The Lived Experiences of Dominican Women with Stage IV Breast Cancer

by

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ABSTRACT

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Background: The diagnosis of breast cancer, for most, elicits anxiety and fear due to the disease and treatment process, which usually has a devastating effect on the person, both physically and emotionally. Would ethnicity change or modify this stereotypical response? This study was done to illuminate the perceptions of Dominican women living with Stage IV breast cancer (advanced breast cancer).

Methods: This phenomenological study explored the lived experiences of Dominican women diagnosed with Stage IV breast cancer using a purposive sample of convenience to illuminate their perceptions of living with advanced breast cancer. Six second-generation United States-born women of Dominican immigrants, residing in the New York City (NYC) area, underwent face-to-face in-depth interviews. Each participant was interviewed once and data was analyzed using the descriptive phenomenological method of Amadeo Giorgi.

Results: The four essences that unfolded in this study were: uncertainty, coping, loving, and believing. The overall meaning of the experience of Dominican women with Stage IV breast cancer is described as one of uncertainty and unknowing; accepting the diagnosis so that thinking results in positive changes and healthy choices; enjoying life through meaningful participation in the lives of others and accepting support; and trusting in God through prayer, faith, and hope to create everlasting memories for their children. The synthesis of the overall structure for these women is to “leave a legacy of love.” Interpretation of the overall meaning of the experience and structure aligned with the Roy Adaptation Model (RAM)’s philosophic principles of humanism and veritivity (Roy & Andrews, 2009). The overall meaning of the experience, as expressed by the participants, was translated to and aligned with these principles.

Conclusions: Analyzing the results of this research, one can infer that adaptation for the Dominican woman does not mean an acceptance of her illness; on the contrary, adaptation in this case is an impetus to build a new environment and a new legacy for her children. Future studies should be done using qualitative and quantitative methodology in order to further explore the phenomenon of parenting in this population.

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I would like to express my deepest gratitude to my family: my husband, Rafael (my soul-mate); my sons, Conrad (my light), Bern (my gift), Mauro (my joy), and Mami (my rock). I love you more than words can say. Thank you for challenging me to be the best I can be and to never settle for anything less. You have brought happiness and peace to my life.

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Finally, and most importantly, to the 6 participants who willingly and graciously shared their experiences with me. I was blessed to have had the opportunity to have our

conversations and humbled by your honesty, courage, perseverance and passion for life. You will always hold a special place in my heart.

A.L.P.

DEDICATION

To the loving memory of my aunt, Gladys Gonzalez,

who went to heaven on July 15, 1982 after battling breast cancer for one year.

She has been my inspiration and strength throughout this amazing journey.

To know you is to treasure life

Your smile, courage and determination deemed

Humbling.

To know you is to treasure life

For in each moment there was laughter despite the pain and disappointments—

Encouraging.

To know you is to treasure life

You met life’s challenges with grace and dignity—

Inspiring.

Thank you for this gift.

By: Alsacia L. Pacsi

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INTRODUCTION

Deep in My Heart

Happy little memories
Go flitting through my mind,
And in all my thoughts and memories
I always seem to find
The picture of your face, mother;
The memory of your touch,
And all the other little things
I've come to love so much.
You cannot go beyond my thoughts
Or leave my love behind,
Because I keep you in my heart
And forever in my mind;
And though I may not tell you,
I think you know is true
That I find happiness
In the very thought of you.
Ben Johnson[1]

Numerous studies have been conducted on women with breast cancer (American Cancer Society [AmCS], 2009; Bloom, Stewart, Chang, & Banks, 2004; Landmark & Wahl, 2002). Of these studies, however, few have been qualitative in design focusing on the lived experiences of these women. Also, the focus has been on Caucasian women, with few on African-American or Asian women (Bloom et al., 2004). Thus far, the review of literature has revealed that very few studies have been conducted on Hispanic women. Moreover, of those that exists, only one was a qualitative study focusing on Brazilian women (Vargens & Berterö, 2007). Since the category of Hispanic ethnicity is

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[1] Ben Johnson is the literary name used by a friend

broad, and there are cultural differences among the Hispanic groups, analysis of one Hispanic group does not necessarily translate to another. Therefore, understanding the experience of Dominican women in particular has the potential to shed light on what is important to them as they battle advanced cancer. With this knowledge, nurses can then determine priorities that would improve their patients' quality of life. The United States (US) Department of Health and Human Service's *Healthy People 2010* (2008) emphasizes the need to deliver culturally competent health care that promotes health, enhances quality of life, and eliminates health care disparities in racial and ethnic minority populations.

For this study, a phenomenological point of view is used to examine the lives of Dominican women with Stage IV breast cancer, hereinafter also referred to as "advanced breast cancer." Studying the various data collection methods, I became intrigued especially with the phenomenological approach to qualitative research and its philosophy. This approach allows researchers to examine participants' lived experiences, rather than snapshots. As I studied this methodology, I began to see the possibilities for the development of a research project that would broaden the understanding of my participants' lives. This inductive process allowed me to sensitively listen not only with my ears, but also with my heart. In retrospect, this process also enabled me to feel comfortable while conducting unstructured interviews with my participants. Listening to the tapes and reading the transcripts brought me back to the actual conversations. This, in turn, gave me a deeper understanding of our interactions as well as their experiences. What I never envisioned was the life-altering changes that happened to me through those conversations. It was like hang gliding…where I felt like a bird, flying in tandem with my participants yet time stood still.

Aim of the Study & Research Question

The diagnosis of breast cancer, for most, elicits anxiety and fear due to the disease and treatment process, which usually has a devastating effect on the person, both physically and emotionally. Would ethnicity change or modify this stereotypical response? I was curious to see if the ethnic background of Dominican women influenced their experiences of living with Stage IV breast cancer. Therefore, the purpose of this study was to explore and describe the lived experiences of second-generation Dominican women, aged 21 and older, with Stage IV breast cancer. This study sought to address the research question: What are the lived experiences of Dominican women with Stage IV breast cancer?

Phenomenon of Interest

The most current data of breast cancer incidence estimated that about 192,370 women were diagnosed with invasive breast cancer in the US in 2009 (American Cancer Society [ACS], 2009; Surveillance, Epidemiology and End Results [SEER], 2009). Approximately 40,170 of these women were expected to die from this disease (Centers for Disease Control and Prevention [CDC], 2009). Of these, 14,000 Hispanic women were diagnosed with this illness, and more than 2,200 died of it, making breast cancer the primary cause of cancer death among Hispanics in the US (CDC, 2009; National Cancer Institute [NCI], 2009). Breast cancer in Hispanic women is more often diagnosed at a later stage than in non-Hispanic White women (CDC, 2009; John et al., 2007; NCI, 2009).

Breast cancer is classified from Stage I to Stage IV (NCI, 2008; National Institutes of Health [NIH], 2008). The classification by stage is based on the size of the tumor, lymph node involvement, and the presence or absence of metastases to distant organs (NCI, 2008; American Joint Committee on Cancer [AJCC], 2002). In Stage I (in situ/local-stage tumors), cancer is usually confined to the breast (ACS, 2009; AJCC, 2002; NCI, 2008); in Stage II (regional-stage tumors), it has metastasized from the lobules or ducts to adjacent tissues or nearby lymph nodes (ACS, 2009; AJCC, 2002; NCI, 2008); in Stage III (regional-stage tumors), it may have spread to axilliary lymph nodes in the breast or chest wall tissue (ACS, 2009; NCI, 2008; AJCC, 2002); and in Stage IV (distant or metastatic cancer), it has spread to distant organs, such as the brain, lung, or liver (ACS, 2009; AJCC, 2002; NCI, 2008; NIH, 2008).

Perceived Justification of the Study

In the US**,** breast cancer is the most frequently diagnosed cancer among Hispanic women (CDC, 2004). Also, Hispanic women are often diagnosed with larger, more invasive breast tumors compared with non-Hispanic White women (ACS, 2007; John et al., 2007). Statistical data show that Hispanic women with Stage III or IV breast cancer have a higher mortality rate than non-Hispanic White women diagnosed with the same stage of the disease (ACS, 2009). Data also revealed that breast cancer is the leading cause of death (28%) among Hispanic women 35-44 years of age (CDC, 2004).

When reporting statistics on Hispanic women, a complex question arose: Who are Hispanics and what does the term mean? Since cultural differences exist as well as unique historical and sociopolitical trajectories, differentiating among ethnicities is important (Pons, 1995). In the US, Hispanic is a term used for people who classify themselves as Cuban, Chicano, Puerto Rican, Argentinean, Colombian, Dominican, Brazilian, Guatemalan, Costa Rican, Nicaraguan, Salvadorian, and other Spanish-speaking nationalities from the Caribbean, Central and South America (Office of Management and Budget, 2008). The focus of this study is on a sub-group of Hispanics, namely Dominicans. Generally, most Dominicans are Spanish speaking; have Spanish surnames; usually, but not always, are Roman Catholic; and have common bonds and beliefs stemming from the history and process of colonization (García-Preto, 1996).

Although the focus is on Dominicans, the in-depth review of the literature revealed that there is no specific ethnic sub-group incidence and mortality data available on Dominican women with breast cancer (Office of the Minority Health Resource Center, 2009). What we do know relates to socio-economic and cultural factors of Dominicans in New York City (NYC). Dominicans are the fourth largest Hispanic sub-group nationally (27.18%), of which 553,980 reside in Manhattan and 133,000 in the Bronx (US Census Bureau, 2000; American Community Survey [AmCS], 2008). According to AmCS' 2005-2007 report, they are the fastest-growing ethnic immigrant group in the NYC metropolitan area (AmCS, 2008; Bosworth, 2008).

Dominicans are among the poorest New Yorkers (AmCS, 2008). A large percentage of Dominicans live in Washington Heights, Inwood, the Bronx, and Corona, NY (AmCS, 2008; Bosworth, 2008). Socioeconomic factors may contribute to poor access to care and delays in diagnosis. In 2005-2007, 37.1% of Dominicans had less than a high school diploma (population 25 years and older) compared to 15% of non-Hispanic

Whites (AmCS, 2008). Approximately 26.1% of Dominican families live in poverty, compared to 16.0% of the total US population; and 48.5% of Dominicans families are headed by single women with children under the age of 18, compared to 28.6% of the total US population (AmCS, 2008).

Culture is comprised of socially transmitted behavioral patterns, beliefs, values, customs, and all the other characteristics of a population of people that guide their decision-making and worldview (Purnell & Paulanka, 2008). Cultural factors may also have an effect on one's health behaviors, beliefs about illness and willingness to seek treatment (National Alliance for Hispanic Health [NAHH], 2001).

Very little research has been done to identify specific differences among Dominicans and other Hispanic cultural groups. One study compared the perception of fatalism between Mexicans and Dominicans (Flórez et al., 2009), while another compared Dominican and Puerto Rican women's perceptions of early mammogram and cervical cancer risk (Goldman & Risica, 2004). Since there are few studies that examine differences, for the purpose of this study, the cultural characteristics cited for Hispanics will be used. For example, *la familia* (the family), *respecto* (respect), *personalismo* (personality), and *confianza* (trust) are important values among Hispanics and as such should be addressed in order to provide high quality health care (Diaz, 2002; NAHH, 2001). Studies have indicated that health care providers need to have adequate understanding of each patient's unique cultural perspective; otherwise, the patient's willingness to seek health care and adhere to treatment may be minimized (ACS, 2009; Institute of Medicine [IOM], 2005). Understanding the culture of Hispanic sub-groups, specifically Dominicans, is part of the aim of this study.

Relevance to Nursing

The nursing code of ethics requires that nurses care for patients with compassion, respecting their dignity, worth, and uniqueness, regardless of socioeconomic status, race, ethnicity, personal beliefs, or illness (American Nurses Association, 2005). People are holistic adaptive systems that adjust to their environment (Roy & Andrews, 1999). In order to promote effective adaptation in culturally diverse populations, it is vital that nurses understand the lived experiences of those for whom they render care. In this study, I sought to understand and gain insight into how Dominican women living with Stage IV breast cancer make meaning of each day when faced with their own mortality.

Assumptions and Biases

My assumption was that the participants would be more open and honest in sharing their feelings and experiences as they related their stories during the interview process because of my shared background with them. As a second-generation US-born woman of a Dominican family, I shared their cultural background, language, values and customs. With this connection, I felt that it would be easier for the participants to identify with me.

My belief was that Dominican women with Stage IV breast cancer would have both similar and different experiences from other women with chronic and/or life threatening illnesses. Literature review revealed that many people perceived women with advanced cancer as having been given a death sentence and, therefore, likely to experience increased physiological, psychosocial, and spiritual distress as members of the

Hispanic community. Typically, many differences exist among Dominican women as compared to other Hispanics.

I believed that the care provided to Dominican women might not be culturally competent, thus having a negative effect on their quality of life. In practice, health care providers do not usually recognize or acknowledge the different nuances associated with Dominicans as compared with those of other Hispanic populations.

Summary

Chapter I outlines the framework of the research study, which explored the lived experiences of second-generation US-born Dominican women with Stage IV breast cancer. To gain a better understanding of the study participants, a phenomenological study was conducted. The aim of the study and the research question were used to guide the interviews.

Justification of the study was to identify ways in which to facilitate the well-being of US-born Dominican women with Stage IV breast cancer, improve their quality of life, and eliminate health disparities. Therefore, I sought to determine whether the participants' ethnicity affected the lens by which they viewed and dealt with their own mortality.

Within the context of nursing, I addressed the classifications of breast cancer in order to clarify the pathological changes that occur in Stage IV breast cancer. Established as the leading cause of death in Hispanic women ages 35-44 years of age (CDC, 2004), understanding what US-born Dominican women face with this illness, what their specific needs are and what nuances are associated with this group become vital in facilitating the delivery of the best nursing care possible. Existing data, however, reveal no information specific to this subgroup; hence, it was my decision to pursue this research study.

