interfere with their medical treatment.

4. Once I finished my presentation, participants were given the opportunity to ask questions regarding the study and their participation in it. Finally, I gave each member of the group a flyer with the research project information and the contact information of the researchers. I also obtained the contact information of those interested in participating.

The sample size for this study is relatively small in order for me to gain an in-depth understanding of the lived experience of pain; I conversed with 15 participants from whom I achieved data saturation. Similarly, qualitative researchers in the field of medical sociology (see Kotarba and Held 2006; Adams and Kotarba 1996; Chafetz and Kotarba 1995; Kotarba and Hurt 1995; Kotarba 1983) have previously used relatively small sample sizes, since the main purpose of the phenomenological method is to recruit participants purposefully so that the phenomenon can be properly understood. Therefore, “what should happen is that purposeful samples be judged on the basis of the purpose and rationale of each study and the sampling strategy used to achieve the study’s purpose,” rather than on the number of participants involved (Patton 1990: 185).

I collected data for this study in south Florida at multiple places: (1) the conference rooms at the Sylvester Comprehensive Cancer Center. The Sylvester Comprehensive Cancer Center is located at 8932 SW 97th Avenue, Miami, Florida 33176. (2) The conference room at the Department of Sociology of the University of Miami, in Coral Gables, and (3) at participant’s home. I interview participants in English and Spanish. In

the text, I kept the quotes in the original language, Spanish, and added the translation into English. Keeping the whole quotes untranslated is a strategy used for two reasons. First, because I am expecting the readers to know Spanish to some degree, and by knowing the language they could check whether the translations were preserving the integrity of participants' voices or not and the readers could benefit from reading and appreciating the original text. Second, some phrases are meaningful in Spanish and could not be recognizable as an English translation. When translating, I carefully take into account the cultural presuppositions and the different sociocultural background of each participant. In the original text in Spanish, I preserved the accented spelling from of the language. Each conversation continued until data saturation was reached, which, according to Creswell (2013), typically occurs when no new data are added to the existing themes. In this study, saturation occurred before reaching the sample size. A copy of the conversation guide can be found in Appendix A.

Phenomenological Research Methods

In this dissertation, I utilized qualitative methodology, particularly phenomenological research methods, to gain a clear understanding of the complex human experiences of pain in adults diagnosed with and treated for cancer. My final product is a document describing the meaning construction of pain (described in the results chapter), which is grounded in human experiences, making it possible for people interested in the topic to analyze and interpret it (Reinharz 1983). However, it is important to clarify that the meaning of pain varies within multiple lifeworlds and the reader of the final document (and of this dissertation) needs to consider each particular framework where the understanding of the lived experience of pain resides. The reality

of pain is thus always attached to human experience and the sources of meanings within the various communities to which each participant belongs (Schultz 1967).

For this dissertation, understanding the process of the meaning construction of pain is more important than explaining pain itself, making this project an appropriate candidate for a phenomenological approach.

Similar to other qualitative research methods, the aim of phenomenology is to translate private and personal knowledge into a public and social understanding, and to render understandable the prose of pain. To do so, phenomenology requires a clear delimitation of the research question as well as active involvement of both the participants and the researcher through interpretative interaction. The interpretative interaction is nonpositivistic (Denzin 1989) and therefore participants' statements regarding their experiences of pain are carefully interpreted. Every participant's experience of pain is novel, emergent, and filled with multiple meanings and interpretations. To capture the core of these meanings, expressed in the prose and narratives, I followed three transformative phases.

Data Collection

The first moment is the data collection phase. According to Reinharz (1983), this step constitutes the first transformation that takes place when the private lived experience is transformed into a public narrative through language. At this stage, I began with the conversations. Contrary to positivistic approaches, qualitative methodologies utilize open-ended questions to grasp meanings, understandings, and interpretations of the experiences of pain that cannot "be obtained by a formal, fixed-choice questionnaire" (Denzin 1989:42).

In phenomenological research, the goal is to encounter a particular phenomenon through a person's narration during a face-to-face interaction (Englander 2012; Davis 1995; Moustakas 1994). As my goal was to examine how pain appears to an individual and how pain is present in an intersubjective community, I initiated the conversation with the question: "Can you please describe, using as much detail as possible, a situation in which you experienced pain?" This question laid the groundwork for a conversation as it "has its foundation in the presence of a subject as researcher to another subject" (Englander 2012:15), and broadened my understanding and knowledge of each participant. I conceived the interview as a conversation (Denzin 1989) where the interviewee personally shared his or her experiences of pain with me and in which I too experienced their pain. The multiple meanings of pain are revealed through the conversation. In this way, knowledge of pain is not data gathered through an interview, but rather is the unfolded story of each participant's narrative of pain (Murphy 2012, Murphy and Min Choi 1992).

The remaining questions followed the response of the interviewee with a focus on pain, shifting from a subject-subject approach to a subject-phenomenon approach (gearing the questions towards pain). By taking a subject approach, I was not isolating the person, the being, but rather, I was allowing the person to describe his or her experiences and how his or her particular cultural and community knowledge influence the manner in which he or she lives and experiences pain.

Following the responses of each interviewee, when needed, I asked for clarification or elaboration. In order to capture the real dimension of each interviewee's pain (and to shift the focus to the subject-phenomenon relation), I probed into respondent's thoughts

on their relationship with their pain. This existential approach is fundamental to exploring the search for meaning of pain, and I used the following probes: “Can you tell me more about the event?” “How do you know that?” and “Exactly what happened?”

Each face-to-face interview lasted anywhere from 45 to 120 minutes and was held in one of either place 1) the conference rooms of the Sylvester Comprehensive Cancer Center, 2) the conference room at the Department of Sociology of the University of Miami, or 3) at participant’s home. Upon arrival to the interview area, each participant was informed of the study’s purpose and procedures, and offered the option not to participate. Those participants who chose to participate in the research project completed the consent form and were free to ask any questions: this was an opportunity to establish trust. All interviews were audio recorded; I made it clear to each participant that the interview would be confidential, in accordance with the confidentiality clause stipulated in the protocol. To ensure confidentiality, all participants chose an alias. All of the interviews were transcribed verbatim from the audio recordings and later reviewed to ensure accuracy.

Transcriptions are an important step in phenomenological studies and they include not only literal statements, but also non-verbal communication notes (Hycner 1985). Memoing is another important data source in qualitative research that I used in this dissertation project. Based on Creswell’s (2013) proposal, I used the following qualitative notes:

- a) Personal notes, in which I recorded my personal reactions, feelings, self-reflections, memories, and impressions;

- b) Methodological notes, in which I described the method used and ideas for possible changes; and
- c) Theoretical notes, which included informed guesses and hunches to follow up on later in the dissertation project.

These notes were taken during and immediately after each interview; my notes helped me to get to know the participants better and to evaluate my own role as the researcher. Indeed, as Magnus Englander puts it: “it is through an openness and reflection on one’s previous phenomenological interviews that one can become a better interviewer” (2012:28). This type of self-evaluation constitutes a training of one’s own empathic abilities (Englander 2012).

Phenomenological Reduction or Data Explication

The second moment is the data explication phase, also known as phenomenological reduction. I deliberately avoided the heading data analysis. For Richard H. Hycner, the term *analysis* means breaking into pieces, losing the whole understanding of the phenomenon; explication, conversely, refers to understanding the meaning of the phenomenon as a whole within the context (Hycner 1985). To have a profound understanding of the experience of pain, I used a simplified version of Hycner’s (1985) explication process. Reinharz (1983) proposed five steps to reach phenomenological reduction: bracketing and phenomenological reduction, delineating narratives of meaning, clustering narratives of meaning, summarizing and validating themes, and extracting general and unique themes.

1. Bracketing and Phenomenological Reduction: Bracketing holds for “serious inspection” of the phenomenon (Denzin 1989:55). This process includes listening to the

conversations and then uncovering, defining, and analyzing the essential elements and structures of the lived experience (Denzin 1989; Hycner 1985). It is important to approach this process with a mind that is open to whatever essential elements and meanings emerge. To do so, I entered into the worldview of the person in pain and tried to understand what it is like to be a pain sufferer. This is possible only when my own personal views and/or preconceptions of pain were not allowed into the study. To properly locate the essential elements and the meaning of the experience of pain, I addressed the bracketing process, following Denzin's (1989) proposed steps, described as follows:

- a) Locate, within the personal narratives, key phrases and statements that speak directly to the phenomenon in question: pain;
- b) Interpret the meaning of these phrases as an informed reader;
- c) Obtain the subject's interpretation of these phrases;
- d) Inspect these meanings and recurring features of pain; and
- e) Offer a tentative statement of understanding of the phenomenon.

It was important during this phase to isolate and deconstruct any preconceptions I may have had about pain that may have influenced my interaction and interpretation. To make sure I bracketed my presuppositions, I them and spoke with the chair of this dissertation about them. According to Hycner, "such dialogue may very well bring out presuppositions that the researcher was not consciously aware of" (1985: 281). This prevented my meanings and interpretations of theoretical concepts from entering into the analysis of the participant's lived experience of pain (Creswell 2013), and enabled me to

be coherent and consistent, as much as possible, with the participant's understanding in his or her own terms (Denzin 1989). This was a really difficult task.

2. Delineating Units of Meaning: Once the interpretations and meanings were bracketed, I listened to each conversation audio recording and reread the transcript several times to get a holistic sense of the entire description and to gain a general understanding, or gestalt, of the participant's pain. I then listed all the statements that could describe and explain the phenomenon. These statements are known as units of meaning, which represent a particular knowledge of the lived experience (Moustakas 1994; Hycner 1985). Moustakas (1994) defines this stage as the horizontalization of the data that highlights the significant quotations and provides an understanding of pain.

Once I listed the units of meaning, I then tracked the literal content: that is, I noted the number of times a meaning was mentioned, as well as how it was mentioned, and I kept the units of relevant meaning and eliminated those which were clearly redundant or repetitive of others previously listed. I also took into consideration non-verbal cues, including intonations, emphases, pauses, and silences, all of which emphasized the literal meaning of a word (Hycner 1985).

3. Clustering Units of Meaning: This phase involves "getting at the essence of the meaning expressed in a word, phrase, sentence, paragraph or significant non-verbal communication" (Hycner 1985: 282). This is the most crucial step of the research process; Reinharz (1983:79) states that without this step, "one is simply recording and recording is not enough to produce understanding."

At this stage, paraphrasing Colaizzi (1978 as cited by Hycner 1985: 288), I engaged in a process that cannot be precisely delineated, for here is where I, as the researcher, got

to exercise academic creativity: “there is more room for ‘artistic’ judgement here [in the clustering unit step] than even before [in previous steps]” (Hycner 1985: 288). During this phase, I did as follows:

- a) I listened to the bracketed elements. I went over the conversations and the list of meanings;
- b) I ordered these elements as they occurred within the experience of pain;
- c) I kept a list of the metaphors respondents used to describe their discomfort;
- d) I indicated how a unit of meaning affected and related to every other unit in the process of being a pain sufferer;
- e) I elucidated the essence of units of meaning holistically and then determined if any of the “units of relevant meaning naturally cluster[ed] together” (Hycner 1985: 284).

At this point, as defined by Hycner (1985), it is difficult to clearly and unambiguously differentiate a gestalt from a unit of general meaning. Once the units of general meaning were identified, I compared them to the main research question and determined whether participants’ responses addressed the main research question. If they appeared to do so, then I noted the unit as a unit of relevant meaning. Statements that were not relevant to the main research question were not included. In case of ambiguity in determining whether a unit of meaning was or is not relevant to this dissertation, I found that it was better to err on the safe side and include the unit of meaning in the study (Hycner 1985). As was previously mentioned, this step required a certain level of judgment on my part. However, as Hycner states, “if the researcher has done a good job of bracketing presupposition, is very open to the data, and yet utilizes a

rigorous approach, it would seem that the danger of inappropriate subjective judgments creeping in would be minimal” (1985: 284).

4. Summarizing and Validating Themes: Once I completed the above steps, I went back to each participant transcript and wrote up a summary of that conversation, incorporating the themes that I elicited from the data (Hycner 1985). This summary gave a holistic context of the meaning of pain. As Ellenerger states, “whatever the method used for a phenomenological analysis, the aim of the investigator is the reconstruction of the inner world of experience of the subject. Each individual has his own way of experiencing temporality, spatiality, materiality, but each of these coordinates must be understood in relation to the others and to the total inner ‘world’” (as cited in Hycner 1985: 291).

At this point, and following Hycner’s (1985: 291) recommendation, I conducted a “validity check.” Whenever possible (for some participants might have been too ill or not interested), I returned to the research participants and engaged in a dialogue with those people concerning what I had found so far. Once I checked the validity, I then looked at the data as a whole and modified or added themes as necessary.

5. Extracting General and Unique Themes: The conceptual categories, or themes, emerge from interrogating the meaning of the various clusters. This process addresses the gestalt of the relevant segment and the clusters of meaning. It also requires the phenomenological viewpoint of eliciting essences, as well as the acknowledgment of the experiential differences among participants (Hycner 1985).

All themes common to most or all participants were clustered together, indicating a general theme. Themes that were unique to a single conversation or a minority of conversations, were compared to the general theme.

Phenomenological Interpretation

The third moment of the method is the phenomenological interpretation, or the synopsis, of the research findings. Once the unique themes are identified, they are placed back within the overall contexts or horizons from which these themes emerged (Hycner 1985). The main purpose of this moment is, as described by Denzin (1989), to furnish the foundation for interpretation and understanding, knowing and comprehending the meaning of the experiences of pain. According to Reinharz (1983: 79), it is in this stage that the researcher transforms the themes “into some sort of a written document... that captures [the researcher’s] thought about the experience” of pain. After writing up a composite summary, Denzin (1989) recommends evaluating the research findings based on four criteria: illumination, contextualization, engulfing, and coherence.

- a) Illumination brings alive or clearly defines the phenomenon that is being studied based on the participants’ narratives.
- b) Contextualization locates the experience within the social, cultural, and emotional boundaries in which the experience has meaning. This process involves situating the phenomenon of pain in the natural world (Denzin 1989).
- c) Engulfing involves including all the relevant aspects of the phenomenon, expanding the framework for interpretation. This is not a finished phase, as time and social contexts change the importance people attach to their lived experiences. Therefore, the interpretation of the lived experience of pain reflects

the understanding of the experience in terms of the “Now and Here” (Denzin 1989:54). The interpretation varies as time and location change.

- d) Coherence asks if the interpretation of the lived experience coalesces into a coherent and meaningful whole. Meaningful quotations, understandable grounds for interpretation, and flexibility for the reader to take a position [whether to agree or disagree with the interpretation] are the main characteristics of a coherent interpretation, according to Denzin (1989).

The composite summary is neither comprehensive nor unfinished – during this phase, “something can be lost and something can be gained” (Reinharz 1983:79) – as it only reflects the interpretation of the themes that are common to most or all of the conversations. Interpretation is always recurrent as it is shaped by a prior understanding of the lived experience. Denzin (1989:64) named this cyclic process the “hermeneutic circle.” Although interpretations are unfinished, provisional, and incomplete, they are conclusive, for conclusion is always drawn in the form of written documents (Davis 1995; Hycner 1985). These documents, like this dissertation, are proper for the scientific discourse on the meaning of experiencing pain that describes the world in general as experienced by the participants (Davis 1995; Hycner 1985).

Ethical Considerations

Moustakas (1994) has determined that clear ethical standards which establish an agreement between the researcher and the participants are fundamental in ensuring the ethical treatment of each participant. In this study, I followed ethical steps and procedures in compliance with the University of Miami IRB process and standards, as well as with the Sylvester Comprehensive Cancer Center (SCCC) Protocol Review

Committee. Both the IRB and the SCCC reviewed the research protocol and gave their expedited approval to this dissertation project. The IRB final approval was received on March 18, 2016 (see Appendix B) and the SCCC on February 11, 2016 (see Appendix E). Due to the changes of strategy to obtain participants, a second approval was requested and granted by the IRB on December 1, 2016 (see Appendix D).

Following the steps of studies with human subjects, before beginning the conversation I reviewed the consent form with each participant. The consent form contains the purpose and process of the study, and explains how privacy and confidentiality are maintained. To ensure confidentiality, I did as follows: 1) stored the consent forms at a secure location separately from all data files; 2) identified each participant by an alias (or pseudonym); 3) destroyed all the audio recordings once they were transcribed, and once I ensured accuracy, and completed the phenomenon reduction and data explication; and 4) limited all data access to anyone except myself and the Principal Faculty Investigator, Dr. Linda L. Belgrave.

Summary

This chapter provided the critical components for conducting a qualitative phenomenological study, including a) the personal and intellectual reason behind the interest in the sociological study of pain; b) the philosophical assumptions that validate this dissertation project as a proper example of phenomenological inquiry; c) the location and criteria for selecting participants; d) the stages of phenomenological research methods; and e) the ethical considerations.

CHAPTER FOUR: FINDINGS

In this chapter, I introduce the findings from the thematic breakdown obtained while exploring participants' lived experiences with pain. This study used a phenomenological method to interpret as closely as possible the lived experiences of adults diagnosed with and treated for cancer who have experienced pain. Using the broad and focused research questions to guide me, I carefully analyzed and reviewed the transcripts of all 15 participants, looking for emergent descriptions of the meaning of pain. This chapter is divided into two sections: participants' descriptions and stages of meaning. In the first section, I move beyond presenting participants in terms of statistics or mere demographic descriptors, and instead I make use of a narrative way of introducing them to the reader; I use participants' voices to describe themselves. In doing so, I hope readers will have a better understanding of each participant's narrative, and, hopefully, readers can create their own empathetic image of each individual. Then, in the second section, I present three stages of meaning: 1) The Awakening of Pain, 2) the struggle to adapt to a shrinking world, and 3) making sense of pain (see Table 1). In the first stage of meaning, The Awakening of Pain, the participant is progressively awakened to a reality of being in pain. In the second stage, participants struggled to adapt to a changing world and reality; of a resisted and alienated life, world, and self. Then, not until the third stage, participants began to make sense of their experiences of pain. Participants fell into a process of meaning-seeking, reflecting on their emotional and physical pain from multiple realms that provide the experience of meaning, and seeking strategies to enhance the overall emotional adaptation and meaning of their experiences. These themes, or stages, of meaning are characterized by distinctive sub-themes, which are

discussed further in this chapter and are represented in table 1. A visual presentation of the meaning process is presented in Figure 4. Here, I begin with participants' descriptions.

Table 1: Stages of Meaning

<i>Themes</i>	<i>Explanation</i>	<i>Sub-Themes</i>
1: The Awakening of Pain	There is a slow and progressive realization of the physical pain that gradually disrupts everyday life. This awakening leads to a conscious realization of their experience and to an emotional awareness of being in pain that includes intellectual and/or emotional understandings.	Pain awareness
		Unbearable pain
		Silent pain
2: The Struggle to Adapt to a Shrinking World	Participants have a disturbed relationship with the world and they feel alienated from it, which forces them to create and recreate a new reality that is conformed to their disturbed world. Consequently, they have to redefine themselves.	Awareness of emotional pain
		Damaged body
		Disrupted life
		Interrupted self
3: Making Sense of Pain	Central to this stage is the continuous creation of a coherent and consistent redefined self, a self that is contained within the boundaries of a damaged body, a disrupted life, and a shrinking world. This embodied self is the focus of the process of giving meaning to pain.	New self-image
		New identity: cancer patient? Survivor? Hero?
		Communicated experience
		Pretending to protect
		Sharing my pain, helping others
		An inevitable experience
Overriding pain		
The triangle of healing		Science
		Spirituality
		The self

Participants' Descriptions

This phenomenological study allowed me to engage in conversations with adults who had experienced pain due to their disease. A total of 13 women and 2 men participated in the study, ranging from 26 to 69 years of age. The participants are an ethnically diverse group: there are 5 Afro-descendants (2 Afro-Colombian women, 1 Afro-Cuban woman, 1 Afro-American woman, and 1 Haitian woman), 6 Hispanic-descendants (1 Honduran woman, 1 Argentinean woman, 1 Venezuelan man, 1 man from New York with Puerto Rican heritage, 1 woman from Nicaragua, and 2 American women with Hispanic descendants), and 4 non-Hispanic women (1 Indonesian woman, who is from Jakarta, and 3 American women). All participants were asked to tell a little about themselves and about their pain. As I studied the phenomenon of pain, I discovered that there were some adults who could speak openly about themselves and their lived experience, while others remained more reserved about sharing their private experience.

I started the conversation with most of the participants using the following question: “Can you tell me something about yourself?” This question referred to their disease and their suffering, rather than to the person they are. What follows is a brief description of each participant, and a direct quotation from that participant in answer to my starting question. I have presented this information as a representation of their voices, translating from Spanish when applicable.

Maria is a 54-year-old Black Cuban woman who has been living in the US for the past three years. She was diagnosed and treated for a chronic myelogenous cancer. In Cuba, she was a teacher of physical education. During the interview, this lady smiled all the time and presented her pain not as a sad or calamitous experience, but rather as something that was meant to be.

Me identifico como una persona noble, inteligente, y agradable. Sobre todo, soy una persona muy trabajadora y muy inteligente ... Así me considero.

I identify myself as a noble, intelligent, and pleasant person. Above all, I am a very hard working and intelligent person ... That is how I consider myself.

Tulio is a 63-year-old Venezuelan man, who speaks both English and Spanish fluently, but he chose to do his interview in Spanish, sporadically plugging in English expressions. Instead of addressing the question, *Who is Tulio?*, he spoke about where Tulio is now, and where Tulio is going to be. Tulio was diagnosed with prostate cancer in 2012 and has been coming to the United States for medical treatment since 2013. He spoke about how he was (and still is) affected by his diagnosis, as well as how others have been affected.

Bueno, nacido en Maracaibo [Venezuela], aunque hmm...sin embargo no conozco mucho de Maracaibo porque mis padres son de Mérida y por cuestiones de trabajo nací ahí. Y he estado dando vueltas en muchos lugares; me críe en Caracas, estude aquí en los Estados Unidos en Boston, trabajé en Brasil, eh, me casé con una Francesa, estuve en Europa. Realmente no me identifico con Maracaibo, ni con Brasil, ni con los Estados Unidos, ni con ningún lugar. Es un poco difícil para mí responder de dónde soy porque uno es de donde come y respire, donde uno se relaciona con la gente.

Well, I was born in Maracaibo [Venezuela], although, hmm...but, I do not know much about Maracaibo because my parents are from Merida and because of work I was born there. And I've been in many places; I grew up in Caracas, studied here in the United States in Boston, worked in Brazil, eh, married a Frenchwoman, [and] visited Europe. I genuinely do not identify myself either with Maracaibo, or Brazil, or the United States, or any place. It's a little hard for me to answer the question:

where I'm from because one is from where one eats and breathe[s] a, where one relate[s] a to people.

Jocelyn is a 26-year-old White woman with Latin heritage. She was diagnosed with and treated for myelogenous leukemia. She was the youngest participant.

Helen, a 60-year-old French woman, has been living in the US for more than 10 years. She was diagnosed with and treated for colon and endometrial cancers. She initially introduced herself in terms of her professional activities and then suddenly shifted her self-presentation towards her disease.

Who am I? [Laughter], I don't know. I am a person, I am a teacher by profession, am a teacher. I have a lot of interests, hmm. I like art, astrology. Well, I had two cancers, I first had the colon cancer, hmm, very, very advanced and then lots of treatment and then after I also had endometrial cancer. That's it!

Catherine is a 60-year old African-American woman, who is a counsellor and works as a case manager of the Child Protective Service of Florida. She was diagnosed with and treated for breast cancer. She talks about her experiences of pain as an internal struggle with her physical appearance, particularly her weight.

Oh gee! Sometimes I don't know. I feel that am... I'm a kind, loving person who likes to help other people. Basically, I guess that's why I'm in the profession that I'm in. Sometimes, I feel like I'm imitating someone, trying to take on that personality or ah... as to be like them. If that makes any sense. You know, sometimes you meet someone that impresses you a lot and you like their lifestyle, like their personality and it's almost like you want to emulate them, you want to be like them, and you start doing the things that they... that you see them do or ah. Presenting yourself that way. So you become a little carbon copy of that person.

Margarita is a 56-year-old Afro-Colombian married woman, who has been living in the U.S. for 16 years. She was diagnosed with and treated for breast cancer. Margarita was the only participant who described herself from multiple spectra: as a mother, as a wife, as a professional, and as a person with cancer. This was the hardest interview

because as she began to describe herself as a person with cancer, she cried during the interview, and so did I.

About myself? Okay. I am. It's a lot that we can talk about myself. Um, I'm a native, not native Indian, but from the island.

Um, personality-wise I'm very proactive, very dynamic, hmm [a] energetic, honest. I love people, I love to serve. I always like to be among people, chatting a little, maybe sometimes too much. But, um, in general, I will say, me as me, I am a people person.

Education-wise, um, I love more what I can learn from people, moreover than looking at all the college degrees that I can have, I love to learn from people and every day I live that process; to learn a lot from people. Because, every small information makes me grow and it makes. I learn, and it makes me change certain ways how I work things.

I have two kids. I am married since 23 years. Um, I have a great husband... Um, I'm very a planning person. Anything that I have to do, I planned it. I like to do things very organized, sometimes that can be [a] defect in me because people that don't know me can think that I can be like OCD. Sometimes it's because the way I like. I, I find something, I like to comply with what I thought if I promised you I'd like to comply. I'm not a military person, I make mistakes like any other human. But, if I say, Lisa I will be here at 5 o'clock, I'll be at 5 o'clock. Hmm, because I always respected people's time and I like to be on time with things that I compromised [sic] myself with. That's a characteristic of my personality that at [a] certain point is positive and [at a] certain [other] point [it] can be negative.

Hmm, the other thing I will say about myself is [that] I have two kids, which is my whole life. Um, my son is a [sic] 20-years old now. Um, for me, he is an admiration and an inspiration, for me. Because, of his own condition I never limit him. Today, I look back as a mom, um, him as an autistic kid, which is an *Asperger*. When they diagnosed him, as a mom, I didn't know how far he will get. So, that was a big challenge when I came to this country. Was a big challenge, it was like a dream break because of the first time child, mom, and first child you dream with all the spectacular dreams and suddenly the dream just falls, like a castle, when you build a sand castle and it's falling down. I have my daughter that I love more than my life. And she was a blessing because I was scared to have a next child. But God gives us Selena and Selena never had a difference with her brother. We never make the two of them feel, that this one is more important. My husband and myself get aboard with all the process. And, today they are two beautiful kids. As [a] mom, I learned so much, because I had what I could compare the difference, as a child who does not have a neurological problem like my son with one that turned normal. Parent wise, I had great parents, my mom was a hard working woman, believed in education one hundred percent, as my dad umm... at certain point umm.

Angelo is a 59-year-old Hispanic single male with a high school education level, diagnosed with and treated for prostate cancer. Before the diagnosis, Angelo was self-

employed, working as a carpenter. Angelo describes himself in terms of the activities that make him feel joy.

Well, I'm born and raised in New York hmm Puerto Rican, hmm. I've, I went to high school of aviation. Hmm aviation, I took the helm... I got my licenses, I became an aviation mechanic. In the 1970s, I, I got laid-off from the airline industry and I just thought of going in, I went into carpentry and my life. And then after that I've been doing carpentry ever since and I enjoy [it] more. Even though I missed the airline industry, I wish I was there now. I wish because you get to travel more, and stuff that I missed is one of them; traveling. Being a self-employed [sic] is not fun, yeah it's not fun!

Tyra is a 60-year-old Hispanic married woman, diagnosed with and treated for breast cancer. She has been living in the US for 39 years.

Cómo qué? Mama de tres hijos, esposa, casada desde cuánto? 30 y pico de años. Vine a este país buscando nuevas oportunidades. Pero esas oportunidades ya se convierten en mitos y leyendas al final de la jornada, ya que todo depende del tipo de vejez que esta teniendo, porque al momento de retirarte depende de cuanto dinero tenez o contas para vivir. Vine a este país a los 21, o a los 22, a los 21 [años] con una hija acuestas y con un marido a cuestas, porque así es la vida.

Like what? Mom of three children, wife, married since how much? 30 and something years. I came to this country looking for new opportunities. But those opportunities have already become myths and legends at the end of the day, because everything depends on the type of old age, you are having, because at the time of retirement depends on how much money you have or what you account on [sic] to live with. I came to this country when I was 21, or at 22, at 21 [years old] with a daughter lying down and with a husband on his back, because that's life.

F.T. is a 41-year-old married woman from Jakarta, Indonesia, diagnosed with and treated for breast cancer. She has been living in the US since 2013. F.T. has a college degree and used to work as a secretary in her country. Today, she is a housewife.

Okay, I am 41 years old. Ah, I have twins, now they are six years old. Ah, I had a cancer on October 2013. I do the chemo, the radiation, and all... ah... and... what else... [Laughs]... and... that's it!

Arline is a 66-year-old White, non-Hispanic single woman diagnosed with and treated for lymphoma. She was born in New York in 1975 and has a double Master's

degree in Human Resources and Business Administration. She works as a cashier teller in a big store and as a substitute teacher. Arline began the interview narrating the painful story of her own mother's death at a young age and never described herself.

Mitzy is a 69-year-old White non-Hispanic married woman, diagnosed with and treated for breast cancer. She has a PhD in Vegetable Science, working at the University of Florida before retiring. Instead of presenting herself, Mitzy focused instead on her work. I am only including a short portion of her presentation.

Hmm, Well, I was in the Peace Corps. Hmm, after I graduated from college, I was in Thailand and from there I went to Nepal, where I had friends working. While I was there, I decided I wanted to work in with plants. Before I did graduate school, I have [sic] not taken enough biology and classes like that so I went back to Cornell, and all that. I mean, I went back to school at Cornell and keep studying some basics. And then I decided I want to do agriculture. So, I can go back overseas and work back with women. Women traditionally do more of the agricultural crops like fruit and vegetables. So, that's how I got in to study vegetable crops. And then, I did not work overseas, I worked here and most of the people that do agriculture are men. [Laughter].

Irmone is a 68-year-old Haitian divorced woman, and a mother of three girls. She was diagnosed with and treated for breast cancer in 2012. She has a Bachelor of Science degree. Today, she is retired. She used to work as an accountant and her income is less than \$20,000 a year. She describes herself in terms of the disease and her painful trajectory of healing.

