

**FAMILIAL SUPPORT AND UNCERTAINTY
IN A MEXICAN-AMERICAN BREAST CANCER POPULATION**

by

Helen Louise Fleischman

A Thesis Submitted to the Faculty of the

COLLEGE OF NURSING

In Partial Fulfillment of the Requirements
For the Degree of

MASTERS OF SCIENCE

In the Graduate College

THE UNIVERSITY OF ARIZONA

2000

STATEMENT BY AUTHOR

This thesis has been submitted in partial fulfillment of requirements for an advanced degree at The University of Arizona and is deposited in the University Library to be made available to borrowers under rules of the Library.

Brief quotations from this thesis are allowable without special permission, provided that accurate acknowledgement of source is made. Requests for permission for extended quotation from or reproduction of this manuscript in whole or in part may be granted by the head of the major department or the Dean of the Graduate College when in his or her judgement the proposed use of the material is in the interests of scholarship. In all other instances, however, permission must be obtained from the author.

Signed: Helen L. Fleischman

APPROVAL BY THESIS DIRECTOR

This thesis has been approved on the date shown below:

Judith A. Berg
Dr. Judith Berg
Assistant Professor of Nursing

4/20/00
Date

DEDICATION

This thesis is dedicated to my partner and soul mate, Peri Jude, who encouraged and inspired me throughout my entire graduate education.

ACKNOWLEDGMENTS

I would like to express my gratitude to my Committee Chairperson, Dr. Judith Berg and Committee members Dr. Carrie Jo Braden and Dr. Sandra Gonzalez Marshall.

I wish to especially thank Dr. Judith Berg for her generosity, guidance, and encouragement through the writing of this thesis. I am very grateful to Dr. Carrie Jo Braden for providing her data and sharing her expertise. And to Dr. Sandra Gonzalez Marshall for her assistance and cultural guidance.

TABLE OF CONTENTS

LIST OF FIGURES	8
LIST OF TABLES	9
ABSTRACT	10
CHAPTER 1 INTRODUCTION	11
Significance of the Problem	14
Purpose of the Study	15
Research Questions	15
Definition of Terms	16
Summary	17
CHAPTER 2 CONCEPTUAL ORIENTATION AND LITERATURE REVIEW	18
Conceptual Framework	18
Uncertainty in Illness Theory	19
Antecedents of Uncertainty	20
Appraisal	22
Adaptation	23
Psychosocial Implications	23
Social Support	24
Critique of Model	26
Summary	27
Social Support in the Literature	28
Social Support and Self-Care	30
Social Support and Adjustment to Cancer	31
Social Support Critique	32
Hispanics and Social Support	34
Familismo	35
Illness and Social Support	37
Psychological Illness	37
Physical Illness	38
Breast Cancer and Hispanics	39
Summary	41

CHAPTER 3 RESEARCH METHODOLOGY	42
Research Design	42
Sample and Setting	43
Human Subjects	44
Data Collection Instruments	45
Breast Cancer Patients' Demographic Data	45
Social Support Questionnaire	45
Uncertainty in Illness Scale	46
Data Collection Protocol	46
Data Analysis Plan	47
Summary	49
CHAPTER 4 RESULTS OF DATA ANALYSIS	50
Demographic Characteristics of the Sample	50
Reliability of the Instruments	52
Findings Related to the Research Question	57
Summary	59
CHAPTER 5 DISCUSSION, CONCLUSION, AND RECOMMENDATIONS	60
Findings Related to the Conceptual Framework	60
Limitations of the Study	62
Recommendations for Further Study	64
Implications for Nursing	64
Summary	65
APPENDIX A PROJECT SHIP II HUMAN SUBJECTS APPROVAL	66
APPENDIX B HUMAN SUBJECTS APPROVAL	68
APPENDIX C BREAST CANCER PATIENT DEMOGRAPHIC DATA	70
APPENDIX D SOCIAL SUPPORT QUESTIONNAIRE	73

APPENDIX E	MISHEL’S UNCERTAINTY IN ILLNESS SCALE	76
REFERENCES		79

LIST OF FIGURES

Figure	Title	Page
1.	Mishel’s Model of Perceived Uncertainty in Illness	21
2.	Conceptual Framework for Familial Support and Uncertainty in Mexican-American Women with Breast Cancer	29