CHAPTER II

EVOLUTION OF THE STUDY

Introduction

The purpose of this study was to explore and describe the lived experiences of second-generation Dominican women, aged 21 and older, with Stage IV breast cancer. This chapter provides the rationale for conducting the study, the historical and cultural contexts of the study population, and the experiential context relating to the research phenomenon. Reflecting on my experience with my aunt who had advanced breast cancer, I found it necessary to become personal rather than maintain the impartial researcher voice.

Rationale

Approximately 192,370 new cases of breast cancer in women were reported in 2009 (CDC, 2009; SEER, 2009). Of these, 27% were invasive breast cancer (CDC, 2009). Of all cancers diagnosed among Hispanic women, breast cancer is the leading diagnosis (ACS, 2009; CDC, 2009). The incidence of breast cancer among non-Hispanic White women was 126.9 per 100,000, compared to Hispanic women, which was 90.1 per 100,000 (CDC, 2009; SEER, 2008). The mortality rate for non-Hispanic White women was 24.4 per 100,000, compared to Hispanic women, which was 15.6 per 100,000 (CDC, 2009; SEER, 2008). Despite the fact that the incidence and mortality rate for Hispanic women are lower than non-Hispanic White women, they are more likely to be diagnosed with and die from advanced breast cancer (ACS, 2009; John et al., 2008; Karliner & Kerlikowske, 2007; SEER, 2008).

Differences have been noted between Hispanic and non-Hispanic White women in relation to access to care, tumor size, insurance coverage, screening participation, timeliness of diagnosis, cultural beliefs, treatment modalities, and communication with health care providers (Garbers, Jessop, Foti, Urivelarrea, & Chiasson, 2003; Giedzinska, Meyerowitz, Ganz, & Rowland, 2007; John et al., 2008; Karliner & Kerlikowske, 2007). These studies controlled for key variables that affect the stages of tumor development, such as access to care, socioeconomic factors, and quality of care delivered. Larger size tumors on diagnosis may account for the number of Hispanic women who need to have mastectomies or combination therapies, such as chemotherapy and radiation (ACS 2009; Eversely et al., 2005).

Of all deaths among Hispanic women from cancer, approximately 15% are from breast cancer (SEER, 2008). The primary cause of cancer deaths among Hispanic women between the ages of 35-44 is breast cancer (15%), (CDC, 2004). The overall mortality for Hispanic women due to breast cancer is 3% (ACS, 2009; CDC, 2009). The overall five-year survival rate for all women with a diagnosis of breast cancer is 88.5%; for Hispanic women, it is 85.8% (ACS, 2009). Although it appears that the statistics for Hispanic women are improving, the focus of this study was to capture the lived experiences of a sub-set of Hispanics, Dominican women. The decision to study this group of women was a result of the unavailability of data that specifically identified the actual statistics on Dominican women.

Historical Context

Individuals whose ethnicity is Hispanic are not a uniform, monolithic group, but they are related to several sub-groups, each with different customs, which creates a uniqueness that embodies cultural identity. In particular, the Dominican identity was created through the amalgamation of slaves from the countries of Africa, France, Haiti, and Spain. The slaves further integrated with the Taíno Indians, who created the Dominican culture (Pons, 1995). Historically, migrations and intermarriages among this group of people produced genetic and cultural differences, referred to as phenotypic variations (Pons, 1995).

The Dominican Republic was discovered by Christopher Columbus in 1492; he named it *Hispaniola* (Pons, 1995). At that time, the island was inhabited by Caribes and Taíno Indians (Pons, 1995) and since has gone on to infuse the French, Spanish, and Haitian cultures. Presently, this island is also shared by Haiti (Pons, 1995).

Today, Dominican Republic is a democratic society. However, emigration patterns indicate that both men and women between the ages of 20 and 39 years old leave Dominican Republic in search of better financial opportunities and quality of life (Vazquez, 2005). Typically, Dominicans marry young and have babies early (Vazquez, 2005). It is not uncommon for Dominican men, both in the US and in the Dominican Republic, to have more than one partner and household (Vazquez, 2005). This is not as common in the US due to financial constraints and increased assertiveness on the part of the women (Duarte & Tejada-Holguín, 1995). The most common family structures, both in the US and Dominican Republic, are the extended family and compound (non-kin), who are considered part of the family (Duarte & Tejada-Holguín, 1995). This structure may provide family stability and support for single women with children in urban areas. The effects of the structure and culture of the Dominican Republic have implications for health care, preventive behaviors and utilization of the health care system, and, subsequently, the diagnosis and treatment of cancer.

Cultural Context

Dominicans raised in the US, like other children of immigrants, must adjust between the social–cultural practices of the US and those of their parents' homeland (Bailey, 2007). Ideally, acculturation involves adaptation of new values and norms while maintaining one's original cultural norms (Sabogal, Marín, & Otero-Sabogal, 1987). The time when acculturation takes place varies from person to person (Bailey, 2007). What is known is that immigrant language loss in the US is associated with each successive generation (Bailey, 2007). However, with new immigrants, Spanish is the language that is understood and used. Since Spanish is their sole language, this often creates communication challenges when interfacing with the health care system. For second-generation Hispanics in the US, English has become the primary language that facilitates their access and utilization of health care (Bailey, 2007).

To facilitate prevention and early diagnosis of illness, one of the challenges for Spanish-speaking populations is being able to possess the appropriate knowledge needed for access to the health care system. For example, in the Dominican Republic, the term *clinica* refers to hospitals whereas *hospital* refers to clinics. In addition, a common language fosters a sense of comfort, communicates cultural sensitivity and an understanding that maximizes teaching about breast cancer. Hall, Hall, Pfriemer, Wimberley, and Jones (2007), in a quantitative study of 31 Hispanic women, found that when a multifaceted, culturally sensitive and linguistically appropriate breast cancer educational program was implemented, there was an increase in knowledge of breast cancer and decreased barriers to mammography.

Using an interpretive phenomenological approach, da Costa Vargens and Berterö (2007) focused on Brazilian women with Stage IV breast cancer and their perspective on life. The findings revealed that the women became more aware of their mortality and reorganized their lives to live life more fully after the diagnosis.

Goldman and Risica (2004) focused on screening for the risk of breast cancer and cervical cancer among Dominicans and Puerto Ricans in Rhode Island. They found that their participants had a strong sense of fatalism associated with breast cancer, as well as feelings of embarrassment relating to medical evaluation and screening.

Ashing-Giwa, Tejero, Kim, Padilla and Hellemann (2007) looked at the predictors of health-related quality of life among women from varied ethnic populations who were breast cancer survivors. Of importance was that Hispanic women reported the lowest level of health-related quality of life, related in part to increased life stressors associated with socio-ecological and cultural factors.

Furthermore, Flórez et al.'s (2009) study investigated the perceptions of breast cancer and screening in Dominican and Mexican women within the context of destiny and fatalism. Findings indicated that to Dominican women destiny was connected to the genetic influence of breast cancer. It served as the impetus for them to actively participate in breast cancer screening (Flórez et al., 2009).

A research study exploring the differences in breast self exam (BSE)—focusing on ethnicity and behavior among a multi-ethnic participant sample—indicated that Dominicans had the least cancer 'worry' and that they practiced the most BSE in the US

(Kudadjie-Gyamfi, Consedine, Magai, Gillespie & Pierre-Louis, 2005). The Dominican women expressed that trust in their providers played an important part in breast cancer screening and adherence to early diagnosis and treatment (Kudadjie-Gyamfi et al., 2005).

The findings from these studies strongly suggest that health care professionals need to consider both the genetic and the cultural influences that exist among women living with this illness. Although there are differences in stage distribution and survival rates between Hispanic and non-Hispanic White women, there is little in the literature that focuses on the lived experiences of Hispanics with advanced stage cancer, particularly Dominican women diagnosed with advanced breast cancer (Buki et al., 2008; Howard, Balneaves & Bottorff, 2007).

Experiential Context

I have had several experiences which have had a profound impact on my life and have influenced my passion for studying Dominican women living with breast cancer. The first time I was personally affected by cancer is the one that I recall best. I was 22 years old and a senior year nursing student at the time that my Tia (aunt), who was Dominican, “my second mother” and confidante, called a family meeting to tell us that she had found a small lump in her left breast. Tia informed us that she had gone to the doctor, had a biopsy, and was diagnosed with Stage III breast cancer, and then concluded the meeting by telling us that she would be having extensive surgery and chemotherapy within a few days. Her approach was pragmatic and her emotion was flat. I was numb. Breast cancer—what did that mean? A few days later, Tia had a total mastectomy with lymph node removal in the left axilla, a prophylactic total hysterectomy. Shortly afterward she was placed on high dose chemotherapy.

I visited Tia whenever possible, and she would reassure me that all would be well. She had a magical way of re-directing the conversation away from herself and never discussing what she was experiencing. Of the few times I did ask, her response was "I had the surgery; I'm now on chemo and cured." I am not sure whether she believed that although it certainly made me feel better. Nevertheless, we all sensed urgency in her voice as she held family gatherings almost every weekend, and our conversations would always end with her saying, "Remember to live your life to its fullest and don't ever settle for anything less."

Tia's condition improved several months later, but one day she called me on the phone and told me to come over because she was not feeling well. When I got there, she was having difficulty breathing; she was pale and weak. I asked if I could listen to her lungs. Her response was "Don't be silly. Now that you are here I feel better." We talked about everything except her experience with cancer. It was a question I did not know how to ask, and it was a topic she did not discuss. That evening my aunt was admitted to the hospital with pleural effusion; her breast cancer had metastasized to her lungs and esophagus. Tia decided to start on radiation therapy, which burned the skin on her chest. I remember putting Silvadene cream on the wound and giving her morphine for the pain. A family meeting was held, and we discussed alternative treatment options with her. It was at this meeting that she pointed out that no one had asked her what she was going through with this disease. She reflected upon her experience and concluded that she did not want to try any other type of treatment. Tia died soon after, but I always wonder what could have been done to improve the quality of her living-dying.

Summary

Chapter Two outlines the evolution of the study focusing on the historical, cultural, and experiential contexts. The historical and cultural sections address the uniqueness of the immigration experience and the influences of the African slaves, French, Haitian, Spanish, and Taíno customs on the Dominican population. The chapter concludes with my description of my personal and most profound experience of having an aunt with advanced breast cancer. This has served as the driving force for my studying the lived experiences of Dominican women living with the illness.

CHAPTER III

METHODOLOGY

Introduction

This study explored the lived experiences of a sub-group of Hispanic women, US-born Dominicans, who had Stage IV breast cancer. The purpose was to obtain a better understanding of their insights into living with this illness. Giorgi's (1970) phenomenological method of inquiry was used for this study because it enabled me to search for common threads that provided an understanding of the participants' lived experiences. Giorgi's method also provided a sequence for me to follow when collecting and interpreting the data.

Background of the Phenomenological Method

In the late 19th century, psychology was acknowledged as a science (Zayed, 2008). During that time, various schools and methodologies were developing, including phenomenology, introspection, and experimentation (Giorgi, 1970). Different research methods were classified under the categories of natural science and human science (Dilthey, 1977). In the natural sciences (e.g., physics, chemistry, and biology), the focus is most often on empirical verification through experimentation (Zayed, 2008). In the human sciences (e.g., psychology, nursing), the focus is on human beings and their environment. Qualitative methods are used to understand the totality of the human experience. The goal of phenomenology is to comprehend the meaning of the human experience (Munhall, 1994).

Edmund Husserl (1913/1972), regarded as one of the great philosophers of the twentieth century, defines phenomenology as the study of structures of consciousness, leading to discovery of the true meaning of an experience and how it comes about. He defines three concepts to facilitate the understanding of the phenomenon under study: *intentionality, Epoché,* and *intersubjectivity* (Husserl, 1913/1972). He believes that consciousness is an *intentional act* of revealing, which is basic to human nature and notes that one should let the experience of the participant *speak for itself* and allow it to reveal itself in consciousness. He also emphasizes the importance of *Epoché,* or *bracketing,* which requires that one set aside his/her biases, ideas, personal knowledge, beliefs, and preconceptions to reflect upon the content that is being presented (Husserl, 1913/1972; Karlsson, 1993). Husserl (1913/1972) referred to this type of reflection as phenomenological reduction. The third concept is *intersubjectivity,* in which Husserl acknowledges that people's shared experiences go beyond materialistic things; therefore, in order to understand Dominican women's experiences with advanced breast cancer, I must be open to the experience and view it through the participants' eyes. I understood the participants' experiences by paying attention to their perceptions and meaning-making, which stirred my conscious awareness.

Husserl's (1913/1972) method of inquiry involves: 1) describing the experience exactly as told by the participant; 2) phenomenological reduction; and 3) the search for essences or meanings of the experiences. Giorgi (1970; 1985; 2005) modified Husserl's phenomenological method of analysis and systematized it so it can be used in the human sciences and nursing (Giorgi, 2005). Giorgi looks at the overall structure of the experience (Giorgi 1970; 1985; 2005), whereas Husserl focuses more on bringing the unconscious beliefs and meanings to the surface.

Description of Method

Giorgi's Existential Phenomenological Method

In Giorgi's (1985) existential phenomenological method, he emphasizes the importance of looking at the essences—referring to the total picture or wholeness of the phenomenon—not just the frequency of individual elements (Giorgi, 1970). Using Giorgi's (1970; 1993) four-step method for analysis of phenomenological data to describe the phenomenon of the lived experiences of US-born Dominican women diagnosed with Stage IV breast cancer, I: 1) read the complete description of each participant's experiences to get a sense of the total picture; 2) set apart the meaning units, which are common threads from each participant's description of the phenomenon being investigated; 3) revealed the psychological insight included in each of the meaning units—more directly referred to as the transformation of meaning units—which are my descriptions of the themes collectively; and 4) combined all the transformed meaning units into a consistent statement concerning the participants' experiences—referred to as the structure of the experiences that may be generalized to the specific population being studied (Giorgi, 1970).