Umm, well, well, I don't know where to start. I am retired, I live in Florida. I'm divorced. I have 3 children, 4 grandchildren, 2 great-grandchildren. And, umm, I was diagnosed with cancer in 2012. I have, we were 5 in the family: 3 girls, 2 boys. I have a brother who passed and a sister who passed of cancer also. And my sister passed of an aneurism. And I have a half-sister and a half-brother. They live in Tunisia, in North Africa. They are Tunisian. And, umm, basically, that's me and [I am] retired.

Debbie is a 55-year-old divorced Hispanic white woman, originally from Argentina, and a mother of two boys. Debbie was diagnosed with and treated for breast cancer. She

has a double Master's in Business Administration and Human Resources, but she is currently unemployed. The day we met, Debbie was heading to a job interview. Her annual income one year ago was more than \$60,000. Debbie is very aware of the impact this disease has on the life of her kids. When Debbie was a child, her mother died of breast cancer. Today, she advocates for early diagnoses. Debbie describes herself in terms of her past experiences with cancer, and how the loss of her mother to breast cancer affected her.

En general, eh, relacionada con mi enfermedad? Yo siempre creí que iba a tener cáncer de mamá por que mi mama falleció cuando yo tenía 13-años de cancer de mama también.

In general, eh, related to my disease? I always believed that I always thought I was going to get breast cancer because my mother died when I was 13-years old of breast cancer too.

Dee is a 38-year-old Afro-Colombian single woman diagnosed with and treated for superior bone and joint cancer. Dee was the musician and youth choir director at her local church in Colombia. She also has a college degree in Environmental Management. She migrated to the United States in 2016 and works as a cashier at a gas station.

Hmm, something like what. It's hard for me to talk about myself to define myself. What do you want to know? Hmm, I'm trying to focus and finding out who is Dee?... Do I have to answer that [question]?... Okay, let me tell you something about me, well. I like nature, hm, seldom I really think about myself, I seldom think about who is Dee. I will more define myself in terms of what I do, rather than who I am. Well... I am in "a crisis existential" here. I am thinking more about what I do... Ah.. I am a very happy person. I like to experience new things, I am not 100% high adrenaline, but I like to feel alive. I don't like monotony. Ah, who am I? I guess I am a responsible person.

Amy is a 37-year-old married Hispanic woman diagnosed with and treated for breast cancer and lymphoma. At the time of the interview, Amy was with a newborn. This child is defined by Amy as a miracle baby. This was her second pregnancy; she had lost

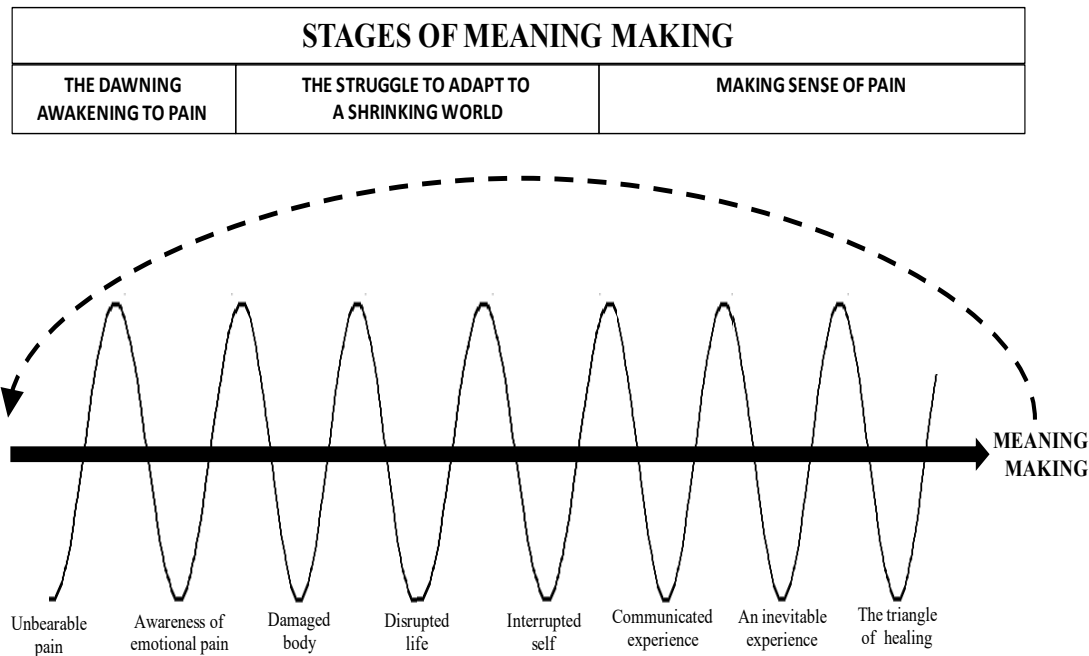
a first baby a couple of months before. Because of her disease, for Amy, being a mother is nothing else than a miracle, as the doctors predicted that she could not (or better stated, should not) have a child and being alive is a gift from God. Amy with her smooth voice narrated her stormy experience; she smiled during the interview, but cried effusively when talking about her newborn child. She is an elementary school teacher with an average annual income of \$40,000 - \$60,000.

Ah! [Laughter] I am going to cry now. I am a very, I considered myself a very strong person. Ah, a person with perseverance; always trying to achieve more than the usual person. I am a person that is passionate about the things that she gets in. Hmm, I love my family. I have a newborn, which I love very much. So, I am an educator, a kindergarten teacher, currently, which I love my job and I love what I do that's why I got into it. Hmm, and I am, I am a cancer survivor, and a Christian. And those are the things that described me, I believed, the most. And a dog lover. [Laughter]

Stages of Meaning

The following section further describes the process of meaning making of participants' experiences of pain. Based on the conversations that were conducted, three themes make up the conceptual framework for understanding the meaning process of cancer-related pain: 1) the awakening of pain, 2) the struggle to adapt to a shrinking world, and 3) making sense of pain (see Table 1). A visual representation of the process of meaning making is provided below.

The following graph (see Figure 4) illustrates the process by which adults diagnosed with and treated for cancer experience and make their pain meaningful. The graph, entitled Stages of Meaning, is not derived from any preexisting theory and is based on my conversations with the participants and my subsequent analysis of their responses.

Figure 4. Stages of Meaning

Far from being linear, each stage of meaning overlaps and provides the context in which meaning takes place. This process follows an oscillatory trajectory. Although the figure illustrates a constant amplitude, the reality is that the disruption of the painful experience varies according to the participants' social and cultural resources (such as access to medical care, social support, among many others), as well as their past experience with pain. The meaning making of pain is an ongoing, dynamic, and interactive process in which adults diagnosed with and treated for cancer as embodied agents are consciously experiencing and interpreting their pain. Thus, participants are doing more than merely having cancer and pain; they are consciously living their cancer-related pain and recreating their life. Participants tack back and forth between the stages of meaning, or fold back on the process of meaning. [This process is represented with the dotted line.]

The initial point of the visual representation indicates the unbearable physical and mechanical pain, which pushed participants to seek medical care. Once the physical and mechanical pain is reduced and the person is left with the conscious awareness of the damage caused by the disease, the emotional pain became predominant. As participants became more and more conscious of the force of their emotional pain, they are confronted with the crude reality of a shrinking world; a world of limitations caused by a damaged body, that disrupted life and an interrupted self causing. This in and of itself is also a source of pain for most participants. It is at this stage that the Cartesian understanding of mind and body is diluted. The damaged body, according to the results of this study, is the scenario where the body and the mind entwined in the presence of pain, and the trajectory of the self interrupted. In order to preserve the self, participants sought strategies from which to grasp meaning, understanding, and thus knowledge of the painful experience. One of the most predominant strategies of making sense of their pain experiences is the communicated experience. By sharing and communicating pain experience, participants acknowledge the significance of the experience in their lives. Similarly, by listening to the communicated experiences of others, participants validate their own experiences. Communicating pain gave participants the opportunity to embody a new way of experiencing pain that required encountering and witnessing others' experiences of pain. Finally, participants strived to explain through reasoning, providing a rationale for their experience. This rationale is founded in the triangle of healing: science, spirituality, and the self, explained as the triad of meaning, or the triangle of meaning. The experience of each participant at this point is different, as it depends on his or her level of pain meaning. However, common to all participants is the search for

meaning that occurs at all stages and at every moment of their experience. Even though I exposed a clear, tangible cut between physical and emotional pain, the moment in which one initiates and the other terminates is rather ambiguous. Pain disrupts the participant's temporality, making it difficult to clearly separate one pain from another. In the following section, I explained in detail each of the stages of the meaning-making process.

Stage 1: The Awakening of Pain

In this first stage, pain is a signal of a body dysfunction that interrupt the participants' everyday lives and push them to seek help. This process is neither abrupt nor immediate; rather, it is a slow and progressive process.

Unbearable Pain

This stage begins with a realization of the existence of physical pain. When asked about their pain, most participants relied on the story of their diagnosis and treatment. Tulio was the only participant who clearly narrated the trajectory of his pain, although he was no longer suffering from physical pain. However, as he narrated how this pain took over his body and his life, he became emotional, as if he was still experiencing that pain. For Tulio, pain was not an experience of the past, but rather a vivid experience of his present.

[se le aguaron los ojos] Una sensación de... la tenía los últimos días antes del diagnóstico, ya yo estaba que no me aguantaba el dolor. Simplemente no aguantaba el dolor. Estaba tomando morfina en gotas. Y, y aun así... [el dolor] es insoportable. Realmente yo no conseguí un calmante, ni siquiera morfina, que me funcionara por más de un ratito ... Como te digo, fue por ... y está etapa ya ... insoportable, afortunadamente no fue muy larga porque ahí me diagnosticaron ... Y apenas me diagnosticaron me pusieron tratamiento y me aliviaron el dolor. Mi dolor comenzó como un lumbago, parecido a un lumbago eh... empezando el año 2012, quizá en navidad. Eh.. En cuestión de un mes o dos meses mi dolor se hizo muy fuerte ... y comencé a ir al médico como a final de Febrero, marzo. Para empezar Marzo me

daban calmante e inyecciones ... el caso es que el dolor iba progresando, por su puesto en esas yo no estaba en una silla de ruedas. Yo estaba eh... moviéndome normalmente. Pero con mucho dolor. Y ya para Abril, eh [el dolor] se convirtió en algo insoportable. No me podía mover de la cama, no me podía... parar.

[His eyes watered] a feeling of... I had the last days before the diagnosis, since I was not able to bear the pain. I just could not stand the pain. I was taking morphine in drops. And yet... [The pain] is unbearable. I really did not get a sedative, not even morphine, that would work for more than a little while. As I say, it was for... and this stage already... unbearable, fortunately, it was not very long because there I was diagnosed... As soon as I was diagnosed they treated me and relieved me of the pain. My pain began as a lumbago, similar to a lumbago eh. Beginning the year 2012, maybe at Christmas. Eh, in a matter of a month or two months my pain became very strong... and I started going to the doctor like at the end of February, March. In the beginning of March, they gave me a sedative and injections. The fact is that the pain was progressing, of course, in those [days] I was not in a wheelchair. I was, ah, moving normally. But with much pain. And by April, eh [the pain] became unbearable. I could not move from the bed, I could not... get up.

Yet, when asked about what was the most difficult about this experience of pain, Tulio responded that pain itself was the most difficult aspect of living with pain.

Lo más difícil del dolor es el dolor mismo. No más que eso. Ese dolor tan grande que yo no concibo como describirlo, no hay palabras para describirlo.

The hardest part of pain is the pain itself. No more than that. That pain so great that I cannot conceive of describing it. There are no words to describe it.

Participants awoke to two types of pain: the physical and the emotional, Margarita says,

My pain... my pain... I would say I have two types of pain: the emotional pain and the physical pain.

In agreement, Helen expressed,

There is a before and there is an after. There is a physical problem, there is a lot of fatigue. First, what's it called, the nerve pain from the chemo. The nerve pain comes for quite a while. And then you have the psychological stuff, you know.

a) Pain Awareness

It is the indescribable intensive pain that awakens some participants to a disruptive reality and forces them to seek an explanation. This quest for a medical explanation was well described by Tulio:

Pero al principio, bueno, yo fui al médico porque tenía unos dolores de espalda que eran excesivamente fuerte. Cuando empezaron, claro ellos empezaron poco a poco fue progresivo. Y, yo al principio lo atribuía a dolores musculares, ah, una vez un médico me dijo que, que, era algo de un nervio que estaba pisado ahí. Eh, me ponían inyecciones para esas cosas [refiriéndose al dolor causado por el nervio pisado], y en eso me pase como dos meses o tres meses. Tiempo en el me vieron otros médicos.

But at first, well, I went to the doctor because I had back pains that were too strong. When they started, of course, they started gradually and progressed little by little. And, I initially attributed it to muscle aches, ah, once a doctor told me that it was something of a nerve that was pinched there. Eh, I was given injections for those things [referring to the pain], and in that I spent about two months or three months. Time in which other doctors saw me.

Similarly, Helen explained how her pain “pushed” her to look for medical care:

I was pushed by the pain, by then, by the fact of the pain. It pushed me to go to the hospital, to be treated, and all that things. And if the doctors in France had not pushed me to go to get treated in a hospital, to get treated and everything, I would just have just gone to an island, down to paradise.

In similar circumstances, pain caused by bodily dysfunction, such as not being able to urinate, awakened Angelo to a shocking reality, that he “had something wrong” in him and his painful experience was caused therefore by that intrusive object inside of his body. This reality caused him to be in fear, looking for help, consequently,

I’ve really, honestly, I, I went into a shock when this happened to me when I was, I was in New York. And I, I was at my mom’s house and I went to urinate and I couldn’t urinate. And this scares the hell out of me, because I wanted to go to the bathroom and I couldn’t go. So, I take myself to the hospital and I went to the hospital and they gave me medicine, which made me go to the bathroom and then, hmm, I was in shock! Because why will a pill help me out? You know, like that. And then I realized I had something wrong in me.

Behind the delay of seeking medical help, participants seek to hide their unconscious awareness of the reality of their health. In Helen's case, the cancer diagnosis was not a surprise, but rather a covert reality.

I had a problem of fatigue before the cancer, and I talked to some doctor here. She's a specialist of chronic fatigue. So, actually, I was not so surprised when I was [diagnosed with] colon cancer. Actually, she said that a lot of people who have chronic fatigue have prostate cancer. When I was In France, I saw a very good pain specialist doctor. Hmm, after some depressing episodes, you know, I was advised to see him; he was part of a team to see me. Because he was a pain specialist, specializing in curative care and when he saw me he said: the depression comes from the chronic fatigue, not from the cancer. Cancer is just, and he used a big word, an epiphonema. Basically, cancer is a side dish of the chronic fatigue. Hell of a side dish!

This first awakening, which begins with the treatment, for most participants was shocking, as Arline explained:

The first [awakening], putting the chemo in my system and knowing that I had it... After I got the initial shock of what I had. You know [laughter]... with the chemo, everything came back to my parents with the chemo. [Her voice cracked and she lowered her voice.] What is this?... The awakening was while I was going through the steps of getting prepared for it [the chemo]... the awakening was when they put the chemo drip in you, you know. And then it was all combined with getting a port, you know... But, it was the actual fact that yes! I am going through chemo. But, my mind, but... at that point the realization came in and said: Yes, you got, you have deal with it. I kind of adjusted my mind that I had to get this done and that was the awakening for me. It's just going to get done... It's true, it's not fictional.

Tulio explained that the news of his cancer was an abrupt interruption of his reality and of his life.

Y...bueno, siempre he sido muy deportista, hago mucho ejercicio. Ah... A mucho gente le extraño que yo me enfermera, porque tenía una condición física bastante aceptable, y además relativamente joven para un cancer de prostate que fué lo que me afectó a mí... Y, bueno, además de eso yo ya tenía un tiempo enfermo, pero eh.. pues se diagnósitico formalmente en ese momento mediante una biopsia. Cuando me dijeron el diagnóstico, mi impresión fue como cuando te dan con un bate por la cabeza, y uno se queda pensando, y por qué yo? ... es una impresión desagradable.

And... well, I've always been very athletic, I do a lot of exercise. Ah... A lot of people were struck when I got ill because I've had a very pretty acceptable health condition and also am relatively young for a prostate cancer, which was what affected me... Well, besides that I was already sick for a while, but hey... well it was formally diagnosed at that time by biopsy. When I was told the diagnosis, my impression was like when you get hit over your head with a bat, and one is left thinking, and why me? ... It's an unpleasant impression.

The awakening to pain coincided also with the dawning search for meaning. It is in the search for meaning that the knowledge of pain begins, as participants turn away from their isolated thinking, and it also serves as a realization of their unconscious worldview. The recognition of the subjective strengths and the realization of the worldview begin by questioning unconscious assumptions. As Tulio expressed it,

Como dije desde el primer día uno piensa y “por qué yo?” ... Mira, la semana pasada me hicieron todos los exámenes de rutina, el check-up, y cuando el médico me dijo que estaba bien del cáncer, no hay nada. Entonces, yo vuelvo a la pregunta que me hice el primer día cuando me diagnosticaron, hace cuatro años y medio, “por qué yo?” Esto es un regalo del Creador. Por qué me escogió a mí entre tantos pacientes que hay para darme a mí este regalo?

As I said from the first day, one thinks, “why me?” ... Look, last week I did all the routine exams, the check-up, and when the doctor told me that I was free of cancer, there is nothing. I then returned to the question I asked myself the first day I was diagnosed, four and a half years ago, “Why me?” This is a gift from the Creator. Why did He choose me among so many other patients to give me this gift?

Tulio's descriptions illustrated the oscillatory nature of the trajectory of meaning making and the way the trajectory folds back on itself.

The understanding of the awakening of pain makes participants more aware of their subjective sensibilities and they begin to recognize their subjective strengths at different stages of the disease. Participants discussed the physical and mechanical pain into three categories, which, in some cases, followed a sequential order of appearance. The first stage corresponds to the pain the participants experience previous to and during the surgery, defined as the unbearable pain and the excruciating pain. The second stage is

the pain after the surgery. This pain, Margarita describes, is “like a burning type of feeling caused by touching a specific part of the body and increases as the anesthesia wears off.” The third physical pain is experienced after the chemotherapy, a pain that wears the person down. The last two are grouped into one, the pain of the treatment.

The physical pain is tremendous. The physical pain, I will say, I will divide it like in three different stages. Hmm, I had to go through the surgery. Hmm, I had the mastectomy, the mastectomy. I did the mastectomy, well that was my only option, because the doctor explained to me where the location and the thing and obviously I went through some stressful moments in the way that the doctor, you know, she... excellent team, she explains to me, you know, we are not programming no [any] surgery right now. And, after the surgery, I had the physical pain, because [it was] six hour surgery... I got up to the room around ten. I was still drowsy and all I was feeling is like a burning. [It] is like if someone burned some part of you. And I was touching my breast to see if it was... what was there... Just touching was... I had to remove my hand from there, the pain; the burn. Is it a pain that you have to live it to know it... Because, the pain, the pain, the pain, the pain... The doctor authorized to give me morphine. So, I was still into my right... “From zero to ten, what is your pain?” [the nurse asked]. My pain is more than ten, but I don’t want any morphine -- I don’t want morphine. And, I started to ask her, “What is my blood pressure?” “Your blood pressure is low,” [answered the nurse]. And... into my whole pain, I started to tell her, “How do you think you [are] going to give me morphine with a low blood pressure? I will die... So, please don’t give morphine... I will take the pain... I could die of a heart attack...” Is those things that... is painful. My physical pain was more after the surgery. After all that anesthesia passed off and you really want [to] sleep, but it hurts... Hmm, The other physical pain was not... was not physical directly like that. The other physical pain that I lived is after chemotherapy. 24-hours after chemo they give a shot that is a medication that name [is] Nulasta. Nulasta build[s] up your white blood cells for you not to get infections, but it worked on your bones. So, you feel like if you have arthritis. The bone hurts, it hurts you. And you’re walking and you’re flying because it hurts. Every bone, every joint in your body hurts. The first 24-hours after Nulasta you have to go to bed. I had to lay down, and I slept 13-hours after that. Just to pass off the pain.

Similarly, Jocelyn indicated the existence of two forms of physical pain: the pain caused by the disease and its treatment and the pain caused by the symptoms.

For Helen, the pain was caused by the disease and this pain occurred in the early stages.

The pain she experienced was caused by a tumor that hindered her body from functioning correctly, causing bodily malfunction and excruciating agony.

Just imagine, the tumor was [as] the size, almost like an orange., you know. So, imagine you have an orange in your rectum... It clogs a lot and you are not going to be able to do number two [laugh], you know, and this is extremely, I mean, is like extreme constipation multiplied by a certain of something, you know. I mean, is an absolute physical, physical and mechanical thing; you cannot go the bathroom, it hurts like hell. I had pain just because, because if you have a tumor in your colon or rectum your stools can't go out. So it can be excruciating pain, excruciating. I mean, is a pain Hmmm like cry, I mean, you can sit on the toilet and cry for one and a half hour, or something like that, because, you know, you have, well, what's called, obstruction. You know, it's, hmm, basically, you thick and cannot go out. So it hurts a lot. That's before, yeah. It happens to me a couple of times, so I had to take laxatives, but it hurts, it hurts to the point, that you know, of screaming. That's what I mean by excruciating, it means like screaming.

Similarly, Tulio described the physical pain as an unbearable pain (“un dolor insoportable”) that was continuous and permanently interrupted his everyday life.

Cuando el dolor no te deja un descanso. Miro yo he tenido muchos huesos rotos en mi vida y no es nada. No es nada. Yo me he roto las tibias que son dolorosas. Me la he roto tres veces; dos veces en la izquierda y una en la derecha. Y... eso no es nada. Ese dolor en la espalda cada vez mayor, 24 horas con dolor con fastidio, no hay descanso. Y eso te agota. Y eso se convierte en algo insoportable, porque no hay un descanso. No hay un minuto de descanso. Todo, todo, toda tu resistencia se va deteriorando porque no hay un descanso nunca.

Ese dolor no hay comparable.... de pronto con el dolor cuando me sacaron las cordales pero bueno al día siguiente ya se había calmado un poquito. Pero este dolor es cada día peor.

When the pain does not leave you a break. I see I have had many broken bones in my life and it is nothing. It's nothing. I have broken my tibias that are painful. I've broken them three times; twice on the left and once on the right. And that's nothing. That pain in the back always greater and greater, 24 hours with pain and with annoyance, there is no rest. And that exhausts you. And that becomes unbearable, because there is no rest. There is not a minute of rest. Everything, everything, all your resistance is deteriorating because there is never a break. That pain is not comparable... maybe with the pain when they removed my wisdom teeth, but well the next day the pain had already calmed down a little. But this pain is getting worse every day.

For Debbie, the pain of the operation was so painful that the memories of the pain brought tears to her eyes.

El dolor era un dolor imposible, imposible, imposible de tolerar. De sólo recordarlo me vienen lagrimas a los ojos.

The pain was an impossible pain, impossible, impossible to tolerate. Just by remembering it bring[s] tears to my eyes.

In addition to the pain caused by the disease, some participants also emphasized how the diagnosis was painful. Irmone, another participant with breast cancer, says,

It was not that I was afraid of the biopsy, umm, because I had had a uterus biopsy in the past. So, it was like, um, okay piece of cake. So I went for the biopsy, which was very painful. I didn't expect it to be [so] painful.

Similarly, Mitzy explained her treatment and the pain it caused:

So, hmm, when I was going through treatment. Well, part of the pain was, hmm, from actually from a node where they take out a lift [lymph] node to see if the cancer and it's, it's, taken out from under your arm. So the arm hurts... when I had radiation, I had a hard time... so I had a pain in that arm. Nothing else was painful from it... They did radiation... and as a result of it, I have a broken rib... it will hurt for a week or so.... So, I still till today has [sic] the effect of the treatment for the breast cancer, yeah... and sometimes it's fine and sometimes it's not. [Laughter.]

The pain that comes from the treatment, explained Helen, is the worst:

The pain from the [treatment], is actually [the worst]. The worst, is actually, the pain from the treatment. Because they give you chemo, then you have the radiation. I have some radiation, that doesn't. In my case it wasn't painful, except it creates a lot of fatigue. I had radiation, so hmm and then so when they decided that the tumor had shrunk enough they operated on me, okay. They operated on me, umm, and, then, so, when I woke-up from the operation, I had the colostomy bag, which means the vacuum cleaner bag... [The] colostomy is, umm, a surgery not even to wish your worst enemy... and the worst thing is having to go the bathroom, which is still still till this day, not as it used to be. I really have to go. Yeah, it's very hard.

There is no one single awakening, but rather multiple facets of it and the multiple awakenings occur at different stages of the disease. For Arline, the second awakening of the disease also occurred when she realized that the once-intrusive elements of the disease needed to administer treatment were no longer needed and are therefore removed from her body.

The realization I had the chemo and they were taking it [the catheter] out and it was just like an awakening and further that I am okay, two years and the doctor said you should take it out three to five years and I said no, enough I am okay. I said if they

have to put it back in they will put it back in, but I wanted to fully live at that point. They asked the doctor if I can have it and he said no you can't have it so [I] am taking it out was an experience for me it was another it was a second awakening for me... The second awakening was, hmm, when I had it taken out. It was the reason why I have to had [sic] it put in to begin with and all the memories that I had it before that hmm, that I went through physically, because I lost weight, and the second was having the port taken out.

The second awakening demarcates the initiation of the emotional awareness. For most participants, the impetus of understanding their painful experience came with the realization of their poor or nonexistent pain-knowledge and with the need of self-knowledge. Pain understanding is a product of the self knowledge that helps shape the participants' awakening to their experience and helps build up an understanding of their own physical and mechanical pain. This understanding helps participants discern the complexity of their painful experience. In some cases, it helps clarify the complexity of the silent pain, explained in the following section.

b) The Silent Pain

For some participants, pain is a permanent and constant experience of their everyday lives that cannot be express or verbalize with traditional language. [This feature of pain is defined as the silent feature of pain.] This was the case with Maria, Jocelyn, and Dee, who lived with pain everyday. These participants lived in permanent pain, a silent 'mate' of their everyday life experiences, knowing that pain would disrupt their lives at any time. This was what happened to the three participants during the interview.

Maria was smiling, during the interview, but at a certain point in time, pain suddenly struck her. Her facial expression changed -she was not smiling anymore- and she lowered her tone of voice. She tried very hard to continue with the interview, yet all of

her efforts ended up being useless. Something was wrong, and she was unceasingly massaging her hands. She then continued with our conversation, saying:

Ahora mismo tengo dolor, se me engarrotan las manos.

I'm in pain right now, my hands clench.

As if she were trying to alleviate my concerns, she then ended up saying: *El dolor es constante, pero no permanente*" (The pain is constant, but it is not permanent.). But, What did she mean by that? Maria, a woman of very few words, did not explain that to me. However, Tulio described his pain as constant and permanent, always there and unchangeable:

Lo que más influye es el hecho de que no hay descanso es continuo, y continuo, y continuo, nunca baja sino que sube y sube, hasta que uno dice: hasta cuándo?

What most influences you is the fact that there is no rest. It is continuous, and continuous, and continuous, but it never stops. It always goes up and up, until one says, until when?

Dee's pain, she explained metaphorically, is a silent pain, always there; it is like the silence, which does not mean lack of sound, but rather the presence of a subtle sound that is not always disruptive. Dee described that her pain was persistent, although she tried multiple kinds of medical treatment and personal strategies, none had any effect, due in part to the inadequacy of language to describe her pain:

My pain has different moments, it just depends on the stage I am in. Pain, pain, as to define pain. I always have pain. But, I get used to living with the pain. In fact, I defined it as a silent pain. I don't know if anything name so [sic], but that is how I called it. What is the silent pain? Is that little pain that is always there that you get used to... it is annoying, is like a "gotero" [dropper] it is there, it is there, it is there and it doesn't matter what you do, it is always there, you know. They are moments that the pain desperates [sic] me more than others, because I can't define it. You know, it is just there, but you really can't define it... But this silent pain is always there and I cannot define it. I can't control it... The silent pain, I have it in this moment, but if I touch myself I don't feel it. If I hit here [pointing to her right arm], but is something inside. I just can't define it. You understand?... The silent pain is

always there. This pain desperate, honestly desperate [sic] [me]. It takes me out of balance. Is not intense so you can't stand it, but it is just constant, like constant... Silent seems to be like if there is nothing there. But if you even listen to the silence, it has a sound... there is something in the air that makes you know that there is silence. So, every time I feel that pain, [it] is not a strong pain, [it] is not that, it is just present.

The previous quote illustrated the inadequacy of language for expressing pain, and the implication of this for pain relief. As Dee mentioned, there is a need to develop a language of pain; one that can answer all questions the biomedical may ask and that could relate participants' experience and knowledge of pain.

For those participants who live with the silent pain, there is no other reality than to be in pain, Jocelyn explains. To this, I agree. [The following is an attempt to clarify my presuppositions.] In 2010, when visiting the cardiologist, after doing a 72-hour Holter, to my surprise, I was asked: Were you in pain? This question shocked me, since I did not experience pain while wearing the Holter. However, the medical results indicated the contrary. I then asked: What should I feel? After a short explanation of my cardiologist, I said, yes, I know that feeling, but it is not uncommon to me; I experience it frequently. My reality, just as for some participants, was to live in pain, was to be co-existing with the silent pain.

Although I had experienced pain and my experience had been disruptive for others, as I lost consciousness when in pain, I had never really comprehended the magnitude of the disruption until I interviewed Jocelyn. Just like Maria, Jocelyn began to feel pain during the interview and she began to rub her hands and knees. After a while, her reaction was most impressive; she screamed out loud, to which I reacted. She then proceeded to apologize and to explained that her pain is sometimes so unbearable that only screaming gives her some type of peace. She then shared the following anecdote:

... I was driving to school on I-95 and the pain in my legs suddenly struck me. This pain comes when it wants to. I had no other option than to pull over the car and I started to scream out loud and waited... after a while the pain went away... Sometimes, I scream out loud in class, my professors are aware of it... I yell in my pain, although I do not quite understand it. Being vocal helps me.

As participants reflect, they become more and more aware of the emotional connotation their experiential pain has, removing the pain from its biological functionality to a more comprehensive and social level.

Those participants who experienced a silent pain believe in the importance of living and experiencing the journey with a positive attitude. Maria believed that positive thoughts are fundamental in mitigating her bodily pain. These positive thoughts not only helped her to control her pain, but also gave her faith in a promising future, one without pain.