LIST OF TABLES

Table	Title	Page
1.	Demographic Characteristics of Mexican-Americans	51
2.	Demographic Characteristics of Anglo-Americans	51
3.	Composition of Household of Mexican-Americans	53
4.	Composition of Household of Anglo-Americans	54
5.	Frequency of Stages of Cancer of Mexican-Americans	55
6.	Frequency of Stages of Cancer of Anglo-Americans	56
7.	Mexican-American Group of Total Social Support Scale	63
8.	Anglo-American Group of Total Social Support Scale	63

ABSTRACT

The purpose of this study was to provide a secondary analysis of Self-Help Intervention Project (SHIP II) data describing the relationship among household composition, quality of social support, and uncertainty in illness. The sample consisted of 197 Mexican-American and 99 Anglo women with breast cancer.

A statistically significant relationship was found only in the Anglo women. Total score on the social support instrument was positively related to Anglo women who lived alone ($r = .28, p = .01$). Total score of social support was negatively related to Anglo women who lived with extended family ($r = -.28, p = .01$).

Results of the study indicate the need for further nursing research into the cultural dynamics of Mexican-American women if appropriate interventions are to be provided.

CHAPTER 1

INTRODUCTION

Mexican-Americans have resided in the United States for generations and represent a prominent minority population, yet little is known about this group by health care providers (Kosko & Flaskerud, 1986). Due to this lack of understanding, optimal health care, at times, fails to reach the Hispanic population. Culturally competent nursing care is a way to bridge the health care gap for minority groups in this country (Kagawa-Singer, 1987; Leininger, 1995; Villarreal, 1995; Cooper, 1996; Smith, 1998).

One of the more overlooked aspects of health care in Mexican-American populations is the influence of the extended family as social support during illness (Castro, Furth, & Karlow, 1984; Kagawa-Singer, 1987; Pérez-Stable, 1987; García-Zea, 1997). Social support has been demonstrated to be an influential variable in health and illness outcomes – including breast cancer (Berkman & Syme, 1979; Muhlenkamp & Sayles, 1986; Northouse, 1988; Hanucharunkul, 1989).

Most of the literature focuses on identifying the various types of social support and its influence on Anglo populations. Less studied has been the cultural differences in what constitutes effective social support during times of illness. Only a few studies have noted differences between Anglo and Mexican-Americans concerning social support. Mexican-Americans are considered to be much more dependent on extended family during times of stress as opposed to Anglos who depend more on nuclear family, friends, and neighbors (Chandler, 1979; Friedman, 1998). To exemplify this, Friedman (1998) found Latino families who were unsupported by extended families during a diagnosis of

childhood cancer, demonstrated greater familial stress. This secondary analysis will consider the influence of the extended family as social support, and uncertainty in illness in Mexican-American women with breast cancer.

The diagnosis of breast cancer creates a state of uncertainty in which a process of personal assessment leads either to a positive or negative adjustment to illness (Mishel, 1988). How one adjusts to the illness can affect self-esteem, quality of life, and ability to perform self-care (Muhlenkamp & Sayles, 1986). The process of adjustment ultimately is implicated in the various morbidity and mortality rates found in illness (Dean & Lin, 1977; Berkman & Syme, 1979; Spiegel, 1989).

Social support has been noted to have a modifying affect on uncertainty, increasing the likelihood of a positive adjustment to the diagnosis of cancer (Mishel, 1988; Northouse, 1988; Woods, Lewis, & Ellison, 1989). The role of the family as a source of social support for individuals suffering from cancer is noted in the literature (Mishel, Hostetter, King, & Graham, 1984; Spiegel, 1989; Woods et al., 1989; Ward, Leventhal, Easterling, Luchterhand, & Love, 1991). But little is known about the extended family as a source of social support.

Significant literature exists indicating that Mexican-Americans, by virtue of a large extended family, enjoy a built in social support network (Keefe, Padilla, & Carlos, 1979; Becerra, Karno, & Escobar, 1982; Sotomayor, 1991; Falicov, 1998). As such, the implication would be that, as a group, Mexican-American women with breast cancer would have less uncertainty related to their diagnosis.

This study was based on a secondary analysis of data from two Self-Help Intervention Project II (SHIP II) studies (Braden & Mishel, Unpublished data). The SHIP II study was completed on minority women diagnosed with breast cancer. The study was composed of Anglo, African-American and Mexican-American women from various cancer treatment clinics and recruited through some media advertisements (radio, TV). For this study, only the Mexican-American women from both studies were considered.