Sample & Recruitment

To be included in this study, participants needed to be: 1) second-generation US-born women of Dominican immigrants; 2) 21 years of age or older; 3) diagnosed with Stage III or Stage IV breast cancer within the past 1 to 5 years; 4) treated for breast cancer; 5) have the ability to speak English; and 6) reside in the NYC area. However, all participants who met the criteria for this research study had Stage IV breast cancer as their primary diagnosis and were actively receiving adjuvant therapy.

Recruitment began after I received Institutional Review Board (IRB) protocol approval from The City University of New York (CUNY) Graduate Center and the collaboration letter from the medical oncologist at the institution from which the participants were recruited. Two oncology research workers at a research recruitment minority outreach center in NYC reviewed the patient database, identified potential participants who met the criteria for participation in the study, informed them of the study, and provided my telephone number. The sampling frame for this research was those potential participants who were identified by the cancer research center. Those who were interested contacted me by telephone, during which time we negotiated a date, place, and time to meet. At this meeting, I determined if the participant was eligible to be included in the study. I emphasized to each potential participant that her participation was completely voluntary, and that no harm or withholding of treatment would occur if she did not take part in the research. Written consent was obtained at this time.

Six second-generation US-born women of Dominican immigrants participated in this study. The number of participants was determined by the principle of data saturation. This occurred when ongoing analysis of data from new participants added to the database revealed that no new information surfaced, and no new categories emerged (Munhall, 2007). Phenomenological studies have been published with sample size ranges from two to ten (Boyd, 2001; Creswell, 1998). The key is to have enough cases to allow the examination of similarities and differences between and among participants but not to have so many cases that I would be in danger of becoming overwhelmed by the amount of data generated (Smith & Osborn, 2003). There is no specific, appropriate sample size requirement for phenomenological studies (Fawcett & Garity, 2009).

Summary

Chapter Three outlines and discusses the background of Husserl's phenomenological method, Giorgi's existential phenomenological method of inquiry, which I employed for this study, as well as sample and recruitment procedures. These guidelines enabled me to systematically collect, analyze and synthesize the data in order to understand the overall meaning and structure of the experiences of US-born Dominican women with advanced breast cancer.

CHAPTER IV

METHOD OF INQUIRY APPLIED

A phenomenological research method, as described by Giorgi (1970, 1985, 1993, 1997, & 2005), was reviewed, and the steps specific to this method were outlined. Following the initial screening of potential participants, the particulars relating to study participants' protection were applied. Those who met the criteria were informed that: 1) participation was voluntary; 2) the conversation would be audiotaped; 3) identity and confidentiality would be maintained by using numerical codes on transcripts and audiocassettes; 4) the conversation would take 90 minutes; 5) the audiotapes would only be heard by me, the professional transcriber, and research committee members; 6) withdrawal from the study could occur at any time during the conversation without any consequences; and 7) all the information gathered would be kept strictly confidential and would be stored in a locked file cabinet in my office, to which I would have the only key. Once each participant was fully knowledgeable of the protocol and indicated to me that she felt comfortable participating, I asked her to sign an informed consent (see Appendix C). The interview took place the same day, following the participant's consent.

The conversation began with an open ended question: "*What is your personal experience living with advanced breast cancer?* Additional questions were used to clarify or seek additional information during the conversation (*Can you tell me more about that? What do you mean by…? How did you feel when…?*). All the questions centered on what it was like to be living with advanced breast cancer. Clarification, mirroring, reflection and acknowledgement were used to continue the exploration of the participants' lived experience. The voice-sensitive audiotapes will be held for five years post-transcription and data analysis, and then will be destroyed by shredding.

Data Analysis

After the voice-sensitive audiotapes were transcribed professionally, I listened to the tapes while reading the transcription to confirm accuracy. I was conscious of my role as the instrument of this study. After each meeting, I documented additional perceptions and recollections from the conversations in a journal that I reflected upon to obtain a clearer picture of the unconscious meaning of the conscious acts of the participants. I also kept a journal to write my reflections regarding the interviews. In the journal, I included the time, setting, and any external circumstances noted during each interview, using participant numerical codes. Details of overt gestures, demeanor, and behaviors provided a complete portrait of each participant in conjunction with the written narrative transcript of each interview. These notes also gave me insight essential to the analysis and interpretation of the lived experiences of Dominican women living with Stage IV breast cancer by providing data that helped formulate the basic structure of the experience.

This process also enabled me to be conscious of my preconceived biases and assumptions. This helped me to put them aside. For example, I was convinced that culture and health disparities would play major roles in the participants' perceptions and the reporting of their experiences. I noted this in my journal and was surprised that this phenomenon did not hold true. This information was beneficial and pertinent to the study, and served to support its rigor.

Giorgi's (1970) phenomenological method of data analysis was applied as follows: 1) I read the complete transcription of each interview to get a sense of the entire picture being presented; 2) I then re-read the narrative to note the transitions in meaning that occurred in order to identify meaning units or themes; 3) I examined the previously determined meaning units for redundancies, clarification, and elaboration by relating them to each other in order to get a sense of the whole; 4) I then reflected on the meaning units and pulled out the essence or core of the experience of the participant; and 5) I formalized a compatible description of the overall meaning and the structure of the lived experience of Dominican women living with Stage IV breast cancer.

Reliability and Validity

Phenomenological research is discovery oriented rather than hypothesis oriented; therefore, reliability and validity do not have the same meaning that they have in quantitative research because the analysis in this study is iterative rather than linear (Munhall, 2007; Morse, Barrett, Mayan, Olson, & Spiers, 2002). However, these concepts are essential to this study when referring to rigor in the quality of the research analysis. The term used to address the rigor is *trustworthine*ss (Guba & Lincoln, 1981). The requirements to assure *trustworthiness* are credibility, transferability, dependability, and confirmability (Guba & Lincoln, 1981). The methods used to ensure trustworthiness were audiotaping of the interviews, peer debriefing, extensive review of transcriptions, committee member checks regarding the data collection interpretation, and journaling. I referred to the methodology and implementation of same to ensure they corresponded with the formation of the research question, literature, recruitment, data, collection method, and analysis. I also used my sensitivity, creativity, and flexibility, along with the above, to remain focused throughout the process of systematically checking and fitting of the data and the conceptual work of analysis. Interpretation was constantly monitored and confirmed by fellow expert committee members.

Two readers were included to confirm the study findings. The first reader, a doctoral-prepared nurse scholar with 25 years of research and practice, was asked to verify the content of the translation. The second reader, a doctoral-prepared nurse scholar with more than 30 years of research practice and teaching experience, confirmed the synthesis and naming of themes and essences. I was looking for 100% agreement regarding the analysis and naming of the themes and essences. The two readers agreed with the themes. We were also in agreement with three of the four essences. The second reader disagreed with the first essence. Upon re-evaluation of the voice-sensitive audiotapes and transcripts, and further discussion with the second reader, the first essence was changed from *Living in the Present* to *Uncertainty*.

Auditability was performed by the two expert committee members and me. The generated data in the audit provided insight such that we changed the first essence to *Uncertainty*. In other words, dependability was established by the audit. Once the change was done, the transcripts were analyzed two more times using content analysis within each theme. After this was completed, the essences of thought were isolated.

Limitations

As this study sought to capture the lived experiences of a subgroup of Hispanic women, some limitations were associated with the design of the research. Due to the different cultural nuances distinctive to this group, findings from this study may not be generalized to other Dominican women or to other women from other Hispanic subgroups. To facilitate an accurate interpretation and understanding of the unique perspectives of the participants, this study included only second-generation, US-born women of Dominican immigrants who were diagnosed with advanced breast cancer and had the ability to speak English. An interpreter and translator were not used because I fully understand the Spanish spoken by Dominicans and was able to translate words that the participants used periodically to describe their experiences with advanced breast cancer. When data is translated, there is a chance for misinterpretation and misrepresentation of data. For these reasons, translators were not used in order to avoid the skewing of data associated with human error.

My potential bias was another limitation of this study. Given that I, too, am Dominican and have lost my aunt (Tia) to breast cancer, I was mindful not to bring my assumptions to the research study. Therefore, I noted my biases in my journal, which helped me to put them aside. I was then able to listen to what the participants communicated with an open mind that facilitated the flow of their conversations. This helped the participants to disclose their thoughts and feelings. In using journaling and confirmability of study findings, I was able to address research bias.

Participants in the study represented a sub-group of Hispanics with Stage IV breast cancer from the NYC area. Due to the cultural nuances distinctive to this group, I used condensed descriptions to explain the historical and cultural background of the participants.

Summary

I sought to understand the experience of second-generation US-born women of Dominican immigrants living with advanced breast cancer. Using a descriptive phenomenological study design, I attempted to increase the understanding of influential factors and the overall experience of breast cancer from the perspectives of those women. The phenomenological method of inquiry was used because of its suitability in capturing the quintessence of lived experience. This method of inquiry was intended to encourage the participants to speak freely about their illness.

CHAPTER V

THE RESEARCH SETTING & STUDY FINDINGS

The purpose of this study was to explore and describe the lived experiences of second-generation Dominican women, aged 21 and older, with Stage IV breast cancer. Amedeo Giorgi's (1970, 1985, 1993, 1997, and 2005) descriptive phenomenological method was used to cluster the meaning units to reveal themes associated with the phenomenon from which these themes and essences unfolded. This chapter presents: 1) a description of the study sample and cultural background; and 2) discussion of the research findings. The chapter concludes with a summary of the findings.

Research Setting

Study Sample

Six second-generation Dominican women diagnosed with Stage IV breast cancer met the inclusion criteria and participated in this study. Five of the six participants were married, and one was separated from her husband. The women ranged in age from 30 to 53 years. Each of them had children, ranging from 2 and 25 years of age. Three had total bilateral radial mastectomies with lymph node removal of affected breasts with reconstruction. One had a right total mastectomy of the affected breast with lymph node removal. One had bilateral mastectomies with reconstruction, and one had a lumpectomy of the affected breast. All of the participants were receiving adjuvant therapy consisting of chemotherapy, radiation, and hormones when this study took place. None of the participants was employed or actively looking for jobs.

Cultural Background

A large percentage of the Dominican population in NYC lives in Washington Heights, Inwood, the Bronx, and Queens. All of the participants of this study began their lives in the Washington Heights community, located in upper Manhattan—north of Harlem. Washington Heights is said to be the "second capital" for Dominicans because the majority of the people who reside there have their roots in the Dominican Republic. It is also referred to by Dominicans as "Quisqueya"—the initial name given to the Dominican Republic by Christopher Columbus (Pons, 2005). Medical assistance is easily accessible, using the Dominican Spanish dialect. The neighborhood offers a range of services and businesses, including restaurants. The spoken language is both English and Spanish, and the churches conduct services in keeping with traditional Dominican customs (Hoffnung-Garskof, 2007).

The Dominican community of Washington Heights is a lively, social, and welcoming group. Their Spanish is easily identified by the over-emphasized roll of the *r's* when they speak (Nguyen & Sanchez, 2001). This community is very traditional and extremely devoted to family, community, and linguistic heritage (Nguyen & Sanchez, 2001). The Spanish language to them is not simply a method of communication, it represents life (Hoffnung-Garskof, 2007; Nguyen & Sanchez, 2001). Speaking Spanish is a way for them to hold on to their ethnic identity, while speaking English facilitates their acculturation to the US culture (Bailey, 2007; Vasquez, 2005).

Study Findings

This section of the chapter presents study findings that were derived from using Giorgi's phenomenological approach. In conducting this study, the research question was used to support me in data collection. The emphasis during data collection was to allow the voices of the participants to emerge clearly, providing important details about their lived experiences with Stage IV cancer.

Giorgi's Method Applied: First Step

The first step in Giorgi's phenomenological data analysis is to listen to the audio recordings and simultaneously read the transcripts. I carried out this function in order to become more familiar with each woman's story and to get a sense of the entire picture of who they were. For this study, each of the six participants' stories was told. Each of the women spoke about her unique experience dealing with advanced breast cancer in response to the research question: "*What is your personal experience living with advanced breast cancer?"* For this study, pseudonyms were used as substitutes for the names of all the participants.

The Participants' Stories

Participant Anna

Anna, a 30-year-old woman with olive toned skin, met me in a small office in the hospital. I was surprised to see how young and beautiful she was. In spite of her lack of hair, which she covered up with a baseball cap, she had very engaging eyes and a 'Colgate' smile that immediately drew me in. When I arrived to meet with Anna, she was already there, sitting in a chair near the window, reading. She raised her head and smiled at me, but I could also see that she was nervous—by the way she bit her lower lip. As I introduced myself to her, I could feel a familiarity, almost like I knew her—that she was not a stranger, but rather an acquaintance that I had known. Of course, we had never met. She immediately got up and moved to the nearby couch so that we would be sitting together and could look at each other. Her first words to me were “Hello, it’s nice to meet you.” She then extended her hand to me.

Anna shared her story with me. She told me almost immediately that she was separated from her husband. At that time, she was physically separated from her husband as a result of immigration status issues. She was in the US legally but according to her understanding, her husband had to return to the Dominican Republic in order to get his papers in order to return to the US legally. When she spoke of this, she seemed sad and somewhat longing for his presence. When she talked of her children, the sadness melted and her face lit up. Anna stated that her daughter, Juanita, was 11 years old with long black hair and is part of a touring ballet company. Her son, Damian, a 2-year-old, was very active—going through the typical terrible twos, saying “no” very often. She shared with me that both children were very beautiful as she smiled and stared off into space.