Los medicamentos ayudan a tener un buen pensamiento, a ser positiva... Tú tienes, aunque el dolor no se te quite nunca, pero, tú tienes que decir: yo sé que se me va a quitar, yo sé que se me va a curar, aunque no tenga cura. Porque a lo mejor dentro de un año aparece la cura.

The medicines help you to have a good frame of mind, to be positive... You have, although the pain is never removed, but, you have to say: I know that it will be taken away, I know that it will be cured, although it has no cure. Because, maybe, within a year the cure will appear.

However, not all participants saw their pain so positively. On the contrary, some lived in anguish. The reason for this anguish, for Dee, was grounded in her inability to pinpoint her pain, to describe it with words. This inadequacy of language to communicate pain increased her emotional pain as she searched for meaning.

When I wake up, if feeling pain, I will try to lay down and not to move just to try to get it into my head the type of pain [I am experiencing]: okay, "es un dolor punzante, es un dolor" [is a stabbing pain] and exactly where am I feeling the pain. Some others, I try to move, to move, just to try like... how to tell you... like if going back to the specialist and get it clear to him will draw him closer to what he needs to do to make me get rid of it [the pain]. Then it is important for me to find a vocabulary

from where I can explain my pain. I don't know if I, [if] you understand what I am trying to say. Is something like that. That's why it is important for me to try to... expose my hands... to see if something improve[s] or worsen[s] the pain.

As Jocelyn, another participant who experienced constant physical pain due to her disease, says:

I embrace this journey. You were to go through it not hating what you are going through.

Jocelyn's meaning of pain comes from her interpretation of herself as a strong woman. However, for most participants, pain is a constant and silent witness of their permanent struggle for normality and is not experienced in such a brave manner. This struggle is worsened because, unfortunately as for Maria and Dee, there is no remedy for their pain, as medication cannot alleviate a silent pain; a pain that has no beginning and no end, that is without form or shape, that is indescribable. At this point, participants begin to reflect on their experience of pain, to assume an attitude that will help them to understand their experience, and to modify their lifestyle. In Maria's words:

Bien dura. La experiencia del dolor es dura, pero te repone. Te hace más fuerte. Duro porque cuando tienes el dolor tratas de remediarlo. Pero cuando ya sabes que ese dolor va a persistir para siempre, te vas creando... ya ese dolor ya no es tan fuerte, porque te lo vas creando dentro de tu mente que tiene que ser así para continuar. Y el dolor se achica a la vez. Tanto el dolor físico como el dolor de la mente son iguales.

Very hard. The pain experience is hard, but it replenishes you. It makes you stronger. Hard because when you have the pain you try to remedy it. But when you know that this pain is going to persist forever, you start creating ... and that pain is not so strong, because you create in your mind that it has to be like this to continue. And the pain shrinks at the same time. Both the physical pain and the pain of the mind are the same.

Awareness of Emotional Pain

Emotional pain is a pain experienced as a result of the disease and the changes the disease cause for the person; is more about feelings. This pain is not a unique form of

pain, but rather a plethora of experiences, participants sustain due to diseases, such as anxiety, depression, fear, melancholy, explained Tulio.

... El dolor físico? porque hay un dolor también... [Señalando la cabeza]... una casi como una depresión, tristeza -- como una mezcla de melancolía con tristeza, una impotencia, todas estas palabras juntas quizá. No concibo la mezcla precisa pero por ahí va.

... Physical pain? Because there is a pain too... [Pointing to the head]... one almost like a depression, sadness -- like a mixture of melancholy with sadness, an impotence, all these words together perhaps. I cannot think of the right combination, but it is something along those lines.

This pain is an inevitable part of participants' everyday life, and unlike the physical and mechanical pain, it cannot be undone. Rather, the emotional pain persists and it hurts participants as they think over their past experiences. As Margarita explained.

Like in all my emotional pain... With the emotional pain you go through cycles, you know. Because every time you look back at yourself, [the] more you have to be strong to not to go through the emotional pain. Because you are transformed, you change even mentally... So, it makes a big change in your body, [and] your whole life changes.

Although emotional pain coexists with physical and mechanical pain, the awakening to emotional pain occurs once the physical and mechanical pain is significantly lesser.

Catherine explained:

I experienced a lot of that [emotional pain] more certain than physical pain. I had physical pain at the very beginning, but that just kind of disappeared really, really fast. But the emotional... pain I went through it quite of bit, you know. But, I can't picture myself. Ah, again, not to impose on someone else, so I dwelt with it.

For Margarita, once the physical and mechanical pain decreased, she gradually became aware of the damage the treatment had caused to her body, changing her self-perception and provoking with it an emotional turmoil:

The next morning, when I get up, I take a good shower and the pain is gone. Because, it is just the effect of the medication. [It] is not... I don't have pain in my body clearing the one that that medication caused. Nothing else. I go back to the emotional pain a lot of times. Because the changes that chemotherapy does in your

body are awful. Right now, my hands have sores. You see here [pointing out to some spots on her hands]. Because the chemotherapy is drying your hands so much that you crack, your skin. All these changes of dark color I have them everywhere in my body. My legs have it, and it's not uniform, but by spots. And... when you look at yourself and see how it changed you...

Similarly, Angelo's emotional journey began when he realized the changes in his lifestyle that both the pain and the disease imposed on him:

The cancer, umm, it's taken a lot out of me, you know. The hmm through the process, it wasn't easy. But me, you know, you are not used to doing these things, you know. You used to, getting up healthy, eating good, and go. So, it's just different, your whole life changes. [It] is not easy, is not.

A critical part of participants' painful experience was feeling more aware of their emotions or seeing things about themselves and their relationships. Even though some participants were informed about the consequences of the medical treatment, few were aware of the emotional damage these changes would cause them. For instance, F.T. explained:

I am aware of the medication, But I am not aware that this is going to happen, this hard. To... be like this. Hard to be like this, to.. hmm... I want to have a normal life, normal life... no anything. Everytime on internet I realize, I realize that the chemo and radiation hmm side effect is not going to go, you know, is not going to go....

Margarita, for example, explained how losing her hair was the key element that awakened her to the reality of her disease, causing her emotional pain.

Every woman loves their hair. I didn't have hair long to my back, but I had hair [starts to cry]. I was aware that it would come off, because of the type of chemo I was receiving. But that was emotionally strong, a pain that I sit down... and I stand up in-front of the mirror and I cried like a baby. Even though I was aware, because when you go to the oncologists, they explain everything -- what you can expect from the chemo, and what not to expect, when you must call them, when you must go immediately to the emergency room--. So, they teach you a lot, it's learning day-by-day. So, I was aware that my hair would fall out.... and it's just like you [are] mowing a lawn, all of my hair started coming out by [a] bunch, bunch! ... And just how the hair started to come out, your scalp gets tender so that it burns, it hurts.

Consequently, the awareness of emotional pain begins slowly and progressively increases. This awareness is characterized by a conscious understanding of the consequences the painful experience has on the lifeworld of the participants. This process, which involves the questioning of the self, makes the “other pain,” as Tulio named the emotional pain, more disruptive than the physical and mechanical pain. As Tulio explained it,

[Clearing his throat]... ese dolor es quizá el más fuerte... Los primeros días... ese dolor eh... quizá no era tan fuerte, pero fue creciendo progresivamente. Porque en los primeros días está uno tan ocupado con el dolor físico... y buscando que hacer y además buscando como... pagar las cuentas. Porque esta enfermedad es de alto costo. Uno está tan ocupado mentalmente en ese... cómo voy a sobrevivir hoy? Que no piensas mucho en otras cosas. Pero luego ya empiezas a sentirte un poquito mejor y entonces empiezas a ver... que no paras de pensar... como dije desde el primer día uno piensa y “por qué yo”. Después hmm qué voy hacer. Yo no sirvo para nada. Uno se pone a pensar en todo.

[Clearing his throat]... that pain is perhaps the strongest... The first days... that pain eh... maybe it was not so strong, but it was growing progressively. Because in the early days one is so busy with physical pain... and looking for what to do and also looking how to... pay the bills. Because this disease is costly. One is so mentally occupied in that... how am I going to survive today? That you do not think much of other things. But then you start to feel a little better and then you start to see... you do not stop thinking... as I said from the first day one thinks and “why me?” After hmm what am I going to do? I am of no use. You start thinking about everything.

For some participants, the damage caused by the emotional pain is more detrimental than the physical and mechanical pain. For Tulio, it was not the physical and mechanical pain he experienced (produced by the spread of the disease all over his body) that caused him major emotional pain, but rather the realization of his limited reality, due to a late diagnosis:

Lamentablemente, no se hizo a tiempo el examen que se debió haber hecho para detectar el cáncer. [Se le aguaron los ojos]. Y eso pues fue nefasto porque perdí algunos meses de tiempo que me hubiera permitido agarrar ese cáncer más, no tan avanzado. Porque, finalmente, cuando se diagnóstico yo ya tenía una metástasis terrible, eh, este, a mi diagnosticaron, eh, un estadio 4. En la escala de Gleason son

7. Yo ya tenía todo el cuerpo absorbido [el cancer hizo metástasis], todo el tórax todo infectado, la columna [vertebral] invadida. Toda la columna infectada. Un pulmón infectado...Una sensación de... Entonces, yo pasé de ser un deportista a estar en una silla de ruedas. No podía ni siquiera caminar del dolor. Terminé en un silla de ruedas en un “wheel chair.” Sicológicamente, el daño fue inmenso.

Unfortunately, the examination that should have been done to detect the cancer was not made in time. [Tulio’s eyes watered]. And that was disastrous because I lost some months of time that would have allowed me to get that cancer not so advanced. Because, when it was finally diagnosed I already had a terrible metastasis, eh, this, I was diagnosed, eh, a stage 4. On the Gleason scale are 7. I already had the whole body invade [methastatic cancer], all the thorax all infected. The [vertebral] column invaded. The whole column infected. One lung infected. A feeling of... Then, I went from being a sportsman to being in a wheelchair. I could not even walk from the pain. I ended up in a wheelchair, in a “wheel chair.” Psychologically, the damage was immense.

Emotional pain, contrary to physical and mechanical pain, affects not only the body, but all of the multiple dimensions that make up a person’s life. Margarita, a Spanish speaker, believed that this emotional pain was more damaging because it was a burden. This imagery is represented by the expression “carrying a procession inside,” which is a Spanish figure of speech that means enduring pain in silence:

Yes, I think it is a burden because you’re carrying a big procession inside. I will say, more than physical pain is the emotional pain. And, emotional pain is more dangerous than physical pain... why I say dangerous is because if you don’t stand up strong, you’ll get depressed...

Similarly, Catherine recounted how having to receive help from her family made her feel the pain of becoming a burden.

I was not able to do certain things and I had to ask someone else to do it, which caused me pain because I felt that I was putting, being a burden. And that's something that I never, I never wanted to be... before, you know, I just come in, you know, I don’t want to ask, I don’t want to be a burden.

Another aspect of this emotional pain is the realization that, due to the disease, many participants are no longer able to work, losing the ability to manage and respond economically and financially in their own lives. This loss of economic and financial

independence affects some participants' self-esteem and causes them pain. Maria came to the US to work, but due to her disease, she was no longer capable of working for a long period of time. Maria was confronted with a new and unexpected reality: she was on disability and could not work. Her disease was diagnosed soon after she arrived in the United States. This fact, one may say, was the only time during the interview that Maria expressed some type of regret or sadness caused by her disease as she was no longer capable of reaching the American dream, and that realization increased her emotional pain. As Maria explained:

Eso más bien es lo que más me ha afectado. En todo este proceso, lo que más me ha afectado es el no trabajar, porque [como] te dije que yo era imperactiva. Yo en Cuba, yo tenía dos trabajos. Y al llegar aquí y presentarse la enfermedad se ha afectado el sistema inmunológico completo. Por muy ... muchas cosas que yo quiera hacer... yo, yo tengo la disposición. Quiero, pero [eso] no cuenta. Y más bien es eso, eso es lo único que me deprime a mí. Porque yo vine aquí fue a trabajar. [Se ríe]. Eso sí, me tiene a mi atormentada. Porque yo quiero trabajar, sé que puedo trabajar, pero más no cuatro horas [diarias], no puedo. Y hay trabajos que no los puedo hacer aunque yo los quisiera hacer, y eso me deprime.

Throughout this process, what has affected me the most is not working... In Cuba, I had two jobs. And when I came here, this disease has affected my entire immune system. I want to do many things... I, I have the disposition, I want to, but that does not count. And rather it is that, that [not being able to work] is the only thing that depresses me. Because I came here [to this country] to work. [She laughs.]. That [not being able to work] tormented me. Because I want to work, I know that I can work, but no more than four hours [a day], I can't. And there are jobs that I cannot do even if I want to do them and that depresses me.

Some participants have become dependent on others to help them complete tasks of everyday life, such as eating, dressing, bathing, walking, and taking care of their children. This dependency, which most of the time is on family members, generates in the person feelings of indebtedness. F.T. felt like she was in debt to her children for not being there completely for them. Although she was always physically present, she could not always perform her role as a mother: playing, cooking, and taking her children to

school. She even manifested sorrow over the lost memory of her daughter's first words.

These feelings of debt and loss caused F.T. deep emotional pain.

I feel obligated, no oblig, I feel obligated to pay my debt to them... It [the word] just came out, I just realize myself... it just came out, I, I, I didn't think about that before. Now, I understand why I've been spoil [sic] the kids like a baby and treat [sic] them like a baby [her voice is trembling and she then cries and her tone of voice reduces]... I feel hurt... it's terribly...

Besides the feelings of being in debt, participants believe that the loss of autonomy will lead to a loss of their roles (as mother, father, breadwinner, and/or caregiver), leading to psychologically negative reactions, such as guilt. Tulio reported that not being able to fulfill his role as the provider for his family caused him feelings of guilt:

Yo... s...siempre todavía aún ... siento... toda clase de culpa por no poder trabajar, por no poder mantener mi familia, porque me han tenido que ayudar.

I... uh ... always still... I feel... all kinds of guilt for not being able to work, for not being able to keep my family, because they have had to help me.

Similarly, F.T. felt guilt for not fulfilling her role as a mother when in pain, when she was "down."

Sometimes, I have my down. And when I am down, I have, the last thing I want to hear is my kids screaming and nagging me, you know. They are kids right, but I can't work. I can't work... and at the end, of course, I feel guilty... The whole day I was not with them, you know, I put them in the playroom, playroom all the time, of course it is not their fault that they want their mommy... I, I probably must feel guilty too, because I supposed to breast feed my kids, but I had to stop...[she started to feel nausea. She stop talking then she laughed] ... For two years I didn't touch them, I mean, I do touch them, that's it. [she cries] ... because those 2-years are from the treatment... and then I left them with the nanny or with my sister... My sister, she just takes over. Sometimes I felt guilty. I should, I shouldn't, I shouldn't be like that [easy to be anger]. I should be like, "Hmm, okay, let's play, oh that's good! Oh, that's beautiful, you are very smart [telling her twins]." Instead of yelling and screaming. So I felt like the whole two years I missed my child development, you know ... I still feel guilty in me [crying] I am not a good mother, I am not a good mother and I should be there for them. I am trying to be a good mother...

Some other participants develop fear: fear of living with cancer, fear of dying, fear of being alone. But the most common fear among all of the participants is the fear that the cancer may come back and that they will have to go through further treatment. F.T. explained that when oncologists say: “you are free of cancer” what they really mean is that the cancer is ‘sleeping,’ but it can be awakened at any given moment:

He does not know that gone means sleeping; it’s just sleeping. Ah... they took the cancer out, yes. But once it’s already spread, it’s spread. Right? And then it just need to wake up. And if I am not taking care of myself and if I, I yeah not taking care of myself it can grow back again. Because every person has cancer, you just need to manage the, manage the, the what?... Manage the life, the life... hmm difficult for, hold on... yeah, everyday life, everyday life.. oh it’s here [pointing to her head] but it [the word] cannot go out.. and... everyday life. They have to change your habit, so the cancer don’t [sic] appear again... the way of life, there you go. [Laughter.] You have to change the way of your life...

Angelo explained how a lump on his chest was a wake-up call and a reminder that cancer and the pain he experienced before may eventually become his reality once again, which scares him:

Your mind has a lot to do with that, in controlling to, I mean like hmm if this should review earlier I find something above my breast. Hmm, I had a.. A lump on my breast, on the right side and it's the source of all this pain and everything. To think that it was coming back [the cancer], I’m scared, just because, to go through that experience in my life to... say that I told you a few seconds ago, it was like... in my mind was to say is it coming back? Or it’s going to reappear. Now with the phase now, where I went back and have had a biopsy done and it came back negative, it... I am more relieved. But, you never know, so it’s ... cured ... It’s a... touch, touch-and-go ... situation, because you never know if it’s going to come back or not. And I have gone through this experience for my ... breast, it’s been like ... hmm... Scared ... you know. You go through a panic attack, which is a bad feeling because you want to know, you want to have answers. My mind tries to stay positive, but ... things do change. You know your life changes, your chemistry, your body, your everything, which is hard. You never know. As I said I have this sore in my breast and ... it gives me a wake-up call again.

This fear is permanent. It is this permanence that makes emotional pain the harshest one. Emotional pain is a constant reminder that cancer has no cure and can only be controlled, Arline explained.

It's an experience for me. My brother gets on the phone and says: "are you cured yet?" and I says: "Mario, I am never going to be cured." And that's one thing that always resonates with, it [cancer] can come back at any time... My brother thinks it's cured, it is curable. And I said: "blood cancer like this is never curable. It's always in you to get it again. Even though they [the doctors] tell you that you are in remission, it is like any other cancer, you know. It could potentially come back. Good chance that it won't, but you never know.

Along with the pain and the diagnosis of cancer, for many participants, comes the awakening to the finiteness of their lives, a reality more strongly evident for some participants than for others. Angelo clearly explained his fear of death when he was diagnosed with cancer:

I was in panic! Yeah, you know, you look at your family, you look at your children and this is all you were working for, for your family and for your children to have good things in life and then to realize that I'm not going to be here.

This realization makes some participants wonder about their everyday lives, about their futures, becoming fearful of the present. F.T. said:

I know it's because of the treatment, but hmm, you know. I mean without those treatment I am not going to be here, I am not going to be seeing them growing. So, either you take it or you not going to see them at all. [Crying].

This doubt leads to the realization of the ephemeral nature of their lives. Angelo explained how this fear was always in his mind and with it the realization that his life was short.

Hmm... Honestly, yes! Because it hmm... you never know if it's going to come back... you know, and knowing that I am the first one in my family to have cancer... it's been... hmm.. You always have it in your mind... you know, that it may come back and, you know, it's a hard feeling. And if done, then I know I am dealing with them, even the way I am on spare time. I am on borrowed time. But hmm... that's the only worry.

Similarly, Margarita explained how this fear reappears anytime people diagnosed with cancer experience any little funny pain. This fear, as Margarita expressed it, caused an emotional pain.

The other thing... when you are a cancer patient... Any little... funny pain that you might get, makes you think: the cancer came back, in your mind... Because you think, Gua! I wonder if I have... this stuff again. I had to do a 24-hour urine, recently... Part of the whole process... and... my whole fear was that my kidney wasn't working, because I start to have some pain over here. I didn't ask them to send it, but that is part of the protocol. And... Because, one of the first things my doctor told me, is that the type of chemo that you get will slow down your kidney, but you need it! You have to run the risk... It [the results of the test] came out good... But every time you have to go to one of these tests... cancer!... back in your memory... I personally every time I have to do those scans, because they send you those scans, you don't think of cancer, but that emotional stuff comes back: I wonder if this thing is coming back again?

Similarly, Irmone described how her realization that her life is ephemeral caused her to panic. This fear caused Irmone to question the core principle of her life, to question God. But it was not until the realization that she would eventually die that the fear of death and the ephemerality of her existence became a plausible and accepted reality.

Well, I was ready to... blast God... I was ready to be mad at him, I was ready to say: how can you do that to me? And... I was ready to... there is a bargaining prayer; I was ready to bargain with him, because I have those little kids [pointing out some pictures on the wall] who are my great-grand children, and, you know, when you have children you love them, but when you have grandchildren, you go crazy. When you have great-grandchildren, you go mad. So you know, how grandmother is always asking: God, please let me live long enough to see my granddaughter get married, before you take me. Well, since I have great, since my great-grand, since my granddaughter is already married, I have one that is not married and... a grandson who is not married. But now... my great-grandkid, I was ready to say: God, please, let's begin. I want to see my great-grandkids get married. Then I started laughing, and I said [to myself]: you want to be like Moses, live 900 years. So, after she gets married, she has a baby what are you going to ask God, for you to see the other one get married too, so, when are you going to die, girl? [Laughs] And I was not afraid of death anymore.

For Maria, rather than questioning God, her diagnosis was a reminder that her existence on earth is not everlasting, but rather is finite.

Cuando me diagnosticaron que tenía cancer, ésa primera impresion, para mi, para mi será por mi carácter, por mi preparación, que me dije: bueno, nacimos para morir; unos mueron en accidentes, otros mueren al nacer. Tenemos que aprender a vivir con esto. Voy a tratar de hacer lo que siempre he hecho, a cuidarme, a tomarme los medicamentos, [y] hacer todo lo que tengo que hacer. Pero, debo aprender a vivir con ella. Y [el diagnóstico] no me entristeció.

When I was diagnosed that I had cancer, that first impression, for me, it would be for my character because of my preparation, that I said: well, we were born to die. Some die in accidents, others die at birth. We have to learn to live with this. I will try to do what I have always done, take care of myself, take the medicines, and to do everything I try to do. But, I must learn to live with it. And it [the diagnosis] did not sadden me.

A few participants were aware of their emotional pain explicitly; Frank (2013) attributes the suppression of emotions to the moral code of society and to the cultural norms and believes that implicitly determines a response to emotional pain. Others, although aware of it, had no words to name it. This was the case with Tulio, who had no words to describe his experience as a “mixture of melancholy with sadness, an impotence.” Tulio could not identify, differentiate, or label his experience of pain. This form of alexithymia, which is defined as the lack of words to describe a person’s feelings, makes it difficult for Tulio to describe his multiple emotions. As Scarry (1985) explains, pain has the particularity to run the language dry. Tulio’s inability to describe his pain increased his emotional pain and isolation. During the conversation his eyes started to water and he pushed the rolling chair he was sitting on a little backwards while looking up to the ceiling. It was evident that he was going through emotional pain. Once he was himself again, he pushed the chair forwards again and continued with the conversation, his voice trembling.

Others came to a conscious realization of their pain during the interview, and this realization is a hard and “touchy” reminder of their past. Expressed Angelo:

This is something new, so how you really know what pain is and that. Is hmm a touchy, touchy situation. I never thought about it that way. Never! I don't think I ever noticed it that way. It's touchy because it's something that happened, and it's I look at it now as behind me, you know. I just want to let it go and it's hard. It's hard to let it go, just thinking about it, it's hard.

For most participants of Hispanic heritage, cancer is associated with death and deterioration. This often limits the participants' ability to face the illness in a realistic way, since this belief leads participants to believe, hopelessly, that they are receiving a death sentence. Margarita, in particular, had worked with oncology patients and was aware of the advances in cancer treatment; nevertheless, when informed about her diagnosis, she had to face up to her own presumption that she associated the word “cancer” with death. Her past experiences overwhelmed her current experiential knowledge.

From this started all this whole pathway, emotionally I started to feel, what I called the emotional pain... the doctor called me... I started feeling the worst feeling that you cannot describe. It was an emotional thing that I didn't know if I should start crying from out there or when I got in the office. [Margarita started to cry, with trembling voice]. When I got in the office, he held me, he said to me: “Margaret, I did not want you to have this news, but you have cancer.” I said: “Oh my God! History is repeating itself...” And, I felt so bad that [I] didn't know if I must start to scream, or start to, and I started crying... My emotional pain was so hard, I could not even move off the chair, I sit down there for a long while... Right now in my brain is all the picture of my family that died of this, especially my mom... I was in so much emotional pain. My emotional pain was because when they said cancer, even though I work in health, cancer for me means, in that moment it means, death... Death!, because I already have so many family members that died from it. So for me was like death.

The emotional awareness of pain took place, for some participants, during the interview.

The awareness was very painful and it increased attention on the participant's experience, which increased the physical pain. This was the case of Maria, who

expressed her pain experience in very few words, but during the interview started to experience pain in her hands. The emotional pain increased as participants remembered their past experiences. Margarita, for example, cried for the most of the conversation while she narrated her story. The new awareness set up a contradiction between prior self-concept and new-self that made the participants re-evaluate their core principles and assumptions by which they had organized their lives, by questioning themselves. This critical questioning help participants to make sense of their experience and of their selves.

Stage 2: The Struggle to Adapt to a Shrinking World

At this stage, all participants face a new world of “restrictive potentialities” (Merleau-Ponty 1962, 143). As participants’ capabilities and choices diminish, they are confronted with a new reality in which they struggle to adapt to the dawning damaged body that limits their everyday life activities.

Damaged Body

Participants are awakening not only to their physical and mechanical pain, but also to a damaged body. By the nature of the disease and its treatment, some cancers create visible and invisible wounds in the person’s physical appearance. Although participants were informed about the possible physical changes, the magnitude of the damage was inexplicable. The awareness of the disease is evident with the damaged body, as participants have no other option but to live with the consequences of the disease. As Tulio described it:

... Además me estoy desapareciendo. Una de las medicinas que tomo sus contraindicaciones dice que impide el crecimiento muscular, incrementando el dolor, no el físico sino el otro dolor.

... Besides, I'm disappearing. One of the medicines I take, its side effects say that it prevents muscle growth, increasing the pain, not the physical but the other pain.

As Amy explained, her awareness of the impetus of her cancer came with the loss of her hair. She believed that no women with cancer can consider themselves a cancer patient until they lose all of their hair. Angelo explained that although his physical structure has changed, the greater damage comes from the consciousness that "something is missing," which caused him to be fearful, to develop a sense of incompleteness.

A lot of hesitation in my life lately, which I didn't have before. Yeah! Like... if I pull myself, or I hurt myself you know, what I am saying, everything is not there, something is missing. So, I just physically, I limit myself to certain things, maybe I am not supposed to.

The sense of incompleteness also comes from the dissociation participants have from their bodies. In Margarita's words:

Looking at my body, one day my husband came into the bathroom and I, and I, and I said: do you see your monster?... And, he said: don't say that. This is ugly. And I said, yes, I am not even half of what I was. I am less of a woman.

Looking different for some participants was problematic. The damaged body allows no space for reconciliation between the physical-external and the internal-perceptual appearances. Tulio described how the external appearance did not match the internal perception he had of himself. What he was looking at in the mirror was not how he perceived himself.

... El Tulio físico está deteriorado, muy deteriorado. Lo que es tu estás viendo ahorita es la mitad del Tulio --yo perdí 20 kilos que no he podido recuperar, y ando desmejorado. Las marcas de aquí [señalando unas marcas negras en las manos producto de la quimio terapia], el cabello se me puso blanco-- es un Tulio físico que me hace sentir un poco... que me da dolor, pero no es un dolor físico sino de otro tipo. Pero no importa, estoy vivo. El Tulio interno es quien uno realmente... es quien te está hablando. Mi cuerpo físico es como mi casa. El que te habla es el mismo o mejor que antes...

... The physical Tulio is damaged, badly damaged. What you see right now is half the Tulio --I lost 20 kilos that I cannot recover, and I'm worn down. The marks here [pointing to some black spots on his hands caused by the chemotherapy], my hair got white—it is this physical Tulio that makes me feel a little... that gives me pain, but not a physical, but other pain. But it does not matter, I'm alive. The internal Tulio is who you really... is who is talking to you. My physical body is like my home. The one speaking to you is the same or better than before...

In order to preserve the integrity of the self, some participants explained their experience from an embodied approach. This was the case of Maria and Tulio. Additionally, the distinction of the body-object is evident in the differentiation participants make of their the 'good' old strong body and the 'bad' actual damaged body. This dissociation, between the perception of body-object, their old strong body and the realization of their new, damaged body increases the "other pain," or the emotional pain; as participants struggle to attribute meaning to their pain experience, they are confronted by the crude reality of a damaged body that causes major psychological damage. Angelo described how the disease had made him aware of his limitations, and therefore he had become more cautious.

This changed my life a lot. Things are taken away, and I am afraid. You know, so, I am cautious about a lot of things, which I never was before. Usually I didn't care, I just go ahead and do it, enjoying it... It's changed my life a lot... I am more cautious, cautious of life, you know, I don't want to hurt myself, I don't want to do anything crazy... So, I just observed a lot of things and... I have my limitations now, before I didn't, I just did what I had to do. And those limitations have been imposed by time, by life.

However, for Catherine, the damaged body helped her to develop a positive self image. Before the diagnosis and medical treatment, she had a negative image and the damaged body disrupted her unhealthy relationship with her body and thus with the self. So, the damaged body reconciled the relationship with the once unperfected body and the self, Catherine explained:

I wouldn't say I'm struggling with being a woman. Because before, you know, I lost my breast, you know, I had issues about how I looked and how I felt about myself. So, it wouldn't be an identity of not being, feeling less than a woman, because I didn't have that. No, it wasn't. It wasn't that because, you know, because as I said, I had issues before. I would look in the mirror and say hmm, I don't like this, this is not good, You know. No, you know. It's not, It wasn't because of that. I'm okay with myself now, You know, when I take a shower, when I get home and I don't have this thing on [the breast prosthesis], I'm just... flat chested. And I say, okay.

Similarly, the damaged body, in the case of Irmone, disrupted an unhealthy relationship she had with her body, reconciling her approach to both the old body and the new body:

But it was another thing again that was very funny, it was like... I... ever since after I had children I always wanted to have a breast lift, I was never satisfied with my breasts. And now they are the most beautiful monument I possess, it is like: Gua! ... Look at those babies. No, No, No, I am not ready to lose it, you know... So... that's what happened.

As participants experience a lack of bodily reconciliation, they become aware of the duality of their body as subject and object. The subject is their "other pain," or emotional pain, and the object is the vehicle through which they experienced the "other pain." In the experience of the "other pain," both bodies coexist, increasing the pain experiences, as the old perfect body is juxtaposed with the actual damaged body. The pain of perceiving themselves differently and incompletely takes a toll on their self-esteem. Both Margarita and Tulio showed strong emotions as they described the pain that looking physically different caused them. Margarita, for example, cried as she stated that she is now a monster. Tulio, on the other hand, as his eyes turned watery, calmly described the extreme pain it caused him to see his physical self damaged in such a short period of time. Participants encountered challenges as they sought to cope with, and adapt to, the frustrations of a damaged body, particularly to face a disrupted life.