It should be noted that cultural differences exist among the various Hispanic groups based on country of origin, ethnic descent, and class. With the acknowledgement of cultural differences, many researchers stress the importance of appropriately labeling the population being studied (Kagawa-Singer, 1987; Pérez-Stable, 1997; García & Zea, 1997). After a review of the literature, however, it was concluded that a lack of consensus exists among researchers on what term (Latina, Hispanic, Mexican-American, Chicana, etc.) was appropriate for which population. In addition, studies noted disagreement within particular Hispanic groups over what label was preferred (Pedersen, 1985). Further complicating this issue was that some researchers chose a term but never defined the population it was intended for.

After careful consideration, the present study used the term chosen by the study cited. This was felt acceptable based on the finding that in spite of cultural differences among the various Hispanic groups, it was noted that all shared in common the valuation and utilization of the extended family unit (Sabogal, Marín, Otero-Sabogal, Marín, & Pérez-Stable, 1987; Sotomayor, 1991).

Significance of the Problem

The incidence of breast cancer in the United States has steadily increased over the last 50 years. Currently, one in ten women will be diagnosed with breast cancer (Wong & Bramwell, 1992). Although reported cases of breast cancer are increasing in the general population, longer survival rates have stabilized mortality rates.

Accurate data on Hispanic women and breast cancer is difficult to ascertain. Modiano (1995) noted that in particular, the data regarding morbidity and mortality was found to be "...scarce, scattered, outdated, and often incomplete" (p. 75). It is felt, however, that the commonly cited statistics on breast cancer in Anglo women are not representative of Hispanic women.

In spite of this, breast cancer is felt to be the most common cancer among Latinas (Chavez, Hubbell, McMullin, Martinez, & Mishra, 1995). In addition, it has been noted by investigators that Hispanic women are more likely to present at diagnosis with late-stage breast cancer, subsequently suffering a higher mortality rate (Coe, Harmon, Castro, Campbell, Mayer, & Elder, 1994; Skaer, Robinson, Sclar, & Harding, 1996).

As of 1996, according to data from the U.S. Bureau of the Census, there were 26.5 million Hispanic-Americans (Friedman, 1998). The Mexican-American population was the second fastest growing group of Hispanics, representing 60% of all Latinos in this country (Sotomayor, 1991; Garcia & Zea, 1997). Although considered a prominent minority group in the U.S., Mexican-American women have been grossly neglected in the research. Some researchers have noted that in part, this may be due to their isolation as a people. Mexican-Americans have maintained their culture more so than any other

group even after several generations (Friedman, 1998).

One of the more frequently reported cultural features of Mexican-Americans is their commitment to the family unit. Friedman (1998) noted this was reflected in data from 1990 Los Angeles County, California data which found that 47.1 percent of Latinos lived in two parent families compared to 24.6 percent of whites. Hispanic families have been perceived as providing a protective barrier to life stressors (Keefe et al., 1979; Mindel, 1980; Becerra et al., 1982). The influence of the phenomena on illness has not been well studied in the literature.

Purpose of the Study

The purpose of the study was to: 1) describe the household composition of Mexican-Americans on social support, and 2) do a preliminary test of social support on level of uncertainty. A description of the influence of the Mexican-American family on the level of uncertainty experienced with a diagnosis of breast cancer could improve patient outcome through facilitation of culturally appropriate nursing care.

Research Questions

1. What is the relationship between household composition of Mexican-American women with breast cancer and the quality of social support as measured by the total score on the social support instrument?
2. What is the relationship between household composition of Anglo-American women with breast cancer and the quality of social support as measured by the total score on the social support instrument?
3. What is the relationship between quality of social support and degree of

uncertainty about illness among Mexican-American women with breast cancer?

4. What is the relationship between quality of social support and degree of uncertainty about illness among Anglo-American women with breast cancer?

Definition of Terms

Acculturation. The individual retains their ethnic values, and also learns the values of the dominant culture (Kagawa-Singer, 1987).

Culture. Patterns of learned behavior and values that are transmitted from one generation to the next (Friedman, 1998).