The story about Anna’s breast cancer was a difficult one for her to tell. She seemed sad, but after pausing for a few seconds she started her story. She explained that one morning while she was taking a shower she felt a lump in her breast, but she did not get upset because she thought that only the elderly got cancer. She recalled that three weeks later she went to the doctor and she still was not concerned because she knew that everything would be all right. She related, with sadness, all the blood work that she had to go through. While telling her story, all of a sudden her facial expression looked as though she was hurting deeply. Her chin trembled as she remembered when the doctor told her that she had breast cancer and was diagnosed with Stage IV. She said “Immediately after that I had a right lumpectomy and I am currently receiving chemotherapy and radiation therapy.” Her major concern was to provide a more peaceful, community-centered environment for her children. She moved to upstate New York to be close to family and friends that she loved and who supported her. She returns to NYC for treatment.

She smiled when she said that what gave her strength to stay healthy and fight this disease were her children. She remembered that since she was a little girl, she found comfort in her religion and that her focus and source of happiness were her children. She stated, “You know, they are my reason for living and not only existing.” She insisted that her main focus now was to teach her children to have healthy eating habits and for her to participate in their activities more than ever to provide life-long memories for them. She dreamt of the possibility of experiencing her daughter growing up to celebrate her sweet 15th birthday (*quinceanera*), and ultimately see her married to a good man. She insisted that she would do whatever it took to make that happen and that faith and knowledge of her disease would help her make the right decisions—emphasizing that she controlled her own destiny**.**

Participant Carmen

Carmen, a fair skinned woman with a short-cropped hair, almond shaped brown eyes, and a welcoming smile, met me in the hospital lobby. She asked that we go to a quiet café where we would not be interrupted. We ordered coffee and sat at a corner table in a Starbucks. She sat comfortably in front of me, sipping her coffee. She seemed relaxed. She began telling me her story by disclosing that she was 40 years old and married with a daughter named Clara who was age 10. Carmen had always lived with the fear that she could develop the disease because she had a positive family history of breast cancer on her maternal side. Carmen stated, “Well I guess I always was afraid that this could happen and last year when I went for my routine yearly exam and a routine mammogram, a solid mass was noted near my right nipple." Her face became very somber when she recalled that she made the decision to do a biopsy and again her eyes filled with tears as she expressed the moment that the doctor told her that she had Stage IV breast cancer, with positive lymph node involvement. Carmen said:

> You have no idea how I felt when the doctor told me that I needed surgery, let alone that I had to have a right total mastectomy with lymph node irradiation and aggressive chemotherapy. I was numbed and overwhelmed at the same time.

She began to cry as she recalled the effects of the medications. However, she said:

> What helped me stay focused was that at the time my daughter was 5 years old. I couldn't bear the thought of leaving her so young and vulnerable. I chose the treatment that the doctors recommended that was most aggressive because I felt this would increase my chances of living longer and see my child grow. I prayed to God and the patron saint, Santa Maria, to help me make the right decisions to give me 10 to 15 more years in my daughter's life.

After months of harsh treatment, nausea, hair and weight loss, she thought that maybe she had more time. Then she was busy and cheerfully creating beautiful memories for her daughter. Carmen spoke of the busy schedule she had for Clara, which involved ballet, piano, religious studies, and Spanish lessons. As she listed the activities, she giggled and said, "Clara is a busy bee. She loves to be outside to play. She's my reason to get up in the morning, particularly after the chemotherapy treatments. Clara, my princess…she keeps me young." Carmen then began talking about her husband. She said, "I am very grateful to my husband, Carlos, and my friends that have been so supportive." She then added, "But most of all, I believe that God and the Virgin Mary will walk with me and with my family through this hard time."

Participant Delia

Delia requested that we meet in Central Park, by one of the hot dog stands. The afternoon we met, the weather was beautiful. The sun was shining and there was not a cloud in the sky. She spotted me first and asked, “Excuse me, are you Alsacia?” I responded, “Yes.” She stated, “I’m Delia.” She then proceeded to extend her hand to me. We walked until we found a bench by the bridge in the park. It was beautiful. There we were, complete strangers, exchanging pleasantries, and yet I felt as if I had known her all my life. Delia’s smile and charismatic personality were captivating. She told me that she was 43 years old, married with 3 children: two girls, Lorena and Michelle, ages 15 and 13, and a boy, Nicholas, age 9.

Through our discussion, I learned that she had a history of hypertension (HTN) and breast cancer on the maternal side of her family. When recalling the two months after having her routine mammogram, her face became so sad before she turned her head to avoid eye-contact with me for a few seconds. As she turned to look at me her eyes were filled with tears and she explained, “While I was doing my SBE, I discovered a painless hard lump on my left breast that went up to my axilla and that lump was protruding out of my breast, causing deformity.” And, “as soon as I could that morning, I made an appointment to see my doctor.” She explained that the appointment was for a mammogram and that, upon examination, her doctor decided to do a core biopsy. With tears coming down the corners of her eyes, like rain falling, she continued, “I had surgery one month later and was diagnosed with Stage IV cancer of the left breast with positive lymph node involvement. I did not think twice, nor did I consult with anyone; I decided to have a bilateral radical mastectomy.” She also stated, “I cannot take my time; I have children and they need me. So when the doctor told me that I had to have radiation therapy and chemotherapy, I told him, you do whatever you have to do; I need to get better for my children." She also described her treatments. She explained: "There are days that I feel awfully bad; but although the treatments are brutal, they are the best because they buy me time to be with my children and I will watch them grow." As she delicately dried the tears from her cheeks, she looked at me intensely and she asked, "Do you believe in the Virgin Mary?" Before I could answer, she said:

> I asked God and the Virgin Mary to give me strength and guidance. You know I have to be here when my children need me. I dream of the day when they tell me that the disease is better and I can plan my children's sweet sixteen parties, their graduations and their weddings.

She recalled her happy memories with her mother and her sweet sixteen parties. At one point, she reached for my hand and said, "I know that you are a mother like me; I can tell just by the way you listen. I hope for you and your children all the happiness that I wish for mine."

Participant Rosa

Rosa also decided to meet with me in Central Park. It was also a beautiful morning and Rosa chose to sit under a huge tree. The smell of the fresh cut grass was so refreshing and for a moment I wished that soon there would be a cure for this awful disease. We sat facing each other and Rosa began the conversation. She stated: "I'm 45 year old. I know I don't look it, right?" She laughed and her face lit up with joy. She stated she was happily married for "a long time" and that she had three children—three boys: Anthony, Christian, and Michael, ages 3, 18 and 25. Different from the other participants, this lovely woman did not have a history of breast cancer on either the maternal or paternal side of her family. She stated that she had done monthly SBE since she was 15 years old and that this time she felt a small lump on the upper outer section of her left breast and her axillary nodes were tender for one week prior to her calling the doctor. She recalled, “For some odd reason I knew it was malignant.” Even though she was diagnosed 3 years ago, her eyes filled with tears when she remembered the day of her diagnosis and recalled having a *bilateral mastectomy with reconstruction*. She spoke of the process that she underwent as empowering herself as she found strength to deal with the illness. Rosa stated, “You know, there were days that I did not care to have one more treatment but the thought that my children would be left without me helped me to be strong and go through the treatments.” With a strong voice, she said, “you know, my 3-year-old prince needs me and that is the reason that I must combat this disease.” She added:

> My other children are adults but they are still not settled; therefore, my job is not complete. Do not believe that I spend my time sobbing. No! On the contrary, I cherish each and every moment that I am with my children. While my family and friends are also very supportive, I am most appreciative but what is important to me is to create moments for my children to draw from so when the day comes they will know that they are not alone and that I will always be with them.

Participant Juana

I met Juana in the hospital lobby where she was sitting and reading *El Diario*. We smiled at each other and shook hands. We then walked to the local neighborhood park. She was tall, pear shaped, sporting a short haircut, with thick brown shapely eyebrows and almond shaped brown eyes. Like the other participants, she too seemed familiar and our conversation commenced effortlessly. We sat on a bench, side by side, and we turned to face each other. Initially we watched the children play in the park and marveled at their flexibility and joy. Juana began the conversation by stating, “I’m 37 years old. It seems like yesterday I was 25. I can’t believe how quickly time passes by!” She continued, “As a young bride, I dreamed that when I got married I would have a great family and to live with my husband until we were both 90 years old." She stated that she had two daughters, Pia and Patricia, ages 5 and 10. She also stated that she did not have a medical history of breast cancer in her family. Juana explained:

> When I was doing my monthly SBE, I felt a lump in my right breast and remembered feeling very scared, and immediately I went to see my doctor. He told me that I needed a biopsy, which was done, and then I had surgery approximately three months later because the doctors told me I needed to have surgery sooner rather than later.

Juana further stated, "I did not want to have surgery during the holidays because I did not want to disrupt my children's festivities. I needed to find the right time and the right words to tell them that mommy had to have surgery." She had a look of sadness on her face, just like the other participants. Juana recalled dark days filled with nausea, pain, and despair brought about by the pain of the surgery, then the treatments of chemotherapy. She stated that treatments and their side effects consumed her life. Her animated and funny facial expressions that I observed earlier disappeared. Her face was expressionless and her eyes fixed, as though she was looking at a horror movie. Her voice became low and sometimes quivered as she recalled her experience. Similar to the other participants, her face lit up when she started to talk about her children. She said:

> I know each day is a gift and I pray to the Virgin Mary that she will not leave me and give me time to see my 'gems,' Pia and Patricia, become adults, to be able to take care of themselves and draw from the memories that we are creating together.

To fulfill this, she said "I go on long walks with them; we sing; we laugh, but most of all, we love each other. Every moment is magical and I always remind them that as long as the sun will shine so I will love them until the end of time."

Participant Laura

Laura, age 40, and I met in the Central Park Zoo. She was sitting on a bench admiring the monkeys. When I approached her, I noticed a well-built woman. She was wearing a pink sassy blouse, cream skirt, and brown suede sandals. My immediate impression of her was that it could not be the participant that I was going to interview. She reminded me of an elegant woman ready to go to a dinner engagement, because she was so well-dressed and seemed happy. When I came a little bit closer, I could see the effects of chemotherapy on her—her tan skin; her grey, thin, short soft hair. Unlike the usual appearance after chemotherapy, she had full, thick brown eyebrows and the most beautiful brown eyes that were not sad. On the contrary, they seemed full of love.

As I approached her I called out her name. She stood up and walked towards me. As we said hello we embraced. She had dimples on both cheeks and her voice was sound, always musical. We returned to the bench and began our conversation. She said:

> I went for my annual gynecological [GYN] exam. You know, after 40 they want you to have your mammograms and all that on a timely basis. So, I went to the clinic for my annual GYN examination. Oh! I can't believe I forgot. I'm the queen of suppression [she laughs]. I was due for my annual but I was more concerned about a dimpling that I noticed on my right breast a week prior to making the appointment, while doing my SBE.

As Laura described her experience with breast cancer, she stated:

> The Family Nurse Practitioner [FNP] sent me for an immediate mammogram, sonogram, chest x-ray and blood to determine what the breast mass was. The mammogram or sonogram or both, I don't recall exactly, showed a solid mass about an inch in diameter in the upper portion of my right breast. The FNP compared the findings of my tests to the previous mammograms. The mass was new. I was told all blood results were normal. However, she expressed her concerns and suggested the need for further testing to clearly determine what kind of mass was present. She recommended I have a core biopsy done. She gave a detailed explanation of the procedure and I agreed to have it done the next day. When I received the call from her, my heart sank. For some reason, I just knew

> the news was not good. She told me what I expected. The results were positive for breast cancer.

Laura described her initial feelings following the news of a positive test for breast cancer. She stated, “I felt like someone punched me in my stomach. The Family Nurse Practitioner was very supportive. Actually, initially she told me she wanted me to come to the office to discuss the findings. I told her, ‘Give it to me straight, Paula. We have known each other for years; I can take it.’ It was a hard pill to swallow.” Laura started to cry and my heart sank. I was very still and listened. Her voice began to quiver and I asked her if she wanted to end the conversation and we could resume it at a later time. She reached out to my hand and squeezed it saying, “No, this is the right time. Thank you for listening.” Laura continued,

> I then called my husband and told him the news. My boys, Alejandro, and Emmanuel, and Miguel, ages 3, 13, and 15, were in school at the time. I was supposed to pick them up but I was so overcome by the news we felt it was best that he pick them up instead.

She added, “All I kept thinking was, this is unreal!” At this point I put my other hand on top of hers and realized that I was weeping with her.

Laura stated that one month later she was admitted to the hospital and had a bilateral radical mastectomy and then had to have both radiation therapy and chemotherapy. Following a short period of silence, she shared with me those things in life that she found so important and drew strength from. Speaking from the heart, she said:

> Love, determination, and happiness are the three things that got me through the hardships of the diagnosis. There is so much more than cancer, there are my children. I am a mother, but sometimes this is not what people see when they look at me. All they see is a young woman who has been diagnosed with breast cancer; but I am not the one you think. I am the one that made the choice not to let the disease consume me and hurt my children. I am so determined to teach them that truly living life means to be happy. I know that every choice comes with its consequences. I could choose to be sad and feel sorry for myself, but I know that

> when you have a child your life is no longer your own. It belongs to the children that you brought into this world. I am a firm believer in the saying that 'Everything happens for a reason.' I do not know what my future will be, but what I do know is that their lives will be destroyed if I become consumed by my disease. I will continue to be a positive and I am going to be known as the best mother for the rest of my life and their life.