Disrupted Life

Participants reported that this disease hindered them from sustaining their normal lives. For F.T. cancer and pain disrupted her normal life, which she also perceived as change of self.

Normal life is like hmm, I can do my activity, I am not tired easily, and I am not so emotional easy, I am very sensitive, hmm, I can, I can talk like it used to be. I can have friends, I can... talk mostly, socialize. Hmm, I still can, I know, I still can socialize now, but it's hurt me back, because I know I have a speech, a speech delay. And, and I don't know what to think, talk about, and it's like ... you know, I have to think to talk, can you imagine? Yeah, I used to have [making noises] and now I even have to think to talk. It's frustrating me. This is not who I am, you know. I love to talk, I love to hmm, hmm... I cannot even think. I cannot even change my mind if my mind is bad, you know.

The previous is almost a form of alienation between the old-self and the evidence of a new self. In this case, F.T. old-self is being changed for, or transformed into, a new-self, which she struggled to accept. This struggle distanced participants from their own experiences and emotions, as they became stranger and alienated from their own experiences. Kathy Charmaz (1983) refers to this process as the "Loss of Self." This censorship has the end result of self-estrangement. Similarly, Angelo said that pain has changed his life entirely; changing the person he used to be, as his life has come to a stop.

To be the person I used to be before, a very energetic Angelo, ongoing. This person is not the same, is not the same energy. Now I go out go do a little work and I close myself inside the apartment, which I never did, I used to come home, take a shower, get dressed, and go. So, it has changed, it changed me a lot. The Angelo of now is very cautious about everything [laughing] he does and says. Before I was a dead devil, I didn't care. Because, I felt like I was always 21, you know: energetic, ongoing [sic], speaking... hmm doing things, hmm... I won't climb on top of a roof, you know, anything like that. And I mean it changed my whole life, yeah, it comes to a stop, you come to a stop. I just go with the flow, the way life is right now, the pace it has taken and I'm doing my things.

The first disruption in the life is the change from being an independent, dynamic and active individual to a dependent and passive persona, to becoming a disabled person. In this regard, Jocelyn expressed that due to the pain she experiences everyday, she is no longer able to live a normal life:

I am a disabled person. Because of the pain I experience everyday, I can no longer live a 'normal' life.

Not being able to live a normal life is one of the greatest sources of the emotional pain participants experience. Maria explained how the simplest thing, such as cutting a rose, was no longer an easy task for her and how this caused her to feel depressed and therefore to be in pain.

Pero mira que [me deprime] por sólo cinco minutos. Mira, por ejemplo, quiero cortarme una rosa, por ejemplo, se me dificulta, y eso... porque aveces me pasan varias cosas seguidas... si pudiera hacer esa cosa no estaría así, si hubiese resuelto aquello... eso me deprime un poco, pero digo a la vez, lo supero. Tu sabes, no hay una semana que me acuesto, que me encierro, que no quiero que nadie me vea, no no ... El dolor es peor cuando te deprimes... cuando te deprimes el dolor aumenta, cuando te deprimes.

But look that [I get depressed] for only five minutes. Look, for example, I want to cut a rose, for example, it is difficult for me, and that... because sometimes several things happen to me at the same time... what if I could do that thing I would not be like this, what if I had solved that... that depresses me a little, but at the same time, I overcome it. You know, there is never a time that I lay down for a week, I'm confined, I do not want anyone to see me, no, no, no... The pain is worse when you become depressed... when you become depressed, the pain increases when you become depressed.

The life course of some of the participants was suddenly and unexpectedly interrupted by their disease and their pain was a constant reminder of their disrupted life. Michel Bury (1982) refers to this process as "Biographical Disruption," as cancer and pain disrupted the cotidianity of participants' everyday life. This awareness of a disrupted life was a source of emotional pain. In this regard, Angelo says:

It's change. A lot of things have changed in my life and it's not... it's not fun. No. It [his life] used to be fun, oh yeah, I was always happy and things changed. I'm ok, I will deal with it. [Laughter]. People don't know how I am, they don't, maybe it's just the way I am. I closed myself and I do, as they said women do, they put up their guards. You know, you protect yourself when you close yourself from man, so. This is just what I've been through and that's it. I wish it didn't happen, but I would be the same person I used to be before: happy and energetic, you know.

As participants become more and more aware of the disruption their experience has caused in their lives, they struggle to redefine themselves in terms of their past history and to construct a new image based on their present and future. In this regard, Margarita explained:

Maybe, I put a wall that they don't motivate me. Because everybody thinks I am okay, I am good, I am doing good, I am looking good. One of the doctors said to me, yesterday, "You don't even look like you have cancer." I said, "I had. Have is present. Had is the past. I was feeling like a dog. I was sick like a dog." But, that is just my personality... But, my way of being is that I can chat with you, but I always have a wall, a distance, of how far that goes, to know me inside. It's an imperfection of a person apparently. But, a lot of times you miss out.

Once participants come to make sense of their painful experience and acknowledge the changes it makes in their lives, they become stronger. As Maria expressed:

Bien dura. La experiencia del dolor es dura pero te repone, te hace más fuerte.

Very tough. The experience of pain is tough, but it replenishes you, making you stronger.

For some participants, the damaged body also caused changes in their interpersonal functioning, resulting in pronounced sexual difficulties, significant lifestyle alterations and disrupted self-image. Angelo experienced the vicissitudes of an internal damaged body, one whose effects interrupted the normality of his life and forced him to question the core social assumptions of his gender identity, his manhood.

My life has changed a lot, emotionally yes, manhood a whole lot, tremendous, and I just take it one day at a time. I know I'm here on borrowed time. Honestly, I was sexually active... Hmm, I could do it anytime at any place, it's the truth. And today, it's hard to get intimate with anybody, because hmm, there is not much of a sex

drive, you lose it; the sensations, the feelings, and all that and so. And then they want you to use pills, Viagra, or Cialis or any other drug to use it. And to me, I don't think I need that. If it doesn't work mentally, then it is what it is. Those [pills] are recommended for the sexual drive, they take something away, and they gave you something, you know. If I have to take something to get me that way [sexually active], then I am scared. Because hmm, especially now with my heart. And knowing that I'm going through this little drama in my life. I really don't want to take anything, because I heard stories, you know, of people having [a] heart attack. This had affected my intimacy with my partner, you know, if you are dating, if you are romantically and sexually active and if you can't please you might go. So you stay by yourself, some women will stay by your side, some won't. If you are young enough and you enjoy making love, then you have to keep your partner happy. Um, if you can't you just have to keep by yourself.

The damaged body is not always, as Tulio and Angelo explained it, visible. The damaged body includes the inner body, feelings and sexual drive. Margarita explained how looking at the mirror forced her to look at both her damaged body and the fact that her sexual feelings were no longer present. This realization caused her to feel pain:

Because when you look at yourself in the mirror and see all the changes in your body... well all your feelings, sexually and everything came out dead, it kills everything.

Similarly, Angelo described that his damaged body was incomplete: "Once your prostate is removed, you hmm... it changes your whole life, you know."

Most participants, due to their disease, awaken to a disrupted life. They go from having a "normal" life to a disabled life with multiple changes. This realization takes place when the medical treatment finishes and participants become aware that the disrupted body will persist, forcing them to create a new self-image and then to further recreate it as they interact with others.

Interrupted Self

The third stage is the interrupted self. The censoring, explained previously, between the old-self and the new-self is not always irrelevant, as participants gain more

understanding of their disease, their experience, and of themselves. The trajectory of the old self is interrupted, and participants are challenged to questioning their assumptions and beliefs, and to transform their old self for a more progressive self. Tulio explained:

Mira, el Tulio interno es otro, como te comente en alguna parte de la entrevista, considero que hay una evolución positiva, una mejora en la escala de valores. Pero todo eso repercute en la actitud en el comportamiento social.

Look, the inner Tulio is another, as I tell you somewhere in the interview, I think there is a positive evolution, an improvement in the scale of values. But all this has repercussions on attitude in social behavior.

In the experience of pain and cancer, participants hold onto the idea of returning to their 'normal' lives and returning to the people they used to be; this is the symbol of a valued self (Charmaz 1983). However, as participants are faced with a disrupted life, they question their self-image and view their developing image as negative. In addition, as Helen clearly expressed, others generally view the experience of people diagnosed with and treated for cancer as temporary, which caused her to experience a disruption of sense of self:

People expect... ah no more chemo, you're good! But you're not, you're not, you're tired.

Similarly, F.T. also expressed that a lack of understanding from her husband caused her to be in pain as her self-image was shaken and her experiences questioned by her husband,

... Because in, in, in Bangkok the oncologist says: you are free of cancer, okay, it's gone, it's gone, and that's what my husband thinks. And ah, of course, because I am the [one] who has it, and I have to, I know what's in me and things. So when my husband says: F.T. Why are... But instead of making me feel better, it's horror me, because why don't you [her husband] just understand. You don't make me feel better, you just make me feel worse, because you know and I know that the cancer is still there. It cannot be gone, it cannot. It's just sleeping...

It is because the lack of positive image of the self (Charmaz 1983) and the poor credibility of the experiences of pain that participants throughout a painful process substituted the familiar and reliable self with a less desirable self, damaged self.

However, for some participants, the transition from the old self-image to the new one is difficult and participants begin to struggle with the difficulties the change brings along.

F.T. explained.

...I, I play with them, but not as play as I... wanted. I forced myself to play with them, but at the end I get frustrated. I, I become, you know, like evil... everything is a big deal, you know. Then, I realize that this is not healthy for them, so everything I want to do like that [to scream], to explode, I just go the room... So when I am like this, when I am not myself, then they can be with my sister.

Similarly to the “loss of self” described by Charmaz (1983), participants develop strategies to reconstruct a new self.

a) New Self-Image

In the process of negotiation and reconstruction, participants struggle to sustain their old selves, presenting themselves positively as heroes or strong warriors. Amy defined herself as a strong woman, which she defined as:

Strong is being able to, to conquer things and to move on when things are..., is not giving-up. Is being able to put down and stand-up again. I consider myself that. In my life, which is, you know, has been, has its ups and downs, more ups, I believe in my heart than downs. Even though somebody may consider things differently, I believe that, that I've been able to be on the floor and to get back up.

Somehow, participants need to find a way to enact their new self-image while still hanging onto the person they once were. Some participants make use of the ‘best’ old self, the stronger self. This attitude is predominant among Hispanics and African-Americans. Hispanics and African-Americans often adopted a quasi-stoic attitude towards their pain, presenting themselves as strong. This behavior is more evident

among women in these populations than the men. At this point, participants summon the courage and strength they have inside of them, which was there in spite of the pain they experience. Margarita faced a disrupted self and constantly resorted to her strong self-image, as she presented herself as a very strong woman. On some occasions, Margarita fluctuated from a strong physical to a strong emotional self, which she compared with a clown, who presents to his audience an altered self-image as a strong person:

Sometimes, I believe I play strong, but I am not that strong... I am not that strong. And, my coworkers, they always said: "I don't know how you can do it, you come to work, you look good." And I say:... I am like the clown; I make everybody smile and I carry it inside. [Crying]... Many people think I am strong... but I am not strong... I am not strong [crying]... Many times, I am feeling the worst, the worst way, but I still keep myself, pushing myself. I push myself sometimes even [to the] extreme... Because, I did my last chemo last Thursday, I stayed home Friday, Saturday, and Sunday. Monday I was back to work. And, I was driving to work and I feel like the world was going to leave me. Because the draining! And the... whole side effect of the chemotherapy is not the typical side effect that the whole day you [will] feel sick and tomorrow you feel good. [It] is like a cycle... You know, like a zigzag, you feel energized and you say okay, let me go to work, and suddenly you start sweating, [feeling] like [if] everything is going [out] from you and you have to sit down... play the fool, deep breath, and play strong. And... That's what I have been doing this whole time. And, and... I mean, I do it that way. It's not the best way.

Similarly, Maria presented herself to others as a strong woman, as a performer who entertains others with a beautiful smile while she keeps the pain inside:

Tengo gente que me quiere mucho tanto allá [en Cuba] como aquí [en Miami]... yo tengo que tener una imagen ante ellos, y esa es la que yo trato de mantener. Entiendes! Soy como un bailarina, que se le acaba de morir su ser más querido. Y, ése día tiene actuación. Y, tiene que ir a bailar y mostrar su cara de alegría, aunque en dolor.

I have people who love me so much there [in Cuba] as here [in Miami]... I have to have an image before them, and that's the one I try to keep up. You understand! I am like a ballerina, whose most beloved just died, and, that day has a performance. And, has to go dancing and show a face of joy, although in pain.

For Margarita and Maria, the interpretation and meaning of their experience of cancer and pain provide the basis for acting or presenting themselves as strong women. Hochschild (1979) defines this type of presenting the self as either deep or surface acting. The deep acting evokes the past experiences and the emotional understanding of these experiences, which determine how participants' present themselves to others, while in surface acting, participants pretend to be strong for the benefit of their family, as Margarita clearly stated. Catherine explains that the reason for presenting herself in a different manner, surface acting, of wearing a "mask" as a strong woman, is because she did not want to worry anyone.

I guess, I wanted it to look like a face of "Don't worry, everything is okay. There is, there is no pain, so you don't have to worry about anything, because I am not worried about anything. Everything is okay, everything is good," you know, you know. You are not showing but late at night when you are by yourself... You are in the car. I remember through the whole ordeal, I broke down one time.

The performance is always done with the audience in mind, their reactions and their involvement (Hochschild 1979). In method acting, or deep acting, the participant becomes the character to such an extent that others, their family, the doctors, are secondary; the performer, of being strong, warrior, exists as the experiences of pain and cancer persist. To a certain point, as participants present and create the new image, as they wear a "mask," they hold onto the hope that the self they portray will eventually be transformed into a better self, into a warrior. As Maria explained:

La experiencia del dolor es dura pero te repone, te hace más fuerte... Ahora mi dolor es producido por esta enfermedad. [Pero] cuando este libre de cáncer, a mi no me va a doler ni los callos. Y esa mujer con cáncer será una guerrera. La guerrera no se detiene ante nada, valora la vida desde una perspectiva alta. Los valores, la familia, la educación que te dieron, lo que vas a proyectarle a los demás. La guerrera no se rinde ante nada --el dolor la mata y no se rinde.

The pain experience is hard, but it replenishes you, it makes you stronger... Now my pain is produced by this disease. [But] when I'm free of cancer, I am not going to experience pain, not even the calluses will hurt. And that woman with cancer will become a warrior. Warriors don't stop at anything. They value life from a higher perspective: the values, the family, the education they gave you, what you are going to project to others. The warrior does not surrender to anything – pain kills her and she does not give up.

Similarly, Tyra described herself as a warrior and a rebel against pain:

Yo me consider una mujer guerrera, rebelde. No creo que sea guerrera, rebelde, rebelde... La misma rebeldía te hace luchar por salir adelante por conquistar [el dolor]. Porque si eres rebelde es porque no estas de acuerdo con algo. Y si no estas de acuerdo con algo entonces debes venir y pelear... debes ir peleando constantemente, tienes que ser guerrera. No puedes ser rebelde y no ser guerrera.

I consider myself a warrior woman, rebel. I do not think I am a warrior, rebel, rebel ... The same rebellion makes you fight to get ahead to conquer [the pain]. Because if you are rebellious it is because you do not agree with something. And if you do not agree with something then you must face and fight against it... you must fight constantly, you have to be a warrior. You cannot be rebellious and not a warrior.

Some other participants were aware of the impact the disease had on their bodies in defining themselves as disabled. As Jocelyn explained:

I see myself as a disabled person. Because of the pain I experience everyday, I can no longer live a "normal" life.

This shift in lifestyle, from independent to disabled, caused participants to experience a loss of autonomy and made them feel that they could neither fulfill their duties nor sustain their lives without the help of others. As Tulio expressed it:

Bueno, yo...creo...que en ese momento tuve que dejar de trabajar. Y afortunadamente tuve un buen apoyo de mi familia, de mi compañera, me traían comida, me atendían. Pero, yo pase de ser una persona 100% activa a ser un incapacitado... total. Lo que implicaba no trabajar... que me cambio la vida. El hecho de no trabajar te cambia todo, pasas a ser dependiente de alguien... de algo... Y bajarme de ahí [de su trabajo] para estar tirado en una cama, yo no encuentro una palabra... más palabras que incapacitado. En una cama, que bueno para ir al baño era un proceso y para llevarme al médico era en una silla de rueda.

Well, I... I think... that at that moment I had to stop working. Fortunately, I had good support from my family, my partner. They brought me food, they attended [to] me.

But, I went from being a 100% active person to being a disabled one ... totally. What it implies not to work... that changed my life. The fact of not being able to work changed everything. You become dependent on someone... of something... And get out of there [working] to be lying in a bed, I cannot find a word... more words than incapacitated. In a bed, that even to go to the bathroom was a process and to take me to the doctor it meant being in a wheelchair.

For some other participants, even while living a ‘normal’ life, the disease had an impact their bodies, and they were disabled, explained Arline.

I am technically, because I am under remission... I am under the Americans with Disability [sic] Act...Is not one of my favorite honors that I have, but it's true...Yes, I [am] still under it because I am under remission, I am under the federal guidelines... federal guidelines says that if you [are] under remission, you have to be treated accordingly, you know...you have the right...

However, what seems really important for participants is for others — their families and society in general — to understand and respect the new self-image that emerges from their experiences. As F.T. explains:

The most difficult things [is] to, hmm, ah, to make people understand who you, your new you... hard word eh, hard words. The new you! Yeah, that’s why... ah, yeah different person, different personality, that, if you know, if you know that.

I was already impressed with Jocelyn’s approach to disability, which was with no shame and even with pride. When Arline expressed emphatically that she was disabled, at that point, I struggled with my own assumptions. I was impressed with the nonchalance with which some participants defined themselves as disabled. Personally, I believe that to be labeled as disabled, or whatever the label is, can impact a person throughout his or her life. Although the impact can be positive or negative, I believe it creates more potential negative influence, to stigmatize and affect the person that is labeled. In addition, because I am an Afro-Caribbean woman, disability could be the cause of some sort of oppression and discrimination. Once in the United States, someone strongly recommended that I should considered being diagnosed as disabled. Due to my

presumptions, I rejected that suggestion. However, I reconsidered this during my interview with Arline, who explained to me that a person labeled as disabled receives many support services that facilitate their everyday life and reduce the risk of being discriminated against. This last impacted me, for I never considered the label of disabled as a strategy to minimize discrimination, but all to the contrary. As a result, I, as do most participants, face a disrupted self, as accepting my reality was painful. I had to come to the realization that yes, I am, and should have been diagnosed as disabled. Suddenly, everything was clear to me. This awareness did not come easily, however; I, too, cried over the loss of my old, strong, and always-smiling self, I renounced to the hero self I proudly exhibited, and I instead invited a more self-aware persona, one who experienced pain and struggled to present myself as the strong woman, the heroine. Sometimes, I find myself trying to return to my old self, but this is impossible, for that self is no longer present. My story is not unique.

a) New Identity: Cancer Patient? Survivor? Hero?

Participants created a new identity that includes elements of their experience associated with their disease, compatible with the limitations imposed by the disease, particularly pain. All participants identified themselves as patients and people with pain.

In Maria's words:

Una paciente de cáncer con dolor. Porque antes de no tener esta enfermedad tenía dolor como cualquier otro ser humano; un dolor de cabeza, un dental, un menstrual. Ahora mi dolor es producido por esta enfermedad.

A cancer patient with pain. Because before, [when] I did not have this disease, I had pain like any other human being: a headache, a dental, a menstrual pain. Now my pain is produced by this disease.

Similarly, Margarita explained that once a person has been diagnosed and treated for cancer, he or she has a permanent fear that it will come back. Therefore, she felt she would always be a cancer patient:

I see myself as a cancer patient, because I know they already took out the cancer from my body. But, cancer only has a treatment, it doesn't have a cure, until now. Science is advancing, it has advanced to the point to have more specific medication[s] to treat us, but up to now they don't have a specific cure. If they get it in time, they can give some life to survive. But, it's not that you are retaliating [labelling] yourself with a sign that says "cancer." But, I am a cancer patient! I don't have cancer active right now. But I'm a cancer patient, I will always be. I will not think everyday of cancer. But I will always have to be seen by doctors, every three months, every six months, because it extends every year. I will always have to be doing tests, because... cancer will always follow you, it will always track you. I hope I'm blessed that I can live 10-20 years and never get it back. But, that's the reason why I see myself as a cancer patient. I am a survivor, but I am a cancer patient.

Catherine explained that there is an important distinction between being a cancer patient in pain and a cancer patient with pain.

I would say, if I had to choose any of those, I would say, hmm, a cancer patient with pain. Because you will always have some type of pain, but if you are in pain you are experiencing that... I think that being in pain, aching, hurting, but if you are a person with pain you are dealing with it, you are going through it, you are not letting it engulf you. You know, hmm, when a person is in pain, it's always... hmm it hurts. But a person with pain, yeah! I got this little pain, but, you know. You are not allowing it [the pain] to rule you. You are, you're controlling it [the pain], it is not controlling you, yeah! You know, so that's how I see the difference, one is controlling you and one is you are controlling it. So, I am in control, it's in my control.

However, not all saw themselves as survivors. This phenomenon has to do with the type of cancer the person has experienced. Tulio, who was diagnosed with a metastatic cancer, did not consider himself a survivor, because biomedical technology has limited options to offer. His world of opportunity was shrinking:

No me identifico con el término sobreviviente. En primer lugar, el término es válido, pero a mí a estas alturas la ciencia me está diciendo que en cualquier momento pueda reincidir y ya no hay más cosas que usar, [no] más cosas que pueda usar; no más

medicamentos. Estoy usando lo último de la último que existe y no me dan muchas esperanzas. De hecho, cuando llego a ver el médico ellos se sorprenden de que todavía este caminando. Las dos últimas veces me han dicho repetidas veces: “you are lucky, you are lucky.” Lucky is not the right word. Yo he trabajado esto, he luchado esto, que eso no es cuestión de suerte. No sólo es de suerte. Yo también le puse.

I do not identify with the term “survivor.” In the first place, the term is valid, but to me at this point, science is telling me that at any moment it can relapse and there are no more things to use, [no] more things I can use, no more medications. I am using the last of the last that exists and they do not give me much hope. In fact, when I get to see the doctor, they are surprised that he is [sic] still walking. The last two times, I have been told repeatedly: “You are lucky, you are lucky.” “Lucky” is not the right word. I have worked this, I have fought this, that is not a matter of luck. It is not just luck. I also did my part.

Contrary to Tulio, Jocelyn, who was trying a new type of medical treatment, an experimental new treatment, had hope for a cancer-free future, and her hope allowed her the pride of labeling herself as a survivor to come:

The doctors are giving me a new medication; it is promising. I am surviving as I fight everyday against cancer. But, [I] hope in the future to be cancer free.

After the interview, I found out that Jocelyn is now free of cancer, and therefore, free of pain. Her hope was not in vain, and her shrinking world has begun to enlarge.

Some participants went through the battle of cancer alone, which affected their emotional awareness of their experience and their family dynamics, as F.T. explained:

Ah, I mean, I realize why am I have to deal with this. I am not just fighting the cancer alone, fighting my body alone and now I have to fight for my marriage also. I am tired. So, if you take me, my new me, now. Okay, lets learn together, it's not done, I am sorry I can't change.

For most readers, the image of survivor fuels the idea that the lives of the participants will return to “normal,” and the disease and the experiences of pain that come with it will eventually be erased from the participants' lives. F.T. said.

...I don't know how to change if I know I will change. I already have enough, I already have enough, I am always trying, trying and can't make it. It's so difficult

it's like, okay, I am almost on the top and now I am coming back... I cannot just reach there, cannot. Probably I can, but it's just difficult.

Similarly, Helen described that the battle to return to normality entails others and the suffering that came from the lack of understanding others had of her experience:

People, hmm, how do you see. People do not see. It doesn't show in your face that you are tired, exhausted, and people don't understand, you know, your fatigue and everything and so, you have, I would say. A lot of people after they are done with cancer, they are nearly worse than at first, you know. Because they don't get the support, you know.

Participants lost their old self and past self, after the diagnosis and treatment of cancer; people were not the same, nor did they return to their previous life, despite their efforts to do so. F.T. described her experience:

I was diagnosed at 37 [years old]. Since 38 [years old] everything hurts. I have to stop and then take a deep breath, come on, let's go. That makes me feel frustrated, I feel tired of being like that. Because, it's annoying, it annoyed me... My husband thinks I am lazy and I just, whatever. Because I don't know how to say it's in me. Every person has a different body as different the way to adopt with [sic] life, especially me. I have a lot of chemicals in me already. You don't know my body. I even don't know my body now. This is just my new me, and you will just have to take it or leave it. Because I am just tired of this... I already have enough, I already have enough, I am always trying, trying and can't make it. It's so difficult, it's like "Okay, I am almost on the top and now I am coming back..." I cannot just reach there, cannot. Probably I can, but it's just difficult. People say, "Keep trying, keep trying." It's easy to say, it's easy to say. "Yeah okay, yeah, okay" [she responds]. I need your support..... People are more understanding if the woman is menopause [sic] than a woman like me... they think I, I [am] lazy.

Participants try to redefine themselves, creating a new image, while in treatment.

However, this process is disrupted after the body is healed. And once again, participants are confronted with a disrupted self and need to redefine themselves in terms of their actual state: survivors. The pain participants' experience at this point is profound, as another story is about to begin. As Helen explained it:

So, I was lucky with that. But after... But the problem is that you need so much help, absolutely so much help in your daily life... And people don't understand. Because

basically people don't understand depression, you know. They think you're cured, you should be good, you know.

Although the image of the survivor seems to present a happy outcome, this was not always the case for all participants. Helen, for example, was unhappy about being alive. She would have preferred to have died in the process than to be alive with her present economic and emotional situation.

I actually regret that I did this [treatment]. I really regret it. Basically, if I'm ever again diagnosed with cancer, I mean. I would never, ever, ever, ever get chemo again, never. I did it, I did it because I was in pretty good condition. Because my financial situation was pretty good at the time, but it's not the case anymore. And then, and as I said, the decision that I regret most in my life, I shouldn't have been treated for cancer.

The image of the person in control gives most of the participants a sense of reassurance that everything will be fine and that they are both the subject and the object of their journey with the capability, ability, and power to redefine the route of their lives. This is a very hopeful image. However, I believe that Helen brings a more realistic image: the image of a hero. A hero has survived a dramatic experience. Most of the time these experiences are related to war. But, in the case of cancer, the battle is both a battle against death, a battle for life, and a lifelong battle. But, the heroism of their experience, explained Helen, does not take place while fighting for their life with treatment, but after being diagnosed as a patient in remission. The real struggle takes place after the medical treatment, when the lifelong battle begins, and others expect the person to be completely healed and to not experience pain, or the aftermath of the disease and the treatment. The reality could not be more different: the real battle of cancer patients, in many cases, takes place years after the medical treatment. In this regard, Helen explained that:

... Each person will say that they had or had had cancer and they said, they called them "ordinary heroes," in French *heroes ordinaries*. Ordinary heroes and, I think, at

that time I didn't understand, because I was actually sick but in a very comfortable position. But, the problem is umm... I really understood it after, you know. When... people said: well your cancer is gone, big deal, I, you know... I didn't lose my hair, you don't lose your hair, you know that only for like breast cancer, you see. That doesn't mean, you know, the chemo is. Chemo is a piece of, umm... Once you [don't] have the chemo anymore, people assume you are okay. You may look okay, I mean. But that, that's when you actually need a lot of help. Because you are very fatigued, as I said. Yeah, it's very hard.

Ordinary heroes find their way through the complexity of their experience, fear, and pain. But, these ordinary heroes have a moral obligation to share their experiences. In Frank's (2013: 107) words, these heroes are obliged to witness and to offer "testimony to a truth that is generally unrecognized or suppressed." In this regard, F.T. explained that the main purpose of her participation in this study research was to share:

One of the reason[s] I called you also is because I want to share. To share because you already know, not every, not every, patient has the same symptom, you know.

This witnessing, as referenced previously, occurs when a participant uses his or her experience meaningfully, turning his or her story and experience into moral responsibility. However, for some participants, the heroic new self-identity is confronted by the harsh reality that cancer has no cure. Although technology had advanced and the expectation of survival of a person diagnosed with and treated for cancer has increased, there is still some type of stigma and shamed attached to the word cancer. Cancer, then, has adopted the repulsive and horrible features of the ancient representations of death; since cancer is considered incurable, some fear to even speak out the word "cancer." This was the particular case of Tulio. For Tulio, the word "cancer" was becoming a taboo word, as it reflected a reality he preferred to deny (he is not a cancer patient). Avoiding using this word gave him hope for a cancer-free future.

Yo me identifico como un paciente oncológico, así me he estado identificando. Y al cáncer lo quito, lo salto. Ni siquiera la menciono. No quiero saber nada de eso. No lo

quiero ni mencionar. El hecho de que sea un paciente oncológico no significa que yo tenga nada.

I identify myself as an oncological patient, that's how I have identified myself. And the cancer I take it out, I skip it. I do not even mention it. I do not want to know anything about that. I do not even want to mention it. The fact that I am an oncological patient does not mean that I have anything.

For Helen, the fact that some people are unable or afraid to mention the word “cancer” is somehow comparable to the Indian caste of untouchables. It is what she defined as the “unpronounceable”:

... The lawyer was not able to say “cancer.” He was so afraid to pronounce the word. And I said, “Oh my God! That's the worst, then, you know.” [In] India, they had the caste of untouchable, and I said, “We are not untouchables, we are unpronounceable,” you know.

In sum, the trauma and dramatic intensity associated with the initial shock of the news of the disease are quickly followed by the dawning awareness of multiple losses: the loss of function, of daily roles, and of taken-for-granted physical safety pushes individuals to retreat from the life they once lived. Some participants curtail their involvement in the world, resulting in a shrinking life, while other participants struggle to keep the world unchanged and prevent feeling alienation from their world. These individuals move forward with determination and positively re-engage with life, yet they face the traumatic reality of a disrupted body and an interrupted self. The interrupted self is the idea that the self is closely tied to the participant's perception of his or her body and its capabilities. For some participants, cancer was a death sentence and their pain was a constant reminder of that reality which disrupted their lives and became part of them. In this case, cancer and pain were a “state of disharmony, disequilibrium, disability... which incorporates a loss of the familiar world” (Toombs 1993: 96) and the interruption of flow of the old, reliable self.

