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COLLEGE OF HEALTH SCIENCES

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Barbara Kreling

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2008

ABSTRACT

Beliefs, Perceptions, and Preferences for Treatment in Latinas with Breast Cancer

by

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BS, University of Rochester, Rochester, NY, 1972
MSPH, Walden University, Minneapolis, MN, 2004

Dissertation Submitted in Partial Fulfillment of
the Requirements for the Degree of
Doctor of Philosophy
Public Health

Walden University
November 2008

ABSTRACT

Research documents that breast cancer is the leading cause of death in Latina females. The exact numbers are unknown, but studies reveal that Latinas with breast cancer underuse recommended follow-up chemotherapy, decreasing their rates of survival. Although several factors may be responsible, cultural influences are a possible barrier. However, there is a gap in the literature about how culture affects decisions about breast cancer treatment. This focused ethnographic study examined the role of cultural beliefs and perceptions in the decision-making process for Latina women about whether or not to receive chemotherapy following a breast cancer diagnosis. Drawing from Douglas' cultural theory of risk, archived in-depth interview data from 20 Latina breast cancer survivors were open coded into 56 primary codes which were then categorized into hierarchical trees of overarching themes and subcategories. Unique elements of the patterns observed in these data were analyzed and interpreted to explain how culture may influence Latina breast cancer patients to underuse recommended chemotherapy. The results of this qualitative analysis revealed that various cultural factors including social role-related themes, avoidance of information and communication, as well as employment and immigration status influenced the treatment decisions of Latina women. Analysis suggested that these cultural factors influenced both the amount and quality of information Latina women had available to make these decisions. Results of this study can accelerate social change by drawing increased attention to cultural differences in medical decision making and by informing the communication process between medical providers and their Latina patients.

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CHAPTER 1: INTRODUCTION TO THE STUDY

Statement of the Problem

Latinos are the fastest growing minority group in the United States, and by 2050, 25% of the U.S. population will be Latino (U.S. Census Bureau, 2000). Breast cancer is the most common cancer among U.S. Latino females, also referred to as Latinas. For this study, the term *Latino* is used to generalize to all persons self-identified as Latino or Hispanic, including those from Latin America and the islands of the Caribbean. The term will be used to refer to Latinos in Latin countries and the United States. Chapter 2 contains a more detailed discussion of the demographics of Latinos in the United States and in the greater Washington, DC, area.

U.S. Latinas are at greater risk than non-Latinas of dying from their breast cancers (Clegg, Li, Hankey, Chu, & Edwards, 2002). Some of the difference in death risk may be attributed to late stage at presentation (Abraido-Lanza et al., 2007; Boyer-Chammard, Taylor, & Anton-Culver, 1999; Clegg et al.). To date, attempts to reduce survival disparities have focused on early detection. However, even after considering the stage of diagnosis, Latinas continue to have poorer survival rates than other groups (Bickell et al., 2006; Katz et al., 2005). Some deaths may be attributed to the underuse of optimal treatments such as chemotherapy and radiation, especially adjuvant chemotherapy (National Institute of Medicine, 2002). A recent study of females who did not receive the recommended adjuvant chemotherapy for their breast cancer found that among Latinas, 23% refused; 52% were considered system failures, that is, no reason was given for their failure to receive treatment; and 25% were not offered treatment by their surgeons

(Bickell, LePar, Wang, & Leventhal, 2007). There are many possible explanations for suboptimal treatment patterns in Latinas, including access barriers, language problems, low health literacy, and bias in the health care system (Geiger & Borchelt, 2003; Guidry, Fagan, & Walker, 1998). However, there is evidence that cultural factors, including perceptions of illness, disease, and cure, as well as other cultural norms and values, may be very important factors in determining the uptake of chemotherapy (Bickell et al., 2006). The research problem in this study addressed Latinas' failure to obtain recommended treatment following surgery for breast cancer.

Need for Research

Although other studies have shown cultural differences in perceptions about cancer and cancer screening (Borrayo & Jenkins, 2003; Perez-Stable, Sabogal, Otero-Sabogal, Hiatt, & McPhee, 1992), little is known about the cultural norms that affect decisions by Latinos to use chemotherapy. Latino cultures share a philosophy of health that is different from those in the United States (Perez-Stable et al.). For example, illness is viewed as holistic and concerned with the experience of symptoms; in addition, the effects of treatment are perceived as part of the illness (Kleinman, 1995). This must be understood as a basis for interpreting the rationale for health behavior (Kleinman).With a thorough understanding of Latino culture concerning illness and disease, one may begin to explore how patients make sense of disease and illness, relate to their providers, and make decisions regarding the use of recommended therapies.

Although there have been few studies of treatment for cancer in Latinos, some research has indicated areas of interest to be explored. First, Latinos fear cancer more than any other disease, but they do not believe that early detection is useful (Ehrmann-Feldmann, Spitzer, Del Greco, & Desmeules, 1987; Flanagan & Holmes, 2000; Manson, Manderino, & Johnson, 1993; Sontag, 1983). Latinas have been found to be less convinced than Whites or Blacks that adjuvant cancer treatment is effective (Chavez, Duran, Baker, Avila, & Wallerstein, 2003). Second, Latinos have been identified as being more fatalistic than other groups, and these beliefs have been associated with low cancer screening use (Chavez et al.; Facione & Giancarlo, 1998; Hubbell, Chavez, Mishra, Magana, & Valdez, 1995; Perez-Stable, Otero-Sabogal, Sabogal, McPhee, & Hiatt, 1994). Third, cultural norms such as an emphasis on the collective good or needs of the family may lead women to defer their own care (Chang et al., 1996) and may impede their use of chemotherapy (Modiano, Villar-Werstler, Meister, & Figueroa-Valles, 1995). Chang et al. found that even when screening has occurred, Latinas have a longer interval between abnormal mammography and diagnostic testing. Fourth, shame and secrecy about cancer may lead the family to withhold information from the patient, precluding informed treatment decisions. In Latino cultures, there is a tendency for the physician and the family to withhold information about cancer from the patient, including prevention, screening, and prognosis (Marin & Marin, 1991). Researchers have found that shame and secrecy about cancer foster mistaken beliefs (Campaña, 1989; Marin & Marin; Perez-Stable et al., 1992).

Evidence from other studies on the beliefs about cancer risks and screening among Latinas has suggested that perceptions and beliefs play a significant role in health behavior. These studies have shown the differences in knowledge and attitudes about breast cancer risk factors among Latinas and White females (Chavez et al., 2003; Facione & Giancarlo, 1998; Hubbell, Chavez, Mishra, & Valdez, 1996). Other studies have highlighted the role of religion; social support, distress, and life disruption; and psychosocial well-being among Latina cancer patients (Alferi, Carver, Antoni, Weiss, & Duran, 2001; Mickley & Soeken, 1993; Spencer et al., 1999). These studies have highlighted the need to understand the culture that underlies these values and norms in medical care. The gap in knowledge is how Latino culture may influence the use of recommended chemotherapy for breast cancer.

Breast Cancer

According to the National Cancer Institute (NCI, 2007), breast cancer is a disease in which malignant (i.e., cancerous) cells form in the tissues of the breast. It is important to understand staging because optimal treatment depends on the type and stage of the cancer, hormone receptivity, and other factors such as comorbidity. After breast cancer has been diagnosed, the staging process is done to find out if the cancer cells have spread within the breast or to other parts of the body. Following are the stages of breast cancer listed on the NCI's Web site:

1. Stage 0: Carcinoma in situ.
2. Stage I: The tumor is 2 centimeters or smaller and has not spread outside the breast.
3. Stage IIA: No tumor is found in the breast, but cancer is found in the axillary lymph nodes (i.e., the lymph nodes under the arm); the tumor is 2 centimeters or smaller and has spread to the axillary lymph nodes; or the

tumor is larger than 2 centimeters, but not larger than 5 centimeters, and has not spread to the axillary lymph nodes.

4. Stage IIB: The tumor is either larger than 2 centimeters, but not larger than 5 centimeters, and has spread to the axillary lymph nodes, or it is larger than 5 centimeters, but has not spread to the axillary lymph nodes.
5. Stage IIIA: No tumor is found in the breast, but cancer is found in the axillary lymph nodes that are attached to each other or to other structures; the tumor is 5 centimeters or smaller and has spread to the axillary lymph nodes that are attached to each other or to other structures; or the tumor is larger than 5 centimeters and has spread to the axillary lymph nodes that may be attached to each other or to other structures.
6. Stage IIIB: The cancer may be any size and has spread to tissues near the breast (e.g., the skin or chest wall, including the ribs and muscles in the chest), and it may have spread to lymph nodes within the breast or under the arm;
7. Operable Stage IIIC: The cancer has spread to lymph nodes beneath the collarbone and near the neck, and it may have spread to lymph nodes within the breast or under the arm and to tissues near the breast.
8. Inoperable Stage IIIC. The cancer is found in 10 or more of the lymph nodes under the arm, in the lymph nodes beneath the collarbone and near the neck on the same side of the body as the breast with cancer, or in lymph nodes within the breast itself and in lymph nodes under the arm. In

Inoperable Stage IIIC breast cancer, the cancer has spread to the lymph nodes above the collarbone and near the neck on the same side of the body as the breast with cancer.

9. Stage IV: The cancer has spread to other organs of the body, most often the bones, lungs, liver, or brain.

Treatment of Breast Cancer

According to the NCI (2007) treatment guidelines, recommended treatments for Stage I, Stage II, Stage IIIA, and Operable Stage IIIC breast cancer include surgery, either mastectomy or breast-conserving surgery, and adjuvant therapy, that is, treatment given after surgery to increase the chances of a cure. Adjuvant treatments include radiation therapy to the lymph nodes near the breast and the chest wall after a modified radical mastectomy; systemic chemotherapy with, or without, hormone therapy; hormone therapy; or a clinical trial of trastuzumab (Herceptin), combined with systemic chemotherapy. These recommendations were important for this study because the researcher sought to recruit women who would have been candidates for chemotherapy based on their disease. Staging has been used by other researchers to identify the use and underuse of chemotherapy in large populations where medical records are available. Because this researcher did not have access to medical records, participant recruitment was based on Stage 1 or higher among females who had had surgery for breast cancer.

Breast Cancer in Latinas

Despite the fact that Latinas in the United States have a 30% lower incidence of breast cancer than White females, breast cancer is the most frequently diagnosed cancer and the leading cancer cause of death in Latinas (American Cancer Society, 2007). With the growth in the Latino population, the number of Latinas at risk for breast cancer will increase dramatically over the coming decades. This group is underrepresented in breast cancer prevention and treatment trials (Marin & Marin, 1991). Studies have found that Latinas have the lowest regular mammography screening rates of any group in the United States (Gilliand, Rosenberg, Hunt, Stauber, & Key, 2000; “Healthy People 2010,” 2004; Perez-Stable, Hiatt, Sabogal, & Otero-Sabogal, 1995). Ell et al. (2002) concluded that Latinas need support for diagnostic follow-up because they are less likely to follow up abnormal mammograms.

Multiple clinical trials have demonstrated the survival benefits of systemic therapy, which is considered part of the standard of care for most invasive breast cancers (Goldhirsch, Colleoni, Domenighetti, & Gelber, 2003; Safran et al., 1998). However, studies have shown that Latinas have fewer consultations with medical oncologists, receive less aggressive chemotherapy regimens, and are more likely to discontinue chemotherapy than White females. They also are less likely than White females to have endocrine therapy prescribed (Bickell et al., 2006; Haggstrom, Quale, & Smith-Bindman, 2005; Polacek, Ramos, & Ferrer, 2007).

Studies have shown that when Latinas receive definitive treatment, their survival outcomes are similar to those for non-Latina White females (Bickell et al., 2006; Elledge, Clark, Chamness, & Osborne, 1994; Katz et al., 2005). However, there has been recent interest in the possible biologic/genetic basis of differences between Latino and non-Latino women at diagnosis. Watlington, Byers, Mouchawar, Sauaia, and Ellis (2007) found that despite equal use of health care services such as mammography, Latinas diagnosed with breast cancer are different from non-Latino women in size, stage, and grade of tumor. Biologic/Genetic differences make it even more important that Latino women have the recommended treatment when diagnosed.

There are many possible explanations for the underuse of chemotherapy among Latinas. These include a lack of insurance, low education, and low income. Studies of chemotherapy use in other cancers (McGory, Zingmond, Sekeris, Bastani, & Ko, 2006; Naeim, Hurria, Leek, & Maly, 2006; Zell, Rhee, Ziogas, Lipkin, & Anton-Culver, 2007) have concluded that socioeconomic status (SES) may be a more important predictor of appropriate care than race or ethnicity. However, a recent landmark study by Bickell et al. (2006) examined the differences among White, Black, and Latino females who had had surgery for Stage I or Stage II breast cancer. Of these, the minority females had double the risk of receiving inappropriate, or no, adjuvant therapy. All the females in this study had access to care. Considering other factors such as comorbidities, the researcher concluded that many of the reasons for underuse in minority females remain unknown. The psychological and cultural barriers involving communication between patients and physicians must be understood for changes to take place.