Furthermore, Laura recalled waking up in the recovery room and asking her husband how their children were doing. She expressed, "I insisted that neither he nor anyone for that matter tell the children what has happened to me." She explained that she wanted to be the one to tell them. Laura's process of informing her children allowed me to gain a greater understanding of Roy's scientific and philosophical assumptions when she stated, "I do not want the children to be scared. This is why I'm determined to tell them myself when I feel the time is right. I don't want them to be scared or fearful." With a voice of firm determination, she added:

> What I want is to be the one to prepare them for the journey we must take together. When everything is said and done my boys are my biggest and most cherished accomplishments. With the help of God we will get through this and be the better for it.

We looked at each other with tears in our eyes, and embraced. For that moment, I felt like the world stood still.

Giorgi's Method Applied: Second Step

Following Giorgi's method, a second review was conducted using only the transcripts. This helped me to note the transitions in meaning that occurred in order to identify the meaning units or themes. The themes were identified by marking phrases in different color highlighter and removing redundancies in the narrative in order to facilitate clarification. Common ideas within the highlighted phrases were clustered and translated into nursing language, called the synthesized, transformed meaning units.

These clusters became the identified themes. For example, Anna talked about her diagnosis, "…everything happened so fast since I was diagnosed"; Carmen stated "when I was diagnosed, it hit me hard and there was just so much going on all at once"; and Delia expressed, "[that it was] difficult, very difficult; my life changed so much, so quickly." These three phrases were clustered and translated into nursing language as *expressed disbelief and was emotionally overwhelmed by the diagnosis*.

Using this approach, twenty-two meaning units (themes) were identified from the analysis of the transcripts and recordings. The themes are as follows:

Themes

- Expressed disbelief and was emotionally overwhelmed by the diagnosis.
- Expressed anger at getting breast cancer.
- Acknowledged that there was no cure for her illness, however, stated she controlled her own destiny.
- Acknowledged the need to receive intense adjuvant therapy to limit the spread of the cancer.
- Emphasized the need to be well informed regarding the disease and the treatments that were being offered.
- Emphasized the importance of receiving intense treatment, however, acknowledged it was difficult to tolerate.
- Spoke of the challenges in developing a relationship with various health care providers under these circumstances.
- Described in detail the adverse affects chemo and radiation therapy had on her physically and emotionally.

- Expressed disappointment over some friends and their lack of support, particularly during that challenging time.
- Focused on combating the breast cancer and was determined to live a productive life. Feared her children would perceive her death as a failure if she didn’t.
- Emphasized that maintaining a positive attitude was essential to achieving positive outcomes.
- Emphasized that her focus was survival—living and embracing each moment with her children.
- Created an environment for her children that would foster peace and promote health.
- Re-evaluated priorities and stayed in close contact with those people in her life that were genuinely concerned and looked out for her.
- Changed the dietary habits for her and her family to foster health and well-being.
- Acknowledged she needed to get her affairs in order and make provisions for her and her children, considering the prognosis.
- Drew from her children’s love to give her the impetus to continue the treatments and the will to live.
- Actively participated with child/children now more than ever.
- Created an environment for her children that would foster peace and promote health.

- Reflected upon her meeting with other women diagnosed with breast cancer and concluded that the most important factor in living with this illness was the individual’s will to live.
- Believed that ‘God’ and the ‘Virgin Mary’ were essential in her life and had helped her deal with the challenges she faced living with the disease.
- Spoke to other women, told her story, and emphasized the need for BSEs and annual exams.

Giorgi’s Method Applied: Third Step: Condensed and related synthesized transformed meaning units derived from the meaning units (themes)

Following the identification of the themes, I reflected on the themes, removed redundancies and clarified and elaborated on them by relating them to each other in order to get a sense of the whole. As result of these reflections I then derived the synthesized transformed meaning units (Giorgi, 1970). Presented in Table 1 are the results of the synthesized, transformed meaning units.

Table 1. *Step 3: Summary of Synthesized, Transformed Meaning Units*

Synthesized transformed meaning units (themes)
I Expressing vulnerability regarding the diagnosis. Thinking of where the cancer will spread next. II Accepting the diagnosis of breast cancer. Setting priorities. Making informed decisions regarding treatments. Enduring the pain and adverse effects of adjuvant therapy. Emphasizing the need to comply with the treatment. Focusing on maintaining a positive attitude. Adjusting to the change in image. Making dietary changes. III Enjoying life to its fullest. Participating in children's lives. Accepting support from family, friends, and health care providers. Promoting breast cancer awareness. Helping women in similar situations. IV Emphasizing the power of prayer to release fear. Relying on their faith and hope to help them fight the breast cancer. Trusting in God to help them leave a legacy for their children. Stressing that they control their own destiny. Knowing that they could live productively with the illness.

Giorgi's Method Applied: Fourth Step
Identification of Essences

I then reflected on the synthesized meaning units and pulled out the core meanings from the subjects' experiences and identified the essences.

Table 2. *Summary of Synthesized Transformed Meaning Units and the Essences*

Synthesized transformed meaning units (themes)	**Essences**
I	
Expressing vulnerability regarding the diagnosis.	Uncertainty
Thinking of where the cancer will spread next.	
II	
Accepting the diagnosis of breast cancer.	Coping
Setting priorities.	
Making informed decisions regarding treatments.	
Enduring the pain and adverse effects of adjuvant therapy.	
Emphasizing the need to comply with the treatment.	
Focusing on maintaining a positive attitude.	
Adjusting to the change in image.	
Making dietary changes.	
III	
Enjoying life to its fullest.	Loving
Participating in children's lives.	
Accepting support from family, friends, and health care providers.	
Promoting breast cancer awareness.	
Helping women in similar situations.	
IV	
Emphasizing the power of prayer to release fear.	Believing
Relying on their faith and hope to help them fight the breast cancer.	
Trusting in God to help them leave a legacy for their children.	
Stressing that they control their own destiny.	
Knowing that they could live productively with the illness.	

To support the essences and demonstrate the research rigor, each of the essences is described and examples from the narratives selected to support the specific essence.

Essence I: Uncertainty

In their descriptive narratives, the participants expressed uncertainty regarding their treatments and prognosis.

The following definition of uncertainty was derived from the themes: Expressing vulnerability regarding the diagnosis *and* thinking of where the cancer will spread next. When these two themes are integrated, the resulting essence can be described as a feeling of vulnerability and unknowing towards the future. Using the definition of uncertainty, the transcripts were reviewed and examples of this essence selected to demonstrate validity. Dealing with uncertainty after being diagnosed with Stage IV breast cancer was expressed as an essence for all six participants. Participants stated that while they were not surprised by the diagnosis because they had initially felt a lump while doing SBE, they were saddened by the severity of the results and the uncertainty about their future. An example of their comments is captured in Anna's comment:

> When I saw and felt the lump in my breast it was hard and round. I called my doctor, made an appointment, went for a biopsy and the results confirmed that I had advanced breast cancer. I was not shocked. I was saddened by what it meant and what impact it would have on my family. The word cancer was such a big word to me. I felt an eerie feeling. I constantly think about it and wonder where it is going to spread next. It's a horrible, difficult, and uncertain feeling.

A participant, Rosa, stated that initially she was dismissive of the potential diagnosis because she did not think that young women with no family history of breast cancer could possibly get breast cancer. She consulted with her relatives and was reassured that she had nothing to worry about. A year later, she went to her health care provider for her yearly exam. A breast biopsy was done and she was diagnosed with Stage IV breast cancer. She stated:

> I just thought it was a little cyst or something that I felt on my breast. I have no history of breast cancer in my family. I thought I was too young to get breast cancer. I thought women over 40 got it. I waited a year before I went to have the doctor examine it. I couldn't believe it when he gave me the diagnosis and I regret not having gone sooner to have it checked out. Now I often think where is it going to spread next and how much more will it affect my life?

Essence II: Coping

In their descriptive narratives, participants talked about coping with fear and frustration.

The definition of coping was derived from the themes, which were: Accepting the diagnosis of breast cancer; setting priorities; making informed decisions regarding treatments; enduring the pain and adverse effects of adjuvant therapy; emphasizing the need to comply with the treatment; emphasizing the need to maintain a positive attitude; adjusting to the change in image; and making dietary changes. When these themes are integrated, the resulting essence can be described as *accepting the diagnosis in a way to promote thinking that results in positive changes and healthy choices*.

Using the definition of coping, the transcripts were reviewed and examples of this essence selected to demonstrate validity. Once the participants received their diagnosis of breast cancer, they arranged for additional tests and set up appointments with specialists. They were frustrated with the long wait for diagnostic tests. They stated that it appeared as if the doctors were not collaborating with each other regarding the participants' diagnosis and/or plan of care because they each repeated the same questions. The following are participants' comments: "It took too long to get a sonogram, MRI, and biopsy, and too long for them to give me an answer as to what specifically was wrong" (Rosa); "There was too much time wasted" (Anna); "It was very depressing and confusing having to explain yourself over and over again to someone new and not having a point of focus with one doctor" (Carmen). Similarly, Delia stated:

> It was difficult to decide what would be the best treatment plan when most of the time I felt we couldn't get past how I discovered the lump. I found the lump and one doctor stated it did not show up on sonogram. He made an appointment for me to have an MRI the follow month and there was the lump! There was too much time wasted.

They all stated that having trust in their doctors helped them deal more effectively with this illness. The participants stated that they searched the internet to see what options were available before making any decisions regarding the treatment. They believed that being well informed of their illness would help them make better choices when planning their treatment. The following are some of their comments: “Trusting my doctors was essential” (Anna); “I wanted to know what the options were but first I wanted to have genetic testing” (Carmen); “The doctors were very receptive to my needs. So I had genetic testing done” (Delia); “I wanted to know all my options before I made any decisions about the best method to treat the disease” (Rosa); “I promised that I would kick its ass. I’m going to fight it to the core” (Laura); “I have cancer; cancer does not have me. I’ll do whatever it takes to fight the monster and I will win this fight…need to comply” (Juana).

All participants realized that in order to combat this illness they had to undergo surgery and receive adjuvant therapy. Three of the participants had bilateral total mastectomies, two had total mastectomy of the affected breast and one had a lumpectomy. At the time of their discussion with me, all six participants were receiving chemotherapy and one was receiving chemotherapy with radiation therapy. The following are reflections of their experiences receiving these modalities of treatment: “I’m not happy about this aggressive chemotherapy” (Anna); “It’s something that had to happen. It is very horrible. It’s a 180 degree lifestyle change” (Laura); “It’s really, really painful; gas and always feeling like I have to go to the bathroom” (Carmen); “The treatment is very bad; it’s just hard to bear. I know it’s a necessary evil” (Delia); “It makes me feel very tired and weak. I fell in the street and the doctor changed it" (Juana); "The pain I feel from the chemo is very strong. And the nausea—I would throw up violently 10-20 times after chemo. So he gave me multiple medications for the nausea" (Rosa).

All the participants agreed that it was important to stay informed regarding the medical regimen, comply with the medical treatment and make dietary changes in order to combat the disease and promote their wellness, despite the changes in body image. The following are participants' related comments: "My life has changed drastically. I'm in the hospital and clinics all the time since I was diagnosed" (Anna); "I had long beautiful hair. Now I look sick and I have no hair and when I put on that wig; it looks funny. My daughter told me that I look beautiful with short hair" (Laura); "My hands and feet are horrible" (Carmen); "I was busty and now look. But my breasts are not what make me a woman" (Delia); "It's hard at times. I want to cry my eyes out and mourn. But the radiation shrinks the tumors and the chemo eliminates whatever cancer is in the bone" (Juana); "This chemo is horrible. My body is being torn up inside. The way I keep my sanity is to think outside the box" (Rosa).

All participants stated that their breast cancer had made them re-evaluate their lives and changed their priorities. One change was related to diet. In line with this, the participant, Anna, expressed:

> I changed my diet. We no longer eat red meat except for special occasions. I eat tuna, chicken, and turkey. Sugar is another element that seems to be dangerous to cancer patients. It triggers more cancer. I cook a lot of brown rice with beans. I'll buy fish and shrimp and boil potatoes and eggs.

Similarly, Laura stated:

> It's very difficult not to eat red meat. It's part of being Dominican. You know what I mean! We eat red meat, rice and beans—that's a meal. The food here is not bad, you know how their food is, but they try their best to give you the food you

> request. Even if, you know, you do not like it, but I eat it. I have my Dominican crackers because theirs were too sweet or too salty. I'm not someone who eats that much, but how nice it is to be able to have something from home.

Essence III: Loving

In their descriptive narratives, the participants expressed positively influencing their children and future generations of Dominican women.

For this study, the definition of loving was derived from the themes which were: Enjoying life to its fullest; participating in children's lives; accepting support from family, friends, and health care providers; promoting breast cancer awareness; and helping women in similar situations. An integration of these themes resulted in the essence of loving, which is described as *enjoying life through the meaningful participation in the lives of others and accepting support*.

Using the definition of loving, the transcripts were reviewed and examples of this essence selected as one way to demonstrate validity. Throughout the conversations, the participants emphasized that loving their children was the primary impetus for participating in treatment for their illness. They expressed the need to nurture and protect their children. Participants explained that they prioritized and arranged their treatments around their children's schedules so as to not disrupt their routines. For the five participants who were married, while they acknowledged that their husbands were very supportive, they focused always on their children. The one participant who was separated also stated that her husband was very supportive and actively involved in helping her with the care of the children throughout the treatment process. Also, that participant stated that she became best friends with her husband then even though she was separated. All the participants stated that their husbands accompany them to treatments and were always available for them.