Stage 3: Making Sense of Pain

The third stage of the meaning process is making sense. At this stage, many participants try to reconcile their past, acknowledge the changes that pain and the disease have caused in their bodies and themselves, and finally grasp the essence of their experiences.

Communicated Experience

The first step of this stage is the communicated experience. The first approach to understand the pain is with medical care professionals. Tulio indicated that he went to see his doctors seeking an explanation for his pain. Unfortunately, he did not always get a proper explanation for his pain, as he was always misdiagnosed; therefore, his lived pain continued.

Al médico le decía acerca de mi dolor casi llorando, chillando. De verdad no sé cómo explicarle [con los ojos aguados]. La verdad no quiero ni recordarlo. Le decía doctor quíteme este dolor, y el [médico] me decía: yo no soy mago.

I told the doctor about my pain almost crying, screaming. I really do not know how to explain this to you [watery eyes]. I really do not even want to remember it. I told the doctor, “Take away this pain, and [the doctor] told me: “I am not a magician.”

Although pain seems to be common to all the participants, conversing about pain was not the core of the medical consultation. Rather, the communication with the physician was focused on the disease itself and the treatment, putting aside pain and the person. Tulio considered the lack of communication between himself and the physician a lack of human relations.

Yo te hable de este doctor y sus fiestas con nosotros, lo que quise decir es que ella es muy dada al trato humano con el paciente. Los demás ni me preguntaban cómo estaba con el dolor. La pregunta era: tiene dolor, si ha bueno tomate esto. Pero de ahí no pasaba la conversación. Aquí [en los Estados Unidos] es peor, Aquí son más fríos. Nosotros allá abajo [in South América] somos calientes en el trato. Cuando conversaba con el doctor [en los Estados Unidos] las conversaciones se concentraban

en el cáncer, en cual es el tratamiento, uno se centra o se centran en cuál es la esperanza de vida, como son los efectos secundarios del tratamiento, toda está parte técnica que... el dolor casi no lo incluyen en la conversación. Al final cuando ya te explicaron todo, le dices al doctor pero me duele, y el [doctor] responde mientras tanto te tomas este calmante. Listo, ahí te dejo.

I told you about this doctor and her holidays with us. What I wanted to say is that she is very much given to humane treatment of the patient. The others did not even ask me how I was with the pain. The question was, "Do you have pain? If you do, okay, take this." But that was not the conversation. Here [in the US], it's worse. Here, they are colder. We down there [in South America] are much warmer in the way we treat people. When talking with the doctor [in the U.S.], the conversations were focused on cancer, which is the treatment. They focus on what the life expectancy is, what are the side effects of the treatment, it's all technical parts that... pain almost is not included in the conversation. At the end when they have explained everything to you, you tell the doctor, "But it hurts," and the [doctor] responds, "In the meantime, you take this sedative. Now you're set."

Not even in the case of a very painful cancer, such as chronic myelogenous leukemia, was pain the center of the conversation. Jocelyn expressed that her communication with doctors was more focused on the treatment and the results:

You know, the doctor is trying this new impressive treatment and he is very happy about the results. So am I. He is no longer questioning my pain. But my pain is still there. I just have to embrace this journey. You just have to go through it not hating what you are going through.

The poor human relations between Tulio and his doctors was also reflected in the manner in which the doctors communicated the news of his diagnosis. This communication, as Tulio expressed it, was dismissive and insensitive, lacking in empathy, which made Tulio to lose confidence in himself. Self-confidence is an important feature of the persona. The person in pain needs to overcome his or her pain experience, or to "come out of the hole" they are in, as Tulio clearly described it.

Eh... Además yo sufrí un poco... quizá por falta de ética de los médicos. No hay un apoyo psicológico... no utilizan anestesia para hablar. A mí me llegaron a decir que yo no llegaba a Diciembre. Y bueno, hasta por lo escrito te dicen que uno no se cura de esto [cáncer de próstata]. Eso está escrito en un folleto que me dieron aquí en el Jackson. Que lo tengo vaya en mi casa. En un folleto específico que te dicen de

cáncer de próstata. Y esas cosas, yo creo... mira son cosas que, que, creo uno... bueno quizá es bueno ser claro y sincero con el paciente. Pero hay a tener un poco de ética porque el paciente necesita cierta confianza para poder salir de ese hueco en el que está metido. Y ahí... pues cuando le hablan así, que no va a llegar a diciembre, y no sé que... uno pierde la confianza.

Eh... Besides, I suffered a little... maybe because of the doctors' lack of ethics. There is no psychological support... they do not use anesthesia to talk. I was told that I would not survive until December. And well, even in writing they tell you that you will not cure this [prostate cancer]. That's written in a brochure I got here at the Jackson. Just go to my house and you can see it. In a specific booklet in which they tell you about prostate cancer. And those things, I believe... look are things that, that, I think one... well, maybe it is good to be clear and sincere with the patient. But you need to have a little ethics because the patient needs some confidence to be able to get out of that hole in which he is. And there... because when they talk to you like that, telling you are not going to live to December, and whatnot... one loses confidence.

The dismissive and insensitive conversation between patient and physician focuses merely on the disease and not on the patient's pain, which is the main reason why some participants seek medical help. Indeed, it is this insidious pain that makes the disease so unbearable. For Tulio, more than the disease, it was the pain associated with the disease that made his experience so difficult:

Sino existiera él dolor no me importaría tener cáncer. Fuí al médico por el dolor. Ayer por ejemplo, la única persona que pregunto si tenía mucho dolor, fue una enfermera que ya me conoce de tantos años de estar hiendo para ya [al Hospital Jackson Memorial]. Y él médico no me preguntó. Bueno, si me dijo "como está?" Yo le dije bien. De haber tenido dolor le hubiese dicho, para eso estoy iendo.

If there was no pain I would not mind having cancer. I went to the doctor because of the pain. Yesterday, for example, the only person who asked if I was in a lot of pain was a nurse, who already knows me from so many years of going there [to the Jackson Memorial Hospital]. And the doctor did not ask me. Well, he said, "How are you?" I said, "Well." If I had had pain I would have told him, for that I am going.

Similarly, Maria explained that communicating her pain was important, yet the communication with her physician neither implied an improvement of her painful experience nor guaranteed healing.

Hay que ser comunicativa, uno tampoco tiene que saberlo todo. En muchas ocasiones ni la explicación, ni el medicamento ayudan a resolver la experiencia del dolor. En [estos] momentos yo tengo una doctora que no es muy comunicativa, es muy buena doctora, pero no es comunicativa. La respeto. Tu sabes. Yo tenía otra doctora anteriormente que sí, hablabamos de todo. Pero esta no es muy comunicativa, pero le digo mira tengo esto o tengo aquello, esta medicina no me sirvió, y ella dice: ha sí, sí, mañana vienes por aquí, y ya. La comunicación con la otra doctora era maravillosa: qué has hecho por estos días que no has venido? Qué hiciste? Tu sabes, parece una persona. Tu sabes que todo el mundo no es igual.

You have to be communicative, but you do not have to know everything. In many instances, neither the explanation nor the medication helps to resolve my pain experience. At times, I have a doctor who is not very communicative. She is a very good doctor, but she is not communicative. I respect her. You know. I had another doctor earlier who was very communicative. We talked about everything. But this one is not very communicative. But I can tell her that I have this or I have that, this medicine did not serve me, and she says, “Yes, yes, come by tomorrow,” and that’s it. The communication with the other doctor was wonderful: she would ask me, “What did you do during [the] days that you have not come? What have you done?” You know, she seems like a person. You know that everyone is not the same.

The duration of this painful experience depends on the time of diagnosis, and the healing of the pain comes with the proper diagnosis, in some cases. For Tulio, the unbearable pain lasted for a very short period of time, yet the emotional damage endured:

Y esá etapa ya... insoporable afortunadamente no fue muy larga porque ahí me diagnosticaron. Yo podría decir un mes. Y apenas me diagnosticaron me pusieron tratamiento y me aliviaron el dolor.

And that stage is... unbearable. Fortunately, it was not very long because that was when I was diagnosed. I could say a month. And as soon as I was diagnosed they treated me and relieved me of the pain.

It is interesting to consider how much of the emotional inhibition stems from the poor relationships between participants and their physicians. However, this is not always the case. Margarita, who has a very solid relationship with her gynecologist of more than 15 years, received a very positive reaction from her physician when she expressed her emotions after receiving the news of her diagnosis. Her physician was concerned not only about the biomedical issues, but about Margarita as a person, as well.

He started telling me so many things that I was aware I have. But no one has told me. That calmed me down. I said, “Doctor, thank you!” He gives me a hug... [I said] “I have never heard anyone telling me all that you have said to me and that’s going to help me. Because, I am going to fight this...” The relation[ship] with this doctor is more than patient-doctor. He is very respectful, very professional. [He] is the person that shows me that I can do this, I can accomplish things. Everyday, I am thankful that I had him because that day I just feel [sic] like I was going to go crazy, when I get that news. Because, I work in health and I know what cancer is. The worst thing for a person that works in health, [for] so many years, is that you are conscious of what is going on, you understand the disease, [and] you know the risk. So, in my mind it was too much. So, the emotional pain was strong.

In understanding cancer and pain, the scientific and biomedical explanations are essentially a sense-making activity. Irmone described how her communication with the physician made no sense to her:

Anyway, when he [the doctor] said... when they said that I had the, then... The initial shock was, ok, what do I do now? And remember, I told you I’m divorced, I lived here by myself so it’s like [there] is no one to come here to share any kind of news like that [with]. So, and, my kids lived in Maryland and I did not want to call them to, until I spoke to somebody that could console me...that could make some sense [of this] with me.

Therefore, a clear and meaningful communication is important. Irmone explains that the communication between physician and patient is rendered meaningless if there is not a shared meaning. The lack of understanding is grounded in the lack of shared meaning of pain between the experiential pain (the one lived by the person) and the measured pain (the one described in the medical results), creating communication difficulties and interrupting the conversation between the physician and the cancer patient. Irmone explains how her inability to understand her physician stopped her from having an “intelligent conversation,” which is fundamental to the overall well-being of the person diagnosed with and treated for cancer, as well as to the well-being of their family.

When, I come back from my doctor, by myself, I didn’t know anything. I could not have an intelligent conversation about what happened. He said something that... I

don't know what he said. He said something like umm... so, what is this? Well, I don't know. [Laughs.]

The main purpose of the “intelligent conversation” between physicians and cancer patients is to unveil the hidden meaning of pain and cancer. If this meaning is not clarified, then participants seek mechanisms to make the communication meaningful. Irmone utilized what I would define as a communication mediator. A communication mediator has personally experienced both cancer and pain and is familiar with the processes and terminology. This person knows and understands the phenomenon. As Irmone described:

So finally, I had to... take a friend with me. Because, she, she had cancer, but she wasn't telling anybody... But, she knew all the terms. And, so when she is talking to the doctor, she could ask him: how about this? How about that? And then, umm... so, she is the one who was explaining to my kids what the doctor said. Because everything went over my head. Because I am still in shock. Because when I ask the doctor, “Okay, what is this?” and he will say, “Well, we are going to have a lumpectomy.” I never heard the word lumpectomy... So, now, I cannot remember two hours later what that word was. You know, so, it's like, “Well, you are going to have a lumpectomy. No, you are not going to have a lumpectomy; I think you should have a mastectomy because then you won't have to take radiation.” What is radiation? I never heard of the word “radiation” before. Oh yeah! I heard about chemotherapy, but barely heard about it and I didn't even know how to spell it. My doctor had to correct [me], because the first time I spelled it on Facebook it was Q-E-M-O. My doctor says “No! It is C-H-E-M-O.” [Laughs.]

The communication mediator also allows patient to validate his or her experience. By validating their experience of cancer and pain, participants become knowledgeable and capable of solving the basic problems of communication and understanding, As Irmone explained:

She came, that woman came, Betsy came, and she talked to me and she told me about herself and then it felt good that somebody who [has] been there, [who] was able to... not people that have no clue about it, you know, [who] think you are being a baby, who think you are this, who think you are, that you're. Somebody who knew what you were going through. Even if they told you the same thing the other people tell you, but it was not [in] the same way, when they said you'll be okay. It's like,

“Okay, I can trust you because you [have] been through it.” But this one hasn’t been through it; “How [are] you going to tell me anything if you don’t even know anything? I know more than you! How are you going to tell me that I am going to be okay?” I need someone to reassure me. And when she [Betsy] came, that’s what she did.

The communication mediator was able to comprehend what the physician was telling Irmone and to translate into a more understandable language, into the language of the lived and experiential language, to Irmone and to her family; she was also able to clarify the meanings and structures of the experience manifested in both contexts, the personal and the biomedical. This mediator is the one having an “intelligent conversation” with the physicians (by asking the right questions), and with the families (by providing the appropriate explanations). The mediator helps the person diagnosed with and treated for cancer make sense of their experience.

b) Pretending to Protect

Once participants came to understand and control their pain from a biological point of view, then they shared their experience of the disease with their family. However, participants varied in the degree to which they verbally and nonverbally expressed their pain to their family. Most participants pretended not to be in pain in order to protect their spouse, children, and family from the emotional distress of knowing them in pain. Some participants expressed their desire to share their emotional pain, yet they feared the consequences of doing so. In Margarita’s words:

I don’t express to people how I feel. [It] is not because I don’t like to express my emotions, but I don’t want to change people’s dynamics, or my family’s dynamics and I don’t like to get them stressed.

Most if not all participants felt a moral obligation to protect their families, for they believed that their family could not bear hearing about the reality of their experience and

the pain they endure, making it next to impossible for them to take the time and make the effort to share their pain. Dee explained she had no one with whom to share her pain: “With whom am I going to share my pain, with[sic], people depend on me?”

Pain communication proposes a cultural ideal. In the cases of Dee, F.T., and Margarita, they presented their lives as: “good,” believing in their capacity to affect how their stories unfold (Frank 2013) and how these stories will affect their significant others. As Maria described it:

Eh cuando me preguntan cómo te sientes? así yo me este muriendo y tenga dolor les digo: todo bien, todo va marchando bien. Lo hago porque no puedo hacer sentir mal a mis hijos.

Eh, when I am asked, How do you feel? Even if I feel like I am dying and with pain, I will tell them: Everything is good, everything is going good. I do so because I cannot make my children feel bad.

Other participants did not express their emotions and their pain in order to protect their children. Maria indicated that not sharing is both a way of protection and an opportunity to teach her children to be strong with love:

Eh... Cuando me preguntan, cómo te sientes? Así yo me este muriendo y tenga dolor les digo: todo bien, todo va marchando bien. Lo hago porque no puedo hacer sentir mal a mis hijos. No, no, no. Y tengo que enseñarles a la vez a ser fuertes. No, no, no. Ese les enseña, porque me hablan como yo las he enseñado. Entiende: mami cómo tu estas, todo bien? si, pero ay mamita mira. No, pero no. Eso te hace fuerte. Mucho mucho cariño, pero fuerte.

Eh... When they ask me, How you feel? Even if I’m dying and I’m in pain I say: Everything is fine, everything is going well. I do it because I can not make my children feel bad. No, no, no. And I have to teach them to be strong at the same time. No, no, no. It teaches them, because they speak to me as I have taught them. Understand: “Mommy, how are you? Is everything okay?” [and I say] “Yes.” But, “Oh Mom, look.” [And I answer] “No, but no. That makes you strong.” Lots and lots of affection, but strong.

Similarly, Tulio indicated that he intentionally avoided communicating his pain to his children in order to protect them and to not cause them pain.

Al final yo me imagino que mis hijos llegaron a saber acerca de mi dolor, pero no estoy seguro. Este tema nunca lo he tocado con mis hijos. Yo, lo he evitado siempre para no causarles dolor a ellos. Yo no quiero que ellos sufran. Uno trata de disimular un poco. Al menos, no lo transmites directamente --- no hablas, no dices: mira, este dolor es así y así -- como te lo estoy contando ahora mismo, no, nunca lo dije.

In the end, I imagine my children came to know about my pain, but I'm not sure. This theme I have never touched [on] with my children. I have always avoided it to not cause them pain. I do not want them to suffer. One tries to dissimulate a little. At least, do not directly transmit it --- you do not talk, you do not say: "Look, this pain is like this and so." As I'm telling you right now, no, I never said it.

Catherine recognized that her greatest fear was to speak boldly to her daughter about her experience, and doing so was the most difficult aspect of her experience:

The hardest thing is, was... talking to my daughter... about my feelings, about... what I was going through. You know, explaining to her, you know, hmm... Whenever I went to the doctor, you know, and she would say, hmm, or before, you know, she would ask anything, you know. We just went through stages that, you know. I would say, "I am okay." I, I, I would, I would minimize and then the hardest thing was how do I just come out and be open and talk to her. And it was hard getting to that point, you know. Just being open and sharing with her everything that the doctor shared with me, the good and the bad, you know. It's kinda, I would, I would minimize the bad and hyper-up [sic] the good. And that was you know, you know I had to give her the complete picture of how things are going, you know. And, and it got better once that happened, it got easier talking to her, you know. And, it felt good, because at least I got somebody I can talk to, you know. At least, say, express... certain things, you know, feelings, thoughts.

Some participants believed that there was a negative stigma associated with cancer, and sharing their pain was equal to worsening their condition. Subsequently, some participants refused to talk about their cancer, leading to normalization of their pain and of their lives with pain. Margarita, for example, avoided communicating her pain experience to her children for two reasons. The first was because of her beliefs that cancer is associated with death and this association could cause in her children a fear

that their mother would eventually die of the disease, as Margarita's mother did. Second, Margarita's core principle was to maintain a stable family dynamic. By keeping her experiences private and portraying an unchanged self, she hoped for a stable family dynamic.

... Because they understand and they know the word cancer is fear and I don't want them to think Mommy will die tomorrow... I don't want them to live with that fear, I want them to always... remember the dynamic that we have and keep their normal life. So, I can feel the worst inside, but I don't show it... But, they know the reality of what's going on. But, I try... even if I [am] feeling worse, drawn-out --- because the chemotherapy drains you. It makes you feel like giving up -- I don't make them notice; I smile, I continue as if nothing [had] happened. Because just to not change the whole family dynamic. Because this [the cancer] changes the whole family dynamic... And, I avoid to constantly in the home be talking about cancer or anything... hmm.. If it has to be talked about and a question comes up, I answer it. But we don't make the dynamic be around that. They know when I have to go do the chemotherapy and things like that. I make it go till that distance. But, I carry it inside... So, I hide the truth from them... I do that... A lot of times... [Coughs.] Evert, my husband, will say, "How are you doing?" Good!... I say, "Good [her voice is breaking up], good I say." He will say, "No, but you look pale." [I answer] "No, but I'm good. I'm good, I'm okay. I [am just going to] lay down a little then I will get up and cook..." and I get up and I cook the food. In the morning I get up and do my son's breakfast because I want him to go to college with his breakfast, I want him to eat breakfast.

Similarly, Maria hid her pain from her family and only discussed technological advancements that could improve her health and her condition:

Con mi familia, lo que pasa es que ellos no viven conmigo entonces no creo en explicarles tanto... Esas cosa no les... Si estoy con ellos y me dá se los explico. Pero si no me da, no les explico nunca lo que pasa cuando estoy aca [en los Estados Unidos]. Les explico sólo lo positivo. Si hay alguna alternativa nueva, eso lo expongo. Nunca lo que yo siento, eso me lo cayo yo.

With my family, what happens is that they do not live with me. So, I do not believe in explaining to them much... Those things I do not... If I am with them and I think it [is] right, [then] I'll give them an explanation. But, if I do not think it [is] right, then I never explain to them what happens when I'm over here [in the US]. I explain only the positive. If there is a new alternative, that I explain to them. Never what I feel. That I keep to myself.

Concealing the pain experience increased the emotional toll on most of the participants since they could not make sense of their pain with their family or with themselves, either. In order to be able to address the reality of their journey, participants needed to come to the realization of their experiences. This realization involved learning and understanding both their physical and emotional pain caused by the disease. Once participants understood these changes and the etiology of them, participants came to the realization that cancer does not always signify death, nor does it even need to be associated with death.

Debbie, whose mother died of breast cancer, chose not to hide her diagnosis from her child, instead making it a family matter. However, decided to conceal the real dimension of her pain and medical treatment to her children and began to pretend that her experiences were normal, in order to reduce her children's fear. Debbie did not share with her children the abruptness of the bodily changes she experienced. However, she did silently make them aware of the pain she experienced:

En esos momentos no me podía perder nada de la vida de mis hijos... estaba ahí con dolor. No se porqué, no se porqué. Nunca he analizado la razón por la cual, pero yo creo que por ahí es. Ya que ellos no me veían presentes ellos iban a pensar: mami esta mal... Yo creo que lo hacia para que ellos no tuvieran la sensación de miedo... Nunca les dije: yo tuve una histerectomía. Eso nunca se los dije... nunca quise compartirles eso... Eso lo mantuve privado.

In those moments I could not lose anything of the lives of my children... I was there in pain. I do not know why, I do not know why. I have never analyzed the reason why, but I think that's where it is. Since they did not see me present, they were going to think, "Mommy is not feeling well..." I think I did it so they did not have the feeling of fear ... I never told them, "I had a hysterectomy. I never told you that ... I never wanted to share that with you..." I kept it private.

Because of Debbie's willingness to show her pain, her children became more watchful of their mother (and she was of them), instead of afraid. This form of communication

enabled some participants to find their pain meaningful as it made their family bonds stronger.

Once participants could understand the meaning of their disease, identifying and understanding the etiology of the original context, they were then able to stop pretending and began to communicate openly with their significant others. Irmone clearly expressed that she could not talk to her children until everything made sense to her. By understanding the disease and her experiences, Irmone was protecting her children:

... My kids lived in Maryland and I did not want to call them to, until I spoke to somebody that could console me... That could make some sense [of this experience] with me. Because I know that, you know, your kids, you are here to protect them. They are not here to protect you. So, you are here to make sense of things that are happening.

Although Catherine did converse with her children about the disease, she minimized the bad and emphasized the good as a mechanism of protection:

Protecting! I don't know, I guess it's just the protecting mode you keep the children... they don't need to know the bad stuff. It's you keep the bad away from them. And... so that they don't have to experience bad things or worry about... thing [sic] and that's, basically, you know, what it was. And I was still in that, I guess, protection mode... you know, as a mother protecting her children from bad things, you know... This is a bad situation, but they don't need to know all the bad, you know, hmm, you know. Don't give them all the bad stuff, you know. If it gets to that, because it may not get to that and then you throw out all the bad stuff out there and now they are worried sick, this and that. You didn't need this.

In many other cases, although the family knew about the disease, some participants opted for not verbally expressing their experiences, filling the communication, in some cases, with gestures of pain, yet also hiding the pain from their children. As Tulio expressed it:

Mi esposa percibía mi dolor sin necesidad de decir nada. Pero frente a mis hijos tratamos de esconderlo un poco, sobre todo con la nena que ahora tiene 16 años.

My wife felt my pain without saying anything. But in front of my children, we try to hide it a little, especially with the baby, who is now 16 years old.

Others found that their pain experience could only be alleviated when it was communicated. For Jocelyn her communication of pain was not always verbal, as she indicated that she expressed pain by screaming; this is also an experience that I personally lived.

My parents knew I was in pain every time I screamed. In the beginning, they used to cry because they didn't know how to help me. Many times they told me that they wished they could take away the pain from me, but they couldn't. Now, they pray for me every time I am in pain. I really don't talk much about my pain. Being vocal is hopeless.

Furthermore, in my conversations with the participants, it became evident that although they hid their painful experience from their children, they did openly share it with others. The process of sharing pain occurs only when adults diagnosed with and treated for cancer had achieved a great deal of understanding and knowledge of their experiences of pain, when the person not only understood the biology of the pain but also the changes that occurs both internally and externally. I define this stage as the pain-understanding.

c) Sharing My Pain, Helping Others

Sharing pain with others, although it may sound public, is a rather private matter; participants only shared their painful experiences with others who could help them in the process of making it meaningful. Margarita clearly stated:

I have people that care for me, in addition to my biological family... But, a lot of times, I deal with my emotional pain alone. Because I choose that, just to keep my stuff. Because that was what I was taught. People don't have to know your problem, they don't have know your life and that's me, the real me. The one you [are] knowing today.

Therefore, I felt that I, too, had to share my painful experiences with each participant. In doing so, I made public my private experience and involved them in my personal process of meaning-seeking. This behavior sent the message that I was not a general audience; rather, I was someone who understood them, and therefore, their experiences resonated with me. This helped since most participants who suppressed their emotions with family and physicians openly expressed and relived their experiences and their emotional pain during the interview. Margarita, for example, who cried for almost the full two hours of the interview, explained how during the interview, her true self was revealed:

In this interview. I take off the mask of the strong woman and live my reality. At work, I keep up the show. In the family, I want the dynamic to go ... I just try not to change the whole dynamic...I avoid giving them stress... I cried just like right now how I feel, because just remembering that day is like reviving that emotional pain. When they told me: you have cancer.

Similarly, Arline, during the interview, started to cry as she remembered the initial stages of her disease:

You know, I cry now because, you know, I have to talk to somebody about it. But, I understand my whole attitude has changed completely about everyday life, making it as best as possible.

In this sense, Catherine explained that only when she decided to openly and honestly communicate and share her experience did she begin to heal:

But, as time goes on, I realize that, you know, how can she understand, how can she help, how can she empathize with you or help you go through this, if you don't show her what you are feeling, if you don't share the bad times, if you don't share your tears, you know, how can she cope with you? So, you know, I mean, you know, it's like when, hmm, it's like, you know, you get to the point that sometimes it will be too late. I will be in tears, you know, but I will still fight back, and she will say, "Mommy, everything is going to be all right."

Some other participants' emotional reactions during the interviews were not as clear as Margarita's. When explaining their pain experiences, Tulio's and Angelo's eyes watered. Tulio started to look up to the ceiling of the conference room as if he was in silent prayer. For a while, he kept silent and then proceeded with the interview, saying: "The truth is that I really don't even want to remember it." (La verdad no quiero ni recordarlo). Angelo, on the other hand, eyes watering, cleared his throat and continued with the interview, shifting the conversation from his painful experiences to his lifestyle changes. For Angelo, this interview was the first and last time he will openly share his intense experience of pain:

This is my first interview, and it will be my last. With my sons I shared, but that's about it. What can they do about it? They will listen, like anybody else will do. So, I don't push it. I just shared with them what I'm going through.

For Tulio, an honest and open communication of his experience could only take place after he had grasped the meaning of his experience and had searched and found multiple forms of healing. Doctors had told Tulio that he would only live 3 to 4 months. After he outlived the biomedical expectations, many people, most relatives of cancer patients, asked about the strategies he used. For, Tulio sharing his strategies of healing with the physicians was also a way to teach them about the meaning of his experience:

Cómo hiciste? Esa es la pregunta más común que yo he estado recibiendo en los últimos años. Tanto que una vez la doctora me llevo a una ponencia en la facultad de medicina, en Mérida [Venezuela]. En el auditorio, me puso [a] hablarle a una pila de médicos en el auditorio acerca de mi experiencia.

"How did you do it?" That is the most common question that I have been getting in recent years. So much so that once the doctor took me to the presentation of a paper at the medical school in Merida [Venezuela]. In the auditorium, she makes me talk to a pile of doctors in the auditorium about my experience.

Amy, on the other hand, questioned her personal approach and how this helped her to survive and to look at her life differently.

Sometimes I can't believe, you know. I feel, sometimes I said, I even considered telling [ask] myself: how did I do it? How did I get back up from those things [the diagnoses and treatment of two cancers]. How did I, hmm, survived? The things I have and be happy. Because sometimes people do survive, but they are sad, they are depressed. I am not depressed. I want to be grateful for what I have, blessed for what I have, and, and I am just a happy person to be able to be here right know and to share this [her story] with you.

However, a number of participants involved in this study used their painful stories to reassure themselves and to enable others to cope with their suffering and with the suffering of their loved ones. For Tulio, sharing his pain stories during this interview and in many other public presentations in Venezuela, served two purposes: sharing his pain was therapeutic for him, since by making public and reviving his painful stories he was reminded that he is no longer in pain. Second, he felt a moral duty to share his success story with others (not of being cancer free, but of being a person free of pain and who has outlived the biomedical expectations), and his story is a message of hope.

No, ahora mismo no tengo dolor físico. Yo diría que voy bien con el dolor depresión-tristeza-y-melancolía. Me siento bien ahorita y por eso estoy aquí. Fíjate, yo veo dos opciones para estar aquí: una, que tengas dolor y a uno le interesa esto [el estudio]. La otra es que te sientas tan bien, como es mi caso, que quieras transmitir algo que pueda ayudar a otro. A mí me han ayudado, mi terapia, mis amigas, y ahora yo necesito ayudar. Que es una cuestión que me sale de adentro -- yo fui ayudado.

No, I do not have physical pain right now. I would say that I am doing well with the pain, depression-sadness-and-melancholy. I am feeling good right now and that's why I am here. Look, I see two options to be here: one, that you have pain and one is interested in this [project]. The other is that you feel so good, as is my case, that you want to convey something that can help others. I have been helped, my therapy, my friends, and now I need to help. That it's something that comes from inside me -- I was helped.

Similarly, Jocelyn spoke openly about her experience of pain and how she had conquered it through public appearance. In 2016, Jocelyn was invited to do her first

public speech, in the form of a mission trip to France and Spain. She expressed the following about this experience:

Always so great to speak with others along the same CML Leukemia journey. During the mission trip, I was able to speak with so many people about my journey and to share with them the glory of God and hope. I am always hoping my story will be used to help others.

Both Tulio and Jocelyn believed that social groups focused on cancer send out a message of hopelessness. Arline, in the same tone, expressed that the stories shared in these support groups are painful stories, are hopeless stories in some way, and that her story was the hope members of the groups needed, but this experience was causing her to feel pain and guilt for being healthy and having a victorious story. This experience was “very painful” for her and caused her strong emotional pain:

So, I even went into a couple of the supports [support groups] for myself, and this was after I went into remission and I couldn't believe the stories in that room and it was a packed room. Incredible stories that people were going through or they had experienced or their loved ones or family or friends had experienced, I started crying. I said, I took the counselor aside after -- I said, “I shouldn't be here. I just should not be here, I am okay,” and he says, “They want you in that room because they want to know that there is a light at the end of the tunnel for them. They want you there because they think that there is still a chance and they want to know that there is somebody that has gone through what they did and completely turned their lives around, completely.” So, I mean, I went back a couple of times, but it was very sad for me. I felt I was too fortunate to be in that room. It was painful for me. Very painful. We are talking about people that have been through cancer for many years and through chemo treatment and it came back and we are not just talking about the older people, you know. There are young people there too, and there's a lot of crying, and me especially. I walked out a couple of times. What the counselor said, “You've got to be there. It's hope to them, you know.”