Extended family. Multi-generations consisting of cousins, aunts, uncles, grandparents, as well as non-blood related members who take on rights and obligations of a relative (Keefe et al., 1979).

Familism. Comprised of a strong identification and attachment of individuals to their families (nuclear and extended) and strong feelings of loyalty, reciprocity, and solidarity among members of the same family (Sabogal et al., 1987).

Household composition. A varying combination of individuals who live within the household, which may or may not be related by blood, and are considered family members (Friedman, 1998).

Nuclear family. Composed of one or both parents and their immediate children – natural, adopted, or both (Friedman, 1998).

Social support. Interpersonal transactions that include one or more of the following: the expression of positive affect of one person toward another; the affirmation or endorsement of another person's behaviors, perceptions, or expressed views; and the

giving of symbolic or material aid to another (Mishel & Braden, 1987).

Uncertainty. The cognitive state of the person when an event cannot be adequately structured or categorized because sufficient cues are lacking (Mishel & Braden, 1987).

Summary

The Mexican-American culture has largely been unexplored by researchers. Much of the existing information concerning this large minority group lacks a basis in research. Of great concern is that Mexican-American women as a group are not being diagnosed with breast cancer until in the late-stages of this disease.

The effects of uncertainty as a stressor is known to have significant implications for the woman's quality of life and her ability to perform self-care, which ultimately may effect morbidity and mortality. Exploring the role of social support in the form of the Mexican-American extended family may lead to further development of nursing interventions affecting outcomes for this population.

CHAPTER 2

CONCEPTUAL ORIENTATION AND LITERATURE REVIEW

The purpose of this chapter is to define the conceptual framework for this study and to explore the relevant literature as it relates to breast cancer and familial support in the Hispanic population. In particular, the influence of social support in Mishel's theory of Uncertainty in Illness will be the focus for exploring the impact of the extended family in a Mexican-American population.

Conceptual Framework

Mishel and Braden (1988) define uncertainty and its domain as "...the inability to determine the meaning of events and [occurring] in a situation where the decision-maker is unable to assign definite values to objects and events and/or is unable to accurately predict outcomes" (p. 98). This definition forms the main premise of Mishel's middle-range nursing theory. According to Mishel (1988), this theory explains how people construct meaning for illness events forming "...an essential task in adaptation" (p. 225).

Mishel's theory of uncertainty in illness offers a good fit with what is known about a woman's psychosocial experience and breast cancer. Cancer has been found to be a uniquely ominous diagnosis with uncertainty as a hallmark for patients and their families.

In a review of the literature, a cancer diagnosis was perceived by patients as creating more alarm and instilling more fear than diseases with a poorer prognosis (Mishel et al., 1984; Vinokur, Threath, Caplan & Zimmerman, 1989). This was further supported by Vess, Moreland and Schwebel (1985) who noted that the diagnosis of

cancer was especially "...viewed by the public as disabling and eventually fatal" (p. 1).

In spite of significant advances in the treatment of breast cancer, uncertainty remains a key component of this illness. In a review of the literature the source for the uncertainty appears to be multi-factorial.

Spiegel (1990) noted that women with breast cancer "...frequently undergo disfiguring surgery, extended radiation and chemotherapy with toxic side effects, and are confronted with the very real threat of death" (p. 1422). In support of this, Wong and Bramwell (1992) found understanding of the etiology as well as insight into individual responses to treatment of breast cancer had "...not kept pace with drug and surgical treatments [with] prognosis in individual cases remaining relatively unpredictable" (p. 363).

In addition, uncertainty for the woman with breast cancer was found to be present throughout treatment and for years to come. The source for this continuing uncertainty was identified as changes in personal identity, work, family life as well as in wondering whether or not treatment was effective (Hilton, 1988; Loveys & Klaich, 1991; Wong & Bramwell, 1992). While Mishel (1988) noted that the treatment itself inherently contributed to uncertainty "...when symptoms of illness blend with symptoms generated by treatment, distinguishability of symptoms becomes an issue" (p. 226).

Uncertainty in Illness Theory

Mishel's uncertainty theory is comprised of three major components: antecedents of uncertainty, the process of uncertainty appraisal and coping with uncertainty.

According to Mishel (1988), these three components form a "cognitive schema" which

represents the “patient’s subjective interpretation of illness, treatment and hospitalization” (p. 225).