All the participants emphasized that the most important thing was to embrace each moment with their children. The following are related comments:

> My 2 year old is always playing on top of me. He is very affectionate. He says I have a booboo on one of my breasts because I have a scar there. He will ask me if I have been to the doctor and I say, ‘Yes baby, I went to the doctor today and I don’t feel so well, because my stomach was really bad.’ He holds my boob. And he says ‘take care of Mami’s boobs,’ and ‘we can’t hurt Mami’s boobies.’ My 11 year old daughter asks a few questions but generally she is withdrawn so we do things together. I did her hair and spoke to her about what she should expect for the new school year. I enjoy my kids. My kids are so proud of me. I draw energy from them. They keep me distracted. Cancer empowered me to make decisions for my kids and my well-being that I would not have done before. We relocated to a place that is much more peaceful. My children’s love gives me the strength to put up with the treatments and gives me the will to live. (Anna)

> I believe my children are a gift. They have always been my focus but now more than ever. I draw energy from them and I want to give them as much as I can before I leave this earth. My role now is like gardening. I’m constantly weeding out [this cancer]; and focusing on taking care and nurturing of the seeds I planted. That’s how I see myself. Just taking out the weeds and planting new flowers and hopefully I’ll have a beautiful garden for me and my kids to have a better life. This is what helps me sleep at night. My children help me find strength within myself that gives me the will to live. Each day with them is a gift. (Laura)

All the participants in the study expressed the importance and the desire to actively participate in making other women, particularly younger women, become aware that breast cancer can strike at any time. They emphasized the need for SBE, annual mammograms and early interventions. This was their expression of care and concern for others. The participant Carmen stated:

> I like sharing my personal experiences living with breast cancer. I hope it will help women take better care of themselves and not take themselves for granted. I want to show my children the right thing to do.

In the same way, participants added that they simply did not want anyone to have to deal with this illness. In particular, Anna expressed, “I do not wish this experience on anyone.” Likewise, Delia stated, “What I would like is for women to learn from my experience—particularly, my children and family.” Also, Laura expressed:

> The more I talk about my experiences dealing with this monster, the less scared they will be, and the more they will actively participate in taking better care of themselves. I know I got the cancer but, more important, I have to teach my children that when life gives you lemons you make lemonade. Being silent about this illness is not an option.

In the same vein, Rosa stated, “The more they know, the more they will take care of themselves. I think that is my responsibility as a mother.”

All the participants repeatedly stated that it was important to maintain a positive attitude to combat advanced breast cancer. They expressed their gratitude for the family, friends, and strangers who had helped them during their difficult times. In line with this, the following are participants’ statements: “My family is very supportive. My 2 year old always tells me how beautiful I look” (Anna); “The girls took me shopping for new clothes and insisted that I think of myself first from now on” (Delia); “My mother and cousin are very supportive. They take me to my treatments and always call me to see if everything is going well with me and the children” (Anna).

Essence IV: Believing

In their narratives, the participants expressed believing in God and drawing from their faith for strength.

The definition of believing was derived from the themes which were: emphasizing the power of prayer; believing that faith and hope are vital in fighting cancer; trusting in God to help them leave a legacy for their children; believing that they control their own destiny; and knowing that they could live productively with the illness. Integrating these themes, the resulting essence is described as: *trusting in God through prayer, faith and hope will help them fight the cancer to create everlasting memories for their children.*

Using the definition of believing, the transcripts were reviewed and examples of this essence selected to demonstrate validity. All participants emphasized the power of prayer. However, their approach varied in dealing with their illness. While they all expressed their belief in God, most of them also stated that they controlled their own destiny and for that reason would be aggressive in treating their advanced breast cancer. Participant Delia expressed:

> I pray to God. I pray and I pray. I'm talking to God constantly. I put my faith, fears, hope, and everything into talking to God and it's released all those things that are going on in my life. I know we were put here by a higher power. Faith in God is comforting. I think that the Lord will cure me if it is his wish because it is my wish. I always relate health to my faith. I don't just pray to God and wait. You have to have faith in a higher power that you connect with and lay your burdens on. I surrender to my God. I said, "Father, if this is what I am feeling, choose the doctors that are going to be right and choose the institution where I am bound." I took the treatment because it was the best one for my type of aggressive cancer and if God didn't want me to have the treatment he would not have let them develop it.

All participants expressed that their priority was their children and that it was imperative to create memories for them which they could draw from to make them stronger. The following are the comments of two participants.

> Right now my focus is my children. I make sure that I spend as much time with them as possible. Every day is a special day when I am with them. I look at it like I'm tending to my garden. I pull out the weeds, plant the seeds, water the soil, and the result will be a beautiful garden. I make sure that they learn and eat healthy food. (Anna)
>
> I go to every dance and piano recital. I always make sure to tuck them in at night and my last words to them are, 'I love you much.' It's important to create memories that they will carry with them for a lifetime. (Delia)

Supporting the Essences and Establish Research Rigor

According to Giorgi (1970), essences are first extracted through my intuition while reading the transcripts. Therefore, the essences are initially derived from my consciousness as the narratives are reviewed. In order to establish the rigor for the qualitative method, I returned to the transcripts to select sections of the narratives that reflected each essence. This method helped to establish both reliability and validity (Munhall, 1994; Morse et al., 2002).

During this process, the essence of *uncertainty* emerged. The initial identification of this essence was of *living in the present*. However, after discussion with the two experts, and further reviewing of the narratives, it was agreed that the essence ought to be *uncertainty*. To make sure the entire committee was in agreement with the findings, the essences, themes and transcripts were submitted to the other members of the committee as well. One hundred percent agreement was obtain by all the committee members.

Giorgi's Method Applied: Fifth Step
Overall Meaning or Structure

Using the final phase of Giorgi's (1993) method, I formalized a compatible description of the overall meaning or structure of the experience by combining and incorporating the insights attained in the previous step. In order to accomplish this phase, the definitions of the essences were derived from the integration of themes specific to the essences listed and then synthesized to create and describe an overall meaning of the experience. From the data findings, the following recapitulates the meaning of the lived experiences of Dominican women with Stage IV breast cancer: *one of uncertainty and unknowing; accepting the diagnosis so that thinking results in positive changes and healthy choices; enjoying life through the meaningful participation in the lives of others and accepting support;* and *trusting in God through prayer, faith and hope to create an everlasting legacy of love for their children.*

After the description of the overall meaning was formulated from the essences, the structure unfolded. I was then inspired to write the following poem:

The Legacy of Love

The legacy of love is a way of being

Fostering, giving, receiving and always forgiving

Grounding our thoughts and guiding our actions

Permitting us to be open to new experiences

Allowing us to cherish each moment wholeheartedly and unconditionally

Providing invaluable insights and strength needed when decisions must be made

regarding holding on or letting go

Enabling us to express ourselves in ways that are profound and immeasurable

The legacy of love is the fuel which feeds our soul.

By,
Alsacia L. Pacsi

In writing this poem, I was able to better synthesize the study data. This helped my understanding of the overall structure for Dominican women living with Stage IV breast cancer, which emphasized a need *to leave a legacy of love for their children.*

I summed up the participants' voices in the following way:

Their Voices

Dominican women's voices resonate as one,

Echoing the need for

Endurance.

Despite the agonizing and often debilitating effects of the treatments, they exhibit
Perseverance.
Despite the feeling of vulnerability that is sometimes overwhelming, there is
Resilience.
Despite the many uncertainties faced,
One voice echoing the necessity to fight 'this monster' and win.
One voice emphasizing the battle is worth fighting in order to create an everlasting legacy
of love for what they most treasure,
Their Children

By,
Alsacia L. Pacsi

Summary

This chapter consisted of a thorough description of the six women who participated in this phenomenological study. The participants' stories were analyzed using Giorgi's method. This method was used to ascertain and synthesize transformed meaning units, essences, and the overall structure of the lived experiences of Dominican women living with Stage IV breast cancer. The research rigor is discussed and excerpts of conversations with these women were given as an example to support the rigor.

I learned that the participants were very knowledgeable about their diagnosis, treatments, and prognosis. They all discussed the various treatments they were receiving and the effects they had on their quality of life. They all stated that the thought of having advanced breast cancer was always in the back of their minds, no matter how hard they tried to suppress it. All participants appeared to be eager to share their experiences and they described them vividly. Throughout the conversations, I thought that the participants were actually reliving their experiences and expressed their emotions as they related them. At the end of the conversation, each of the participants thanked me for posing the question and listening to them. They expressed gratitude for having the opportunity to tell their stories.

CHAPTER VI

REFLECTION ON THE RESEARCH FINDINGS

Introduction

The data findings from this study indicated that the lived experiences of the Dominican women with Stage IV breast cancer *was one of uncertainty and unknowing; accepting the diagnosis so that thinking results in positive changes and healthy choices; enjoying life through the meaningful participation in the lives of others and accepting support;* and *trusting in God through prayer, faith and hope to create an everlasting legacy of love for their children.* To fully understand this research phenomenon, it was important to draw parallels from the literature review. Results indicated that research studies, although similar (a focus on participants' lived experiences) and addressing Hispanic women with breast cancer, did not focus specifically on Dominican women. Even so, nearly all of those studies recommended that future studies target more culturally discrete populations. The review of literature in this section does not include those recommendations.

Synthesis of Data

Sammarco and Konecny's (2008) quantitative study relating to Hispanic and White women living with breast cancer focused on social support, quality of life (QOL), and uncertainty among breast cancer survivors among 89 Hispanic women: 61 Puerto Rican; 14 Caribbean; 10 Central or South American; and 4 other. The findings indicated that their perceptions of social support and uncertainty were significant indicators in their QOL. In this study uncertainty was one of the essences derived from the synthesized transformed meaning units (themes) and it contributed to the overall structure that unfolded.

In a study exploring the lived experience of Brazilian women diagnosed and treated for breast cancer conducted by Vargens and Berterö (2007), their focus was more on the experiences of breast cancer as a chronic illness. The themes that unfolded and subsequently interpreted were: developing a positive outlook on life; making efforts to hide illness from the family and others; the desire to be acknowledged as a woman with certain needs; and reflections on body-image and self-image (Vargens & Berterö, 2007). The researchers found that the essence that unfolded was "*living side by side with the phantom of death*" (Vargens & Berterö, 2007, p. 471 [italics added]). In their study, women diagnosed with advanced breast cancer focused more on their awareness of their own mortality, which was the impetus for them to change their priorities while voicing the need to do as much as they could to live the best life possible (Vargens & Berterö, 2007). In the present study, the Dominican women were more focused on effective adaptation and leaving a legacy for their survivors.

Manuel et al. (2007) conducted a research study using a mixed method approach: a qualitative and quantitative cross-sectional study. This inquiry investigated the coping strategies of women 50 years or younger, middle and upper class non-Hispanic white women. The results indicated that those women used wishful thinking and positive conscious readjustments as coping strategies to deal with breast cancer (Manuel et. al., 2007). In the qualitative portion of the study, the younger women cited various strategies used to deal with breast cancer depending on the stressor. For example, they reported the use of social support, positive cognitive restructuring and making key changes that helped them cope with their illness (Manuel et al., 2007). My research study on Dominican women did not focus specifically on coping, but more on the participants' experiences and the ways in which the diagnosis of cancer was life-altering.

Badger, Segrin, Dorros, Meek and Lopez's (2007) quantitative study focused on a diverse group of women with breast cancer to test the hypotheses that telephone-delivered psychosocial interventions (telephone interpersonal counseling [TIP-C]) lowered anxiety levels in both the participants and their significant others when dealing with Stage I-III breast cancer. Badger et al.'s (2007) research also suggested that participants and their partners, who received telephone-psychosocial interventions and participated in a group exercise, also experienced symptoms of depression and anxiety. In using the TIP-C method, participants' psychological quality of life was improved when compared to those in the attention control group (Badger et al., 2007). The Badger et al. (2007) study consisted of a majority of white participants whose stage of breast cancer was between Stages I-III.

A qualitative interpretive phenomenological study was done to provide understanding of the role of destiny and fatalism among Hispanic women. In a sub-group of Dominican women, their fatalistic attitudes toward illnesses like breast cancer served as an impetus for screening and primary care (Flórez et al., 2009). The purpose of that study was to explore the meaning of Dominican women's perceptions of breast cancer and screening, within the cultural context of destiny or fatalism, living in NYC (Flórez et al., 2009). Study data indicated that Dominican women viewed destiny as a genetic factor not related to a divine supernatural process (Flórez et al., 2009). They discovered that to the Dominican women, destiny served as the impetus for active participation in cancer screening (Flórez et al., 2009). The participants' beliefs in fatalism account for their position that a late diagnosis was related to *descuido*—carelessness (Flórez et al., 2009). Also, the research indicated that fatalism was not a deterrent for Dominican women to have cancer screening. Furthermore, the research proposed that assumptions of fatalism should be viewed as a complex concept, influenced by cultural beliefs and that generalizations are often inaccurate (Flórez et al., 2009). Similar to the findings of Flórez et al. (2009), all of the participants of this research inquiry underwent yearly mammogram screenings. Yet they were diagnosed with Stage IV breast cancer. This raises an important question: Are there other factors, such as biological, environmental and/or genetic, that may account for the rapid growth and the diagnosis of advanced breast cancer among Dominican women?

A possibility for diagnosis of advanced breast cancer among Dominican women may be addressed by the work of Hall, Hall, Pfriemer, Wimberley, and Jones (2007). They investigated the effectiveness of multifaceted, culturally sensitive, linguistically appropriate breast cancer education among Hispanic women in Arkansas. The result of this quantitative study indicated that multifaceted, culturally sensitive and linguistically appropriate breast education programs increased awareness and knowledge-base and decreased the barriers to mammography (Hall et al., 2007). This current study also addresses the issue of critical education relating to breast cancer, specific to Dominican women.