Demographic Profile of Latinos

Latinos are the fastest growing minority population in the United States. By 2000, there were approximately 36 million Latinos living in the United States, representing 13% of the total population (U.S. Census Bureau, 2000). Based on census data, researchers have estimated that the actual population from this ethnic group is undercounted by as much as 30% to 50% (Capps & Passel, 2003; Grieco, 2003; Singer, Friedman, Cheung, & Price, 2001). The U.S. Census Bureau predicted that by 2050, 25% of the U.S. population will be Latino, making this the single largest minority group in the country. The greater Washington, DC-Baltimore region has one of the largest urban concentrations of Latinos in the country, and persons of this ethnicity are largely clustered in contiguous tristate counties (i.e., District of Columbia, Maryland, Virginia). The populations of these urban communities are predominately of Central (and South) American ancestry, with the greatest numbers from El Salvador (Capps & Passel; Grieco; Singer et al.).

These groups also are distinct in that 52% to 64% have recently immigrated to the United States, compared to an average of 29% nationally; often lack legal residence status; are poorly educated (21% have less than a Grade 9 education); and are predominately monolingual in Spanish. A total of 32% to 46% are estimated to be uninsured, and at least 20% are living in poverty, a rate that is twice the national average (Capps & Passel, 2003; Grieco, 2003; Singer et al., 2001). At present, there are limited data on the health status cancer care needs of this understudied Latino subgroup.

Cancer Disparities in Latinos

The cancer burden among U.S. Latinos is difficult to evaluate for a variety of reasons. The Surveillance, Epidemiology, and End Results (SEER) Program, established in 1973 as part of the NCI (2007), collects cancer incidence, treatment, and survival data to monitor the burden of cancer on the population of the United States. By virtue of the location of the original SEER registries, until recently, the majority of cancer data has focused on Latinos of Mexican decent (O’Brien et al., 2003). With the expansion of the Centers for Disease Control and Prevention’s state-based registry initiative, data on additional Latino groups are now being included in cancer statistics and census categorizations (as cited in O’Brien et al.; Ries, Kosary, Hankey, & Edwards, 1999). However, efforts to identify persons of different Latino ancestry are in their infancy, and the reliability and validity of current methods are variable in application (North American Association of Central Cancer Registries, 2003). In addition, although cancer rate denominators are based on census counts of participating self-identified Latinos, numerators are often based on nonstandard medical record reports of ethnicity to cancer registries, possibly leading to biased estimates of cancer rates (Stewart, Swallen, Glaser, Horn-Ross, & West, 1998). Finally, population surveys often do not include sufficient numbers of Latinos to identify stable rates of health behaviors, especially within Latino subgroups (Stewart et al.).

Based on current data, it appears that Latinos have higher than average rates of cancers that are related to infectious agents (e.g., cervical, stomach, and liver cancer; O’Brien et al., 2003; Ries et al., 1999). For other cancer sites (e.g., breast and colorectal cancer), U.S. Latinos seem to have lower incidence rates than average (O’Brien et al.), but if they do develop cancer, they are more likely than Whites to be diagnosed at late stages of the disease and are more likely to die of the disease (Hedeen & White, 2001; O’Brien et al.; Richardson et al., 1992). This disproportionate burden of cancer death and illness may be the result of multiple predisposing, reinforcing, or enabling factors operating at the individual and community levels, such as low use of screening rates;

erosion of access to services; and/or difficulty obtaining timely, high-quality, culturally competent cancer care. With increases in obesity and other lifestyle changes associated with immigration and acculturation, Latinos in the United States also may become increasingly at risk for common cancers. Moreover, with the dramatic growth of the Latino population, even if lower incidence rates persist, the absolute numbers of individuals at risk for cancer will increase over the coming decades. Thus, Latinos have a significant and disproportionate burden of cancer death and illness, and some of this burden is attributable to treatment that is less than optimal. Although many factors influence treatment use, there is evidence that beliefs, perceptions, and cultural norms are important to individual patient decisions. At present, little is known about these culturally based attitudes that may affect Latinas' decisions to use chemotherapy.

Nature and Purpose of the Study

Because of the researcher's employment and involvement in the Latin American Cancer Research Coalition (LACRC), she, along with two colleagues, gathered a large amount of qualitative data from Latina breast cancer survivors. The archived data, gathered in 2004, included more than 400 hours of interview transcriptions. The objective of this study was to analyze these data, which had not been systematically analyzed previously. The focus of the analysis was to explore these narratives to identify cultural beliefs, values, and norms that may explain Latinas' decisions to use, or not use, recommended adjuvant therapy for breast cancer. The purpose of the study was to provide a deeper understanding of the cultural barriers to treatment, which if addressed, may assist efforts to improve decision making and eventually decrease mortality from cancer among Latinas.

Theoretical Framework

The theoretical basis of this study was cultural theory and the cultural theory of risk. Arising from anthropology, cultural theory posits that beliefs and values are shared among participants, beliefs and values are learned, and behavior is patterned (Helman, 2007; Kleinman, 1995; Morse & Field, 1995). Further, the study was based on the medical anthropological theory of Kleinman that disease is not an entity, but an explanatory model. He argued that disease belongs to culture and to the specialized culture of medicine. It follows that to understand the behavior of a culture, one must understand how disease and treatment are perceived by those in the culture.

The cultural theory of risk arises from cultural anthropology. It posits that the perception of risks arises from each society's attempts to explain misfortune (Douglas, 1997). Ethnography is the primary tool of anthropological research (Creswell, 1998; Patton, 1990; Woolcott, 1994). Focused ethnography, or particularistic ethnography, is a limited ethnography that focuses on a single problem within a small group and which has been used increasingly in medicine, especially in nursing research (Morse & Field, 1995). Like ethnography, which focuses on the question, "What is the culture of this group of people?" (Patton, p. 67), focused ethnography asks the question, "What is going on in this group about this issue or problem?" This method uses the steps of (a) comprehension of the individual's experiences, (b) synthesis of categories within narratives, (c) identification of cultural norms in the data, (d) theorizing by comparing beliefs and values in the data with those in the literature, and (e) retextualizing by comparison with existing theory. Focused ethnography results in description, analysis, and interpretation of cultural themes, but it does not result in model development and in substantive theory (Wolcott). Rather, it results in an interpretation of cultural themes. This interpretation may be compared and contrasted to existing theory.

The researcher chose a qualitative research design because it was well suited to a study in which not enough was known about the topic to frame clear questions and where the issues were complex, sensitive, and difficult to access. Although cultural issues may be examined by using a general population of Latinas, there is evidence that females who have been newly diagnosed with breast cancer change their views and perceptions. For these reasons, the researcher chose to analyze the interview data provided by 20 newly diagnosed patients. As discussed in detail in chapter 3, the selected method was focused ethnography using in-depth interviews. The product of this study was a descriptive theory that may be used to improve practice and, ultimately, to save lives.

Study Design and Collection of the Archived Data

The following is a description of the methods used to collect the archived data. Newly diagnosed, foreign-born, Spanish-speaking Latina breast cancer patients (i.e., diagnosed within the last year with local and regional breast cancer) were identified by three physicians: a surgeon in Washington, DC; an oncologist in Montgomery County, MD; and an oncologist in Arlington, VA. These physicians were selected by the researcher as those to whom Spanish community clinics refer and who see the most Spanish-speaking patients. They identified the patients and allowed LACRC staff to introduce the study and obtain consent. The females were interviewed in their homes by a team that included at least one bilingual, bicultural interviewer. This was a purposive, convenience sample of women who were diagnosed in the past year, who were referred to LACRC, and who agreed to participate. The goal was to interview 20 women, a number suggested by Morse and Field (1995) as adequate for a qualitative study. Most interviews were conducted in Spanish and were recorded with the participants' permission. The open-ended, unstructured question protocol was designed to encourage candid narration about the cancer treatment experience. Probes were added to be used if a topic was not mentioned (see Appendix A). Interviews ranged from 2 to 3 hours. Audio tapes were transcribed and back translated into English.

Specific Research Questions, Hypotheses, or Objectives

The overarching research question in this study asked, "What are the cultural beliefs, values, and norms that influence Latinas in choosing to have recommended chemotherapy?" Although this culture also shares language and practices, the researcher believed that beliefs, values, and norms were the most likely to affect health behavior relevant to this inquiry. As mentioned previously, little is known about how shared beliefs, values, and cultural norms may influence health behavior in this population. Because it is generally accepted that culture and acculturation affect general health care beliefs and utilization, a study of the beliefs and perceptions about chemotherapy in a diverse Latino population should identify important targets for future interventions aimed at improving outcomes for this understudied population.

Definitions of Terms

Breast Cancer: Defined by the NCI (2007) as a disease in which malignant (i.e., cancerous) cells form in the tissues of the breast.

Culture: For the purposes of this study, culture is defined as shared systems of ideas, concepts, rules, and meanings that influence how persons live life and make sense of events (Helman, 2007).

Latino/Latina: These terms are used to denote individuals living in the United States who were born or who can trace their ancestry to one of the Latin American countries, including islands of the Caribbean, and who speak Spanish or Portuguese. This is a cultural categorization, not a racial one. Although Latinos in the United States are heterogeneous, with disparate migrational and socioeconomic characteristics, the researcher assumed that members of this group share some common basic cultural values that make them members of an identifiable group. In addition, the sample of Latinas studied here was more homogeneous demographically than the U.S. population of Latinos.

Recommended Chemotherapy: A term that refers to NCI guidelines for practice. All of the female participants in this study had stages of cancer where chemotherapy would have been recommended. For instance, Stage O would not indicate treatment with chemotherapy, but Stage 2 would most always indicate chemotherapy (NCI, 2007).

Limitations of the Study

The sample size of a qualitative study is not meant to predict to a larger population. The goal to interview 20 women was selected a priori to answer the research question and to ensure saturation with the topic. Likewise, it cannot compare groups, such as groups of more or fewer acculturated patients, or nationalities, both of which may be relevant to the study and should be investigated in the future. This sample, mostly low-income, unilingual, new immigrants from Central America, was not expected to reflect the range of experiences of U.S. Latinas. However, this sample did reflect the demographics of Latinos in the Washington, DC, area. In addition, most of the women were recruited from two oncologists, further limiting the heterogeneity. Because of the homogeneity of the sample, the lower end of the recommended number of 20 was chosen to be feasible within the scope and timeframe of the study (Lincoln & Guba, 1985; Morse, 1994). As explained by Morse, “Comprehension is complete when the researcher has conducted enough participant interviews to describe the events, incidents, and exceptions form an emic perspective” (p. 37). This level of comprehension was achieved with the planned 20 interviews. If additional interviews had been needed for saturation, the data collection would have continued.

A qualitative study relies on volunteers and does not attempt a representative sample. Because some of the females were recruited from two oncologists referred from the LACRC, they may have been more acculturated than females who do not visit an oncologist. However, because all of the referring physicians were Spanish-speaking specialists who see most clinic patients, their patients may have been less likely to speak English. An examination of cultural beliefs and perceptions of non-English-speaking (less acculturated) females was expected to provide the richest material because less acculturated woman are more likely to retain their cultural values.

Another limitation was working with two languages. However, bilingual and bicultural interviewers were present for or conducted all of the archived interviews. Body language and other subtleties can be lost using transcriptions, but both interviewers took notes during the interviews, and these notes were added to the data in the software. Five percent to 10% of each audio tape and transcript was reviewed by a second Spanish speaker.

Scope of the Study

This study examined the cultural reasons, that is, the beliefs, values, and norms, which may have influenced 20 Latinas to choose, or not choose, adjuvant treatment, especially chemotherapy, following a diagnosis of breast cancer. It is understood that there may have been many factors not directly related to culture, such as access to care, and that these factors may also have been influential. Moreover, these factors may have been difficult to separate from cultural differences in a population with low education, poverty, and language differences. Because the sample was demographically homogeneous, these questions were not answered by this study. Instead, the researcher attempted to focus on cultural factors. Finally, this study was not designed to identify females who had refused chemotherapy and to learn the reasons for their decisions because (a) the researcher did not have data on specific diagnosis or recommendations, and (b) the purpose of the study was to identify overall cultural influences.

Significance of the Study

This study was the first study that that this researcher knows of its kind with this population. It may lead to interventions to change beliefs and perceptions of adjuvant therapy, especially chemotherapy, following breast cancer. The results may be used by clinicians in their practices to improve their communication with Latina patients and by other groups to provide educational and counseling interventions. These results also may inform researchers about cultural influences on the decision to accept chemotherapy as a treatment for other cancers, especially other female cancers. The findings also may be used by other researchers to explore health behaviors for other diseases.

Disparities in cancer mortality are a public health concern. A woman of color in the District of Columbia is twice as likely as a White female to die of breast cancer. Efforts to reach the Latino community have too often involved simply translating English materials into Spanish without understanding how Latino cultures make sense of illness and treatment, the literacy level of the audience, and other barriers. Health communication efforts will not be successful without a deeper understanding of the target audience. Positive social change is necessary to reduce cancer mortality among Latinas.

Social Change

Many changes will need to be made to impact the growing disparities in breast cancer mortality in minority women in this country. As discussed in chapter 2, different cultures require different interventions to improve care. Basic to the development of new interventions is a fuller understanding of each culture’s values, beliefs, and norms regarding disease, illness, care, and treatment. This study may provide information about relevant cultural factors among a group of Latinas with breast cancer to inform interventions to improve practice. Only with this understanding can changes be made to reduce the number of minority women dying from breast cancer.

Summary

The following chapters outline the study. Chapter 2 presents an overview of the relevant literature on cancer in Latinas, Latino culture and illness, Latino cultural norms and values, the theoretical basis of the research, and qualitative research methods. Chapter 3 describes the methods used in the study, including the primary and secondary research questions and the data collection and analysis methods that were used to answer them. Chapter 4 presents results of the analysis and answers to the research questions arising from the interviews. Chapter 5 is a discussion of the interpretation of results, role of the researcher, social significance of the study, and recommendations for change.