Antecedents of Uncertainty

The first component of Mishel’s theory is the antecedents of uncertainty and is comprised of: the stimuli frame, cognitive capacity and structure providers (see Figure 1). The antecedents are key to the interpretation of illness events in that they “...offer the information that is processed by the patient” (Mishel, 1988 p. 225).

Stimuli frame. Mishel (1988) views the stimuli frame as the primary antecedent variable. This variable has three subsets: symptom pattern, event familiarity and event congruence, which provide the structure for the patient’s cognitive schema. Symptom pattern literally refers to whether or not there is a recognizable pattern to symptom presentation. Event familiarity notes whether the situation has recognizable cues that might offer meaning. And, event congruence facilitates understanding by determining if there is “...consistency between the expected and the experienced in illness-related events” (Mishel, 1988 p. 225).

Cognitive capacity. The stimuli frame is influenced by the two remaining antecedents of uncertainty: cognitive capacity and structure providers. Cognitive capacity is the patient’s ability to process information. This capacity can be effected by a number of factors, for example; drugs, information overload, etc. Mishel (1988) notes that a limited cognitive capacity will reduce the ability to process and understand the components of the stimuli frame.

Structure providers. Structure providers consist of credible authority, social

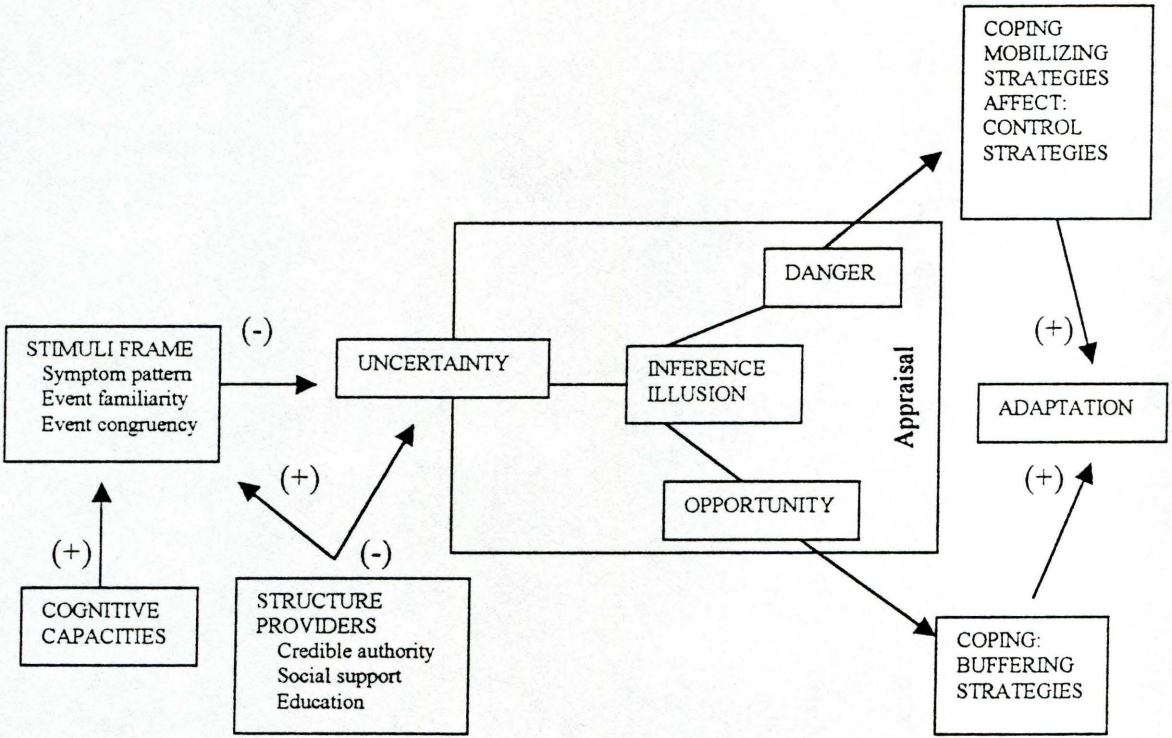


Figure 1. Mishel's Model of Perceived Uncertainty in Illness.

support and educational level and represent "...the resources available to assist the person in the interpretation of the stimuli frame" (Mishel, 1988 p. 225).