However, other participants, who were not so public, preferred to share their pain in closed groups. Most participants were members of cancer support groups. In these groups, each participant shared openly their experiences of dealing with cancer and pain. This step was an essential way for participants to compare their own experiences with

those of other people. In this case, support groups provided a platform upon which individuals with similar ailments could come together and discuss their sufferings and experiences, a platform from which the cancer and pain stories were shared and compared, and a scenario in which the experience shows itself as a real experience. Like a number of other participants, Irmone found it helpful to “chat” with other women about their experiences and hear about other women’s experiences. When interviewed, she explained this in some detail:

But this one hasn’t been through it, how are you going to tell me anything you even know anything [sic], I know more than you! How are you going to tell me that I am going to be okay. I need someone to reassure me. And when she [Betsy] came that’s what she did. And then I joined that, umm, support group... I join, what I think it is very important also, you know, I join, well... Before, before I started taking chemo, I start calling places that, you know, the nurse navigator told me like, you know, like Guilda’s club and those places. And it happened that I talked to this woman, she was very nice and she came to see me here [at her home]. And I was telling her, I did want to take chemo. She didn’t tell me whether to take chemo or not. It was good to have someone listening to you. Because, she came during the hardest part of everything and that’s the part I know that God was with me every single part of it. It was because I never felt alone, although, I was alone I never felt lonely, because I know God was with me all the time.

Similarly, Margarita reflected on how having a group helped her:

I go to a support group. It [meets] one time a month; the second Tuesday of every month, up there in Davie. I started going to it... Next month will be my third time. One of the ladies of the church, Mrs. Ruth, is a survivor of... breast cancer... and even though she... it happens [sic] five, close to six years [ago], she still go to the support group because she likes to help other people and do things And, she invited me to go. And it has been very good because in the groups they are ladies that although they are ladies that have already passed all this story, they still feel [like] a part of the group and they go to support the other ones that are coming in new. So you have ladies that are just starting the problem... ladies that, ladies that are like in my case, just starting the chemotherapy. You have ladies at different stages of the problem. It’s a good group. It’s not a crying group. We motivate each other. We have different speakers. You learn from each other, you learn from the speakers. This group is coordinated by a nurse, who is a 19-year survivor of breast cancer.

However, as members of these support groups expressed their experiences (some successful, others unsuccessful), these groups displayed hopelessness, as Jocelyn indicated. Participants wanted support groups that conveyed the message of victory.

Similarly, Tulio believed that:

Nosotros tenemos un grupo, yo nunca fui a estas reuniones que llaman de apoyo. Yo nunca participé, no me llama la atención. Pero, recuerda que te conté que me hice amistad con la oncóloga que me hizo la terapia con quien aún tengo contacto, ella cree mucho en la parte psicológica, y promueve toda clase de reuniones entre sus pacientes. Que no son reuniones para sentarnos así, así en una rueda. Son reuniones para que nadie hable de eso [del cáncer] está prohibido hablar de eso [el cáncer]. Aquí nadie está enfermo. Las reuniones son fiestas, paseos, celebraciones de todo tipo, siempre hay alguien cumpliendo años, ella tiene casi 300 pacientes. Todas las semanas hay fiestas, el que se quiera emborracharse emborracha, el que quiera comer chorizo, come chorizo, empanadas fritas se las come, ahí no hay nada prohibido. Y bailamos, echamos chistes, hay fiestas de fin de semana en una hacienda. Y ahí, terminamos todos unidos. Y como te digo si yo te muestro un video tú no creerías que esa gente son pacientes oncológicos. No puede ser, no, no. Una alegría unas ganas de vivir, todos saltando, todos bailando. Y ella nos maneja de esa forma. Eso ha sido muy positivo y ver que nos releja también. Y sino estando, igual, no le estás dando importancia [a la enfermedad y al dolor] están viviendo su vida, bien. Lo que es muy difícil. Ella logra distraer tu mente del problema.

We have a group, I've never been to these meetings that are called support groups. I never participated, they do not attract my attention. But remember, I told you that I made friends with the oncologist who did the therapy, with whom I still have contact. She believes in the psychological side, and promotes all sorts of meetings among her patients. They are not meetings to sit like this, in a circle. They are meetings so that nobody talks about that [cancer]. It is forbidden to talk about it [cancer]. No one here is sick. The meetings are parties, walks, celebrations of all kinds. There is always someone celebrating a birthday. She has almost 300 patients. Every week there are parties, who wants to get drunk, gets drunk; who wants to eat sausage, eats sausage; fried empanadas, eat them; there is nothing forbidden. And we dance, we make jokes, there are weekend parties at a hacienda. And there, we all end up together. And as I say, if I show you a video you would not believe that these people are cancer patients. It cannot be, no, no. A joy, a desire to live, all jumping, all dancing. And she manages us that way. That has been very positive and you see that it also relaxes us. And if you are, even, you are not giving importance [to illness and pain]. You are living your life, well. Which is very difficult. She manages to distract your mind from the problem.

As discussed earlier, social belonging, particularly to a support group, led some to a positive attitude and thus to the reduction of emotional pain. Sharing and experiencing

others' painful experiences validated some participant's experiences, providing the experience of pain with meaning. However, some other participants asked for a support group in which they could share similar sociodemographic features and medical conditions, since these will render meaning to their experiences and to the communication process. Although cancer support groups, in some cases, fill this gap, there is an evident need for either emotional pain support groups or for more emphasis on the emotional pain suffered by people diagnosed with and treated for cancer. At the end of our conversation, F.T. walked me to the car, and during this brief interval, she looked at me and asked with a very strong accent, "Liza, are all the stories of cancer as happy as the magazine reflected it? Are all your participants with a supportive husband?" I was shocked by this question and hesitated a little before answering. "No," I responded, "not everyone has a perfect and lovely story as the magazine reflected." I then proceeded to ask her, "Do you go to any support group?" "No," she responds. "All the people with cancer that I meet with are older women, or already have older children."

An Inevitable Experience

Several participants felt that their experience is an inevitable experience that shapes all other forms of reality. Maria states this in the following narrative:

Bueno, cada cual nace con su astral. Cuando nace cada cual viene al mundo con su astral con lo que vas a proyectar desde que naces, desde que tu mama te pare, de ahí viene el astral. Cuando inhalas, el astral se introduce y ése es el astral que vas a tener. Lo que me pasa en la vida es lo que me tocaba. No te tocaba a ti, sino a mi.

Well, everyone is born with an astral. When everyone is born, we come to this world with an astral with what you are going to project from birth, from the moment your mother gives birth to you, hence the astral. When you inhale, the astral is introduced into you and that is the astral you are going to have. Whatever happens to me in life is what had to happen. It was not for you, it was for me.

The reality for most participants was whatever they experienced, and it was experienced as a resistance, as something that was meant to be. For many participants, their relatives experienced cancer also, and yet struggled internally with it and sought to experience it differently. Mitzy explained:

There is this family history of cancer, so, hmm, so I wasn't totally surprised that I got cancer. Hmm, because, hmm, two grandparents died of cancer, my mother's mother and my father's father. My mother's mother had colorectal cancer. My father's father had prostate cancer... I was prepared for a diagnosis, because in the back of my mind, I knew I was more susceptible than much people, you know.

Debbie, aware of her mother's and aunt's experiences with cancer, was on a permanent search, making sure that the story (early death due to breast cancer) would not be repeated:

... Siempre "in the back of my head" yo decía cada seis meses me debo ir a chequear. Porqué? Por toda la historia familiar. Y siempre en algún momento yo me decía, en algún momento este [la enfermedad] me va a venir a mi también...pero cuando fui diagnosticada dije: "esta historia no se puede repetir." [refiriéndose a la historia de su madre.]... si yo no estuviese estado pre, pensando, y buscando. No buscando, pero uno tiene que estar consciente de su cuerpo... es muy importante que uno reconozca su cuerpo y pueda identificar... y bueno lo encontré [el cancer] y por suerte era en stage 1.

... Always in the back of my head, I said to myself, "Every six months I should go and check." Why? Because of the whole family history. And always at some point I was saying, at some point, this [illness] is going to come to me too... but when I was diagnosed I said: "This story cannot be repeated." [Referring to her mother's story]... if I was not pre... thinking, and looking. Not looking, but one has to be aware of his body ... it is very important that one recognizes his body and can identify ... and well, I found it [the cancer] and luckily it was stage 1.

For Margarita, her diagnosis was a sign that her mother's story was repeating, to which she expressed: "Oh my God! History is repeating itself! [Sniffing and crying]."

For Arline, whose parents both died of cancer, she experienced her diagnosis as something that was preordained, yet she had the fortune to survive the disease, unlike her parents, who did not

They say, you know, my mother passed away of breast cancer, for two years she suffered. My dad passed away of brain cancer, where do they get these from, it wasn't in the family for them. I mean, my parents were the first of their siblings to pass on [cries], but, you know, they were young. So I consider...I am sorry, I consider myself very lucky because I have outlived them in the years, and my brother, you know, he was born with a hole in his heart and he lives up in New York and he takes care of himself.

This theme was not totally new to me. As phenomenologists postulated, in order to comprehend the other person, I must first understand his or her experience in my own image. In this sense, after the accident, I told myself many times that it was meant to be. I had to be shot so none of my daughters would be hurt. This, I believe, helped me to understand my experience, providing it with meaning and confronting me with the reality of the ephemera of my existence and the limits of my knowledge. I could not confront my reality with others.

Contrary to my experience, some participants confronted the limit of their knowledge and understanding about pain and cancer with the experience of their relatives. Some participants were aware of the disease, as they lived the experiences of their significant others (mother, brothers, and aunts). Margarita, for example, was completely aware of the physical impact the disease has on the person diagnosed with it because she worked professionally with oncological patients. She was also aware of the emotional impact of the disease because her mother and brother both died of cancer.

My mother, hmm, from mother's side, I have a lot of family with cancer problems. My first experience with cancer was my brother. My oldest brother, he died of leukemia. And he was energetic, a business administrator, and was doing very well and one day he just felt sick. He went to the doctor in Bogota, and that was it. That

was my first experience. Then after that, three years after he died, my mother was diagnosed with breast cancer... So, we had to live that part with her. She survived nine years, the breast cancer, and after nine years [lowering her voice], the cancer came back. So, with my case, because of my family history, I always do my mammogram. Every year, I go to my physical, my doctor, I do my mammogram... In December hmm 19 of 2015, yes, last year December, I... for the first time my doctor said, you know, now we have to do 3-dimensional! It's an earlier detection, higher technique. And, I was happy, you know, new technique, new stuff. And I went and did my mammogram... And everything started from there. From there this whole emotional pathway started.

Most of the participants come to understand their experience by acknowledging and knowing the experiences of others, of their mothers. This was the case with Irmone, F.T., Margarita, Mitzy, and Debbie: they were exposed to their relatives' experiences and these experiences affected them. As Margarita compared her own story to her mother's, her emotional pain seemed meaningful. For she believed that she would die and leave her children in pain, just like her mother did. Similarly, Debbie, who lived through the death of her mother due to cancer, expressed that cancer has been always a latent reality. As Debbie reflected on her mother's history and how it has impacted her life, she refused to make her children experience what she had lived with her mother, and tried to change her life story for it not to repeat:

Todo lo charlabamos [ella y sus hijos], todo se los dije. Porque el día que tuve la cirugía llega el más chico y me dice: "mami era cancer?" Y yo le digo: "Sí, era cancer, pero el doctor me dijo que lo saco todo y ahora vamos hacer tratamiento para que no vuelva." Esa fue mi respuesta comparada con cuando a mi mama la diagnosticaron. Nunca se dijo la palabra cancer, nunca. Por que cancer en los años 60 era un, digamos, era morir. Y en esos momentos a mi nadie me dijo que mi mamá tenía cancer...siempre fue ocultado. Mientras que aquí desde el inicio todo lo que sabía, todo lo que no sabía siempre se los compartía [a mis hijos]... Ellos nunca tuvieron ese miedo de que mi mamá se iba a morir. Yo, en esa época, todo los días iba a la, dónde la cama de mi mamá todas la noches a ver si estaba respirando.

We all chatted [she and her children], I told them everything. Because the day I had the surgery, the kid comes and says, "Mommy, was cancer?" And I said: "Yes, it was cancer, but the doctor told me I got it all and now we're going to get treatment so that he does not come back." That was my response compared to when my mom

was diagnosed. The word “cancer” was never mentioned, ever. Because cancer in the 60’s [1960s] was a, let’s say, it was dying. And in those moments, my [sic] nobody told me that my mom had cancer... it was always hidden. While here from the beginning everything I knew, everything I did not know was always shared [with her children]... They never had that fear that my mother was going to die. I, at that time, everyday I went to the, where my mom’s bed every night to see if I she was breathing.

At this point, my lack of experience of cancer-related pain related to my capacity to empathize with the participants’ stories; when I analyze and interpret their narratives, I understand their stories and their pain, and thus I better understand my own pain. I am given a unique opportunity to shroud the other narratives and life experiences in my own. In doing so, I adopted a phenomenological shift, or *epoché*, the participants become the object of my interpretation, of my comprehension. This means that the alterity of the participants is reabsorbed by my interpretation, by my knowledge of their experiential pain. Unfortunately, not all participants had the opportunity to know about cancer and the pain of others prior to their experience. Those participants, unaware of any past family history of cancer, had difficulty making sense of their experiences as they had no close person with whom to reflect or compare their history. This was the case of Angelo, who says:

I was in shock because in my family, we don’t, nobody ever had cancer, I am the first one of my family. So, now I am worried because of my children, you know. You never know, I hope and pray that this doesn’t touch anyone in the family. Other than that, I told my boys to get a check-up now, everything is okay.

Similarly, Irmone expressed that the lack of knowing about her family history was problematic, as she could have reflected on her aunt’s cancer experience, had she known about it earlier:

But then something funny happened. My aunt, mother’s sister, she is my mother’s half-sister, she told me she had a cyst and they removed the cyst. But, now she has, her arm is getting big[ger], you know, like lymphoma... and she said she had that

like twenty years ago. And, the other day she [her aunt] was sitting in her nightgown and it was open and I saw she was missing one breast. So, I'm kind of ticked off about that, where I want to talk to her about that. But, again, I don't want to go into her private [sic]. But, I feel like things like that, you [sic] then, the next generation needs to know. Because we are swearing it's [breast cancer is] not in the family, when it may be in the family. It's just that people are hiding it.

a) Overriding Pain

For those participants for whom cancer was an inevitable event, and for those to whom cancer was a surprise, the outcome was to make their experience a meaningful one. However, before participants could determine strategies for making their experience meaningful, they first had to address and overcome their pain, as Tulio described.

...Cuando estas en silencio, en la cama en las noches, todos duermen y uno tiene los ojos así (señalando los ojos muy abiertos). Pues, muchas veces piensas en cosas duras, dices: no voy a poder. Pero al día siguiente, te levantas y te pones a hacer tus patadas y hacer tus respiraciones.

...When it is silent, in bed at night, everyone sleeps and you have your eyes like this [pointing to his wide eyes]. Well, you often think of hard things, you say: I will not be able to. But the next day, you get up and get to do your kicks and practice your respirations.

The strategies participants use to override their pain oscillate from denial to conscious adoption of behavior to overcome their pain. However, as the painful experience becomes disruptive, participants seek ways to override their pain and thus regain control of their lives. Irmone, for example, overrode her emotional pain and regained her "sense of control" by shaving her head:

I realized I didn't have any control of anything. I lost all control. And one thing I knew, I said, I had control of -- I heard people saying how they cried when they saw their hair falling in the shower and my brother when he was taking the chemo he was living with my sister and she said, she used to say I don't know how you can take it this is so disgusting all that hair you are -- and I said: that's one thing I have control of. I am going to cut it [off], to shave my head before anything starts falling. Because I don't want to wake-up in my bed to find [my] hair and go into the bathroom to find

[my] hair. And I think that gave me, um, a sense of control, which made me feel better. And, and that's what I did. I went and had my hair shaved before I even started chemo.

The behavior each participant consciously adopted is strongly associated with their culture, from which the experiential pain was invested with meaning. For Irmone, cancer was related to a loss of autonomy, which she experienced with her brother, and the hidden aspect of cancer, lived by her aunt, who denied having cancer. For Maria, on the other hand, maybe because of her athletic background, she consciously overcame her pain by focusing on other activities and by pushing her body to respond to her intention to “get up” and never to give-up. These aspects of the experience of pain makes of the person diagnosed with and treated for cancer, to my belief, a “strong person,” as described by Amy.

There is also a strong cultural component to her strategy to override her pain. For Maria, her disease and the pain that came with it were meant to be and, consequently, she had no way out of it. So, she preferred to live the experience privately and with a positive attitude:

Mis dolores me despiertan en las madrugadas. Los calambres. Los calambres [son] muy fuertes, los dolores... Por el calambre se me encoje todo. Pierdo estabilidad. Pero no, no me pongo a llorar. Me quedo sentada a pasarme la mano y a lavarme la mano. No me quedo ahí todo el tiempo. Me digo, como no me voy a parar! Si me paro.

My pains wake me up at dawn. The cramps. The cramps [are] very strong, the pain... Because of the cramp, everything retracts. I lose stability. But no, I do not cry. I sit down to rub my hand and to wash my hand. I do not stay there all the time. I tell myself, I will not stop! Yes, I get up.

Similar to Maria, Margarita, who has a strong Christian background, was more concerned about her family, especially her children, during the process of her disease and did not want to make her family, coworkers, and relatives worry about her.

Margarita then presented her experience in a very stoic manner. This perspective makes Margarita tolerate the pain as much as she can.

Many times, I am feeling the worst, in the worst way, but I still keep pushing myself, pushing myself. I push myself sometimes even [to the] extreme. I drag myself and I push myself. And I push myself because it is just the way I'm dealing with it. And I push myself. I'm coming in the car and I start feeling tremendous [sic] and tears will come and I say, "My God, you have to help me, you have to help me, God. Help me, God!" And I put my faith in God. I say, "God, I won't allow fear to take [control of] me."

However, for Catherine, presenting her pain stoically caused immense curiosity in her coworkers, which in turn irritated her.

It used to kinda irritate me when at the job, I had when I was working, at Fort Lauderdale, my coworkers, you know, would ask me: are you okay? How are you doing? You know, hmm, and I am like: I am fine, everything is fine. [The coworkers reply] "Oh, if that was me, I don't think I would handle it that well," Okay, handle what? Okay, I was diagnosed with breast cancer... what do you want me to do? Every time you see me, do you want to see me in tears, you want to see me goo goo crying, you want me to feel sorry for myself? No!... I can't. I don't have time for that!

Spirituality may also play an important role in diverting pain during this process, as is evident in Dee's approach. She was deeply involved in multiple activities that distracted her from the silent and permanent pain she experienced. As she focused her attention on these other activities, her pain seemed to feel less intense. So, her personal and intentional behavior helped Dee to override pain. Although her pain was still there, it did not seem to bother her as much.

I custom [used to] so much just to have it there that sometime I not even realized that I have it. How I know that I have it and that "se me está intensificando"[it is intensifying] is because "me miro las manos y las venitas pequeñas estan todas levantadas" [I look at my hands and the small veins are all swelled] [sic]. I feel that I get so custom [used to] the pain that I noticed a "rasgo físico" [physical trait], I notice the "venitas" [little veins]... Sometimes, I get distracted and don't pay it much attention. But some others, I don't know.

In sum, in order for people to know about cancer and pain, the rhetoric and the conversation with others are the main mechanisms through which these individuals come to understand the pain. This strategy is more important than the discourse about knowing, discourse that the biomedical field renders profane. The main purpose of the pain conversation, as Irmone expressed it, is not only to gain knowledge about cancer and pain, but also to nurture and to regenerate the new reality, of which Irmone and many other participants were becoming a part. This knowledge would not give participants the “power” to dominate their new reality, but it will provide them with the tools necessary to facilitate their trajectory through this new experience, and, in some cases, giving participants the strategies needed to overcome their pain. These strategies are explained in the following section.

The Triangle of Healing

This stage extends the genuine knowledge of pain. Many participants come to realize that their bodies are at the center of their experiential pain; however, meaning comes from another sphere. Meaning is the embodied experience of pain, the phenomenon of the search for meaning beyond the body that was common to all participants. However, the depth of each explanation varies according to the degree of emotional awareness. Some explained and attributed meaning to their experiential pain from only one point of the Triad: Science, Spiritual, or Self, while other participants derived their meaningful experience from all three elements of the triangle. These individuals became aware that their bodies and minds were unified, as explained by Maria, and that both are connected to the self and to the spiritual act of knowing. These are part of what I will discuss further as an integral element in the triangulation of meaning. As Tulio expressed it, the

why question in either case, of a cancer diagnosis or of a surprising news of a healing, leads initially to a search for meaning. This quest for meaning begins with a search for healing. In Tulio's words:

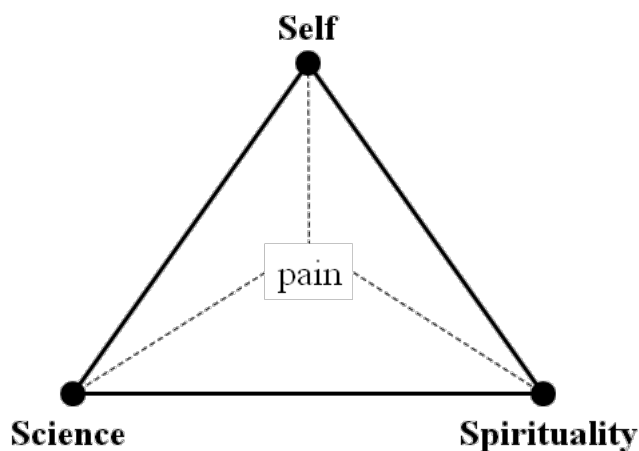
En el desespero por curarse, uno agarra lo que cree le pueda funcionar. Eh, yo he llegado a la conclusión que en esto hay tres cosas que hay que tomar en cuenta -- hay un triángulo ahí. Uno es la fe. La fe en nuestro creador, sea de la religión que seas. Hay una fe que te ayuda a tener confianza, a ser optimista. El otro es la ciencia. No voy a dejar de ir al médico de hacerme la quimioterapia. Todo eso es importante. Y en tercer lugar esta uno mismo. Uno debe luchar; no se puede tirar al abandono [y] debe tener una actitud positiva. Yo creo que las tres cosas son básicas--no puede faltar ninguna de ella. Yo trabajé las tres.

In desperation to seek healing, one grasps onto anything one believes can work. Eh, I have come to the conclusion that in this there are three things that must be taken into account -- there is a triangle there. One is faith. Faith in our creator. The religious denomination does not matter. There is a faith that helps you to have confidence, to be optimistic. The other is science. I will not stop going to the doctor to get my chemotherapy. Everything is important. And the third is oneself. One must fight; one cannot go the way of abandonment [and] should always have a positive attitude. I think these three things are basic --- none of them can miss. I used the three of them.

The Triangle of Healing (see Figure 5) denotes a range of possibilities that explain pain beyond the biomedical field and place it in the midst of the three elements of the triad.

The triangulation of meaning describes what is external, such as medicine; what is internal, the self; and what is intermediate, spirituality.

Figure 5. Triangle of Healing



The healing of pain relies on the intersection of the three points of the triangle. Few participants found meaning in their painful experience at the intersection of the three points, while the vast majority focused mainly on two of the points: spirituality and science. This complex understanding of pain violates the whole dualistic approach to the body imposed by the biomedical field and takes into account the person, the self. For Tulio, his experiences were meaningful once he understood that his healing was beyond the scientific approach and relied mainly on the interaction among three elements that compose what he termed “the triangle of meaning.”

As described by Tulio, pain coexists in all three points at once. Therefore, all three points of the triangle contributed to his healing and provided the experience with a significant meaning. When I asked Tulio what happened when any of the points of the triangle were missing, this was his response:

Esa no fue mi experiencia. No te puedo responder con precisión. Pero lo que creo que podría pasar es más dolor. Cuando estás tenso y estás pensando en el dolor, ésa tensión ahí, [y] como te decía, no fluye la energía. Sí, creo que las tres son muy importantes.

That was not my experience. I cannot answer you accurately. But what I think could happen is more pain. When you are tense and you are thinking about the pain, in that tension there, [and] as I was telling you, the energy does not flow. Yes, I think all three are very important.

Participants used at least two aspects of their everyday lives to attribute meaning to their experiences. In this phase, all participants needed to extend the interpretation of their lived experience through objective and empirical knowledge about the disease. This knowledge, in a first instance, comes from the scientific understanding of cancer. Once the scientific approach explained the changes in functionality, participants sought an explanation to their experience or an answer to the “why me?” question. This question is

answered in the spiritual approach to pain. Yet, pain is not totally meaningful. After the physical pain is conquered and the why me question addressed, participants then sought to have a more profound understanding of both the cancer and the pain, and of the changes caused on their self-perception, their identity, and their world. The knowledge at this point is more integrative, for it encompasses all aspects of the person's life: emotion, body, spirituality, and the self; individuals enter into a wider sphere of reflection, which occurred through the conscious reflection of the self. Finally, via recognition and reconciliation with deeper realities (scientific and spiritual) and the understanding of their experience that results, participant's grasp a holistic knowledge of their pain, and it, thus, becomes meaningful. Although the relationship between the points of the triangle is not always direct or linear, as described previously, a sense of meaning of the lived experience of cancer and pain exists at the intersection of these points.

a) Science: Scientific Knowledge of Cancer and Pain

Science is the first point in the triangulation of meaning. As when the participants were in pain, the first attempt for healing and meaning was within the biomedical field and the scientific knowledge of the disease portrayed by this field. The first point of the triangle represents the biomedical field. This section begins with the discussion of participants' research for meaning within the biomedical field. It is science in all its splendor. As explained by Helen, although her cancer was diagnosed late, her doctors did an awesome job, saving her life:

The cancer was diagnosed very late, you know, and I was very lucky to have an extraordinary team of doctors. The colon cancer was diagnosed in France and the endometrial cancer was diagnosed here [in the US].

Similarly, Angelo considers that he was blessed because the doctor operated on him.

Once, I found out that I... I had to go for a biopsy. I did 12 biopsies, 9 came back positive and then that's when I started moving faster because I didn't want this thing to blow up inside of me. Yeah! You know, to continue, to spread, you know. So, I got really panicky... I met a doctor, Oslin, in Jackson South. And he hmm he never operated on a Wednesday and he actually did it for me after he found out the results. This doctor was a blessing! He says my time frame would have been pretty, pretty short.

More than the scientific advances, though, it is clear is that participants know that these physicians cared and helped in the search for healing. As Angelo expresses it:

I'm telling you one thing, I thank God for what he [the doctor] did. You know, I recommended him to a lot of people that have problems that I met... Yeah! It's important to know somebody who cares. That's important, especially in the medical field. Yeah! Very good.

As Tulio later explained, cancer patients need to know that their physicians have faith in the sciences and want to transmit that hope to them. Honest conversation is important, but the reality of their disease shrinks participants' options of healing.

... cuando te dicen [los médicos] que ya no te vas a curar, y esas cosas. Y uno cree que él médico lo sabe todo. Por lo menos la gran mayoría de las personas van al médico porque se supone, que el médico sabes más que tú y yo de eso. Y si te dice eso, pues--- es difícil. El médico te puede decir eso. Pero antes, o en el medio, debería añadir: pero tú si puedes, por esto, o por lo otro.

... When they [the doctors] tell you that you will not be cured, and those things. And one believes that the doctor knows everything. At least the vast majority of people go to the doctor, because it is assumed that the doctor knows more than you and I do about it. And if he tells you that --- then, it's hard. The doctor can tell you that, but before or in the middle, he should add, but you can if, by this, or by the other.

Dee manifested an urgent need for the proper vocabulary to explain her pain, which would have helped to alleviate her pain.

It is important to define what type of pain you have and I could not define this one that is always there. So, I'm in the search to try to find the vocabulary of how, because I am going to meet back with my doctor, and I want to describe. Osea [That is] if describing it [the pain] is going to... I don't know, maybe "es una desesperación mía, del mismo desespero, no sé" [because of the desperation of the

same despair, I do not know]. I really can't tell. But I have that clear. I personally would like to be able to, when I go back to the doctor, to tell him that, look this pain, that I described as silent pain, I am really feeling it like this, this, this. Porque es un dolor que ni siquiera lo puedo [because it is a pain that I can't even]... How to tell you know, I come to the point that I can't even define, like exactly where it is or what it is.

A clear and honest conversation with a physician is the first step for participants to have not only hope in scientific advances but also in the physician. For Irmone, this was not the case. In one of her first conversations, the physician, in an attempt to minimize the impact of the biomedical treatment, misinformed Irmone, indicating that there would be no need to do chemotherapy. When she was later required to do the chemotherapy, Irmone refused to do it. She began to believe that all her medical treatment and diagnoses were nothing else than a conspiracy of the biomedical field to earn money from her suffering. Her trust in the scientific knowledge diminished and fear took its place, pushing Irmone to seek strategies for healing in other places.

And they all think I should do it [the chemo]. But I still refused to do it, because you [referring to the doctor] didn't tell me I had to do it. So, I went to see a second doctor at the hospital. I changed my doctor, because the insurance is not going to pay for the second opinion. So, if the doctor, so they said, unless you changed doctor you can't have, then I said I will change doctors. And I changed doctor[s], and she told me: "Oh, with the chemo you will have a 95 % chance" and blah, blah, blah, and then, I have a friend, friend, a friend [of the] family that um she is also, she is not here. Because by then, I swear all the doctors are getting together to make money off me. [Laughs]. It has nothing to do with the cancer being real. It is about money. Okay. And then, I have a friend who is in Indianapolis. She is my sister in law's cousin, so she is the director of the hospital, oncologist also... by then I have spoken to like 7 to 10 people. I mean, I'm talking about professionals who work in the field, who told me that I have to do it and I still [do] not trust them.