CHAPTER 2: REVIEW OF THE LITERATURE

Introduction

The review of the literature was undertaken to answer the following subquestions relevant to the primary research question: What are the cultural beliefs, values, and norms that influence Latinas in choosing to have recommended chemotherapy?

1. What are the cultural beliefs about disease and illness and about cancer?
2. What are the cultural values and norms that may play a role in medical decisions?

In order to ground the study in previous research, the researcher began by examining the literature in the following areas:

1. The incidence and prevalence of breast cancer among Latinas.
2. Mortality from breast cancer in Latinas.
3. Evidence that Latinas underuse chemotherapy.
4. Which research methods are the most appropriate for this study?

Organization of the Literature Review

This review begins with evidence of the efficacy of chemotherapy for breast cancer and its underuse by minority women, particularly Latinas. To explain this underuse, the researcher examined the literature on the underuse of health care in Latinas and presents findings about the role of SES, language, and other possible barriers to the use of healthcare services among Latinas. The theoretical basis for the enquiry and the qualitative tradition underlying the methods is presented next. To narrow the focus to cultural factors, the primary topic of this study, the researcher examined the literature on Latino culture and health. This focus included Latinas' beliefs, perceptions, and cultural values regarding disease in general and cancer and cancer treatment in particular. The review concludes with a summary of possible interventions and social change activities to improve mortality statistics for Latinas with breast cancer.

A review of what is known about Latino culture and health care is included. Keyword searches of the literature included *culture* and *Latino* and *disease*, *chemotherapy* and *Latina*, and *cancer* and *Latino* in several databases, including CINAHL, Ovid, and Medline. The next step was to select references from the most relevant articles and then access those articles and books. When this step was complete, the researcher cross-referenced citations to ensure that all relevant literature was included. This literature included theories, methods, and interventions. Textbooks were used to obtain information about qualitative methods, conceptual models, and qualitative research traditions.

Breast Cancer Statistics for Latinas

Breast cancer is the leading cause of cancer death among Latinas in the United States. Latinas also have higher breast cancer mortality than non-Latina White females, despite lower age-adjusted incidence rates (Abraido-Lanza et al., 2007). Some of this disparity may be accounted for by lower screening rates (Goel et al., 2003) and limitations in access to timely care because of SES factors (Selvin & Brett, 2003). This disparity also may be the result of inadequate access to appropriate treatment after diagnosis. After diagnosis, adjuvant systemic therapy is the single treatment modality with the greatest potential to reduce survival disparities. Thus, many Latina deaths may be attributable to disparities in access to optimal treatments such as chemotherapy. Bickell et al. (2006) and Katz et al. (2005) discussed the role of access to medical care in the underuse of follow-up treatment in Latinas. Multiple clinical trials have identified the survival benefits of systemic therapy, which is considered part of the standard of care for most invasive breast cancers. For example, Goldhirsch et al. (2003) presented evidence of the survival benefit of systemic therapy. However, Latinas have fewer consultations with medical oncologists, receive less aggressive chemotherapy regimens, are more likely to discontinue chemotherapy, and are less likely than White females to have endocrine therapy prescribed.

Bickell et al. (2006), Katz et al. (2005), and Polacek et al. (2007) presented studies that agreed on the direction and extent of these disparities. Bickell et al. and Katz et al. concluded that when Latinas receive definitive treatment, their survival outcomes are similar to those for non-Latina Whites. However, there has been recent interest in the possible biologic/genetic basis of differences between Latino and non-Latino women at diagnosis. Watlington et al. (2007) found that despite equal use of healthcare services such as mammography, Latinas diagnosed with breast cancer are different from non-Latino women in size, stage, and grade of tumor. Biologic/Genetic differences, which may explain some of the disparities in mortality, make it even more important that Latinas have the recommended treatment when diagnosed.

Underuse of Chemotherapy by Latinas

There are many possible explanations for the underuse of chemotherapy by Latinas, including a lack of insurance, low education, and low income. For instance, Zell et al. (2007) studied chemotherapy use for pancreatic cancer and concluded that SES is a more important predictor of appropriate care than race or ethnicity. As noted earlier, Bickell et al. (2006) tested the hypothesis that underuse of chemotherapy is the result of a lack of access to care. They found that minority females with equal access to medical care had double the risk of receiving inappropriate adjuvant therapy, based on established guidelines and controlling for comorbidities and other factors. This study concluded that other factors, such as psychological and cultural barriers, must be understood for changes to take place.

Theoretical Basis for the Inquiry

The theoretical basis for this study was cultural theory and cultural theory of risk (Douglas, 1997). The theory of culture posited that the views of individuals in the culture are determined by the culture. Cultural theory assumed that members of a group with a common outlook will impose order on reality in particular ways and that culture determines how an individual perceives disease and illness.

The cultural theory of risk (Douglas, 1997) posited that the views of individuals on matters are shaped by the nature of social groups of which they are a part. Thus, patterns are set in cultural relationships, namely, the expectations and value systems of people belonging to the distinctive groups. The theory assumed that members of groups with a common outlook are disposed to impose order on reality in particular ways. Cultural theory explained risk as a social construction that occurs through the processes of value identification and trust building.

All human activity relies on social construction. Douglas (1997) asserted:

> All knowledge and everything we talk about is collectively constructed. Language is no private invention. Words are a collective product, and so are meanings. There could not be risks, illnesses, dangers, or any reality, knowledge of which is not constructed. ..all evidence has to be constructed. (p. 123)

Thus, perceived risks are a product of collective construction. Cultural theory explained why researchers prefer to study beliefs, values, and norms as they relate to a culture rather than a collection of individuals. By understanding the underlying values, it is possible to explain attitudes and preferences in a way that makes sense within the culture. Douglas developed this theory as a way of, “vindicating the so-called primitives from the charge of having a different logic or method of thinking” (p. 3). For example, there is always some explanation for misfortunes that befall individuals with any social group, and those explanations are consistent. Assigning blame imposes order on random misfortune. Understanding this logic is key to comprehension of behaviors. In an earlier study, Douglas and Wildavsky (1983) provided clarification of the cultural theory of risk. They explained that even though people in developed countries live longer than they did 50 years ago, and even though there are fewer hazards, people feel more at risk. By this theory, the reason is attributable to the rise of environmentalism and is socially constructed.

Kleinman, Eisenberg, and Good (1978) studied clinical issues from an anthropologic and cross-cultural research perspective. They distinguished between disease and illness, a differentiation that shed light on cross-cultural differences in response to medical care. Illness is a patient's experiences of disvalued changes in states of being and social function, whereas diseases are abnormalities in the structure and function of body organs and systems. Modern physicians are concerned with disease, whereas patients are concerned with illness. Kleinman et al. made the point that there often is not a one-to-one relationship between disease and illness and that one may exist without the other. Illness is culturally shaped in the sense that how one perceives experience and copes with disease is based on explanations of sickness. Indigenous healers seek to treat illness rather than disease. Cultures that have a history of healers expect and trust attention to illness. Maduro (1983) also discussed the significance of the individual's cultural heritage and experience in that person's definition of illness and disease. This distinction is relevant to the current study because chemotherapy has the effect of curing disease by increasing illness.

Helman (2007) discussed the distinction between concepts of illness and disease. He provided case histories of illness without disease and disease without illness. In the discussion of disease without illness, he stated that this is an increasingly common occurrence because of improved diagnostic technology: Diagnostic abnormalities in the body are found, but the patient does not feel unwell. He ascribed some patient noncompliance to this situation.

Theory and Latin American Culture

Culture, although complex and multifaceted, is an important influence on health behavior. Culture is generally viewed as comprised of shared ideas, meanings, and values; it is socially constructed and learned, not genetically created and transmitted; and it includes patterns of behavior guided by common ideas, meanings, and values. Ethnicity has several meanings: collective culture of a minority group within a larger society; ethnic origin, or place of ancestry; and ethnic identity (Huerta & Macario, 1999). As an ethnic group, or community, Latinos share core cultural values that differentiate them from other groups.

Following the work of Kleinman et al. (1978), Chesla, Skaff, Bartz, Mullan, and Fisher (2002) contrasted Whites (European Americans) with Latinos in their perceptions of disease. She described personal models of illness understanding based on an individual’s complex sense of the disease, including the cause, nature, and course of the disease. These models are experiential, biomedical, and psychosocial. A significantly larger percentage of the Latinos, compared with Whites, ascribed to an experiential model, that is, holistic and concerned with the experience of symptoms. Second, the Latino sample perceived effects of treatment as part of the illness.

Saint-Germain and Longman (1993) conducted a study examining attitudes toward breast cancer among 409 Latino females over the age of 50 living in Tucson, Arizona. Some of the findings illustrated the difference between perceptions of illness and disease. The females defined health and illness by symptoms and also by the ability of the person to carry on with his or her daily activities. One participant commented that if one can still work, one is not ill. The roots of these understandings and perceptions lie deep within the cultural memory of a tradition of folk healing.

Foster and Anderson (1978) stated that to understand Spanish-American health beliefs, it is essential to understand the popular medicine of the countries from which they are derived. They commented, “For example, contemporary Mexican-American folk medicine makes little sense unless the reader understands its humoral antecedents and Catholic rituals and belief having to do with supernatural patrons petitions for help and the fulfillment of vows” (p. 75).

Curanderismo

Curanderismo is a diverse folk healing system of Latin America. Although practiced less in recent years in urban settings, its existence in cultural memory shapes, “a coherent world view of healing that has deep historical roots” (Maduro, 1983, p. 1) and can influence culture bound syndromes in clinical practice of general medicine. Maduro outlined the philosophical premises present in the worldview of Latino patients. Curanderismo is a holistic system expected to treat physiological, psychological, and social maladjustments. Following are its underlying propositions according to Maduro:

1. Because the mind and body are one, disease can be caused by strong emotional states; hot and cold substances relate to and balance and harmony (some medications are thought to be hot).
2. The patient is an innocent and passive victim.

3. Illness may be caused by the separation of body and soul. This can mean self rather than soul in a secular sense and has relevance to immigration and acculturation. The curandero will sometimes treat the soul, but not the body;
4. The responsibility for cure resides with the entire family.
5. There is interpenetration of the natural and supernatural worlds. Treatments may include penance, prayers, and sacrifice.
6. Sometimes, a sick person needs to be resocialized because the acculturative stress of American life and weakening traditional values can cause illness related to loss of the soul. As a treatment method, ties to the community are reestablished, and the patient accepts a more conservative Latin American worldview.
7. The healer is expected to interact openly. The healer is warm, friendly, and personal, with a connection to the sacred and gift or calling (llamada) to healing.

Foster and Anderson (1978) described the view of health underlying Latino folk medicine as an, “equilibrium model” (p. 74). Equilibrium is expressed in the humoral pathology belief that to be healthy, the body must keep a balance between hot and cold calides (qualities or elements). Thus, the role of the healer is to restore balance (Foster & Anderson). As discussed next, various substances used for treatment are believed to have humoral qualities.

It can be argued that more acculturated Latinos in the United States have no memory of these traditional values. Kay (1978) studied Mexican-Americans in a large Southwestern city. She found that of 30 Mexican-American females, none was aware of the hot and cold system of classifications. She found that many health beliefs and behaviors came directly from humoral assumptions and were identical to those in communities in Mexico, where humoral distinctions are common knowledge. She concluded that traditional medicine shapes modern beliefs and behaviors, even when it is not consciously ascribed to or known.

Problems of Treatment

Helman (2007) stated that “in order for medical treatment to be acceptable to patients, it must ‘make sense’ in terms of the Explanatory Models” (p. 111). Agreement between patient and doctor about the method and purpose of treatment is as important as agreement about the diagnosis. This is important if the treatment involves unpleasant physical sensations or side effects that may induce, in effect, a form of temporary illness (Helman). Prescribed medication may not be taken if it is perceived to cause illness or if the patient does not feel ill, and a medication may also not be taken if relatives or friends have previously had side effects from it (Helman). Also, people may use medications in ways that make sense to them. For instance, a medication thought of as a hot drug may not be used if certain side effects appear, such as a rash, which is thought to be caused by a hot imbalance (Helman).

The distinction between illness and disease and adherence to an experiential model of disease in Latino culture can be traced to the history of curanderismo and its underlying philosophical premises. These premises also may be used to understand the cultural norms of fatalism, respeto, and collectivism, all of which may be relevant to Latinos' views of cancer and cancer treatment.

Latino Beliefs and Perceptions of Cancer

Certain basic values shared by Latinos have been identified by various researchers as influential in health behavior. As stated by Marin and Marin (1991), "There is a level of disagreement among researchers as to the meaning and implication of some of these values" (p. 11). Following are a few of the characteristics relevant to this study.

Fatalismo

Fatalismo is a Latino cultural norm that has been studied extensively by healthcare researchers. According to Perez-Stable et al. (1994), fatalism is the belief that the course of fate cannot be changed and that life's events are beyond one's control. They surveyed a random sample of 844 Latinos and 510 Anglos. They found significant differences in misperceptions about the causes of cancer, attribution of symptoms (experiential differences), and fatalistic beliefs. For instance, significantly more Latinos ascribed to the statements that "having cancer is like getting a death sentence," "cancer is God's punishment," "there is very little one can do to prevent getting cancer," "it is uncomfortable to touch someone with cancer," and "they would rather not know if they had incurable cancer" (Perez-Stable et al., p. 3219). These differences were significant after considering gender, education, age, SES, and self-perceived health status. In contrast, Abraido-Lanza et al. (2007) reviewed the literature about fatalism in Latinas regarding cancer screening. They made the point that fatalism is difficult to measure reliably and separate from the powerlessness and stress of lower SES and racism.