Uncertainty in illness results when the antecedents as stimuli lack specificity, familiarity, consistency, completeness, clear boundaries or do not correspond with an existing frame of reference (Mishel, 1988). Uncertainty in and of itself is neither positive nor negative and must be appraised before a determination of whether a danger or opportunity exists.

Appraisal

In Mishel's (1988) model, inference and illusion are the two processes used by the patient to evaluate uncertainty in illness. Inference is based on the person's belief system and includes their sense of mastery, locus of control and learned resourcefulness. If the uncertain event does not correspond to past learning or the patient has a predisposition toward an external locus of control, the event is appraised as dangerous. The outcome of appraisal through inference can be altered, with uncertainty viewed as an opportunity with input from significant others. General knowledge is provided and the appraisal altered when significant others recall related situations.

Illusions are defined by Mishel (1988) as "...beliefs that are viewed in a particular light with emphasis on their favorable aspects" (p. 229). In effect, uncertainty opens the door for an illusionary interpretation of the event. Mishel (1988) labels this illusionary event as being in effect denial. Mishel (1988) notes that denial has been judged as a maladaptive response, but in fact may be "...appropriate in situations in which individuals are helpless to influence the outcome or in which the outcome has a negative,

downward trajectory” (p. 229). Illusion, in such situations, maintains hope and can be fostered by significant others or health care providers leading to the appraisal of uncertainty as an opportunity.

Adaptation

Once the uncertainty has been appraised as either a danger or an opportunity, the patient enters a coping phase preceding adaptation. If appraised as a danger, mobilizing techniques are employed in an attempt to reduce the uncertainty. If these techniques are ineffective then affect-control strategies are activated to manage the emotional response (Mishel, 1988).

In contrast, if the uncertainty is appraised as an opportunity, it usually is as a result of illusion as stated previously and viewed as a positive. Buffering strategies are employed to support the uncertainty by “...blocking the input of new stimuli that could alter the view of uncertainty as an opportunity” (Mishel, 1988 p. 231). In effect, denial is maintained through avoidance, selective ignoring, reordering priorities and neutralizing.

Finally, if the coping phase is successful, adaptation will occur. Mishel (1988) defines adaptation as “...biopsychosocial behavior occurring within persons’ individually defined range of usual behavior” (p. 231). Mishel (1988) further notes that adaptation has been operationalized as psychosocial adjustment, recovery, health and quality of life.

Psychosocial implications

When uncertainty is appraised as a danger, and the individual is unable to negotiate effective coping, the possibility of a harmful, maladaptive outcome exists. Mishel (1988) found that uncertainty was associated with a negative evaluation of the

future, depression, distress, low quality of life and poorer health. These findings have been supported in a number of relevant studies.

Hilton (1988), in a qualitative study of 16 women with breast cancer, found uncertainty generated anxiety. Further supporting this finding was the results of a correlational study by Wong and Bramwell (1992) of 227 women who had been surgically treated for breast cancer. This study found a significant relationship between uncertainty and anxiety.

In a study by Mishel et al. (1984) on 54 women with gynecological cancer, uncertainty was significantly correlated with a negative ability to change things, a lack of motivation to try and feeling that the future was bleak. In addition, a correlational study of 403 men diagnosed with prostate cancer found uncertainty related to low scores in adult role behavior, e.g., shopping, running errands, etc. (Germino, Mishel, Belyea, Harris, Ware & Mohler, 1998).

These last two studies further illustrate the findings by Braden (1990) on 288 chronically ill subjects. In this study, Braden (1990) found the degree of uncertainty about illness events was found to predict "...disruption of problem solving skills and the extent of the learned helplessness response" (p. 24).

Social Support

The use of social support in Mishel's model plays a significant role for the individual seeking adaptation. Through research, Mishel and Braden (1987) found that "...the function of social support changes over time and influences different aspects of the phenomenon of uncertainty in each stage of the cancer experience" (p. 56). The

effects of social support will be discussed in all three major components of the model: antecedent of uncertainty, process of uncertainty appraisal and coping with uncertainty. The effects on the first component, antecedent of uncertainty, were demonstrated in data collected by Mishel and Braden (1988) in a convenience sample of 61 women with gynecological cancer. In the study, the antecedent *structure providers* was proposed as having a direct and indirect influence on uncertainty.