Cancer patients in particular cannot deny medical attention while seeking healing in other spheres; rather, they must find a strategy to always be able to include the scientific, medical understanding of the disease.

b) Spirituality: The Subtle and Subjective Knowledge of Pain

Spirituality, for most participants, is defined as a personal search for meaning and purpose which may or may not be related to religion. Mitzy defines spirituality in terms of the “right mindfulness,” which will allow the energy healing, reiki, to pass through the body. This “right mindfulness” is achieved through religion, faith and/or Buddhism:

Hmm, well, when I was living in Thailand... part of the Buddhist philosophy is that you do things with the right mindfulness. Do you understand what that’s mean [sic]? You do things with good intention. So, hmm, I have some friends that do that... I do reiki, [it] is like an energy healing.

The assumption of a cyclical relationship among all aspects of a participant’s life, expressed by Mitzy with the Buddhist principle of “mindfulness,” is similar to the interconnectedness of Tulio’s triangle of healing.

Pain often opens people to the spiritual aspect of their lives. For some others, spirituality relies on the belief in God. Arline explains:

I never thought I was spiritually [sic] in any way. I never thought because I am Jewish, but I never thought I was religious, but, you know, it doesn’t hurt to pray [a] little bit. Well, I don’t go to temple as much as I should. But, I do, I do look up on occasion, most days anyways, but, you know, when I am in the condo I often say, “Where are you now? Are you listening to me?” that kind of thing, but uh, it’s, you know, it’s an enlightening experience. It really is.

The definition of spirituality encompassed any belief that gives meaning to the pain participant’s experience, bringing faith, hope, and control. Maria expressed this as a representation of the theological virtue triad: faith, hope, and charity, when referring to her process of healing: “Fe, esperanza, y caridad es lo último que se pierde” (Faith, hope, and charity are the last things one loses.)

Similarly, Margarita explained that during her moments of the worst agony, her faith in God gave her hope:

And I put my faith in God. I say, “God, I’m not going to let fear take me. I will make this go ahead. I will do all that I have to do. I mean this already, help me, help me.” And, I think every time I say “Help me,” so many times, he answered me immediately. And, that’s what I do, you know, everyday since I’m dealing with this.

Tulio, on the other hand, explained that in his search for meaning and healing, he set his faith in everything. Tulio’s story is one of complete hope — hope in a promising future, hope for a cure — and this is certainly a far more desirable state of mind than hopelessness or despair for Tulio.

En cuanto a la fe, mira, yo llegué a ir a la gruta de la virgen de Lourdes, en Francia, y cosas así.

As for the faith, look, I got to go to the grotto of the Virgin of Lourdes in France, and things like that.

Similarly for Maria, hope is a morale builder and a sustainer of the permanent search for healing:

Voy a tratar de hacer lo que siempre he hecho, a cuidarme, a tomarme los medicamentos, hacer todo lo que tengo que hacer. Pero debo aprender a vivir con ella [con el cáncer].

I am going to do what I have always done, take care of myself, take my medication, do everything that I must. But, I must learn to live with her [with the cancer].

Hope is a spiritual need common to all participants. They must have hope for a cure in the future, or have “intransitive hope” (Frank 2013: 205), which is the hope people have from no specific source, but that leaves open a promising future without pain and without cancer. There is a clear relationship between hope and a will to live, lending understanding to the experience. Many of the Hispanic participants manifested this intransitive hope. Jocelyn, for example, expressed that even though she knows there is no cure for her cancer, she allows herself to believe in the possibility of healing:

Even though the pain never goes away, you have, you have to tell yourself: I know it will go away, I know that I am going to be cured. Although it has no cure. Because

maybe within a year the cure appears. Faith, hope, and charity are the last thing[s] you lose.

Through the process of healing and resistance, most participants came to realize that there are multiple forms of spirituality, each varying according to the participant's individuality and culture. This spirituality encompasses multiple dimensions. Crystal healing is one of them, and it includes the use of crystals, gems, deep relaxation strategies. Crystal healing is believed to cleanse the body meridians, which are pathways through which energy travels. This therapy is believed to promote energy balance and, consequently, can help heal disease and alleviate pain. Tulio describes:

Yo también he utilizado mucho la cristaloterapia, colocando cristales, es algo[que] funciona a través de los chacras. Es algo Hindú. Y esa experiencia con los cristales fue muy bonita, agradable. Yo no sé hasta qué punto esa terapia con los cristales te va a curar directamente, pero mira eso te relaja, te abre la mente, eh. Y eso te ayudan a que el flujo de energía de adentro, y la energía negativa que está adentro, salga a través de los chacras. Porque los cristales vibran en la misma frecuencia, sobre todo el cuarzo, en la misma frecuencia que nuestra materia. Y, colocaron en sitios estratégicos cristales que reciben energía del universo y facilitan que tu absorbas esa energía. Fíjate que a mí me llamo la atención que la primera vez que me los pusieron [se refiere al cuarzo], me lo dejaron un rato. Cuando me los quitaron me dijeron: "tócalo para que veas". Cuando lo toque estaba sumamente caliente, más caliente que yo. Y eso de dónde salió, si el cuarzo es una piedra fría? Y me dije: "aquí hay algo". Seguí y como yo ví que era algo desinteresado porque ni siquiera me cobraban cuando me lo hacían. El hecho de que no cobraran me hace pensar que no hay un interés económico detrás de esto. Porque, uno empieza a dudar cuando ve que hay un interés económico. Mira, me los colocaban y yo sentía una relajación, clara que iba acompañado de un ambiente, escuchando música mantra o una música muy suave, respirando, y al mismo tiempo había algunas personas que trabajan acupuntura que me daban un masaje en los pies. Pero en el caso este, te sientes que estás en una nube y eso ayuda. Quizá eso no sea lo que te cura directamente pero eso crea en ti un, no sé, un bienestar completo. Sentirse bien en el momento. Y esos momentos hay que procurar multiplicarlos. Porque de lo contrario, eso de estar enrollado en la vida....

I also used crystal healing a lot, placing crystals. It is something that works through the chakras. It is something Hindu. And that experience with the crystals was very nice, nice. I do not know how much that therapy with crystals will cure you directly, but look that relaxes you, it opens your mind, huh. And that helps you to flow the energy from within, and the negative energy that is in, to go out of the chakras. Because the crystals vibrate at the same frequency, especially the quartz, on the same

frequency as our matter. And, they placed in strategic sites crystals that receive energy from the universe and facilitate that you absorb that energy. Notice that I was struck by the fact that the first time they put it on [it refers to the quartz], they left it for a while. When they were taken away, they said to me, "Touch it so that you may see." When I touched it, it was extremely hot, hotter than my body temperature. And where did that come from, if the quartz is a cold stone? And I said to myself, "There is something here." I continued and as I saw it was something disinterested because they did not even charge me when they did it. The fact that they did not charge me makes me think that there is no economic interest behind this. Because, one begins to doubt when he sees that there is an economic interest. Look, I put them on and I felt a clear relaxation that was accompanied by an atmosphere, listening to mantra music or a very soft, relaxation music, and at the same time there were some acupuncture people who gave me a foot massage. But in this case, you feel like you're in a cloud and that helps. Maybe that is not what cures you directly, but that creates in you ah, I don't know, a complete well-being. Feel good in the moment. And those moments, we must try to multiply them. Because otherwise, that of being all wound up in our life.

Tulio explained that although these quests for healing may not necessarily heal the person, they give the person a temporary peace, which is what the person needs most during the experience. The possibility of well-being in the face of horrific disease is latent. As Maria expressed it, the faith and hope in healing are the last thing a person should give up.

None of the participants indicated that they were ill because God punished them or because they did something bad. On the contrary, they questioned God for meaning, and once they understood that the meaning was within them, they came to a peace with God.

Explains Irmone:

I go to church a lot and it's like, and I have a lot of friends who do not go to church and it is like, umm... God really has a good sense of humor, because... look at me going to church and trying to be good, and... look what happened to me and all my friends who never go to church not even want to hear about church and they are okay. But, then ... I got back to my senses and I said: and I think that was the turning point of my life, and that's why I told you that that date was very important. I said to myself, "I don't know why I reason like that," but it was like that, you know what... your body, the devil can do anything he wants to, the enemy can do anything he wants to your body, because at the end of the day your body is going to rot, no matter how you live, how, how long you live... you [are] going to go down the earth

and turn into dust. But, your soul is what you need to be saved. And at that time, I said, “Okay, I am not going to go there...” and... I have been peaceful ever since.

Most participants sought their disease and painful experience as a wake-up call from God, a moment to change. As Angelo explains:

When my pain started, I just turned it over to God and I start[ed] praying and he was my partner and he still is. That’s help, oh, yes... and my prayer, and my family... I turned it over to God and... just keep praying and... and I am changing my way of eating too, yeah, it’s important too. I add vegetables, a lot of fruits, so, in that sense, I have changed me too.

Most participants saw a spiritual understanding of their experience of pain outside of institutionalized religions. But while the emergence of spirituality in the participants’ narratives reflects a contemporary cultural trend, it also opens the possibility for the sociological study of fundamental but previously neglected aspects of pain. Spirituality, for most participants, is a realm of social action where their autonomous ability to choose is paramount, reflecting self-agency and produces a range of meaning that varies by culture. All participants claim to knowledge relay on their spiritual faith and hope for healing. Faith and hope in this sense are forms of consciousness. Knowledge cannot be separated from the experience or from both faith and hope (Garret 2002). However, new understanding comes from the scientific and spiritual understanding participants have of their experiential pain. But, such discoveries are not determined by biomedical discourse or theoretical narratives, but rather by that which makes it possible: participants’ inspiration. The “inspiration comes from embodied, emotional” pain (Garret 2002: 67). Many questions stayed unanswered at this point, that future studies should contemplate: what is the effect of spirituality and practices of the experience of pain in adults diagnosed with and treated for cancer? How do doctors and biomedical institutions take

account of the spiritual needs of adults diagnosed with and treated for cancer? What forms of spirituality enhance the life of adults diagnosed with and treated for cancer?

c) The Self

Many participants struggle with a disrupted self, one that emerges from the dynamic between scientific care and experiential pain. Tulio expressed that his healing began with the understanding that he also has a major role, and that the participation of the self in the process of healing should not be taken for granted.

A mi me costo mucho tiempo, mucho, mucho entender que quien se cura es uno mismo. Igual que la hierbita que te mencione antes, no hay ningún médico que te puede curar, ni ningún, ninguna hierba, ni ningún nada. Es uno mismo quien al final quien se cura. Porque el médico te puede quizás dar una orientación, te puede facilitar una medicina que te ayuda a curar. Pero es tu cuerpo el que se cura al final. Tu cuerpo decide si cicatrizes o no una herida. Por más que tu le pongas medicina, tu cuerpo puede reaccionar para bien o para mal. Y como te digo, me costo un poco comprenderlo, “realize it”. Porque, eh, si el cuerpo decide que no, es no.

It cost me a lot of time, a lot, a lot of understanding that the one who heals is [the patient] himself. Like the herb I mentioned earlier, there is no doctor who can cure you, nor any, any grass, nor anything. It is oneself who ultimately heals. Because the doctor can give you an orientation, can provide you with a medicine that helps you heal. But it's your body that heals in the end. Your body decides whether or not to heal a wound. As much as you put medicine, your body can react for better or for worse. And as I say, it took me a while to understand me, [to] “realize it.” Because, eh, if the body decides not to, it's no.

However, as Frank (2013) expresses, the creation of a new self-image begins when the experiential pain is shared with others and the process of healing begins. As described by Tulio, his pain and his experience would be intolerable without a positive orientation, without the confidence in himself and the hope for a cure.

Si en el momento en que te dicen: “mira yo no te puedo curar, tú vas a vivir 3 meses, 4 meses,” pues uno empieza a pensar que no hay remedio, que es verdad, que a lo mejor tienen razón. Y cómo, cómo mi cuerpo se va a curar?

If at the moment you are told, “Look, I cannot cure you, you are going to live 3 months, 4 months,” well, one begins to think that there is no remedy, that it is true, that maybe they are right. And how, how is my body going to heal?

As the self is diminished due to the process and in many times due to the lack of physicians’ ethics, the person succumbs into a “dark” world, where depression, anxiety, and sadness become his reality. Self-confidence in one’s healing is the most important aspect of the healing process, explains Tulio:

Pero hay que tener un poco de ética. Porque el paciente necesita cierta confianza para poder salir de ese hueco en el que está metido. Y, ahí pues cuando le hablan así que no va a llegar a diciembre, y no sé que, uno pierde la confianza. La confianza en uno mismo --en que uno se va a curar, en que uno va a poder a salir de esto, va a salir adelante y va a poder tener una vida normal. Que es con lo uno sueña en ese momento-- Si usted tiene una gripe, muy fuerte, y tú eh sabes de una u otra forma que dentro de tres días vas a estar un poco mejor y eso va a pasar es más fácil aguantar el malestar de la gripe, que si te dicen que esa gripe no se va a quitar nunca. Cuando la confianza se destruye viene la depresión, la melancolía, la tristeza ah la verdad no sé sigamos hablando a ver si se me ocurre una palabra mejor.

But you have to have a bit of ethics. Because the patient needs some confidence to be able to get out of that hole in which he is. And, there when they talk to one in that way, that one will not lived out until December, and I do not know that, one loses confidence. Self-confidence - that one is going to heal, that one is going to be able to get out of this, will get ahead and will be able to have a normal life. That is what one dream[s] about at that time -- If you have a flu, very strong, and you know in one way or another that within three days you will be a little better and that will happen, it is easier to endure the malaise of the flu, then if they tell you that the flu will never be removed. When self-confidence is destroyed, [it] [be]comes depression, melancholy, sadness ah, I really do not know how to keep talking to see if I can think of a better word.

The self, according to Tulio, let the most important vertex of the triangle. The self is the missing link between the scientific beliefs and expectations and the spiritual interpretation. It is through the self that the person, as both subject and object, comes to experience integrally their pain and the cancer trajectory, as the self abides in the body and overlaps the fictitious borders that split mind and body.

Un día conversando con la oncóloga, decía, aquí hay pacientes que con el mismo diagnóstico, se les aplica el mismo tratamiento y unos se salvan y otros no. Unos responden para bien y otros no. Con el mismo diagnóstico y el mismo tratamiento, entonces, qué es lo que pasa? Debe haber algo más, entonces. Y ése algo más, mi conclusión en lo personal, está aquí adentro ... Y es ahí, donde hay que trabajar mucho desde un punto de vista ético de los médicos. Para mí esa es la única explicación que 2, o 4, o 10 personas con el mismo diagnóstico, con el mismo tratamiento, unos respondan bien y otros no.

One day talking to the oncologist, she said, there are patients with the same diagnosis, who received the same treatment, and some are saved and some are not. Some respond for the good, and others do not. With the same diagnosis and the same treatment. So, what's up? There must be something else, then. And that something else, my personal conclusion, is here inside. For there to be a cure... And that's [an area] where we have to work a lot from the point of view of medical ethics. For me, that is the only explanation why 2, or 4, or 10 people with the same diagnosis, with the same treatment, some respond well and others do not.

As explained by Tulio, it is the harmonizing of the self of the cancer patient through which the person in pain finds hope of an eventual healing. However, the hope for healing, or an eventual healing, it is not always relegated to the person diagnosed with cancer, but rather to the body functionality in conjunction with the effectiveness of the medical treatment. At this point, cancer patients are in need of strategies that will help them rebuild their disrupted self and reconstruct their self-image, during and after treatment.

In sum, the interconnectivity of pain is a graph that helps us understand how pain is related to every aspect of a person's life, and how the self mediates the patient's understanding of the scientific explanations of physical and mechanical pain and the spiritual meaning of the pain they experience. The self, through the conscious awareness of the painful experience, provides this experience with meaning within both spectra, the scientific and the spiritual, from which each pain is explained.

Summary

There are three important stages that make up the meaning and the experience of pain among adults diagnosed with and treated for cancer. Participants experience pain in different ways. Some only experience the physical and mechanical pain that comes with the diagnosis and treatment, while others, although experiencing physical and mechanical pain, also experience emotional pain. This pain is worse than physical pain, as it affects aspects of the person that determine the essence of who the person is and how the person identifies him- or herself, that makes him or her aware of the ephemeral nature of existence, the dramatic changes to his or her body, and with it, the disruption in the flow of the self. These realizations caused major changes in all participants, some changes positive, others negative. But, in either case, the change was not subtle. It was sudden and abrupt, leaving no space for the person to slowly adapt to the changes.

However, as participants' lives and selves change, they consciously embark on a quest for meaning. This process is initiated by communication. The communication of pain occurs along the trajectory of painful experiences, although at different stages of the experience, pain is communicated to different audiences. At the initial stage of the disease, where pain enfolds the entire life of the person, pain communication is restricted to medical care professionals. At an intermediate stage, where physical and mechanical pain are controlled and somehow explained from a biomedical point of view, pain is shared with husbands and wives, and with children. This communication, however, is not always verbal. The knowledge and understanding of pain began when physical pain diminished and it is characterized by major understanding of the lived experience. Since the physical and mechanical pain no longer exists, it would be fair to say that pain is

retroactively shared with a broader audience at this stage. In doing so, participants compare their experiences with others who experience and live the same pain. This sharing validates the participants' experience and makes it meaningful, as participants acquire knowledge. But, most importantly, participants have the moral aim to share their pain.

For some participants the sharing and communication of pain comes after having an understanding of their painful experience, while for others, understanding of the painful experience comes from sharing. There is not a direct and evident causal relationship. However, in either case, each participant seeks to understand and therefore make meaning of his or her pain experience in one or more vertices of the triangle of meaning: science, spirituality, and self. The self is the most important element of this triad, as it regulated and mediated the relationship between the other two. It is through the self that the person in pain becomes both subject and object of his or her experience and meaning, acquiring knowledge about his or her particular experience of pain.

For most of the participants, the effects of pain were so quick and so short that they were done before participants had time to realize the impact. In short, many of the participants were unaware of their pain; they even deny it. But this was not the case for Tulio, Maria, Margarita, Jocelyn, Dee, and F.T., for whom their pain comes from inside and transcends the limits of the physical. They were aware of their pain. However, pain was not the focus of their attention; rather, the self was. These participants utilized their pain as a means of being in the world by attributing meaning to and a reason for their pain. This process of reflection thwarts all attempts to view pain as tangential to a participant's personhood. In conclusion, participants come to know what the essence of

their experience is through personally experiencing both the physical pain and the emotional pain, as well through the self.

CHAPTER FIVE: FINAL THOUGHTS

Writing this chapter has been one of the most difficult tasks of this research study. In this chapter, the birth of understanding and interpretation take place in its own completeness (Moustakas 1994) through self-dialogue and reflection on the participants' experiences. During this process many questions come to my mind: What words should I use? How should I properly interpret the expression and words of pain? What should I do to avoid misrepresenting other peoples' words? How do I explain in words the emotions I experienced during these conversations? or How can I explain my pain? Is this permanent questioning part of the research process? I strongly believe that it is. Once again, I am finding myself reading and reviewing the literature. It is at this point that Scarry's (1985) and Morris's (1991) words become vivid; words are neither proper nor adequate to describe the participants' and my experiences of pain.

So, how, then, can I draw a conclusion from each person's experience? Or what conclusions do I draw from participants' narratives? Thinking about a conclusion has created in me an unnecessary and inappropriate burden (Patton 2002). For as Harry F. Wolcott explains in 1992 (as cited by Patton 2002), the idea of conclusion should be questioned in qualitative studies, or the assumption that a final chapter of a dissertation should build toward a dramatic climax. Therefore, I deliberately avoided the heading conclusions. Instead, in this chapter, I tried to be completely honest in describing the participants' experiences and to be faithful to my understanding by providing an interpretative document with the major findings presented in Chapter Four and by considering these thoughts in the context of the limitations of this research project.

[A note of clarification: I intentionally use the words “cancer patient” and “participant” interchangeably. As shown in the previous chapter, most participants considered themselves to be both cancer patients and participants in this research project.]

The Communicated Pain

Communication comes from the Greek word *Eidos*. The essence of pain comes from the experience and meaning pain has for the person who experiences it. The communication of pain is the phenomenon of describing the essence of pain: what pain is and what it means. But communicating pain is a difficult process that requires the participant’s ability to label his or her pain (Kotarba 1983). Communicated pain offers a possibility to escape from the disrupted reality and reverse the sense of isolation from the world and from the body, relieving the “aching solitude of pain” (Biro 2013: 16). As cancer patients communicate their pain, they see themselves through the experiences of others as they observe the effect of pain on each other’s bodies and selves (Biro 2013).

Communicated pain turns the private experience of pain into a public verbal story that the audience can reflect on and from which they can grasp meaning (Frank 2013:98). The process of communication was not limited to the conversations during these interviews. Most participants had an initial conversation with their physicians, then with their relatives, and finally with others. In communicating with physicians, participants aimed to share and to inform about their pain. Describing pain at this stage entails a form of intercultural communication that requires a competent communicator (Murphy and Choi 1992), or competent communication mediators. The communication mediator is a person who has experienced pain and cancer and understands the scientific aspect of the

pain experience, promotes rational behavior, and facilitates the exchange of information between the patient and the doctor, without acting impulsively. The communication mediator will facilitate the acquisition of knowledge, reducing the differences that are an impediment to the shared meaning (Murphy and Choi 1992). Although most participants indicated that they went alone to see their physician, the necessity of a competent mediator is evident. It is also evident that there is an urgent need for a change as to how doctor-patient communication take place (Murphy et al. 2013). Physicians need to focus their attention on the biography, rather than solely on the measurement indicators of pain.

As participants attempt to communicate their personal and subjective pain, they cannot completely exteriorize or verbalize the intimacy of their experience, as the unmoored “pain is everywhere and nowhere” (Biro 2010: 40). Here, I want to suggest that there is also another form of communicating pain, that of sharing the perception and experience of pain that neither primarily limits it to the biomedical field nor exposes it as an object. The sharing of pain that I want to bring to the fore is one that is not grounded in the assumption that mind and body are separated. Instead, I want to draw attention to the sharing aspect of pain, which focuses on the immediate intercorporeal element of pain that transcends the boundaries of the physical and mechanical pain and cross the boundaries into the emotional awareness that generates a doubling of the embodied awareness (Krusk 2001).

Pain is an extreme state of human existence that represents a place beyond words; it sometimes cannot be shared or communicated. However, pain continuously exposes the body “as a lived body embedded in the world” that permanently intertwines with other bodies, explains Käll (2013: 33). This intercorporeality of the self in pain bridges the

individual and private experiences of pain into a social and cultural context, in which pain is situated (Krusk 2001). This notion challenges the assumption that the body is a self-enclosed entity with clear and distinctive boundaries (Käll 2013). The intercorporeality is then the process by which the boundaries between bodies and understanding of pain are permanently created and recreated, where the self is permanently reaching out and coming to be in relation to other realities (Käll 2013). During this study, the intercorporeality became evident when witnessing some participants' nonverbal expressions of pain, an emotional language of pain that made public the private features of pain (Scarry 1985). This includes movements, facial expressions, body postures, tears, and prolonged silence. These elements of the emotional language of pain are profoundly significant as participants found a way to communicate their pain beyond words. The vocabulary of pain, then, is no longer polluted by words, but rather is recreated as its own language, full of interpretations. Once they communicate their emotional pain, participants were no longer moored in a shrinking world, but rather faced an open world of multiple interpretations and meanings.

As the participants express their pain verbally and nonverbally they are removing the boundaries and the singularity of their intercorporeal experiences with the world, and bringing in other bodies, other stories, other realities, and other meanings of pain. As some participants expressed and exposed their emotional pain, my understanding shifted focus from their individual understanding to building a relationship with them. I was somehow connected to each participant and to his or her experience of pain as I experienced in my own body. This intercorporeal connectedness (Krusk 2001), explained in the latter writings of Maurice Merleau-Ponty (1962), challenges the dualistic

understanding of pain as a self-enclosed experience and instead brings out a corporeal connectedness as the very foundation upon which pain is explained. Through this corporeal connectedness (Krusk 2001), I experienced their pain and I was challenged to understand their pain. Understanding was difficult to find while facing the magnitude of the pain participants experienced in their own lives and bodies because of the embeddedness of the story (Frank 2013).

Through my own embodiment and embeddedness in the world, I responded to the participants' expressions of pain; I shed tears while participants cried, I took a deep breath while participants' looked into the void to hold back the tears. I felt each participant's pain through my pain "that is mine alone, though formed by my feeling-with the pain of the other" (Käll 2013: 35). This corporeal response, explains Krusk (2001) is a direct physiological and emotional response to the participants' experience of pain. By doing so, I apprehended the participants' pain. This is not to say that I completely experienced their pain, since it is not possible to do so. But rather, in Krusk's (2001: 175) words, the participant's experience of pain transcendence into my reality becoming a "doubling of embodied awareness." This doubling awareness is both the proximity of my response to the participants' pain and the distance in the awareness that the pain I experience is not the same as what the person experienced (Krusk 2001). This makes manifest a bond of emotions that sustains the singularity of the experience, making it communicable. In spite of the isolated feature of pain, some participants find a space where their pain can be shared and communicated, shaping how participants define themselves, and how I define myself, as well.

Instead of understanding intersubjective and connectedness of the self to the other or, vice versa, it is necessary to have a stand-in-between the approaches of pain, in which the constitutive forces of both self and other in relation to one another can be recognized (Käll 2009); the relationship between the self and others is a two-way street (Mead 1934). This recognition of the in-between feature of the self and of others occurs in the “communicative space,” where pain is expressed and experienced simultaneously (Käll 2013: 36), and where pain is communicated. As pain is not perceived distantly from its expressions, pain is then embodied (Käll 2009), and lived and relived in my experience of participants’ pain. In this communicative space, pain not only transformed participants and their worlds, but also, it transformed me. When confronted with participants’ pain, I was transformed from neutral observer to witness of pain (Käll 2013), closing the distance between the participants and myself. The immediacy of the participants’ pain and experiences is before me without relief, to the point of it affecting my everyday life and becoming my reality; I dreamed I was diagnosed with and treated for cancer. I felt the painful agony of waiting for the diagnosis during a mammogram. I even dreamed about my own death due to cancer. However, although I lived, to some extent, the participants’ pain, my understanding of their pain was limited. There are limitations to my understanding of others’ pain that even these conversations could not overcome.

The expressive space is the foundation of the similarities between the self and others, between the participants and me, from the image of myself in pain mirroring the participants’ experiences of pain. However, it is in the communicative space that “it becomes clear that I can neither know the other in the same way as I can know myself nor

myself in the same way as the other knows me” (Käll 2009: 82), yet it delineates a space from which the meaning of pain can be understood.

This identification is related to participants’ perceptions of their bodies. As Frank (1991) argues, cancer patients come to the realization that their bodies are no longer a source of pride, but rather a source of agony, pain, and fear. The body is then an unreliable thing, which is experienced as contingent and no longer controllable; it has become the damaged body. The damaged body is often looked upon, in Charmaz’s (1999) words, as a deadly oppressor, while the old body, although imperfect, is cherished (Frank 2013). This contrast between the old, reliable body and the new, damaged body is problematic (Frank 1991) and a source of profound emotional damage (Bendelow and Williams 2002; Leder 1990), because the person is confronted with a damaged body that cannot be transformed. Metaphorically speaking, the damaged body is like “a kind of car driven around by the person inside; it breaks down and has to be repaired.” However, for most participants, the damaged body cannot be repaired. There are no restitution stories since their bodies cannot be cured (Frank 2013). Participants are aware that all their efforts to return to the normal body are fruitless.

However, it is only by communicating their pain that participants can claim the interruption of their lives due to their disease and recreate themselves. The communicative pain begins in the wreckage, having a change of body image, a damaged body. The body image is the result of an attitude towards one’s body that is influenced by participant’s personal history, attitudes, and beliefs. Thus, the damaged body is the product of the participant’s perception and internalization of the social and cultural understanding of an ideal body, and the current image of the body. This image is a central

aspect of the participant's identity, as it influences the way participants think about themselves and interact with and communicate to the world. It is through the communicative pain that the limitations contained in a shrinking world are transformed into another reality. Participants come to the understanding that their limitations contained in the damaged body can be overcome by adopting multiple forms of healing, which allow them to realize that, in some cases, the body can be molded and transformed, helping them to regain a sense of control by acting and reflecting upon the damaged body.

Through the process of communicating pain, participants are able to name and verbalize their experiences and their pain. This process of labeling their pain constitutes the fundamental aspect of making sense of pain (Kotarba 1983). During the study, most participants expressed their pain emotionally, and, in many cases, some were not able to verbalize or articulate their pain. Undoubtedly, the problem lay in the word *pain*, as the word of pain by itself serves little meaning (Kotarba 1983), because it does not describe the pain experienced nor the meaning of the experience. In short, words, or the simple name of pain, are not sufficient to describe the pain participants' experienced. Tulio, for example, could not grasp one word, one label, that could contain the multiplicity of emotions and that could add meaning to this painful experience. Maria, on the other hand, used one word, "other," to encompass the shady and complicated aspect of emotional pain.

However, when referring to their physical and mechanical pain, some participants used expressions like "hurt like hell," "dolor insorportable," and "feeling like a dog" to explain the magnitude of their experiential pain. This experiential pain transposes the

boundaries of physical and emotional pain and lies at the center of the person's identity and experience. However, each label was directly related to the speaker's meaning. For Helen, who experienced an excruciating pain, enduring this pain and all of the changes the disease caused in her life, said it was like living in hell. This hell, a reality which she wanted to abandon, manifested in her desire to die. For Tulio, for whom the pain pushed him to become that which he despises the most, "un invalid," a disabled person, the pain of his reality was unbearable. For Margarita, who has a strong connection to her body and her own self-image, the transformation and damage the disease caused to her body made her see herself as "monstrous" and as a dreadful dog. This self-image was extremely painful for her.

Only when each participant could think aloud about his or her pain (which happened for most of them for the first time during the interview), could they somehow grasp some sense of the meaning of their pain, and in some way break with the vicious circular dynamic in which pain had trapped them (Kotarba 1983). Although this process of meaning-making is extremely important and invaluable for most participants, it leaves me with a lot of unanswered questions, yet it is a very good starting point for future studies, which can explore what pain is and how it defines us.