Respeto

Respeto is a cultural norm that has relevance to health care. Maduro (1983) commented:

> Respeto not only describes power distance, it also implies decency, a common humanness that requires people to interact with each other on that level first in spit of age, sex, class and caste differences. Even when there are social status differences in behavior, one must first establish rapport and respect: in Latino culture all other social relationships and interactions are dependent on that foundation. (p. 874)

This is sometimes described as simpatía, the need for smooth interpersonal relationships in which criticism and confrontation are discouraged. Other core Latino cultural values include familisma, the significance of the family, and collectivism, the importance of friends and extended family in helping to solve problems (Perez-Stable et al., 1994). In an assessment of quality of life by Juarez, Ferrell, and Borneman (1998), Latino cancer patients reported having their family as the most important for coping. In Latino culture, when one family member is sick, everyone is expected to help. Arruda, Larson, and Meleis (1992) found that Latino patients with cancer identified comfort as the most important value. This included nurturing, security, quality of life, familiar environment, normalcy, and ánimo (internal spiritual strength). The most significant characteristics of comfort mentioned were feeling integrated and nurtured.

Religion also is important to Latinos in the face of illness (Mickley & Soeken, 1993). They attribute healthiness to a gift from God and illness as a test from God, reflecting a holistic view of health. In addition, much Latin-American curing involves the concept of a healer with supernatural powers. Rather than assign this role to a curandero or to home remedies, they identify God as the ultimate healer. Foster and Anderson (1978) commented:

> For many illnesses, Spanish-Americans frequently seek the intervention of saints, the Virgin, or Christ, lighting candles and praying at their altars. Often vows of solemn promises are made to "miraculous" images of Christ or the Virgin: if the request is granted, the petitioner must fulfill his or her part in the bargain. (p. 76)

Complementary medicine is used by Latino females either with other treatment or by itself. Alferi et al. (2001) investigated factors predicting the use of complementary therapies in a multiethnic sample of non-Latino White (64%), Latino (26%), and Black (10%) females with early-stage breast cancer in Florida. Fifty-two percent of the Latino females reported using complementary medicine, including herbs and psychoreligious therapies (Alferi et al.).

Secrecy

Another value that influences Latinos' heath behavior is secrecy about cancer. Juarez et al. (1998) found that the word cancer is not mentioned in the patient's presence and that it is not uncommon to find family members not disclosing a cancer diagnosis to the patient based on the belief that knowing is in the patient's best interest. Secrecy also protects the privacy of the patient and family, although it may have the effect of isolating the patient from social activities. The concept of social death is useful for understanding secrecy.

Anthropologists such as Foster and Anderson (1978), Helman (2007), and Kleinman (1995) described rituals of health illness and the management of misfortune that are common to many societies. They described rituals of social death that come before or after biological death; usually, these are funeral and grief rituals. In some circumstance; however, social death may happen when individuals are alive physically but in subtle ways less alive socially in the eyes of wider society and sometimes their own families (Foster & Anderson). Sometimes, the diagnosis of a serious disease such as AIDS or cancer can signal social death; in a culture where this is the case, there is significant motivation to keep the diagnosis a secret (Foster & Anderson).

Time Orientation

Latino cultures tend to be more present oriented than mainstream American culture, which tends to be more future oriented. For instance, there is less planning and worry about the future and more importance on the present. This cultural trait may be relevant for the use of treatments that may be needed in the future but may cause illness in the present (Marin & Marin, 1991).

Latinas' Knowledge and Beliefs About Breast Cancer

Studies of Latinas' use of preventive services for breast cancer have found on average that Latinas have a lack of knowledge that creates misperceptions about breast cancer. For instance, Perez-Stable et al. (1992) surveyed 844 Latinos and 510 Anglos in a prepaid health plan. The Latinos were significantly more likely to believe that cancer is caused by sugar substitutes, bruises from being hit, microwave ovens, ingestion of pork and spicy foods, breastfeeding, and antibiotics. The Latinas were significantly different from the Whites in these beliefs, even accounting for gender, education, age, employment, country of residence, and health status.

Although studies such as the one conducted by Facione and Giancarlo (1998) have identified cultural differences in perceptions about cancer and cancer screening, little is known about the cultural norms that affect Latinos’ decisions about the use of chemotherapy. For example, in one study, Latinos were less convinced than Whites or African-Americans that cancer treatment is effective (Perez-Stable et al., 1992). Latinos also tend to be more fatalistic than other groups, and these beliefs have been associated with low cancer screening use (Perez-Stable et al., 1994). Other cultural norms, such as an emphasis on the collective good or needs of the family, often lead women to defer their own care and may impede the use of chemotherapy (Modiano et al., 1995). In addition, secrecy also may lead the family to withhold information from the patient, precluding informed treatment decisions.

This qualitative study was designed to fill gaps in current knowledge about cultural beliefs and perceptions that affect chemotherapy use among Latina breast cancer patients. The results are intended to inform the design of future interventions to improve breast cancer outcomes in this growing minority population.

Method

Because very little is know about the influence of culture on Latinas' choices of breast cancer treatment, the researcher used the qualitative method of ethnography for an inductive and formative study. In other words, the researcher expected that description, interpretation, and hypotheses would emerge from the data rather than being guided by them (Morse & Field, 1995).

Cultural theory was described by Helman (2007) and others as behavior that is patterned by shared beliefs and values. Ethnography is the primary tool of anthropology (Creswell, 1998). Focused ethnography, or particularistic ethnography, is a limited ethnography that focuses on a single problem within a small group (Morse & Field, 1995). It provides a means of gaining access to the health beliefs and practices of a culture or subculture in order to understand how disease and treatment are perceived by those in the culture. Like ethnography, which focuses on the question, "What is the culture of this group of people?" (Patton, 1990, p. 67), focused ethnography asks, "What is going on in this group about this issue or problem?" (Morse & Field, p. 26). According to Morse and Field, it has been used increasingly in medicine as a way to improve practice. They explained that this method uses the steps of (a) comprehension of the individual's experiences, (b) synthesis of categories within narratives, (c) identification of cultural norms in the data, (d) theorizing by comparing beliefs and values in the data with those in the literature, and (e) retextualizing by comparison with existing theory. Focused ethnography results in description, analysis, and interpretation of cultural themes, but it does not result in model development and in substantive theory (Wolcott). Rather, it results in an interpretation of cultural themes. This interpretation may be compared and contrasted to existing theory.

The researcher chose a qualitative research design because it was especially well suited to a study in which not enough was known about the topic to frame clear questions and where the issues were complex, sensitive, and difficult to access. Although cultural issues may be examined by using a general population of Latinas, there is evidence that females who have been newly diagnosed with breast cancer change their views and perceptions. For these reasons, the researcher chose to analyze the interview data provided by 20 newly diagnosed patients.

Other Methods

Qualitative research is indicated for studies where little is known and where the questions beginning with “Why” and “How” can be answered. Creswell (1998) identified five traditions: biography, phenomenology, grounded theory, case study, and ethnography. Biography is appropriate for the study of an individual. Phenomenology explores the experience of a phenomenon. Grounded theory is the most appropriate when the researcher is attempting to develop a theory.

The research question being asked in this study sought to understand how culture influences behavior. This required collecting data from many persons within the subculture of Latina breast cancer survivors. A biography of one individual would not be sufficient because studying the psychological effects of the phenomenon of breast cancer, although interesting, would not answer the specific research question. Grounded theory was not indicated because it is not one of the expressed goals of this study to develop theory. Therefore, within qualitative research traditions, focused ethnography was chosen as the method most suited to answer the research question.

Ethnography evolved from cultural anthropology by such researchers as Cassell (1992), Davis (1992); and Germain (1979). It was incorporated into healthcare research by nurse anthropologists to study the effects of culture on health care (Davis), institutions (Germain), or professional organizations as cultural systems. As Morse and Field (1995) reported, “Ethnography, always informed by the concept of culture, is a generalized approach to developing concepts and understanding human behavior from an insider’s point of view” (p. 23). Focused ethnography, which was developed by health scientists, is more delineated. For instance, a topic is chosen before data collection activities. Focused ethnographies are used primarily to improve practice (Morse & Field). The data collection method most often used in focused ethnography is the in-depth interview. This method allows the researcher to focus on a topic while allowing the respondent to describe and discuss it in depth. Thus, rich text is generated. As discussed in detail in chapter 3, the selected data collection method was in-depth interviews. The product of this study was a descriptive theory that may be used to improve practice and, ultimately, to save lives.

Summary

The literature showed evidence of the efficacy of chemotherapy for breast cancer and its underuse by minority women, particularly Latinas. To explain this disparity, the researcher examined the literature for factors that may describe possible barriers to the use of recommended treatments by Latinas. Based on cultural theory arising from anthropology, cultural factors were identified as important to Latinas' beliefs and perceptions regarding disease in general and cancer treatment in particular. Chapter 3 describes the research method. Chapter 4 contains the results of the analysis described in chapter 3. Chapter 5 includes an interpretation of the findings and offers recommendations for practice.

CHAPTER 3: RESEARCH METHOD

Overview of the Research Design

The goal of this study was to examine the beliefs and perceptions of Latina breast cancer survivors about chemotherapy. Because this enquiry was in an area where there has been little or no research, it was a formative study, using the tradition of focused ethnography. This method was designed to collect rich, open-ended data, analyze them, compare them to existing literature, describe cultural themes, and suggest how they relate to aspects of behavior. This description may then be used to inform practice. As such, the researcher did not ask questions that would fit the domains of existing theories or models, such as the health belief model, because to do so would have limited the exploration. Rather, the enquiry was based on the theory of culture, that is, that cultural beliefs, values, and norms influence health behavior.

This study began with qualitative data already collected and archived. Using an inductive, qualitative method, the researcher analyzed data gathered in 2004 that were based on interviews with 20 newly diagnosed females. The combined interviews totaled approximately 40 hours of transcribed and translated data.

Qualitative Research

Qualitative research is indicated for studies where little is known and where the questions beginning with “Why” and “How” can be answered. Creswell (1998) identified five traditions: biography, phenomenology, grounded theory, case study, and ethnography. Focused ethnography was chosen as the method most suited to answer the research questions. The data collection method most often used in focused ethnography is the in-depth interview. This method allows the researcher to focus on a topic while allowing the respondent to describe and discuss it in depth. This method generates rich text.

Data Collection

During the data collection effort, the females were identified and recruited by physicians whose practices include many Latinas. Interviews were conducted at a time and place convenient for the participants in Spanish or English, according to their personal preference. The interviews were audio taped, transcribed, and translated into English if necessary. Focused ethnography was selected because it is appropriate for describing and interpreting information on a special topic within subcultural groups (Creswell, 1998; Morse, 1994). Focused ethnography arises from health sciences and is usually used to improve practice. It is different from classical ethnography because the topic, rather than emerging from the data collection and analysis, is elected before data collection commences. Rather than developing theory, it results in description and interpretation on a specific topic (Morse, 1989; Muecke, 2007).

Ethical Protection

This study was approved by the IRBs of the medical center where the data were collected and Walden University (IRB approval #07-25-08-0286130). All respondents at the time of consent were informed of HIPPA-stated patient rights:

1. The patient’s right to confidentiality.

2. The patient’s right to refuse participation.
3. The patient’s right to discontinue the study at anytime during the study.
4. The patient’s right to refuse to respond to questions that he or she deems inappropriate or uncomfortable.
5. The potential benefits and harmful effects of participating in the study.
6. The incentives that will be provided for participation in the study.
7. The design of the study and what will be expected of the patient if he or she chose to accept participation

Once these rights were discussed with the participants, they were given a written consent form to review. Any questions that they had were answered prior to their signing the consent form. The females then had the choice to refuse or accept participation in the study. If they refused to sign the form, they were thanked for their time and energy. If they accepted, they were instructed where to sign and date the consent form, and then the consenter (MD or interviewer) also signed and dated the consent form in the appropriate area. All patients received a copy of the signed consent form for their personal records. All information was confidential and was not linked to the participants by name. All data reports and publications used only grouped, unidentified data.

Context of the Study

This study was conducted as part of the Latin American Cancer Research Coalition (LACRC), an NCI-funded regional Community Network Program (CNP). The goal of the LACRC is to use community-based participatory research to promote cancer control in Latinos in the metropolitan District of Columbia area (Kreling et al., 2006). The LACRC includes 6 community clinics, 2 community hospitals, 1 comprehensive cancer center, a local Spanish language health radio program, and numerous advocacy organizations (Kreling et al.). The community clinics serve Latinos almost exclusively and provide primary care regardless of the individuals' ability to pay (Kreling et al.). The current study was conducted with the cooperation of the LACRC's research program. All study procedures were approved by the IRB of the medical center where the researcher is employed.

Setting and Sample

Latino females who were within 2 years of their breast cancer diagnosis were recruited for the original study in 1996. Because the researcher was interested in identifying beliefs about chemotherapy, inclusion was restricted to females with invasive cancer. The females were recruited from the CNP clinics, the oncologists and surgeons who accept referrals from the clinics, and a local Latino-serving cancer support network. The females were told that their decision to participate would not affect their care at the clinic or from their providers and that their names and personal information would remain confidential. All participants provided written informed consent and received $40 for their time. To examine the question, “What are the cultural beliefs, values, or norms that influence Latinas in choosing to have recommended chemotherapy?” the researcher used the qualitative method of focused ethnography, which is grounded in the assumption that, “culture is viewed as a system of knowledge used by human beings to interpret experience and generate behavior" (Spradley, 1980, as cited in Morse, 1989, p. 45). Focused ethnography permits an examination of health-illness beliefs and practices and the local language used in relation to them (Muecke, 2007).