Luquis and Villanueva-Cruz (2006) conducted a structured qualitative study to explore perceptions, attitudes, and knowledge regarding breast cancer and screening behaviors among Hispanic females in the Pennsylvania south center area. The 44

Hispanic women who participated in the study were distributed as follows: 20 Puerto Rican, 20 Mexican/South American, and 4 other. The findings indicated that among the groups of women, cultural factors, such as family and fatalism, impacted participants' knowledge of breast cancer screening and early detection (Luquis & Villanueva-Cruz, 2006). The majority of the participants stated that they would prefer the health care providers and educators to provide breast cancer education in Spanish (Luquis & Villanueva-Cruz, 2006). This information may be helpful in aiding health care professionals and educators in creating user-friendly breast cancer education and screening promotional programs for Hispanic women. This may help to clarify their misconceptions related to breast cancer prevention and early detection. The study also acknowledged that culturally sensitive, multifaceted health care needed to be more tailored, especially in the case of Hispanic sub-group in order to promote health (Luquis & Villanueva-Cruz, 2006). This relates to the current study which proposed that Dominican women respond differently to their life-situations than other Hispanic groups.

A quantitative study centered on assessing the body image and sexual issues faced by women 50 years and younger, diagnosed with breast cancer, during the period of receiving treatments (Fobair et al., 2005). From 1994-1997, 398 White Hispanic, 29 African American, 45 Latina, and 86 Asian women participated in this study (Fobair et al., 2005). The research indicated that 33% of the participants experienced several problems associated with body image over time (Fobair et al., 2005). The sexual problems were related to decreased mental wellness and being married—conflicts with partners who had difficulty understanding the women's feelings and vaginal dryness (Fobair et al., 2005). Fifty percent stated that they were no longer sexually active because they lost the desire (Fobair et al., 2005). These findings, however, were not consistent with the findings of this current study; nor did Fobair et al.'s (2005) study focus on Dominican women as a sub-group.

Kudadjie-Gyamfi, Consedine, Magai, Gillespie, and Pierre-Louis (2005) studied the influence of *cancer worry* on breast self-examination practices of Dominican, Haitian, African American, European American and English-speaking Caribbean women. Results indicated that Dominicans had greater adherence to breast self-exam guidelines compared to the other ethnic groups and expressed the least *cancer worry* (Kudadjie-Gyamfi et al., 2005). These participants expressed that BSE was effective and performed BSE more often. Haitian women were just behind to the Dominicans; however, they expressed performing BSE less frequently (Kudadjie-Gyamfi et al., 2005). In this current study, the Dominican women reported that they did conduct SBE; however, it was not sufficient in detecting their advanced breast cancer.

Garbers, Jessop, Foti, Uribelarrea, and Chiasson (2003) investigated the reasons why Mexican and Dominican women from medically underserved communities in NYC did not seek breast cancer screening. The participants were Dominican and Mexican women on Medicaid and/or Medicare. The study indicated that 44.6% of Dominican women cited the issue of fear; while 52.3% of Mexican women cited *descuido* (carelessness) and lack of information for not getting cancer screening (Garbers et al., 2003). These findings differ from those of the current study which found that the participants did in fact utilize breast cancer screening.

Reflections from a Nursing Model Perspective

The overall meaning of the experience of Dominican women with Stage IV breast cancer is described as *one of uncertainty and unknowing; accepting the diagnosis so that thinking results in positive changes and healthy choices; enjoying life through the meaningful participation in the lives of others and accepting support;* and *trusting in God through prayer, faith and hope to create ever lasting memories for their children.* In reflecting on the literature review and the overall meaning statement above, I employed Dr. Callista Roy's nursing model to further shed light on this study.

The conceptual nursing model of Dr. Callista Roy provided additional insights into the study. In the Roy Adaptation Model (RAM), the main concept of adaptation corresponds to effective development of the person, who is interdependent with others. Roy uses the terms "mastery" or "integrative adaptive outcome" which show that the RAM is consistent with the "purposefulness of human kind," "the unity of purpose of human existence," and "activity and creativity for the common good"—all indicating that there is a possibility for transcendence (Roy, 2009, p. 28). Similarly, adaptation in the RAM "contributes to the overall goal of health care, that is, to promote the health of individuals and society" (Roy & Andrews, 1999, p. 54), and "to enhance system relationship through acceptance, protection, and fostering of interdependence and to promote personal and environmental transformations" (Roy & Andrews, 1999, p. 55).

Roy wrote, "The Roy Adaptation Model's philosophic assumptions clearly recognize the ideal that each person is to have maximum freedom to realize his or her potential; this ideal stemmed from the belief that human life has common meaning, purpose and destiny" (Roy & Andrews, 1999, p. 331). Roy (1988) developed explicit assumptions related to the two philosophic principles of humanism and veritivity. Humanism, drawing from philosophy and psychology, acknowledges that the person's perceptions of human experiences are the key to knowing and valuing (Roy & Andrews, 1999). In naming and explicating her philosophical assumption, Roy derived the word "veritivity" from the Latin word *veritas*, which means truth (Roy, 1988; 1997). For Roy, veritivity addresses the principle of human nature that asserts all human existences have a common purpose. In veritivity, unity of purpose of humankind and working towards a common good, individuals value meaning and life and should therefore be seen in the context of the purposefulness of human existence in their society (Roy, 1988).

Roy's description of veritivity includes the concept of persons as thinking, feeling human beings imbued with a sense of meaning, purpose, intentionality, and free will. Roy also emphasizes the importance of human diversity, but maintains that truth rises above individual attributes to unite all humankind in a universal manner. The universality of the human experience is conveyed in the first defining characteristic, which is the "common purposefulness of human existence" (Roy & Andrews, 1999, p. 32). The common purpose of the Dominican women in this study was to enjoy life through the meaning of participation in the lives of others and accept support and trust in God through prayer, faith and hope, with the goal of creating everlasting memories for their children. Through the telling of their stories about their journeys, the participants embodied the concept of veritivity, which in turn supported their transcendence of the illness.

In this descriptive qualitative study, which centers on the lived experiences of Dominican women living with Stage IV breast cancer, I drew from Roy's concept of veritivity in an attempt to gain further understanding of the women's perceived reality.

Data findings indicated that these women were able to adapt to a life of uncertainty and unknowing and accept their diagnosis, which allowed them to adapt positively by making meaningful changes in their lives and healthy choices. This process allowed connections to be made between Dominican women and the concept of veritivity as a philosophical approach to their reality.

Data showed that these women adhered to the various forms of surgeries and adjuvant therapy, changed their diets, and readjusted their lives as a way of dealing with uncertainty and knowing and accepting the diagnosis so that their thinking resulted in positive changes and healthy choices.

Roy's philosophical assumptions inherent in the concept of veritivity are: 1) persons use human creative abilities of awareness, enlightenment, and faith; and 2) persons are accountable for the processes of deriving, sustaining, and transforming the universe in order to achieve effective adaptation (Roy & Andrews, 1999, p. 35). These Dominican women diagnosed with Stage IV breast cancer embodied creative abilities of awareness, enlightenment and faith, which were revealed in the overall meaning of the experience. Awareness was shown in accepting the diagnosis. Enlightenment was evidenced through enjoying life through meaningful participation in the lives of others; and faith was seen in their acceptance of support and trusting in God through prayer, faith, and hope. They were able to change the focal stimulus (cancer) into contextual stimuli (their children) and vice versa.

According to data, Dominican women with Stage IV breast cancer empowered themselves through faith by enlightening and redirecting their energies into what was important to them—their children. This is an example of their transcendence through an “activity and creativity for the common good” (Roy & Andrews, 1999, p. 34). For these women, the common good was creating a legacy of love for their children. Their children represented the future generation. These women’s creation of everlasting memories for their children serves as an example of providing for “the unity of purpose of human existence” (Roy & Andrews, 1999, p. 34).

In summary, the participants’ ability to adapt with strength and power has led them to develop a legacy of love for the children. Research findings indicated that as they face their mortality, they transcended their illness and showed their ability to put aside their pain. Roy’s scientific and philosophical assumptions provide the basis to better understand the uncertainties that participants experienced in redirecting their energies towards taking care of their children and also setting examples for increasing breast cancer awareness among others.

Relevance for Nursing

Implications and Recommendations for Nursing Research

Based on this study, the following recommendations are made for consideration for future research: 1) Replication of this research should be done with participants of different ethnic, racial, and socioeconomic backgrounds. For example, studies should include single and divorced mothers, with and without children. 2) Replication of this research is needed using participants who were diagnosed between the ages of 20 and 30. 3) Replication of this research is needed using participants who are terminally ill with Stage IV breast cancer at the time of the study. This did not apply to any of the participants in this research. 4) Future research should be done to compare similarities and/or differences of Dominican women with Stage IV breast cancer to European, non-European American and other Hispanic groups. 5) To decrease the cultural health disparities among the women with Stage IV breast cancer, it is imperative that future qualitative studies be done to understand what these women are experiencing in their own words. By knowing what is important to the participants, we can use the information to promote a sense of well-being by providing quality health care. 6) More research is needed to explore the relationship between illness and transcendence, especially when the diagnosis is Stage IV breast cancer.

Analyzing the results of this research, one can infer that adaptation for the Dominican woman does not mean an acceptance of their illness; on the contrary, adaptation in this case is an impetus to build a new environment and a new legacy for their children. Future studies should be done using qualitative and quantitative methodology in order to further explore the phenomenon of parenting in this population. Due to the unpredictability of life for these women after diagnosis, it becomes evident that the phenomenon of parenting for this population merits a more thorough investigation.

Implications and Recommendations for Nursing Practice

Study findings indicated that Dominican women with Stage IV breast cancer were most concerned about being able to live long enough to care for their children and create a legacy of memories for their children. Nurses caring for these women could support this desire by including the children in the planning of care. Assisting these women to create lasting memories through the use of media such as videotapes—to be played for their children's graduation from high school, *quinceanera,* their wedding and other significant events—is one approach to help them realize their parenting goal. Another opportunity is for them to write letters and journals to their children that can be opened at intervals. This could carry on the memories of the women in their children's lives.

Nursing interventions need to include the approach of asking Dominican women (as well as others) about their needs in order to facilitate active participation in their care. Realizing also that, for these women, family is an integral part of their decision making, it is also important for nursing students to learn that family has many meanings for the different cultures; for Dominican women, an extended family may include uncles and aunts as well as close friends.

Implications and Recommendations for Nursing within the context of Health Disparities

In this study, I pointed out the impact of advanced breast cancer on second-generation Dominican women. The need for additional research that focuses on specific ethnic groups and sub-groups is again supported. Ashing-Giwa et al. (2007) examined health related quality of life (HRQOL) and its predictors among Latina, African, Asian, and European-American women with breast cancer. This quantitative study indicated that ethnic, cultural, and social-ecologic influences on HRQOL were complicated and further studies using larger samples were recommended (Ashing-Giwa et al., 2007).

I recommend further research addressing health care disparities as well as including researchers who share a common language with the population being studied. For example, in this study Dominican women are representative of the Hispanic population. In the setting where the study data were collected, the health-care providers were from many Hispanic cultures, including Dominicans who spoke Spanish. The recruiters of the study participants were also Dominican, as was I, the interviewer. This cultural similarity appeared to have provided a comfortable environment for participants to openly verbalize their thoughts, feelings and concerns.

Future studies are recommended to further explore the phenomenon of parenting as related to the study population using qualitative and quantitative methods. Due to the unpredictability of the lives of these women after diagnosis, it is apparent that the phenomenon of parenting for this population merits a more thorough investigation.

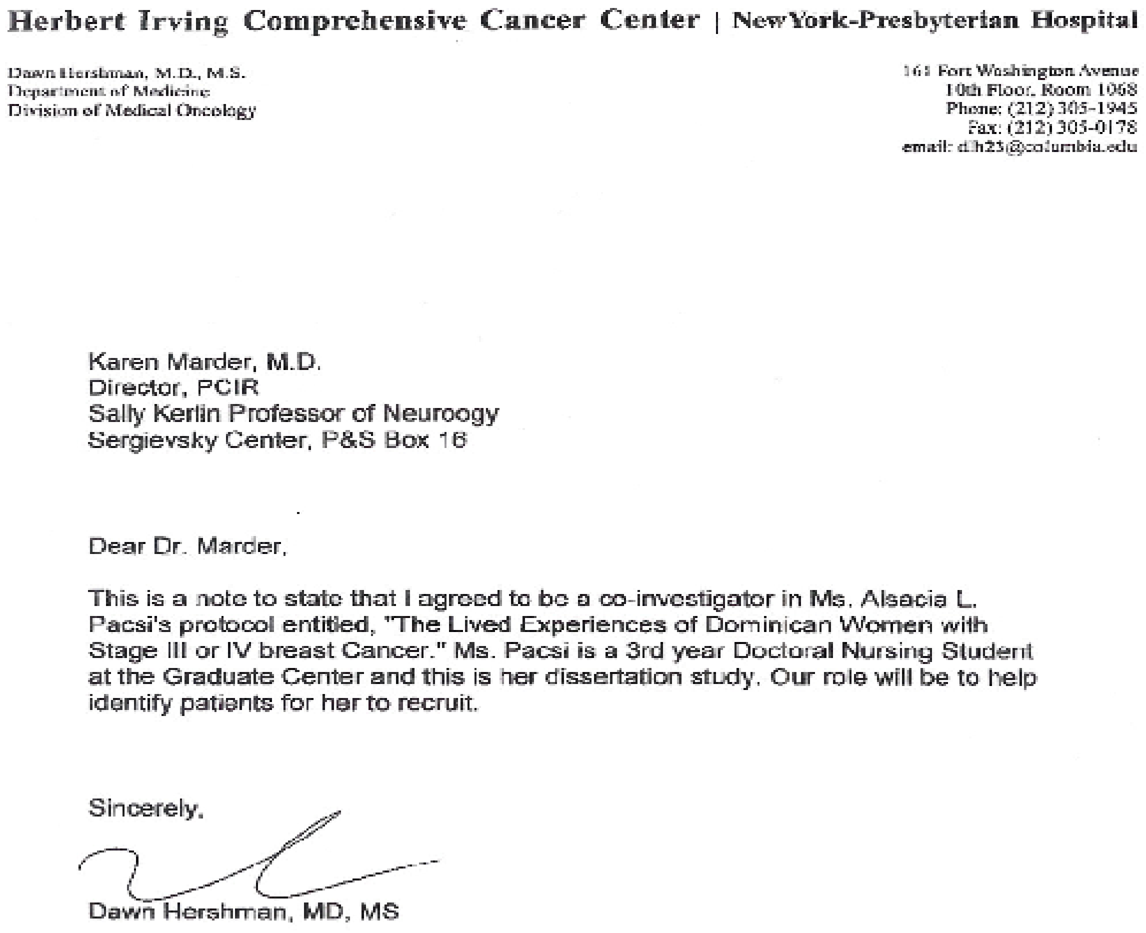
Summary

This phenomenological study explored the lived experiences of Dominican women diagnosed with Stage IV breast cancer (advanced breast cancer) using a purposive sample of convenience to illuminate their perceptions living with advanced breast cancer. Six second-generation women of Dominican immigrants, residing in the NYC area, underwent face-to-face in-depth interviews. Each participant was interviewed once and data analyzed using the descriptive phenomenological method of Amadeo Giorgi (1970, 1985, 1993, 1997, 2005). The four essences that unfolded in this study were uncertainty, coping, loving, and believing. The overall meaning of the experience of Dominican women with Stage IV breast cancer is described as one of uncertainty and unknowing; accepting the diagnosis so that thinking results in positive changes and healthy choices; enjoying life through the meaningful participation in the lives of others and accepting support; and trusting in God through prayer, faith and hope to create ever lasting memories for their children. The synthesis of the overall structure for these women is to ‘leave a legacy of love.’