Indirectly, as a structure provider, significant others affected the experience of uncertainty via the impact of affirmation on symptom pattern (Mishel & Braden, 1988) (see Figure 1). Significant others provided input concerning the predictability in the symptoms reported, thus reducing the uncertainty concerning the state of illness.

Directly, social support influenced the impact of uncertainty through significant others use of affirmation. Social affirmation acted to reduce the complexity inherent in cancer treatment and the system of care. Social support likewise influences event familiarity in the *stimuli frame*. Mishel (1988) noted that event familiarity refers to patterns developed overtime and through experience in a setting. This process, in turn, forms a “cognitive map” which is generated through a variety of input including social sources.

In the next component of the model, social support influences the appraisal of uncertainty by effecting the process of inference or illusion. Inference can be based on general knowledge of a similar situation that had a positive outcome, uncertainty then being interpreted as beneficial (Mishel, 1988). This generalizable information is obtained through recall of situations by either the patient, significant others or health care

providers.

Illusion can serve as an adaptive coping strategy reducing stress and allowing uncertainty to be appraised as an opportunity. The generation of illusion can be fostered by significant others or by health care providers in an attempt to support patients' hope (Mishel, 1988).

Finally, in the last major component of Mishel's model: coping with uncertainty, significant others affect adaptation through influence of coping methods. In particular, uncertainty can be reduced by use of two coping tracks: mobilizing or affect-management.

Mobilizing contains several strategies, one of which is "information seeking." Mishel (1988) notes that clinical studies have found information seeking to be an effective means to modify uncertainty. One study noted the acquisition of such information is through significant others which subsequently is utilized to form "...time tables and probabilities and to form a framework to order the illness-related experience" (Mishel, 1988, p. 230).

Critique of model

There remains some ambiguity concerning aspects of the uncertainty in illness model. Mishel (1990) herself noted this concern and defined it best in her paper entitled the *Reconceptualization of the Uncertainty in Illness Theory*. Of significance was the two appraisal processes of inference and illusion. It was the outcome of this process which determined whether uncertainty was to be labeled an opportunity or a danger. Mishel noted that this key aspect of the model contributed to a static, closed system view

of uncertainty and the individual.

In Mishel's (1990) reconceptualization of her model, she attempts to remedy this by making reference to Pool's chaos theory. According to Mishel (1990), Pool noted that although chaotic processes were complicated and unpredictable, it allowed for "...a healthy variable in a system's response to a variety of stimuli" (p. 259). Although Mishel (1990) makes a compelling argument about the compatibility of the two theories, it has not been operationalized, and as Mishel acknowledges, lacks empirical support.

The final concern of this model is its use as a framework for an ethnic population. Germino et al. (1988) was the only study found in the literature which directly addressed the use of this model in an ethnic population. It evaluated patterns of uncertainty in a white vs. African-American population diagnosed with prostate cancer. Significant differences between the groups were found – raising concern over the generalizability of data from primarily white samples. The study concluded by noting the need for further application of the uncertainty in illness model to ethnic groups.

Summary

In summary, Mishel's Model of Uncertainty in Illness accounts for the individuals subjective process in interpreting illness events. Mishel's Model demonstrates in a stepwise fashion the processing, appraisal, and eventual adaptation to illness.

A key influence of the type of adaptation the individual makes to the illness event occurs through the structure providers. This study, in particular, will focus on the structure provider *social support*. Social support as an antecedent of uncertainty provides a critical role in the formation of the cognitive schema interpreting the significance of

uncertainty in the illness event. Mishel's Model of Uncertainty in Illness was modified to represent the key components for this study (see Figure 2).

Social support in the literature

Social support has been noted to be an important variable in a myriad of biological and psychological illnesses (Dean & Lin, 1977). In a review of the literature, Dean and Lin (1977) found stress to cause or increase susceptibility to illness ranging from neoplasia to depression. Dean and Lin (1977) noted in these studies that the countering force to stressful life events was social support. Furthermore, social support was exerting its effects through acting as a stress-mediating or buffering system.