Collection of Archived Data

The researcher conducted in-depth semistructured interviews. This approach combined the practical advantages of the structured approach with the open-ended discourse style of unstructured listening. Data were gathered to identify cultural themes, that is, "patterns of recurring messages that represent organizing principles in the cultural system under study" (Morse, 1989, p. 47). The interviews were organized around an interview guide that consisted of closed introductory material and an open-ended grand tour question to encourage a narrative followed by specific prompts or probes. The interview protocol was developed by the ethnographic method of eliciting a narrative about the topic: "Now, I'd like to ask you to tell us about the time you were diagnosed with breast cancer. What happened?" Based on the first responses, probes were added and asked, if necessary.

The researcher and two colleagues conducted in-depth semistructured interviews of 90 to 120 minutes in length with the Latina breast cancer patients. The interviews took place in the women's homes and were conducted by the researcher and two trained bilingual female interviewers who were members of the LACRC. The interviews were audio-taped with permission of the participants. Each interview was translated and transcribed by a transcription service soon after being conducted. The translations were reviewed by bilingual staff.

Trustworthiness of the Data

The first step in assuring reliability was in the selection of the sample. A purposeful or theoretical sample was chosen because of the breast cancer experience of the participants and their willingness and ability to be interviewed. The sample was chosen to be representative of the knowledge domain, not demographic characteristics. For this reason, it was not expected to be generalizable in the usual sense. However, the sample was relatively homogeneous, made up of a large percentage of low-income, low-education, new immigrants. For this reason, even though they were not chosen to represent a demographic group, they may have been characteristic of others who shared their demographics. The homogeneity of the group also insured validity. Saturation was achieved before the 20 interviews were completed. The interviewers included two bicultural, bilingual Latinas and one breast cancer researcher who were present for the interviews and case review. The knowledge and experience of the three allowed them to confirm the credibility of the data.

The interviews were long and detailed, with probes for accuracy. This method provided the assurance of credibility. Demographic data were used to obtain factual information to triangulate with qualitative data and to check interpretations. Interviewer bias was addressed by using two interviewers who would review the case findings. In addition, the biases of the individual interviewers were identified and put aside, or "bracketed." Interviewing was continued until the data became "saturated," that is, until the themes were repeated (Lincoln & Guba, 1985).

Data Analysis

The study was designed to comprehend cultural influences by obtaining narratives focused on an illness experience. The narrative resulted in thick description of a series of events in the words of the respondents (What happened after you were diagnosed with breast cancer?). Because all participants in the sample were Latino breast cancer patients, themes from an emic perspective could be identified as cultural when they were linked to an etic perspective by the researcher by comparison with existing knowledge. For instance, there is a large amount of literature describing the views and decision-making behaviors of breast cancer patients in the general, non-Latino culture in the United States. Themes that were unique to this group of Latinas could be assumed to derive from the group context or culture.

Data transformation consisted of three processes described by Woolcott (1994) as description, analysis, and interpretation. The researcher used NVIVO, an advanced qualitative analysis software program that aids researchers in handling, coding, and analyzing large quantities of data (QSR International, 2005). It allowed for initial open coding, coding into themes, and selective categories of themes. This ensured the integration of information at different levels of analysis.

According to Wolcott, (1994) the process of description addresses the question, "What is going on here?" (p. 12). By reading the narratives, the researcher, from an etic perspective, perused the data until she comprehended the answer to that question from an emic perspective. In other words, the data instructed the researcher about what was going on from the perspective of the patients, using the patients' own language, and displaying their reasoning and assumptions. The researcher then began a process that Morse (1994) defined as synthesizing, that is merging several stories to describe typical patterns or an average story and sifting, a process of shaking off the insignificant material.

The process of analysis (i.e., making sense of it) involved highlighting commonalities and patterns, identifying and sorting themes, and contextualizing (Woolcott, 1994). Stated values and norms were identified in the stories. Next, linkages were made between emic and etic perspectives by comparing and contrasting cultural values and norms from the data with existing literature, established theory, or other cultural groups. According to Woolcott, the process of interpretation involves making sense of what is going on in a larger context and reaching out beyond scientific data for understanding. In this focused ethnography, interpretation was used to make recommendations to improve practice and make suggestions for further research. It also was used to suggest application to other settings and populations.

Summary

The methods used in this study were chosen as the most effective for answering the primary and secondary research questions. Because culture is key to answering the research questions, culture theory and focused ethnography were used to analyze the data. Using established qualitative analysis methods, efforts were made to assure the reliability and validity of the results. Chapter 4 contains a discussion of the analysis and the results, and chapter 5 interprets the results and offers recommendations.

CHAPTER 4: RESULTS

Processing the Archived Data

The process of generating, gathering, and recording the archived data was discussed in chapter 3. In-depth interviews were audio-recorded by two interviewers with the respondent’s permission. These recordings were then transcribed and translated by a transcription service. The transcriptions were reviewed by the original bilingual interviewers, who listened to the original recordings, when necessary. Electronic files of the transcriptions were entered into NVIVO software for processing. The interviews, which were from 90 to 180 minutes long, resulted in a massive amount of data. QSR (2005) NVIVO was used to manage the data and to aid in handling, coding, and analyzing them. The program allowed for initial open coding, thematic coding, and selective categories of themes. This management tool allowed the researcher to integrate information at different levels of analysis. The program also has the capacity to record demographic and other data as quantitative data to be used to sort cases by various attributes such as age or country of origin. This tool made it possible to display demographic details of the sample.

First, the data underwent open coding, a process that allowed the researcher to identify small chunks of data and to code them. For instance, when the subject of the patient’s children was raised in any context, the section of text was coded as Children. These code names were saved, and the entire data set was reviewed to identify other passages that should be coded Children. In open coding, the context is not considered.

For example, a discussion of “wanting to have children” and a discussion of “getting support from children” would both be coded Children.

Open codes were allowed to overlap. For instance, “getting support from children” might have been coded “children,” but it also might have been coded as Support. The open coding phase identified 56 codes. These codes were then grouped into categories, or trees. Each tree had subcategories, and each subcategory had coded passages. These categories were developed by the researcher and were informed by perusing the entire data set. A list of codes is shown in Appendix B.

Data Analysis

Comprehension and Description

The first step in the analysis was a thorough reading of all transcripts to answer the question, “What is going on here?” By reading the narratives, the researcher perused the data until she understood the answer to the question from the perspective of the patient. In other words, by reading the data from the patient’s perspective and wording, she began to understand the patient’s reasoning and assumptions.

Synthesis

Handwritten notes were taken by the researcher as she read the transcripts. These notes were later used to synthesize the stories into typical patterns and stories. The software also was used at this stage as themes or typical patterns were suggested by perusing the open codes in a category. For instance, “cause of cancer” contained eight open codes and one of them, “punishment from God” appeared in six passages.

Analysis

Analysis can be described as making sense of it. It involved identifying commonalities and patterns by sorting themes and contextualizing. Typical stories revealed the stated values and norms of the patients. To move to an etic perspective and to identify cultural values contained in these narratives, the researcher compared and contrasted cultural values and norms from the data with existing literature, established theory, or other cultural groups. For instance, “punishment from God” fit established theory of Latin American cultural values and perspectives concerning illness and disease.

Interpretation

Interpretation followed the presentation of results. It involved seeing the issues in the context of literature from the general U.S. population. Grounding the findings in other literature and identifying cultural influences led to greater understanding of Latino values that affect behavior.

Evidence of Quality

Several steps were taken to ensure data quality. First, the interviewing team reviewed all the translated transcripts. Two researchers performed the initial coding separately, after which they discussed the codes and agreed upon differences. Most often, differences were in the size of the passage, not in the code, itself. The researcher decided on categories after reading all the transcripts and reviewing codes. The frequency of codes was examined and compared to patterns perceived by the researcher. These categories, as well as the resulting interpretation, were reviewed by the original bicultural interviewing team who were present for the interviews.

Results

As shown in the demographics in Table 1, the median age group of the sample was 40 to 49. Most women were from Central or South America. Of the 20 participants, 12 spoke little or no English. Eighteen of the 20 were employed when diagnosed, many as housekeepers. Ten women had to leave their jobs when they became ill. Many of the women had few family members in the United States and relied on their husbands or parents from Central America for care giving. Because most of the women had children, husbands had the multiple roles of caregiver, childcare provider, and wage earner.

Table 1

Demographics of the Study Sample

ID	Age	Marital status	Children	Years in US	English	Education	Work before	Work after	Family context
1	50-59	M	2-4	4-5	None	Some HS	Yes	No	Patient has a husband, son, and daughter. The daughter translates. The husband is a caretaker at a church. No other family
2	60+	S	1	> 20	Fair	Some HS	Yes	Yes	Patient has a sister, brother, daughter and large family nearby.
3	30-39	S	1	4-5 years	Little	Some college	Yes	**NR**	Patient has no primary caregiver. She lives with her brother and his wife who don’t take care of her and demand rent. No other family
4	50-59	S	No	11-20 years	Little	Some college	No	NA	Mother and patient went to live at her sister’s house after her diagnosis. Patient’s mother wasn’t told patient has cancer. There is no other family in the area.
5	40-49	M	2-4	6-10 years	None	Some HS	Yes	No	Patient has a husband and two daughters and one boy. Her mother-in-law came from El Salvador for one month for surgery. Patient’s oldest daughter is her interpreter. Her husband has to work – “money is an issue with three children.” No other family.
6	60+	W	1	6-10 years	None	Grade school	Yes	No	Patient has a friend who helps her. She lives with her brother who is no help. Patient lost her housekeeper job. There is no other family in the area.
7	40-49	M	2-4	11-20	Little	Some HS	Yes	Yes	Patient has a husband but no other family in the area. Both work – at a restaurant and cleaning. They send money to their children in El Salvador.
8	40-49	M	2-4	4-5	Fair	College	Yes	No	Patient has an American friend who helps her, since patient’s husband is a truck driver. There is no other family.
9	40-49	M	2-4	11-20	None	Grade school	Yes	No	The patient’s husband works as a cleaner at a hospital. They have two young children and no other family.
10	50-59	Sep	2-4	1-3	Little	Some HS	Yes	No	Patient lives with her two teenagers. She has an aunt and uncle in the area but only her uncle speaks English.
11	50-59	S	2-4	6-10	Fair	Some HS	Yes	No	Patient has a daughter who is 20 years old and has a small child. The daughter works to support them. There is no other family
12	50-59	M	2-4	< 1	Little	Some HS	No	No	Patient has a son but no other family. Her son translates. She is separated from her husband.
13	50-59	S	1	> 20	Fair	Grade school	Yes	No	Patient gets help from two friends. She has a son who lives near by but she didn’t tell him about her cancer. There is no other family.
14	30-39	S	2-4	1-3	Little	NR	Yes	Yes	Patient has no other family in the area. Her mother is visiting from Peru to be her caregiver. Her mother doesn’t speak English and is worried about husband who is ill in Peru.
15	30-39	M	2-4	11-20	Fluent	College	Yes	No	The patient’s husband is American. They live together with two children.

16	50-59	S	No	11-20	Fluent	College	Yes	No	Husband’s mother lives with the couple.
17	40-49	M	1	< 1	Fluent	College	Yes	No	Husband visited from Ecuador for her surgery then left. Patient is staying with a friend.
18	40-49	M	No	< 1	Fair	Technical training	Yes	No	Husband is in a wheelchair. Landlady helps the couple. No other family.
19	30-39	M	2-4	11-20	Little	Grade school	Yes	Yes	Husband is the primary caregiver. He does construction and can’t take off work. They have two young children and there is no other family in the area. The patient’s mother and father took turns visiting from El Salvador.
20	30-39	M	2-4	11-20	None	Grade school	Yes	Yes	Patient lives with her mother, husband and three children. There is no other family in the area. She had support from her church

Themes

The following sections show the themes as they were organized to answer the research question, “What are the cultural beliefs, values and norms that influence Latinas in choosing to have recommended chemotherapy?” and the subquestions, “What are the cultural beliefs about disease and illness and about cancer?” and “What are the cultural values and norms that may play a role in medical decisions?” Although the themes overlapped, they were organized for clarity into the following overall groups: (a) Role-Related Themes, (b) Employment/Immigration Status, (c) Beliefs and Knowledge of Disease and Treatment, and (d) Information and Communication. The themes synthesized from the data are presented with representative quotations. Next, they are compared and contrasted with existing literature to identify them as cultural themes.

Role-Related Themes

Social support. Latinos in this sample relied exclusively on extended family for assistance and support, both social and instrumental. However, as shown in the column labeled “Family Context” in Table 1, the immigrant status of the females who were interviewed left them without either extended family or support. The women expressed feelings of vulnerability because of the lack of nearby family and the reality of being in a foreign country. Very few of the couples had extended family in the area. For most of the women, their husbands were their only support, but most of those husbands were employed in one or more low-paying, hourly jobs in cleaning or construction, so they could not take time off work. This lack of support was a barrier to treatment for some of the women. Also, because many of the couples had limited English, their children often were their translators, limiting communication with doctors. One woman explained:

> It was not easy. And it is not easy now. If this illness had affected me 10-15 years from now, maybe I could accept it, but I was not here in this country for long. We do not have family, we do not have anyone. My children never have been with their father because he has other responsibilities and he does not care too much. It is hard to live in the US because I am not with my family. [She cried]

The sense of “not having anyone” was exacerbated by reliance on family as the only source of assistance. Almost none of the women had friends or other contacts outside the family who helped them.