Pain is an invisible experience that cannot be seen because it is experienced internally; therefore, it cannot be easily defined. Cancer patients cannot properly label their pain and thus cannot reflect upon it, for this would require the ability to stand back and take a look at it. However, when experiencing pain, participants become external observers of their experiences, licensing pain to control, alienating them from their experiences and the world in which these experiences occur, creating a feeling of

fragmentation (Ha'elyon and Gross 2011; Shilling 2007; 2001). This feeling of fragmentation is vivid in the damaged body. The damaged body, thus, has profound and lasting implications for the sufferer's well-being and results in the creation of a new self, where the once-imperfect body is questioned, while the person tries to overcome the loss of the old, perfect, and reliable body (Charmaz 1999). Charmaz (1994) contends that the process of creating a new self, which rooted out of the lost of self (Charmaz 1983), involves the negotiation of a struggling identity trade-off and with it, the emergence of a damaged body, I would add. In other words, the new self emerges out of a negotiated struggle between the damaged body and the person's goal. This struggle is gendered, as men and women are faced with different gender and identity dilemmas (Charmaz 1994). The negotiation takes into account the meaning of pain and the participant's understanding of the social and cultural expectations of his or her role and understanding of masculinity and femininity. Body image is a central aspect of a person's perception and internalization of social expectations that picture men as the strong, the protector, and the provider (Sheridan 1992; Wall and Kristjanson 2005), creating in men a false consciousness. The results of this study show that men experience a loss of physical independence due to cancer, reducing their sense of masculinity and hindering their capacity to demonstrate masculine characteristics of strength, activeness, virility, and stamina. Women, on the other hand, negotiate their roles as caregivers and challenge the gender role boundaries as care receivers. The discrepancy between the self and the inability of both women and men to live up to these social expectations create a negative emotional response. In other words, the potentialities and capabilities of sufferers are restricted (Merleau-Ponty 1962) and limited to the boundaries of the damaged body.

Indeed, the acquisition of a new and undesirable identity, the loss of self, and the disturbance of taken-for granted routines all produce emotional distress (Frank 2013; Charmaz 1983). Similarly, as these people face the lack of fulfillment of the social roles, they develop a sense of debt. All these negative emotional responses to their experience of pain also contribute to their experiential pain.

The perception and visibility of the damaged body determine the degree to which each participant experiences the disease (Belgrave 1990). Those participants with visible changes to their bodies experience major emotional pain, more than those who are virtually without any visible transformation. Similarly, the emotional pain was stronger for those participants who perceived greater damage to their physical appearances and independence. Consequently, each participant's experience of the emotional pain varied according to the characteristics of the damaged body and the extent to which the damaged body dominated his or her everyday life (Belgrave 1990) and disrupted participant's everyday life (Bury 1982). However, the communicative pain of the bodily transformation and of the life disturbance would minimize the pain and the consequences the self adults experienced.

However, most participants see their damaged bodies as a story that can only be lived (Frank 2013). This story begins with the disrupted life and the interrupted flow of the self. Even though the interruption of the self appears seamless, as participants transform their interruption into the culmination of their life story and strive to return to their old selves, the interruption is flawed. The damaged body grounds the participant's narrative within a limited world; however, as the participant's capacity to act upon the limited world gradually fades, the damaged body attempts to become permanent and some

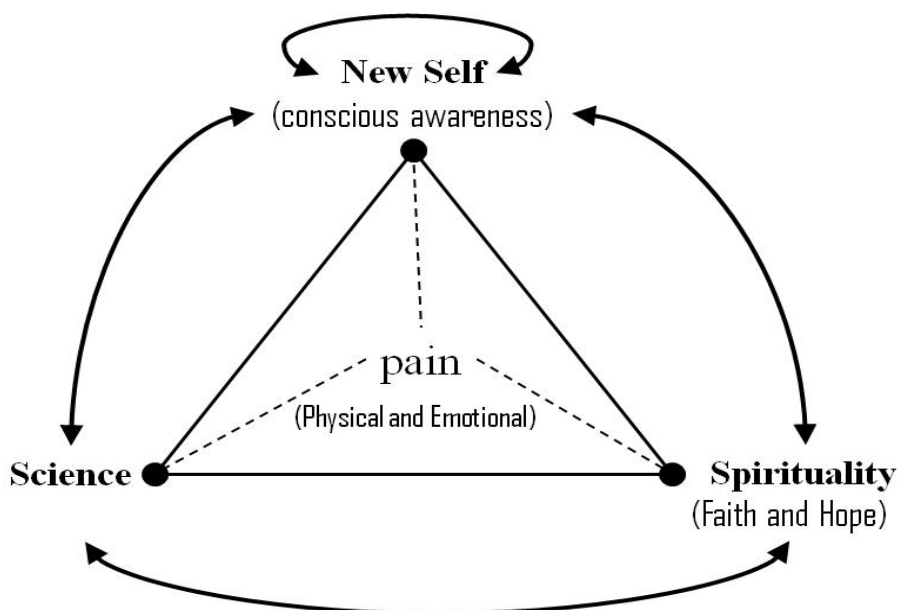
participants fail to see the end of the transformative process. The damaged body, for most participants, then, becomes a culmination project (Shilling 2007), rather than an experience that can be modified. This can become problematic, since participants rely on the old body and the restitution is grounded in the old, normal body, rather than in their health (Frank 2013). Consequently, it is in the process of making sense of the old, damaged body through the communicative pain, and in the search for care and meaning, that the new self emerges.

The Self in the Process of Meaning of Pain

Although each participant already has a self, this self is interrupted by the disease and is questionable due to the damaged body. So, as participants interact with others and observe others' reactions, they gradually become aware of the limitations of the disease and their pain. Their once broad world is shrinking and limited to the confines of the damaged body. Participants, then, start to think about their experience and pain, and become aware that they are thinking of their former selves, placing their damaged bodies and selves as objects of their thinking and knowing processes.

Participants consciously initiate the process of reflexivity (double arrow to the self; see Figure 6), becoming aware of the limitations that the damaged body has placed on them and of how others see people diagnosed with and treated for cancer and how they see themselves (Frank 2013). This specific process of reflexivity (Mead 1934) moves each participant out of his or her individual sense of self, pushing him or her to think about pain in a broader spectrum, to reflect on the experience from the point of view of others and from the perspective of the generalized other.

Figure 6. The Triad of Meaning: the Self, Science, and Spirituality



Moreover, while each participant's relationship with his or her damaged body is affected by its unpredictable and unreliable nature, it has also become a continual threat to the person's identity. As participants attempt to preserve their old selves, this self-image is challenged and questioned by the damaged body, forcing participants to undergo the painful process of creating and recreating a less desirable self-identity. However, most participants find no problem identifying themselves as survivors. This new self-identity entails more than living out the disease and overcoming the damage; it also encompasses a social and moral obligation. As Frank (2013: 137) explains it, survivors do not have "any particular responsibility other than continuing to survive" and to offer a truthful testimony of their journey. The testimony of the lived experience is made public through communicative pain. Communicative pain is not confined to maintaining the appearance of normality or the virtuous presentation of the self, explained Bury (2001), but rather to evidence the disruption of both the disease and pain and how these are

turned into a self-redefinition and a self-renewal (Bury 2001). With communicative pain, participants are therefore actively engaged with their pain and with a moral opening, to become a witness and to share the experience of pain (Frank 2013). It is in the moral action of sharing that participants identify more clearly their personal values and senses of self (Frank 2013, 1991; Bury 2001).

Although they are sharing the truth of their experiences, most participants do experience uncertainty, for there is a conscious struggle to gain sovereignty over their experiences (Frank 2013). In doing so, participants first come to understand the self and the changes of their reality, and then they place the self within multiple realities as they strive to be successfully ill, or part of the remission society (Frank 2013). The remission society, as defined by Frank (2013), refers to the large numbers of people who live with cancer, live in states of recovery short of a cure, or live due to an unspecified form of healing (Frank 2013). However, for some, there is the inevitable reality of a present without a cure. These participants could neither identify themselves as survivors nor as cancer patients, since they are both. Other participants presented themselves as strong warriors, who are constantly battling their enemy, cancer and pain, fearlessly but with intense pain. I firmly believe that these are the proper behaviors of a hero. Similarly, for Frank (2013), people diagnosed with and treated for cancer need to be regarded as heroes, not of some type of war, but of their own life stories. Through the hero-self, people diagnosed with cancer are given the opportunity to redefine themselves and to take control of their lives. Additionally, they have the moral responsibility to conquer their disease and with it all the negative aspects of it, calling for a shift from seeing the hero as a wounded soldier to the hero as a person diagnosed with and treated for cancer who lives

and experiences pain: as Frank (2013: 134) terms it, they transition “from the hero of force to the hero of perseverance through suffering.” These heroes and soldiers on permanent duty are called to save others through communicative pain, in which the message of the possibility of broadening their world is real and creating a new self is a palpable reality shared with others experiencing cancer and pain (Frank 2013). The lived and experienced pain of most participants entails, as Jocelyn called it, a journey of learning with the moral duty to share with others (Frank 2013). Therefore, the remaking of the new self culminates in shared and communicated pain, through which participants’ experience and gain self-awareness of their new identities. Otherwise, pain becomes a useless suffering (Frank 2013).

These new selves: the strong and the hero self [although multiple selves may emerge, only these two are most relevant to this study] entail both the participants’ aspirations and social expectations. It is in the permanent dialogue of the individual aspirations and social expectations, that each participant is involved with, that the two realities: the scientific (public) and the spiritual (private) become meaningful. The scientific reality refers to the ideas, understandings, and models of pain of the biomedical field. The lack of individual adjustment to any of the models of the biomedical field causes participants to become anxious and to doubt their experience of pain. The effect of such doubt is amplified when participants focus their attention on their damaged bodies and the lack of consistency of their narratives (Murphy et al. 2016; Bury 2001). For example, the scientific point of view, the biomedicine, is more concerned with evidence-based narrative, while those living with cancer-related pain expressed their experiential pain through the narratives of communicative pain, which is influenced by the socio-cultural understanding of cancer,

as explained by Frank (2013) and Bury (2001). Margarita, for example, cries as she remember her stormy diagnosis, because in her culture being diagnosed with cancer was a sure death sentence: cancer equates to death. The socio-cultural understanding of the disease add, in this way, a complexity to the communication process.

The spiritual aspect of the meaning of pain, on the other hand, is motivated by curiosity and the participant's openness to other strategies of alleviating pain and therefore provides meaning to the experience. Although the scientific approach uses language to inform about pain, the spiritual component overcomes language and is embedded in the social and cultural meanings of pain. The spiritual aspect of pain requires a conscious reflection on the experience while undergoing different strategies to overcome pain and the limits of their capabilities in a shrinking reality. These two realities complement each other as participants create their own coherent understanding of their incoherently lived pain and develop their own means of communicating and sharing pain through language.

The new self, one postulates, is the link that bridges the scientific understanding of the experience of pain and the spiritual spectrum in the communicative space, making of pain a meaningful experience resulting from the intertwined relationship of the two realities with the self. Although pain is at the center of the triad, it is also in the middle of the relationship of the multiple selves (Käll 2013), where pain takes place within the lived-body, in which awareness and emotions are grounded. Pain, therefore, is located in the in-between multiple realities (Jackson 2005). Pain resists the traditional boundaries that seek to limit it to one reality, overcoming the traditional Cartesian dualism. Therefore, pain, rather than being physical or mental, biological or psychosocial, or

scientific or spiritual, is all of these simultaneously. *It is scientific and spiritual*. Pain is therefore a lived-experience of the lived-body (Williams 2006) and of the person in pain; consequently, pain is an active participant in the construction of this person's reality (Merleau-Ponty 1962). The person in pain is by no means a passive observer of the painful experience. However, it is only through conscious awareness that pain, then, becomes an object of the participant's scrutiny and knowing. And only when it is communicated does that pain become meaningful, as participants recognize the power that language has to create, recreate, and deconstruct their experience and their world. However, as Scarry (1985) notes, this is not easy. Pain, according to Scarry (1985) and Kotarba (1983a), is a lonely experience that sufferer possess and that can neither be shared with nor communicated to others. Although most participants tried to open themselves up during the interview, there was always something that remained unspoken. Pain, stated Käll, (2013:29) is an experience "that is at the same time experienced as intimately" personal. This limits most participants' abilities to externalize, communicate, or share it (Shilling 2001, Frank 1991, Freund 1990). However, as participants begin to take increasingly complex elements of their pain experience as objects, their worldview becomes more complex because they can see and act upon more elements; they interact with the world. Pain is constituted by the scientific models of pain, the spiritual understanding of pain, and the self's meaning of pain. The manner in which participants move from subject pain to object pain, which can be labelled, is gradual and not an abrupt result of the meaning-making process.

The strategy of making meaning of pain, presented here, is a complex and dynamic process: pain is known and communicated, initiated by the process of labelling or naming

it, linking particular forms of expressions of pain to cultural senses of subjectivity and identity, and collapsing the multiple temporal, social, psychological, physical and emotional dimensions of pain. Yet it is not a definitive approach to the process of grasping the meaning of pain. For pain is, then, an embodied experience that intertwines both the object and subject features of the lived-experience of pain (Van der Veek et al. 2012). The meaning of pain and the strategy of providing it with meaning are different and multiple because each person's history enfolds multiple realities. Hence, pain is an embodied experience, in which the participants' emotional, social, and cultural contexts and experiences are integrated and interpreted, providing the pain with meaning (Williams 2006). This embodied experience is consequently a product of the meaning-making process that makes possible the ascription of thought and sensation to people's lived-experiences (Bendelow and Williams 1995, Merleau-Ponty 1962; Shilling 2007, 2001).

In sum, in this study, I have analyzed the experience and meaning of pain among adults diagnosed with and treated for cancer, developing a model of meaning. This model is constituted by three moments. At the first moment, there is the immediate unity of self and pain and an awareness of being in pain. In this stage, pain is perceived. Perception corresponds to the stage of feeling pain, through which the self is felt in a certain way and pain is partly negated and emergent as a particular experience. At the second moment, there is a permanent and constant struggle to adapt to a shrinking world and a changed reality. The third moment is a conscious and intentional process of making sense, where there is the continuing process of the negation of pain and of the awareness of pain. The sense-making corresponds to the stage of conscious search for meaning outside of the

pain experience. It is at this stage that the self becomes explicit and shows itself active, praxis, seeking for meaning of pain beyond the biomedical understanding (Aldrich and Eccleston 2000). The understanding and the subsequent meaning given to experiential pain is, first, associated with the participants' sense of purpose and coherence.

Participants strive to comprehend why pain has occurred and what impact it has had and will have on their future; causal attributions and explanations are formed to account for current unfortunate circumstances. Second, a participant's ability to assign meaning to pain enhances his or her sense of self-mastery (Charmaz 1994), where, for example, the limitations imposed on the participant's lifestyle due to the pain he or she experiences are significantly attenuated by the beliefs that he or she can control the pain or can, despite the pain, undertake activities without harm (Kotarba and Seidel 1984). Although these three stages are described as three distinct and different postures towards pain, it is evident in this study that these are successive stages of the meaning process of experiencing pain and that sufferers can move back and forth between them as their situations change. In other words, once the participant's experience of pain is analyzed, the self and pain are interlaced into one unified entity, known as the pain-afflicted person. Then at the second moment, there is the awareness of pain and of the permanent negotiation of the mechanisms that make sense of pain, while in the following moment there is a continuing process of understanding the multiple manners in which pain is meaningful. These features of pain are what makes it a relevant subject of study in medical sociology. Future sociological studies of pain and cancer should focus on the self and on identity. Additional studies should further the understanding of what self the person in pain wishes to become and how this new self can shape the cancer patient's

illness and self-esteem (Frank 2013). Second, research that emphasizes the political construction of pain and pain-related action is sorely needed. Although we are beginning to sketch a picture of pain as a discursive political event that informs the social construction of the self, there is still little detailed work that describes how meaning is created and given agency in environments of power.

These three stages that articulate the stages of meaning in terms of the relationship between the self and pain give the basic structure for the understanding of pain. Within the framework of these three stages of meaning, the experience of pain can be interpreted in three ways. First, the physical and mechanical pain is questioned, pushing persons to find themselves in pain without awareness of the emotional connotation of the experience of pain. There is just this feeling of pain, but nothing else. Since there is no self that can express its pain, this kind of pain is inexpressible, or unable to be expressed since there is no self to express it. Second, the person is pushed to define his or her pain. It is clear that in a person, pain becomes a reality and a lived experience that is not always easy to explain or to label. Yet, this process constitutes the beginning of the making meaning of pain. Third, the person feels and is aware of his or her pain and consciously seeks strategies to give meaning to the experienced pain. The person then subjectifies the pain, recreating a new self as the continuity of the previous self is disrupted.

Regardless of the stage of meaning, participants' interpretations of their pain are related to their life course. In general, the life course approach gives particular attention to the historical understanding, past experience of pain, and gender roles, and it is not necessarily related to age. Future studies should approach cancer-related pain from this

perspective, giving particular attention to the connections between individuals' past understandings of pain and the socio-economic contexts in which they live.

Ethical Challenges of the Research Project

“Interviews are interventions” states Patton (2002), and so are conversations. Conversations affect and transform the life of both participants and researchers, as they lay open thought, feeling, and knowledge of the phenomenon of interest (Patton 2002): cancer and pain. Patton (2002) defines intervention as a process in which both participants and researchers are exposed and affected by the other's reactions. This process, conversing with adults diagnosed with and treated for cancer, reveals previously hidden realities to the participants, realities that they did not know were there. And the researcher is then witnessing the conscious awareness of a knowledge. In this way both the researcher and participants are becoming knowledgeable. This learning and acquiring knowledge from the process of communication, which is an outcome of participatory and collaborative inquiry, Patton (2002) defines it as an intervention.

While it is not possible to determine how the intervention process will affect researchers or participants, it is important to consider the connectedness and interconnectedness between both (Patton 2002) and the intercorporeality (Kall 2013; Krusk 2001). Through the conversations, participants are directed to a reflective process. Participants are forced to know, to think, and to speak out loud to a neutral listener about their experiences, their impressions, and themselves. For some, this is the first time they consciously reflected upon their experiences of pain and the meaning it has had for them; some participants realized that they had never before thought about their experience in such a manner, or at least had not been consciously aware of their thoughts. This process

is by no means either an easy or an emancipatory one. Although the purpose of the conversation is not to transform people, after listening for approximately two hours to painful stories and being completely aware of participants' biographies, I was emotionally drained and participants were left with the sorrow of an emotional pain they were now aware of. At the end of these conversations, everyone's lives were changed.

As I was being changed by the narrative of each participant, I was no longer neutral, but rather an active participant in this process of the construction of knowledge. As a researcher, I was not "unresponsive to [other] human[s]... great deal of pain" that unfolded during the conversation, while participants brought forth painful memories of their experiences. Their stories, then, became mine. So, how can I repay participants for sharing their stories, for making their most precious selves available to me? This questioning became more evident when participants asked for help, asking me, "Do you know a cancer group that I can relate to?", "Are all families as supportive as the TV shows them to be?" and "How can I overcome this pain?" Unaware of the existence of any specific group that they could relate to, I could not give them any advice, other than to refer them to cancer support groups. This leaves me with my own pain, the pain of not being able to do more, of having to limit my participation to listening and accepting that I may have left them with greater pain. How could I justify interfering with their lives and leaving them?

Aware that I was being intrusive (as some old wounds, and some not so old, were opened during the interview), I made follow-up phone calls to the participants. This step is recommended in the methodology (Hycner 1985). They appreciated this opportunity to share their experiences with a non- "neutral listener" (Patton 2002: 432). It was in these

calls that valuable stories not shared in the first conversation unfolded, as participants released the “psychological pressure of secrecy or deceit” (Patton 2002: 432). These stories are not consolidated in this dissertation project. However, it is evident that future projects should include a follow-up conversation, which would reveal the profound sentiment of the participants' experiences of pain. It is in the repeated conversations that participants will tell “things they never intended to tell” in the first conversation (Patton 2002: 432). These calls seem to help the participants, as I called only those vulnerable to their pain and who had not achieved a full knowledge and understanding of their experiences.

The purpose of every research project is to increase knowledge and, to some extent, to modify the life of the participants as study results are transformed into policies. The purpose of a research project is never to transform the researcher's life, yet my life was transformed. This research project, as with many qualitative studies, is highly personal and interpersonal. As participants opened themselves up about their experience, I was transported through their narratives into the lived and experiential world of having cancer and pain. As I was exposed to the painful details of the experience of pain and cancer, and participants' narratives begins to shape my reality, I began to have nightmares about my own death because of cancer, dreams of how my reliable body had become a damaged body, and I began to fear things that I was not previously afraid of. Neither the Institutional Review Board nor the permanent conversation with my chair could anticipate the degree to which this study affected my life, the intrusiveness of other experiences in my life. At this point, it is clear that conversation is both a powerful strategy in the construction of knowledge and a potential stressor. Future studies,

therefore, should consider the potentialities of this narrative in the constructions and deconstructions of the researcher's everyday life.

As asked previously, at the beginning of the chapter, is this painful process part of the research methodology? Maybe. However, as Patton (2002: 432) urges, researchers "need to be debriefed... to help them process and deal with the things they heard" and to use their observations and feelings as part of the data. I debrief in the analysis and use my suffering in the interpretation of the conversations. I permeate the participants' experiences through the lens of my experience of pain, as I could not remove myself from the process of construction of knowledge since I was already part of it. My concern is with the participants' stories, seeing the effort to make their stories public as my moral duty, as Frank (2013) explained, and to make myself visible as my ethical responsibility. Therefore, my moral imperative is with the reader; whom Frank (2013) defined as, the persona these stories are shaping and transforming.

I want to end this chapter with the idea I began with. Thinking of a conclusion has been an unnecessary and inappropriate burden, as I only had to share with the reader my impressions of this research project and make audible the participants' voices. Therefore, it is the reader who should take a position and make a conclusion. My moral responsibility is to allow the reader to think about the stories and to resonate with the participants' experiences of pain, anticipating the multitude of possible conclusions. Therefore, giving my conclusion, not concluding is, in itself, a form of conclusion, and a mechanism to interact with the reader, as well.

APPENDICES

Appendix A: Conversation Guide



IRB Study Number: 20150937

Date and Time: _____

Alias: _____

Question #1: Can you tell me about yourself?

Question #2: Tell me about your pain?

- How long have you had it?
- Has it changed since it started?

Question # 3: How has pain changed your life?

- What do you do to make your life better?
- What is the most difficult and easiest thing about living with pain?

Question #4: How do you let other people know about your pain?

- Why do you believe others have trouble or ease accepting your pain?

Question #5: How do you see yourself, as a person in pain, or a person with cancer in pain, or a cancer-patient in pain? And why?

[General probes will also be used during the conversation, such as “Please tell me more about that,” “How did that make you feel?”, “How do you know that?” and “What else did you do?”]

Appendix B: Consent Form



IRB Study Number: 20150937

The Experiences of Cancer and pain

I am asking for your voluntary participation in the research project. Please read the following information about the project. If you would like to participate, please sign in the appropriate space below.

Purpose of Study: The purpose of this study is to describe adults' experiences with cancer and pain.

Procedures: If you participate, you will be asked to answer questions related to your experience of pain. For that purpose, I will ask you questions about your understanding of pain, the ways pain changed your life, and how you share or communicate your pain with others. I am neither measuring nor evaluating your expertise, rather I want to know about your experience of living with cancer and pain.

The length of time for the interview is estimated to be between 45 to 90 minutes. I will be audio-recording the interview. It is done that way to make sure I can get your answer in your own words. I will transcribe your responses word-by-word. After checking for accuracy, the recording will be erased.

Risks and/or Discomforts: I do not foresee any risks to your participation in this interview beyond possibly being emotionally upset in discussing your experience. If you are emotionally upset, please notify me and I will skip the question or reschedule the interview for another day.

You are free to skip questions that you don't want to answer, or withdraw from the interview at any time without giving any reasons. If you do not wish to be recorded, this will mark the end of the session.

Benefits: There are no personal benefits from participating in this study; however, it will help us understand people's experiences of pain.

Confidentiality

Your real name will not be used in any report related to the study. During the interview, I will refer to you with an alias. The alias will also be used in any direct quotes from your interview and on documents related to the study as well. You can either choose your alias or I will give you one.

Only I and Dr. Linda L. Belgrave will have access to the transcription of the interview and I will be the only person to have access to the audio recording of the interview. All documents related to the study will be stored in a password protected online storage system maintained by the University of Miami.

Compensation: At the end of the interview you will receive \$20 as a symbol of gratitude and compensation for your time.

Right to Decline or Withdraw: Your participation in this study is voluntary. You are free to skip questions that you don't want to answer. You can withdraw from the study at any time. Withdrawing from this study will not affect in any way your medical treatment at the Sylvester Cancer Center, at the UM, or at the Jackson Memorial Hospital.

Contact Information: If you have any question or comments concerning the research study, please call me at (305) 284-1762 or you can also send me an email at l.hayesmathias@umiami.edu You can also contact my research supervisor Dr. Linda L. Belgrave at (305) 284-6762 or l.belgrave@miami.edu
If you have any question about your rights as a research participant, contact the University of Miami Human Subject Research Office at (305) 243-3195

Participant Agreement: If you agree to participate in this study, I ask you to please sign this document. Once signed, I will give you a copy of the consent form.

I have read the information in this consent form and I agree to participate in this study and to be audiotaped. By signing this form, I acknowledge that all my questions and doubts regarding this study and my participation have been answered.

Name of Participant

Signature of Participant

Date

Name of Person Obtaining Consent

Signature of Person Obtaining
Consent

Date

Appendix C: IRB Approval

- Submission #: 20150937 Issue Date: 3/17/2016

UNIVERSITY
OF MIAMIUniversity of Miami
Human Subject Research Office (M809)
1400 NW 10th Avenue, Suite 1200A
Miami, FL 33136Ph.: 305-243-3195
Fax: 305-243-3328
www.haro.miami.edu**APPROVAL**

March 17, 2016

Linda Belgrave
305-284-6129
l.belgrave@miami.edu

Dear Dr. Linda Belgrave:

On 3/17/2016, the IRB reviewed the following submission:

Type of Review:	Initial Study
Title of Study:	The Embodied Experience of Pain: A Phenomenological Study of Pain in adults diagnosed and Treated with Cancer
Investigator:	Linda Belgrave
IRB ID:	20150937
Funding:	None
Documents Reviewed:	<ul style="list-style-type: none"> •PRC Approval Letter_signed 2.11.2016.pdf •CITI GROUP4 •RecruitmentFlyer_R03092016.docx •InterviewGuide.docx •Liza Hayes_CV_10162015.pdf •ConsentForm_R03092016.docx •SociodemographicForm.docx •Social_and_Behavioral_Responsible_Conduct_of_Research_Course_1.pdf •Course_in_the_Protection_of_Human_Research_Subjects G1.pdf •Conflict_of_Interest_mini-course.pdf •Protocol_R.docx

The IRB approved the study from 3/17/2016 to 3/16/2019 inclusive. Before 3/16/2019 or within 45 days of the approval end date, whichever is earlier, you are to submit a completed Continuing Review to request continuing approval or closure.

- Submission #: 20150937 Issue Date: 3/17/2016

If continuing review approval is not granted before the expiration date of 3/16/2019 approval of this study expires on that date.

To document consent, use the consent documents that were approved and stamped by the IRB. Go to the Documents tab to download them.

NOTE: Translations of IRB approved study documents, including informed consent documents, into languages other than English must be submitted to HSRO for approval prior to use.

In conducting this study, you are required to follow the requirements listed in the Investigator Manual (HRP-103), which can be found by navigating to the IRB Library within the IRB system

Should you have any questions, please contact: Vivienne Carrasco, Sr. IRB Regulatory Analyst, (phone: 305-243-6713; email: vcarrasco@med.miami.edu)

Sincerely,

[This is a representation of an electronic record that was signed electronically and this page is the manifestation of the electronic signature]

Amanda Coltes-Rojas, MPH, CIP
Director
Regulatory Affairs & Educational Initiatives

Appendix D: IRB Modification Approval

UNIVERSITY
OF MIAMIUniversity of Miami
Human Subject Research Office (M809)
1400 NW 10th Avenue, Suite 1200A
Miami, FL 33136Ph.: 305-243-3195
Fax: 305-243-3328
www.hsro.med.miami.edu

APPROVAL

December 2, 2016

Linda Belgrave
305-284-6129
l.belgrave@miami.edu

Dear Dr. Linda Belgrave:

On 12/1/2016, the IRB reviewed the following submission:

Type of Review:	Modification
Title of Study:	The Embodied Experience of Pain: A Phenomenological Study of Pain in adults Diagnosed and Treated with Cancer
Investigator:	Linda Belgrave
IRB ID:	20150937 (MOD00015056)
Funding:	None
Documents Reviewed:	•Protocol_R2_changes tracked.docx •Recruitment_Letter11232016.docx

The IRB approved the study from 12/1/2016 to 3/16/2019 inclusive. Before 3/16/2019 or within 45 days of the approval end date, whichever is earlier, you are to submit a completed Continuing Review to request continuing approval or closure.

If continuing review approval is not granted before the expiration date of 3/16/2019 approval of this study expires on that date.

NOTE: Translations of IRB approved study documents, including informed consent documents, into languages other than English must be submitted to HSRO for approval prior to use.

In conducting this study, you are required to follow the requirements listed in the Investigator Manual (HRP-103), which can be found by navigating to the IRB Library within the IRB system.

Should you have any questions, please contact: Vivienne Carrasco, Sr. IRB Regulatory Analyst, (phone: 305-243-6713; email: vcarrasco@med.miami.edu)

Sincerely,

[This is a representation of an electronic record that was signed electronically and this page is the manifestation of the electronic signature]

Khemraj (Raj) Hirani, MPharm, Ph.D., CPH, RPh, CCRP, CIP, RAC, MBA
Associate Vice Provost for Human Subject Research

Appendix E: **SCCC Approval****PROTOCOL REVIEW COMMITTEE**

DATE: February 11, 2016

TO: Linda Belgrave, PhD

FROM: Arnold Markoe, M.D., Sc.D., Chairman
Protocol Review Committee
Sylvester Comprehensive Cancer Center

A handwritten signature in black ink, appearing to read 'Arnold Markoe', is written over the printed name and title of the sender.

PROTOCOL: eProst# 20150937 "The Embodied Experience of Pain: A Phenomenological Study of Pain in adults diagnosed and Treated with Cancer"

The study, **eProst# 20150937 "The Embodied Experience of Pain: A Phenomenological Study of Pain in adults diagnosed and Treated with Cancer"** has been reviewed and given expedited approval by the SCCC Protocol Review Committee (PRC). You may now proceed with your submission.

If you have any questions please contact Laura Varela, Manager of Research Support, at (305) 243-7185.

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