Interpretation of the overall meaning of the experience and structure aligned with Roy’s Adaptation Model (RAM) philosophic principles of humanism and veritivity (Roy & Andrews, 2009). The overall meaning of the experience, as expressed by the participants, was translated to and aligned with these principles.

APPENDIX A

Letter of Collaboration from Dr. Hershman



Herbert Irving Comprehensive Cancer Center | NewYork-Presbyterian Hospital

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Department of Medicine
Division of Medical Oncology

161 Fort Washington Avenue
10th Floor, Room 1068
Phone: (212) 305-1945
Fax: (212) 305-0178
email: dlh23@columbia.edu

Karen Marder, M.D.
Director, PCIR
Sally Kerlin Professor of Neuroogy
Sergievsky Center, P&S Box 16

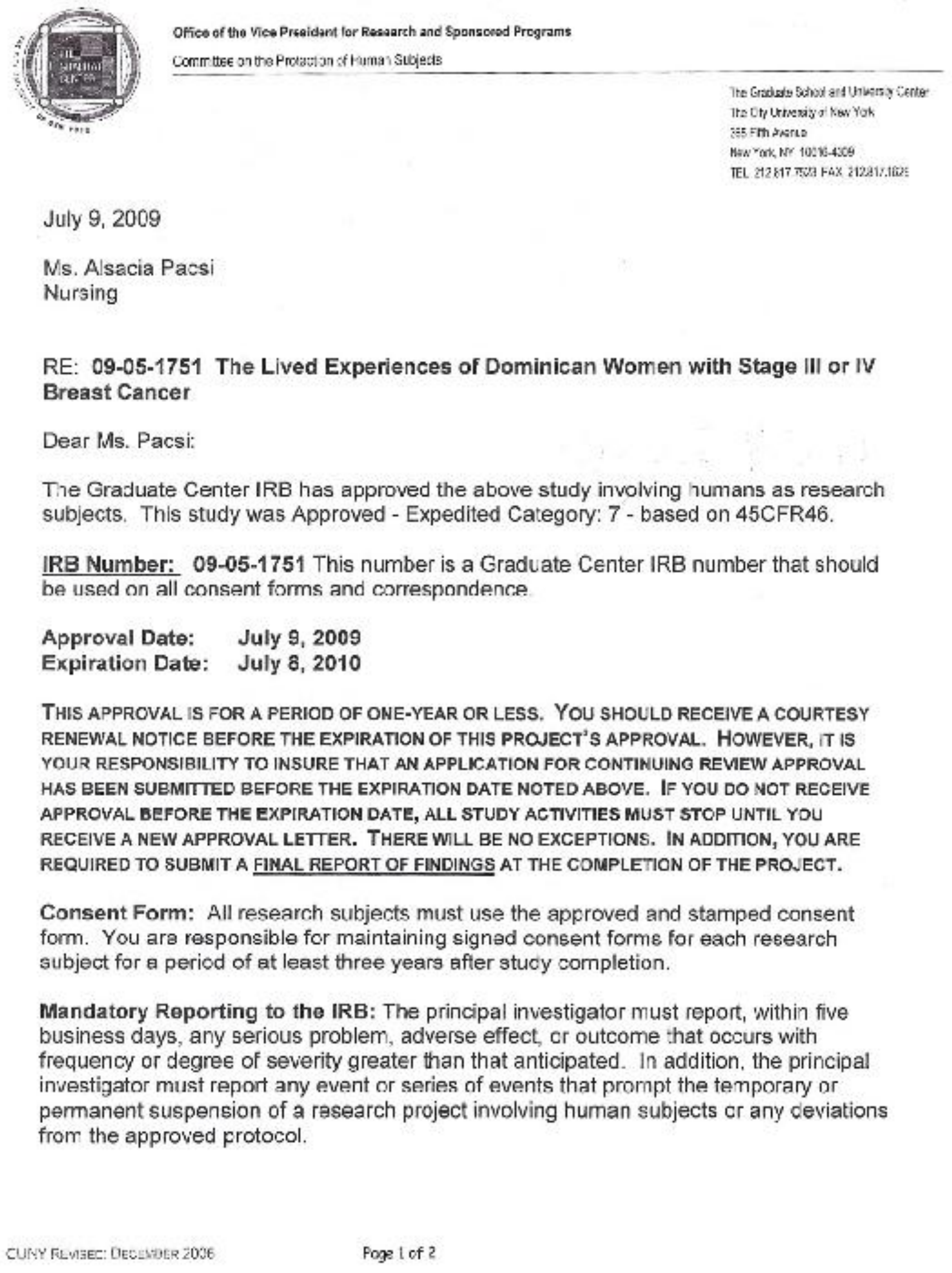
Dear Dr. Marder,

This is a note to state that I agreed to be a co-investigator in Ms. Alsacia L. Pacsi's protocol entitled, "The Lived Experiences of Dominican Women with Stage III or IV breast Cancer." Ms. Pacsi is a 3rd year Doctoral Nursing Student at the Graduate Center and this is her dissertation study. Our role will be to help identify patients for her to recruit.

Sincerely,

Dawn Hershman, MD, MS

APPENDIX B



Office of the Vice President for Research and Sponsored Programs
Committee on the Protection of Human Subjects

The Graduate School and University Center
The City University of New York
365 Fifth Avenue
New York, NY 10016-4309
TEL 212.817.7523 FAX 212.817.1629

July 9, 2009

Ms. Alsacia Pacsi
Nursing

RE: **09-05-1751 The Lived Experiences of Dominican Women with Stage III or IV Breast Cancer**

Dear Ms. Pacsi:

The Graduate Center IRB has approved the above study involving humans as research subjects. This study was Approved - Expedited Category: 7 - based on 45CFR46.

IRB Number: 09-05-1751 This number is a Graduate Center IRB number that should be used on all consent forms and correspondence.

Approval Date: July 9, 2009
Expiration Date: July 8, 2010

THIS APPROVAL IS FOR A PERIOD OF ONE-YEAR OR LESS. YOU SHOULD RECEIVE A COURTESY RENEWAL NOTICE BEFORE THE EXPIRATION OF THIS PROJECT'S APPROVAL. HOWEVER, IT IS YOUR RESPONSIBILITY TO INSURE THAT AN APPLICATION FOR CONTINUING REVIEW APPROVAL HAS BEEN SUBMITTED BEFORE THE EXPIRATION DATE NOTED ABOVE. IF YOU DO NOT RECEIVE APPROVAL BEFORE THE EXPIRATION DATE, ALL STUDY ACTIVITIES MUST STOP UNTIL YOU RECEIVE A NEW APPROVAL LETTER. THERE WILL BE NO EXCEPTIONS. IN ADDITION, YOU ARE REQUIRED TO SUBMIT A FINAL REPORT OF FINDINGS AT THE COMPLETION OF THE PROJECT.

Consent Form: All research subjects must use the approved and stamped consent form. You are responsible for maintaining signed consent forms for each research subject for a period of at least three years after study completion.

Mandatory Reporting to the IRB: The principal investigator must report, within five business days, any serious problem, adverse effect, or outcome that occurs with frequency or degree of severity greater than that anticipated. In addition, the principal investigator must report any event or series of events that prompt the temporary or permanent suspension of a research project involving human subjects or any deviations from the approved protocol.

APPENDIX C

The Graduate Center
City University of New York
Doctor of Nursing Science Program
Room 3317
365 Fifth Avenue
New York, NY 10016-4309

Alsacia L. Pacsi
Lehman College
T3 Building, Room 226
250 Bedford Park Blvd West
Bronx, NY 10468

Consent Form

My name is Alsacia L. Pacsi and I am a doctoral student in the Doctorate of Nursing Science (DNS) Program at the Graduate Center of the City University of New York (CUNY), and Principal Investigator of a project, entitled “The lived experiences of Dominican women with Stage III or IV Breast Cancer.” This study is expected to enhance the nurse’s understanding of women living with breast cancer and to provide information that will be helpful in designing nursing interventions to address the needs of Dominican women with breast cancer. I would like permission to interview you about your experience living with breast cancer.

Your participation in this study is completely voluntary. You can refuse to participate, or if you elect to participate, you may discontinue your participation at any time. In either case, you may do so without penalty or loss of benefits to which you are otherwise entitled. To preserve confidentiality, all transcripts and audiocassettes will be numerically coded; no names will be used.

This interview will take 90 minutes. The audiotapes will only be heard by the principal investigator, the professional transcriber and research committee members. All the information gathered will be kept strictly confidential and will be stored in a locked file cabinet in my office to which only I will have access.

The risks from participating in this study are no more than what you may encounter in everyday life. Your participation in this study may cause you anxiety, if so a physician or mental health professional will be able to talk to you at your request. When I finish this study, with your permission, I may publish the results but names of people or any identifying characteristics will not be used in the publications. If you would like a copy of the results please provide me with your address and I will be glad to send you a copy.

If you have any questions about the research, you can contact me at (718) 960-8552 or email me at apacsi@gc.cuny.edu, or my advisor Professor Vidette L. Todaro-Franceschi RN PhD at (212) 817-7980 or vtodaro@hunter.cuny.edu. If you have any questions about your rights as a participant in this study you can contact Ms. K. Powell, IRB Administrator, at The Graduate Center, City University of New York, (212) 817-7525 and her email is kpowell@gc.cuny.edu.

By signing this consent you are agreeing that you have been fully informed of the nature of the study and that you have volunteered to participate.

Print Name: ________________________________

Address: ________________________________Email: ___________________________

________________________________Phone:___________________________

Participant's Signature: ______________________________Date: ____________________

Researchers Signature: ______________________________Date: ____________________

I agree to have this interview audio-taped. Please circle one.
Yes No

___________________	______________	_____________________	____________
Participant's Signature	Date	Investigator's Signature	Date

Thank you for your participation in this study. I will give you a copy of this form to take with you.

APPENDIX D

Participant Survey Questionnaire

Date: __ __/__ __/__ __ __ __

1. How old are you? ____
2. Where were you born? ________________________
3. What year did your parents come to the US? ___________
4. What is your marital status? (Please check off one.)
   ____Single ____Married ____Divorced ____Widowed
5. How many children do you have? ______
6. How old are your children? (Please write down their ages.)
   _______ _______ _______ _______ _______ _______ _______
7. What is your highest level of education? (Please check off one).
   ___Elementary School ___High School ___ College ____Graduate School_____

What is your current working status? (Please check off one).

   ____Working for pay at a job or business full-time.
   ____Working for pay at a job or business part-time.
   ____Working from home full-time.
   ____Working from home part-time.
   ____Working, but not for pay, at a family-owned job or business full-time.
   ____Working, but not for pay, at a family-owned job or business part-time.
   ____Not working at a job or business and not looking for work.
   ____Not working but looking for work.

8. What kind of cancer were you diagnosed with? Please check off one.
   ____Stage III breast cancer ____Stage IV breast cancer.
9. How old were you when you where diagnosed? _____
10. What religion do you practice? (Please check all that apply).
   ____Catholic
   ____Protestant
   ____Evangelical
   ____Agnostic
   ____Atheist
   ____Eastern Orthodox
   ____Hindu
   ____Jewish
   ____Mormon
   ____Muslim
   ____Buddhist
   ___Other__________________

Thank You

APPENDIX E

List of Support Group Services for Participants

The two support groups and counseling services for advanced breast cancer patients used by the institution where the PI will do the study are as follows:

SHARE
http://www.sharecancersupport.org/programs.php?pw=&lang=s&path=none&type=18&view=type.This program offers services in English and Spanish. Toll-free breast and ovarian cancer hotlines**:** 866-891-2392.

Other support groups available:

Dominican Women's Development Center;212.568.6616; Rosita Romero, Executive Director; 519 W 189th St, Ground Fl, New York, NY 10040

Community Association of Progressive Dominicans; 212.781.5500; Soledad Hiciano, Executive Director; 3940 Broadway, 2nd Floor, New York, NY 10032.

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