One barrier to follow-up treatment was a need for social support, both instrumental and emotional. In the Latinos, a lack of social support was directly related to the absence of family members. The Latino reliance on family made it less likely that the women would ask neighbors for help, for instance. Another factor in this reliance on family was a value of secrecy about cancer.

Gender roles. The women in the sample adhered to the traditional female gender roles of mother and wife. With few outside resources and a cultural tradition of little male involvement in child care, the mothers felt they alone are responsible for their children’s care. The women reported feeling an obligation to provide for their children and their extended families. One woman was the sole support for her children. She said, “In my country, people don’t want to spend money to go see a doctor because this money could be used to feed their children or family. They don’t have (a source of income).” Speaking of her children in Central America, she said, “I send them everything from here. I think that if something happened to me, what would be[come] of them? They don’t know how to take care of themselves.”

Child care. Traditional, strict gender roles can be a barrier to treatment. Latin women in general take full responsibility for the well-being of their families; self-care is a lower priority. Because the responsibility for children and home is not usually shared with men, there is discomfort when a woman is unable to perform her usual duties. One woman feared that she would not be able to take care of the children. She said:

> I mean you probably are going to feel tired, you are going to have fatigue, you are going to have nausea. So you won’t be able to keep going with your life as usual. I know my husband can take care of himself, but I don’t know about my children. Sometimes you feel indispensable. I thought that if something happened to me there would nobody who could do these things with them. Who would go over their homework, would feed, would console them at home. Men don’t do. My husband is great and everything, but he would not [do] that. Who would talk to them; give them affection, a hug? That was the hardest thing.

*Sexuality and body image. S*exuality and body image were minor themes in our interviews, mentioned much less than economic, communication, and childcare issues. Hair loss, however, was mentioned often. One woman commented, “I felt I wanted to die. I did not want to get it [chemo].” She was asked if it was because she was afraid. She replied, “Because of my hair. Because the Latinos notice these things more that the people from this country.” Another woman said:

> I think that one of the reasons why Latina women don’t go for treatment is a cultural issue. Chemotherapy evidently affects your sexual lifestyle. That means that in a period you are not going to have sexual relations or you won’t feel like you want it, and that’s always going to disturb in your family life.

Yet another woman said, “I may not be useful for a man as a woman with no hair, eyebrows, eye lashes and I may not lead a marital life.” Several women expressed the fear of losing their husbands during their treatment.

Childbearing. Younger women in the sample expressed concern about being able to bear children after treatment. They had some conflicting and confused information on that topic. “In talking to a lot of Latinas, some women that I talk to they think that they won’t have their family, they wouldn’t be able to have kids after chemotherapy.” When the interviewer asked another woman, “Did he (the doctor) tell you could have a baby?” She answered, “The doctor told me that I had to control myself. There were no guarantees.”

Latinas who adhere to strict gender roles view self-care as less of a priority, even when seeking treatment. One woman stated:

> As Latino women, we prioritize our husbands, our children, the family, and we stop caring for ourselves, and we could have a discomfort and wait until it goes away. We don’t think that us as women could also get sick. When we wake up and seek treatment is too late. Anxiety is caused by responsibility for children with no other support.

These traditional, strict gender roles can be a barrier to treatment or a facilitator. For example, responsibility for children may have been a facilitator to following treatment recommendations when the woman believed that chemotherapy would help her live longer. One participant commented:

> Surely, at the fourth round, I said I did not want to do it anymore. I did not want it, I did not want have anything to do with it. But my daughter gave me courage. She told me I had a son I had to fight for, that I had to live because I was needed. So I did one more and finished the chemotherapy.

Employment/Immigration Status

The SES of the poor and newly immigrated women in the study sample included complicated interactions of poverty, job insecurity, lack of health insurance, low education, and language barriers. One woman said her first thought was, “How am I going to go to treatment if it is not cheap?”

Apart from treatment costs and the lack of health insurance, important issues related to the often precarious economic situations of the women and their families affected chemotherapy decisions. Most of the women were employed at the time of their diagnosis, whether married or single, and their incomes were needed by the extended families here and in their native country for subsistence. Most of the women and their husbands were employed in unskilled, low-paying hourly labor such as housecleaning and construction, which provided no compensation for sick leave or personal leave. If the woman could not work because of treatment, her salary would be lost; if her husband was needed to provide child care, transportation, or other assistance to her, his salary also might be lost.

In addition, the jobs often were not secure. The participants feared losing their jobs if they took too much time off. This was an issue for the women as well as for the husbands/caregivers. As one woman said, “It’s difficult to get time off from work. There are always problems with the bosses. Even if you have insurance and everything, there’s a problem because nobody wants to miss work.”

The cultural norm of respeto, unique to Latino immigrants, interacted with these work realities. For example, some women were hesitant to discuss their illness with employers (superiors) or to request special treatment. One woman said:

> Since one always thinks about eating. That's why you have to work because you don't have kids, nothing. I asked my boss for permission to come in earlier and leave earlier too. I told him I was receiving some therapy. He never knew. The other work mates asked what was happening with me. They thought I was being favored, but to date, they don't know anything.

Many women reported keeping their treatment secret from employers. One woman expressed these conflicting pressures as too difficult to manage. She said, "Sometimes you don't want to not go to work. Sometimes you want to die instead of getting treatment."

Insurance. The women in the sample who had no insurance were eventually able to receive treatment from governmental and charitable sources. However, many of the participants said that most women do not know about these resources. Some women expressed concern about using these resources, and others felt that they were not entitled to get a second opinion or to ask questions because they were accepting help. One participant stated:

> He (the doctor) told me surgery and chemotherapy, but I would have liked to consult with another doctor if I had known how to speak English. I also was blinded and said to myself that if the doctor said that I needed the mastectomy then he should do it once and for all. I did not check with other doctors.

Beliefs and Knowledge of Disease and Treatment

The women expressed the view that Latinas from their countries do not know anything about chemotherapy. They said that most people have not heard the word and that those who have heard the word do not know what it means. They acknowledged that they also had not known anything about chemotherapy before they had cancer. They presented several reasons for this lack of knowledge. First, there is a cultural norm of secrecy about cancer that extends to cancer treatment. Also, as one woman noted, when poor people in their countries get sick and die, they often have had no medical treatment, so chemotherapy is never discussed. Sometimes, the knowledge that the women gained from experience or from others was incorrect. Several women spoke of their fear of information and general avoidance of anything concerning health and treatment (e.g., “Illness, no, it’s over there”).

Some of the women who had heard of chemotherapy had many misconceptions about it. Most relevant was the belief that chemotherapy is not effective. Table 2 is a summary of the participants’ narrative comments about chemotherapy. It is presented in table format to highlight the degree of misunderstanding.

Table 2

Perceptions of Chemotherapy

“There were some masks which I thought were used in chemo. I thought they would make the women wear the masks.”

“I knew that in many cases it would not work. That’s what I knew. But I did not know about how the treatment was. I was never interested in obtaining information. There are people that get informed about it, but I was so afraid that …..(I didn’t want to learn).”

“What I hear people say chemotherapy does is that it damages the body.”

“I thought that cancer meant death and that chemo also meant death.”

“I thought that with the chemo, they would pass you through a machine. Many people thought that too. Nobody had that information about chemotherapy.”

“I heard that when you die you die, but chemotherapy helps. My friend mentioned that even when you receive the chemotherapy, you still die.”

“I only heard it (chemo) from a neighbor. It’s not in open conversation. I don’t know if it’s because of the fear or if it does not exist (in country of origin).”

They told me that I would first need to go to a doctor, an oncologist, to see if I needed chemotherapy. When they told me this, I think that this was the biggest fear and blow that I had, bigger then knowing I had cancer. Because my grandmother, on my mother’s side also died of cancer and I saw her suffer for a year. This was terrible. She suffered a lot. And we were all with her the whole time, so Oh! When they told me chemotherapy, I said, “Oh, my God!” I said that I did not want this, I won’t do it.

Many women said that their expectation before treatment was that chemotherapy was “very painful.” They learned about the side effects of hair loss, nausea, fatigue, and other symptoms either immediately before or during treatment.

I did not know the significance of chemotherapy because I had never heard that word. Cancer yes, because I had experience with my mother, but 35 years ago. I thought that they would be giving me ultraviolet or radio laser, and put a liquid-ultraviolet to hold the cancer, since this is what they did to my mother. This was the concept that I had of breast cancer.

If they told you [that] you have cancer and then they give you chemotherapy, which is going to make you lose your hair, she said. She also said, “I was not going to be able to care for myself. That I would need somebody to help me like a handicapped person.”

Because these responses were so discrepant from those of other breast cancer patients in the United States, they highlighted the lack of experience and education that results in misconceptions about the barriers to chemotherapy use.

Information and Communication About Chemotherapy

The timing of information about treatment was not optimal to decision making in the women who had many misconceptions about chemotherapy. Most of the women who were interviewed received little or no information about chemotherapy before their first treatment. Only at the time of treatment were they given information about potential side effects. The women who spoke English; were educated; and had someone else to help them obtain information (e.g., a patient navigator, support group, educated relative) had enough information to make an informed decision before treatment. Of note, very few of the women were given information about the benefit of chemotherapy. For those women who believed that chemotherapy often does not work and harms the body, this information was crucial and could have facilitated the decision to use chemotherapy. One woman commented:

> He (the doctor) told me that he had to give me chemotherapy and radiation treatment and all of that. I was ignorant about all of that because I had never heard talked about chemotherapy or radiation. I did not know what I was going for.
>
> From knowing that they were going to do the first chemotherapy, I was scared of the medicine and I had a lot of questions. Everybody spoke English. At the moment when you're having tension you can't emit words and ask questions even though you have the interpreter in front of you. And what about survival? Did the doctor tell you anything about that? The lifespan you had? No, we did not talk about that. Did you ask? No, because my oncologists did not speak Spanish. And at that clinic nobody speaks Spanish.
>
> I, from the first moment, did not want chemotherapy. I accepted chemotherapy, Why? Because I ask a lot of questions, because I have the will to know more, but not everybody are predisposed like me and a lot of people, because I even heard people did not want to know it during the consultations with the doctor at Nueva Vida. They get stuff (written material), they give them the appointment and everything and the people say no. Why? Because it is a lack of information I think, no? Ignorance of not knowing exactly what chemotherapy is really for.

> I think there are a lot of factors (why a woman wouldn't want treatment): first the fear of what chemotherapy is; what reaction will produce; what will cause; how my life will be from now on; what will happen.

Most of the women who were interviewed revealed that they were not comfortable asking their doctors any questions. This discomfort was related to language, education, lack of health insurance, and a reticence to communicate with their doctors. The women described it as follows:

> I only cried. I did not ask. I don't ask questions. I take my friend to make the questions. I have fears of asking questions. (Doctor) told me that I spoke English and how come I don't ask questions. I would let her ask the questions and then she would tell me to take the pill everyday at the same time and that I will be ok. I don't like to ask questions. I get there and I don't know what to do.
>
> The language factor prevents us from expressing what we want to say. If you ask, they (the doctors) will answer, but if you want to ask and you don't know how then ….. I asked a few things and I understand better when they talk to me than me talking. That was my problem in my case. But in fact I did not understand the importance of chemotherapy in the body. I could not talk to (the doctor) directly. I had interpreters.

Avoidance. Another barrier to communication that was shared by many of the participants was a preference for little information. Some patients spoke of not wanting information because it made them anxious. For instance, as an example, 1 patient said that after her diagnosis in a physician's office, she did not want to go anywhere else. "No, I did not want to go anywhere." They had information in the doctor's office, but she said, "Yes, they have books in Spanish, but I was not interested in reading them. So I never had any."

Interactions with doctors. Doctors were the most powerful force for information and communication. Written materials were not helpful, and the women often did not discuss their cancer with others. One woman said:

> I accepted the treatment. I accepted because it came from the mouth of the doctor because she said that this was what could save me. But I did not investigate; I did not have any chance to investigate. I did not have the opportunity to talk to other doctors. I would have liked to have a doctor that spoke Spanish, to ask questions, to be satisfied. Here the only thing I can do is accept, because we were going against time. I did not know anyone with experience. So the only thing left was, I was on the horse so my only option was to ride it.

There were two exceptions of doctors being successful at communication. The first doctor was able to communicate despite language problems. The second took the time to discuss the prognosis in simple, understandable terms. Comments included the following:

> The surgeon was a person that always talked to me. He was kind and was the greatest medical support even though he did not speak Spanish. Signaling and gesturing me, he made me understand what he was talking about. He told me about him, that he had been operated for prostate. He told me, “Look at me, at my age, I’m old and I still live to take care of grandchildren and to enjoy their company. So you are going to live many more years. Stick that idea in your head.” So he was the one that talked to me like that. So I said that if he said so, then it must be truth. So, it was worth it that I would start the treatment. He explained it to me. He told me about that. He told me I was going to lose my hair, that I was going to have vomits and headaches, but that I would overcome them at the fourth, third day. Things occurred the way he told me. It happened to me. My hands and nails turned black. He tried to find information in Spanish unsuccessfully.
>
> They gave me some information in English. That’s why I never read them. When we went find out about the options, the doctor who did the mastectomy found out about this oncologist who was going to make the decisions. He put in the computer that if I did not get the chemos, I’d have 70% chances of having the cancer grow back, and a 30% of not having it grow back. If I got the chemo, these numbers would be the other way around. So 70% would mean that the cancer does not grow back, but he does not guarantee that this may not grow back. So, I

> will always have a big percentage of chances that this grows, and it could grow anywhere, not only in the breast.

Interpretation

The themes that emerged from the interviews can be compared to existing literature about cancer treatment in women. When compared to existing literature about Latinas and cancer, the similarities suggested that the themes were consistent with recognized Latino values. When compared and contrasted with literature about the general population of (mostly) White breast cancer patients, the contrasts identified values unique to Latinos. By grounding the findings in other literature and identifying cultural influences, it became possible to see the issues in a larger context and reach out beyond the data for understanding. Interpretation allowed the researcher of this focused ethnography to make recommendations to improve practice in similar settings and populations.

Role-related themes. Studies of Latino culture have identified the importance of familisma and collectivism in social support and machismo in strict gender roles. Because of the value of familisma, Latinos are reliant on family for social support and are less likely to seek social support outside the family (Alvirez & Bean, 1976; Sabogal, 1987; Campaña, 1989). Gender roles for women include the responsibility for everything associated with the home, including caring for children, sick family members, and older relatives (Marin & Marin 1991; Vernon & Roberts, 1985). It also includes the role of wife: being available sexually, valuing body image, and being able to bear children. In summary, role-related themes have been documented in the existing literature about Latino culture.

In contrast, the U.S. majority population of breast cancer patients have fewer concerns about fulfilling their roles and more concerns about dealing with symptoms such as nausea that are affecting their quality of life. Although some patients reported concerns about how their cancer will affect their families, this concern was related to their family members' psychological stress, not to survival. However, like Latinos, some breast cancer patients from the majority population have general financial concerns (Lindley et al., 1999).

Employment/Immigration status. The women who were interviewed were concerned not only with fulfilling traditional roles but also for earning a living and, often, for sending money to relatives in their home countries. Thus, problems of poverty, financial insecurity, and immigration status interacted with traditional values. For instance, financial insecurity added to Latino values of respeto (power distance: respecting those in authority) and secrecy about cancer, so a Latina breast cancer patient did not inform her employer of her illness. Likewise, the combination of respeto and a lack of health insurance made the women afraid to question their doctors about their cancer treatment. The women in this sample did not have private insurance, but they did have medical care for their cancer from a variety of sources. However, what was perceived as charity made them less empowered to question authority.

Immigration status also had several effects on the women’s lives. First, they often were isolated and without extended family. Next, it was more difficult for family members to travel to care for them. The literature has documented Latinos’ lack of knowledge about cancer and treatment (Perez-Stable et al., 1992). There are several reasons Latinos misconceive the cause and course of cancer and the benefits and side effects of treatment: They are likely to come from countries with a cultural norm of secrecy about cancer, late diagnosis (higher morbidity and mortality), and inadequate treatment for pain and other symptoms.

In the sample interviewed by this researcher, the women’s fears and misconceptions were striking. In addition, none of the women reported that a doctor or a nurse provided specific information about the process until she arrived for the first treatment, after having made a decision.

In the general U.S. population, several studies have shown that patients’ expectations of chemotherapy side effects are significantly worse than their actual experience with chemotherapy, that is, once they have had it. This difference is increasing as progress is made to make chemotherapy less toxic with decreased side effects and patients’ expectations are staying the same (Carelle et al., 2002; Lindley et al., 1999; Passik, Kirsh, Rosenfeld, McDonald, & Theogold, 2001). However, this researcher does not know of any study that has questioned women about the process of getting chemotherapy and radiation. Personal experience, however, has suggested that the average American woman can be expected to know how radiation and chemotherapy are given. Although she may fear the side effects, she does not fear the process of receiving treatment.

Information and communication. Avoidance of information about medical topics (bad news) is a value shared by Latinos. This value has been explored in the literature, especially in cancer and palliative care literature (Blackhall, Frank, Murphy, & Michel, 2001). The belief is that truth is harmful and it is better not to know and to leave things in the hands of God. This is in contrast to studies in the general U.S. population that have concurred that most cancer patients want information about their disease and treatment (Cassileth, Zupkis, Sutton-Smith, & March, 1980; Sutherland, Llewellen-Thomas, Lockwood, & Trichler, 1989).

Summary

The 20 interviews yielded a large amount of data. To make the data understandable and useful for practice, it was necessary to process them through several steps, including coding, categorizing, reading for comprehension, synthesizing, and comparing the results to existing literature. This process resulted in a rich description of how 20 Latinas with breast cancer made sense of their illness and treatment. It also described how their beliefs and preferences, acting in the context of their lives, may have influenced their decisions about follow-up treatment such as chemotherapy. The following chapter includes an interpretation of the results, the significance of the results, and implications for practice.

CHAPTER 5: SUMMARY, CONCLUSION, AND RECOMMENDATIONS

Overview

Breast cancer is the leading cause of death in Latino females. In the Washington, DC, area, Latinas, as well as other females of color, are twice as likely as White females to die of diagnosed breast cancer. Although most research has focused on disparities in early detection, there is evidence that there are disparities in follow-up care and that Latinas are less likely to receive optimal follow-up treatments such as chemotherapy after they have been diagnosed and received surgery. There is additional evidence that there are cultural reasons for treatment disparities not attributable to insurance status and access to care.

The purpose of the study was to explore the reasons Latino females may be less likely to receive follow-up treatment for breast cancer. The objective of the study was to examine relevant cultural factors by analyzing in-depth interview data from 20 Latina breast cancer survivors for whom insurance may have been an issue, but access to medical care was not an issue. A deeper understanding of the phenomenon was sought in order to inform future efforts to improve care and reduce mortality.

The specific research question asked, “What are the cultural beliefs, values and norms that influence Latinas in choosing to have recommended chemotherapy?” Subquestions also were raised: “What are the Latino cultural beliefs about disease and illness and about cancer?” and “What are the Latino cultural values and norms that may play a role in medical decisions?”

Using the overall framework of culture theory and the method of focused ethnography, the data were analyzed and interpreted to explain how culture may influence Latina breast cancer patients to underuse recommended chemotherapy. An emphasis on culture required a comparison of key themes with other cultural groups and existing literature about Latinos. The results of the analysis confirmed the influence of culture on the health decisions and behavior of Latino breast cancer patients.

Summary of the Findings

Culture-specific factors such as strict gender roles; avoidance; respeto (i.e., the tendency not to challenge authority figures); familisma (i.e., not asking for help outside the family); and secrecy about disease (fear and shame about cancer) were found to be influential. In addition, demographic factors, including immigrant and employment status, were influential, especially when combined with cultural values. For instance, the need to support children by working two jobs can add to a tendency to secrecy and avoidance so the breast cancer patient does not follow through with treatment. Social support, traditionally supplied by family members, often was missing in this immigrant group. Because the women were very concerned with fulfilling the strict gender roles of wife and mother, the issues of body image, sexuality, childbearing and childrearing were primary concerns. The researcher also found pervasive gaps in knowledge and access to information in this sample, a gap which often supported mistaken beliefs.

Communication with physicians was less than optimal for many of the women because of language barriers, a cultural reticence to ask questions, and feelings of disempowerment because of a lack of insurance. An important finding relevant to decision making was that the women had exaggerated fears of chemotherapy and undervalued its benefits, even after communicating with doctors and nurses. Information about its side effects and the process of chemotherapy often was given too late. Written information, even in Spanish, was not helpful.

Interpretation of the Findings

Previous studies have found that both cultural norms and immigrant status are influential in the health behaviors of Latinos (Alferi et al., 2001; Borrayo & Jenkins, 2003; Campaña, 1989). The results from this study highlighted the barriers created for Latino immigrants who have little local family support and cultural norms of familisma and strict gender roles. Although many interventions focus on the barrier of insurance status, the results indicated additional barriers created by a lack of caregiver support and the need to continue working.

Other studies have reported that Latinas’ beliefs about cancer are different from those of White women and that those perceptions and beliefs play a significant role in their health behavior (Facione & Giancarlo, 1998; Hubbell et al., 1996). Latinos fear cancer more than any other disease, and the shame and secrecy about cancer foster mistaken beliefs (Hubbell et al.). In addition, Latinos are less convinced than Blacks and Whites about the effectiveness of cancer treatment. However, they are very concerned about the side effects from cancer treatment and are more fatalistic than other groups (Perez-Stable et al., 1994). The results confirmed these findings and showed the extent and nature of misconceptions about chemotherapy. These results indicated that information will be more useful if patients' misconceptions are addressed immediately.

Communication is an important moderator to barriers created by SES influences and beliefs. In Latino cultures, there is a tendency for physicians and family members to withhold information about cancer from the patients, including prognosis (Blackhall, Murphy, Frank, Michel, & Azen, 1995). There also is a reluctance of patients to ask questions and challenge authority figures (Marin & Marin, 1991). These barriers exist in a population in which communication is needed to turn misperceptions and fear into good decisions. Good communication includes Spanish-speaking providers or good translation (not using children), providers who understand existing perceptions and beliefs, an understanding of Latinas' communication style, and an understanding of the power of physicians in the dyad. Ideally, the doctors would know the women's family status and responsibilities and the pressures on them to continue to function.

Implications for Social Change

This study was the first study that this researcher knows of its kind with this population. It may lead to interventions to change beliefs and perceptions of adjuvant therapy, especially chemotherapy, following breast cancer. The results may be used by clinicians in their practices to improve their communication with Latina patients and by other groups to provide educational and counseling interventions. These results also may inform researchers about cultural influences on the decision to accept chemotherapy as a treatment for other cancers, especially other female cancers. The findings also may be used by other researchers to explore health behaviors for other diseases.

Disparities in cancer mortality are a public health concern. A woman of color in Washington, DC, is twice as likely as a White female to die of breast cancer. Efforts to reach the Latino community have too often involved simply translating English materials into Spanish without understanding how Latino cultures make sense of illness and treatment, the health literacy level of the audience, and other barriers. Health communication efforts will not be successful without a deeper understanding of the target audience. Positive social change is necessary to reduce cancer mortality among Latinas.

Researcher's Experience

As a breast cancer survivor, I had radiation 5 days a week for 5 weeks. At the time, I was working at home as a consultant with a flexible schedule. Every day at 5 p.m., when it was the least busy, I would drive 5 minutes to the hospital, enjoy a cup of gourmet coffee, have my radiation, and leave in less than 20 minutes. One day as I was waiting for my treatment, I began talking with another patient who was Latina. She told me that she was employed as a housekeeper in another suburb. She had to take two buses to reach the hospital, so the daily routine took her 2.5 hours. When she got home, she had children to feed and care for. She was afraid of losing her job because she had to leave early. She told me that she was so exhausted, she was thinking of stopping treatment. She also said that if her doctor recommended chemotherapy, she probably would not have it because if she had it, she could not take care of her children and “it doesn’t do that much good anyhow.”

This meeting made me realize that what might seem like an irrational choice to forego chemotherapy, when seen through my eyes, made more sense when see through the eyes of this woman. I knew that in the Washington, DC, area, women of color are twice as likely as White women to die of breast cancer. I also knew that although the focus has been put on late diagnosis, this is not the whole story. Black women and Latinas were not getting the follow-up treatment that would keep them alive.

In order to improve cancer care, as part of the Latino Cancer Care Consortium (LACRC), two colleagues and I had the opportunity to talk with 20 Latina breast cancer patients about everything that happened following their diagnosis. They all had access to medical care, although most were poor. As I listened to the interviews, I heard beliefs and values that did not occur in the majority population. It occurred to me that a systematic and thorough analysis of these data might reveal cultural and contextual reasons Latinas may choose or reject follow-up treatment for breast cancer. An understanding of these reasons and insight into the culture might help healthcare educators and providers to support Latino patients in making such important medical decisions.

My experience as a patient, training as a researcher, and opportunity through the LACRC made me enthusiastic about this exploration. As someone from outside the Latino culture, I could conduct the analysis from an etic perspective. As a cancer patient and researcher, I had an insider’s understanding of the concerns of non-Latina breast cancer patients with which to compare. As an outsider, during the study, I learned to move beyond stereotypes. For instance, I asked a lot of questions about spirituality, expecting it to be an important factor. Instead, unexpected themes emerged, for instance, the importance of secrecy about cancer and job insecurity. As I proceeded to analyze the data, I was shocked to find out the misperceptions about the process of getting chemotherapy and about the extent to which Latinas underestimate chemotherapy's benefits. If I had attempted to educate the woman I spoke with about chemotherapy, I would have missed her possible fear of what she perceived as the unknown horror of getting chemotherapy. I might also have missed her reluctance to ask questions or to share her beliefs.

Recommendations

Informed by this study, I would make the following recommendations regarding the provision of education and decision support to women following breast cancer surgery:

1. Written material, even in Spanish, is not helpful for most Latinas. If it is used, it should be developed for the population. It should not be a translation of English materials.
2. Because Latinas may not know the process of getting chemotherapy, physicians, nurses, or navigators should take the newly diagnosed patients on a tour of the chemotherapy site and allow them to see the facility and equipment and speak with the chemotherapy nurses.

3. Latinas may not know about the side effects of chemotherapy and may have had negative past experiences or beliefs. Physicians, nurses, and/or navigators should assume that patients have no knowledge of what to expect from chemotherapy and may have exaggerated fears. Conversations to elicit and address patients' fears should include discussion of the improvements made to reducing the toxicity of chemotherapy.
4. Latinas may not understand the benefits of chemotherapy. Discussions should include clear and simple explanations of the expected outcome associated with having or rejecting chemotherapy. This could be reinforced with simple diagrams.
5. Latinas may be afraid of asking questions. Time should be spent encouraging questions through all phases of any discussions. Bicultural navigators are very helpful. Another approach is to suggest questions that other women have asked and to answer them.
6. Latinas are less likely, given their culture of defining health as feeling well, to understand the logic of treating a "disease," if they feel well, with a treatment that creates "illness." This difference should be addressed. A woman may be feeling well, so she may not think that she needs treatment.

7. Latinas are very concerned about functioning in their roles as wife, mother, and employee. They may have job insecurity and financial responsibilities here and in their birth country. In many areas of the United States, there are resources to help cancer patients with transportation and child care. Latinas may not know about these services, so a resource guide may be helpful. Also, a bicultural navigator could help the women access services, find a Spanish support group, and, possibly negotiate with their employers.

In summary, these guidelines, based on the data derived from this study, may be helpful in any setting where there are cancer patients, especially newly diagnosed patients before treatment. They should be reviewed by doctors, nurses, social workers, navigators, or others who see cancer patients. The data indicated that professionals should rely less on the use of written materials and commit more staff time. They highlighted the usefulness of patient navigators, especially bicultural patient navigators, decision support tools, and Spanish support groups.

Dissemination

These results will be submitted as an article to a peer-reviewed journal for cancer researchers and clinicians. They also will be presented to the LACRC in Washington, DC, and to the American Cancer Society.

Recommendations for Further Study

The results of this study suggested that further study, including other cancers and other chronic diseases in the Latino population, be undertaken based on these insights into cultural understandings of illness. The results confirmed the influence of culture on health behavior in cancer treatment, suggesting the potential for future studies of other ethnic groups, such as Chinese and Whites.

An important area of further study is the development and testing of interventions to provide education and decision support for Latinas with breast cancer. Using the aforementioned guidelines, new materials and approaches could be designed to target Latinos.

Summary

The most important message from this analysis is that not all patients are the same. Culture and context matter if the goal is to reduce disparities in mortality rates from breast cancer. In America’s multicultural society, one cannot rely on a commonality of understanding, values, and life context for which existing educational materials and approaches were developed. What is a rational health decision for a woman of one culture may not be a rational health decision for a woman from a different culture. Not attempting to understand the thinking of those of different backgrounds will result in the failure to deliver the best care.

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APPENDIX A: OPEN-ENDED INTERVIEWS

“Please tell me about when you were diagnosed with breast cancer and what happened”

Allow the narrative to continue. 60-90 minutes

Ask the following questions, if not mentioned in the narrative:

> What did the doctor say to you when you were diagnosed? What were the pros and cons of having chemo? What did you think the side effects would be? What were the most important reasons for you to having chemo and the most important reasons for you not having chemo? What were your biggest fears and worries?
>
> What about your husband, children, other family, or friends? What did they think? How did your husband react?

What did you think would be the results of treatment? On survival (how much time would it add?)? Side effects? Why – where did you get this information?

Do you know anyone else who had chemotherapy? If so, what did you learn from them?

Who did you tell about your cancer? Did you pretty much tell everyone? Why not? How did you think people would treat you?

What do other people you know think about breast cancer and about chemo? Whom did you talk to about your decisions? Try to remember as much as possible about your conversations. What did people tell you either for or against chemotherapy? Who had the strongest opinions about chemotherapy? What were they?

What do people you know think chemo does to you or does for you? What do people from your country think about chemotherapy? What did you think about cancer and chemo before you had it? How have your family and friends treated you since you've had cancer?

Did you think about why you got cancer? What are the mistaken ideas that people you know have about chemo?

Why do you think women who have come here from Latin countries might be less likely to have chemotherapy?

APPENDIX B: LIST OF CODES

Number of Nodes: 151

1	about diagnosis
2	admiration
3	advice from others
4	attitude
5	away from home
6	barriers to chemo
7	Birth after 30
8	blow to the breast
9	body image
10	careless
11	cause of cancer
12	change from illness
13	childbearing
14	children
15	compare origin to US
16	consumption of chicken
17	continuous sexual relations
18	denial
19	depression
20	diet
21	environmental contamination
22	extended family
23	fatigue
24	fear, anxiety
25	femininity
26	Gods punishment
27	hair
28	husband-partner
29	infections
30	Information
31	knowledge and percepts chemo
32	knowledge of others cancer-chemo
33	knowledge-percepts of cancer
34	language-literacy
35	money for family
36	money-insurance
37	natural medicine
38	nausea
39	pain
40	reaction others
41	rejection
42	response to diagnosis
43	role of mother-wife
44	secrecy
45	sex
46	sexuality

47	skin
48	smoking
49	spirituality
50	stress
51	support others
52	time for chemo
53	tradeoffs
54	trust of hospital or MDs
55	wanting death
56	work
57	(1) /Feelings
58	(1 1) /Feelings/attitude
59	(1 1 1) /Feelings/attitude/about diagnosis
60	(1 1 2) /Feelings/attitude/admiration
61	(1 1 3) /Feelings/attitude/advice from others
62	(1 2) /Feelings/change from illness
63	(1 2 1) /Feelings/change from illness/away from home
64	(1 2 2) /Feelings/change from illness/careless
65	(1 3) /Feelings/denial
66	(1 4) /Feelings/depression
67	(1 4 1) /Feelings/depression/spirituality
68	(1 5) /Feelings/fatigue
69	(1 6) /Feelings/fear, anxiety
70	(1 7) /Feelings/Gods punishment
71	(1 8) /Feelings/husband-partner
72	(1 9) /Feelings/pain
73	(1 10) /Feelings/rejection
74	(1 11) /Feelings/reaction others
75	(1 12) /Feelings/spirituality
76	(1 13) /Feelings/stress
77	(1 14) /Feelings/wanting death
78	(1 14 1) /Feelings/wanting death/barriers to chemo
79	(1 15) /Feelings/secrecy
80	(4) /Gender Role
81	(4 1) /Gender Role/Birth after 30
82	(4 2) /Gender Role/body image
83	(4 3) /Gender Role/childbearing
84	(4 4) /Gender Role/children
85	(4 5) /Gender Role/continuous sexual relations
86	(4 6) /Gender Role/femininity
87	(4 7) /Gender Role/hair
88	(4 8) /Gender Role/rejection
89	(4 9) /Gender Role/role of mother-wife
90	(4 10) /Gender Role/sex
91	(4 11) /Gender Role/sexuality
92	(4 12) /Gender Role/skin
93	(5) /Employment~Immigration
94	(5 1) /Employment~Immigration/away from home
95	(5 2) /Employment~Immigration/compare origin to US
96	(5 3) /Employment~Immigration/money for family
97	(5 3 1) /Employment~Immigration/money for family/children

98	(5 4) /Employment~Immigration/money-insurance
99	(5 4 1) /Employment~Immigration/money-insurance/language-literacy
100	(5 5) /Employment~Immigration/time for chemo
101	(5 6) /Employment~Immigration/work
102	(6) /Communication with Doctors
103	(6 1) /Communication with Doctors/secrecy
104	(6 2) /Communication with Doctors/trust of hospital or MDs
105	(6 3) /Communication with Doctors/Information
106	(6 4) /Communication with Doctors/knowledge and percepts chemo
107	(6 5) /Communication with Doctors/knowledge-precepts of cancer
108	(6 6) /Communication with Doctors/language-literacy
109	(6 7) /Communication with Doctors/language-literacy 2
110	(6 8) /Communication with Doctors/tradeoffs
111	(6 9) /Communication with Doctors/trust of hospital or MDs 2
112	(7) /Social Support
113	(7 1) /Social Support/extended family
114	(7 2) /Social Support/husband-partner
115	(7 3) /Social Support/reaction others
116	(7 4) /Social Support/support others
117	(7 5) /Social Support/extended family 2
118	(7 6) /Social Support/rejection
119	(7 7) /Social Support/reaction others 2
120	(7 8) /Social Support/response to diagnosis
121	(7 9) /Social Support/secrecy
122	(7 10) /Social Support/support others 2
123	(7 11) /Social Support/wanting death
124	(8) /Knowledge of Cancer~chemo
125	(8 1) /Knowledge of Cancer~chemo/about diagnosis
126	(8 2) /Knowledge of Cancer~chemo/barriers to chemo
127	(8 3) /Knowledge of Cancer~chemo/advice from others
128	(8 4) /Knowledge of Cancer~chemo/careless
129	(8 5) /Knowledge of Cancer~chemo/cause of cancer
130	(8 6) /Knowledge of Cancer~chemo/consumption of chicken
131	(8 7) /Knowledge of Cancer~chemo/diet
132	(8 8) /Knowledge of Cancer~chemo/environmental contamination
133	(8 9) /Knowledge of Cancer~chemo/Gods punishment
134	(8 10) /Knowledge of Cancer~chemo/hair
135	(8 11) /Knowledge of Cancer~chemo/infections
136	(8 12) /Knowledge of Cancer~chemo/Information
137	(8 13) /Knowledge of Cancer~chemo/knowledge and percepts chemo
138	(8 14) /Knowledge of Cancer~chemo/knowledge of others cancer-chemo
139	(8 15) /Knowledge of Cancer~chemo/knowledge-precepts of cancer
140	(8 16) /Knowledge of Cancer~chemo/natural medicine
141	(8 17) /Knowledge of Cancer~chemo/response to diagnosis
142	(8 18) /Knowledge of Cancer~chemo/smoking
143	(8 19) /Knowledge of Cancer~chemo/tradeoffs
144	(8 20) /Knowledge of Cancer~chemo/cause of cancer 2
145	(8 21) /Knowledge of Cancer~chemo/blow to the breast
146	(8 22) /Knowledge of Cancer~chemo/consumption of chicken 2
147	(8 23) /Knowledge of Cancer~chemo/denial
148	(8 24) /Knowledge of Cancer~chemo/depression

149	(8 25) /Knowledge of Cancer~chemo/diet 2
150	(8 26) /Knowledge of Cancer~chemo/environmental contamination 2
151	(8 27) /Knowledge of Cancer~chemo/fatigue

CURRICULUM VITAE

Barbara A. Kreling

SUMMARY

Ms. Kreling is a health care researcher with more than 25 years of experience in qualitative and quantitative research methods. She has used focus groups and other qualitative methods to study patient decision-making, quality of life, end-of-life and issues in gero-oncology. She was Survey Director of a landmark study of patient decision-making, the SUPPORT study, funded by Robert Wood Johnson. She has lectured on focus group methods and survey research for the George Washington University School of Public Health and for Georgetown University Medical Center and has conducted qualitative research projects for many organizations. She is currently on the faculty of Georgetown University at the Lombardi Cancer Center, where she is conducting research projects in cancer control. Currently PI of an NCI-funded study of end of life care in Latinos, she is developing an intervention to improve end of life care in minority populations.

PREVIOUS EXPERIENCE

SUPPORT Study. The George Washington University was the National Coordinating Center for a multi-site study funded by the Robert Wood Johnson foundation. The study of medical decision-making and prognosis collected chart and interview data from approximately 10,000 critically ill, hospitalized adults; families; and their physicians. Ms. Kreling directed the survey portion of this study.
HELP (Hospitalized Elderly Longitudinal Project). Ms. Kreling was the Survey Director of this study of 1,400 hospitalized, elderly patients. Patients, family members, and physicians were interviewed at four sites on issues including preferences for care and quality-of-life. **Center to Improve Care for the Dying, George Washington University Medical Center**. Projects included focus groups of bereaved family members to evaluate the effectiveness of the book Handbook for Mortals, and preliminary development of the Toolkit to Measure End of Life Care.
American Hospice Foundation, Hospice Report Card. Qualitative study of hospice families. Development of survey instrument and reporting format. Consumer testing of hospice report card.

GEORGETOWN

Special Populations Network grant, created the Latin American Cancer Research Coalition **(LACRC)** for the study of cancer in Hispanics in the Washington, DC, area. Ms Kreling was Research Director and PI of a qualitative study of Latina survivors of breast cancer.

Community Networks Program grant, continues the work of the Latin American Cancer Research Coalition (LACRC) for the study of cancer in Hispanics in the Washington, DC area. Ms Kreling was Research Director.

End of Life Care in Latinos. Ms. Kreling is PI of qualitative study of Latinos funded by NCI. This study provides preliminary data for an intervention.

Shared Decision-making in Older Women with Breast Cancer. Ms Kreling received a grant to analyze OPTIONS data to identify determinants and outcomes of shared decision-making in a cohort of older women with breast cancer. (**Kreling B.,** Figueiredo, M., Feng, S., Mandelblatt, J. Shared Decision-Making In Older Women. Presented at **ASPO**, March 2005).

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Sofaer, S.,**Kreling, B.,** Stakeholders Perceptions of Healthy People 2000, (Report to ODPHP,1997)

Naierman, N., **Kreling, B.** Towards a Hospice Consumer Report Card, (Report to American Hospice Foundation 2001)

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PRESENTATIONS

Kreling, B., Figueiredo, M., Feng, S., Mandelblatt, J. Shared Decision-making in Older Women with Breast Cancer. Oral presentation to American Society for Preventive Oncology, March 2005, San Francisco, CA.

Kreling, B. Decision Support for Older and Minority Women with Breast Cancer. Oral presentation to American Public Health Association, Dec. 2005, Philadelphia, PA.

Kreling, B, The Latin American Cancer Research Coalition, A Community Network Program. Presentation to The Moffitt Cancer Center, Cancer Culture and Literacy Conference, Thursday, May 18, 2006, Sheraton Sand Key Resort Clearwater Beach, FL