Although there are many sources for social support, the "primary group" was viewed as being principally responsible for fulfilling social functions. The family was identified as the best example of a primary group. According to Dean and Lin (1977), this was because the family had the following distinct features which they identified as social support functions:

- a) emphasis on mutual responsibility, caring and concern; b) strong mutual identification; c) emphasis upon the person as a unique individual rather than upon his/her performance; d) face-to-face interaction and communication; e) intimacy; f) close association and bonds; and g) provision of support, affection, security, and response. (p. 407)

Considerable empirical support for Dean and Lin's (1977) premises were found in the results of a study by Berkman and Syme (1979). The focus of their study was to determine the relationship between social and community ties and mortality. This

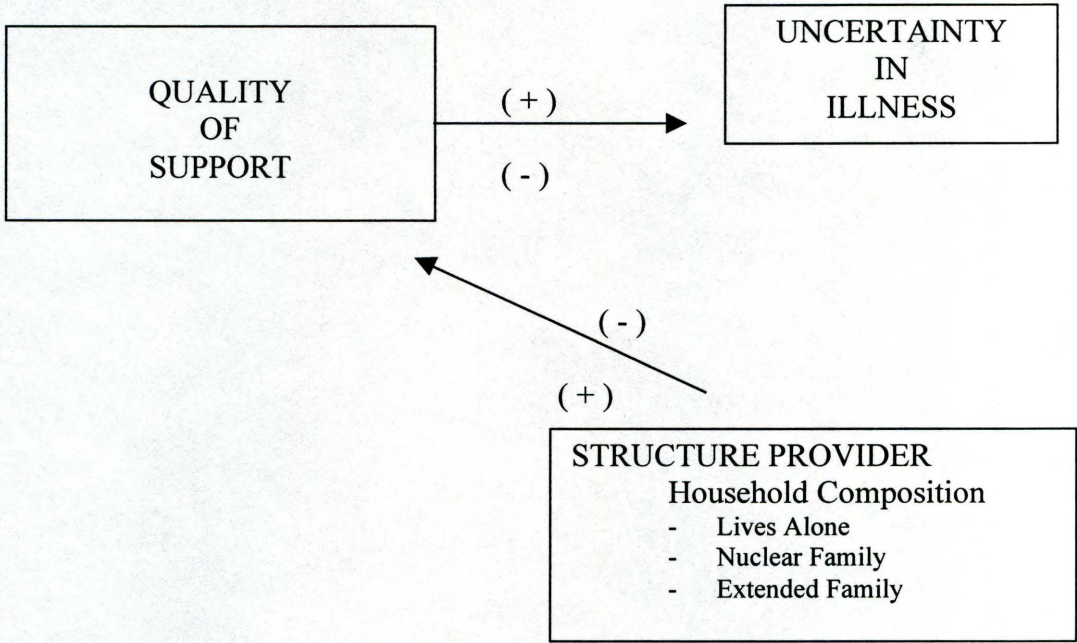


Figure 2. Conceptual Framework for Familial Support and Uncertainty in Mexican-American Women with Breast Cancer.

longitudinal study was performed on a random sample of 6, 928 adults in Alameda County, California, with a nine year mortality follow-up. Social contact was categorized into four sources: 1) marriage; 2) contacts with close friends and relatives; 3) church membership; and 4) informal and formal group association. The respondents were then asked to rate the level of contact with close friends and relatives as “high,” “medium” or “low.” The study also divided the subjects according to sex and age groups.

After 9 years, individuals with social ties, regardless of the type, lived longer than respondents who did not have social ties. Contact with close friends and relatives was the most cited social tie, regardless of sex or age. Individuals who reported having few friends and relatives, or with little contact with them, had higher mortality rates.

Social support and self-care

One apparent way that social support exerts its healthful effects is through self-care practice. Hubbard, Muhlenkamp and Brown (1983) conducted two separate studies with a total sample population of 230 individuals. The subjects were asked to fill out two questionnaires – one measuring social support and the other health practices. The social support questionnaire consisted of 25 statements designed to tap five dimensions of social support: intimacy, social integration, nurturance, worth and assistance. Health care practices was measured by a questionnaire using 24 items which considered 6 categories: nutrition, exercise, relaxation, safety, substance use and prevention practices. The results for both samples found that a strong correlation existed between social support and health practices. Of particular interest was that social support was found to be influential when the source was someone other than a spouse – such as a confidant

(Hubbard et al., 1983).

In a review of the literature, Muhlenkamp and Sayles (1986) noted that although there was much agreement on the relationship between social support and better health, the specific mechanism was not clear. Their findings did provide empirical and theoretical evidence to point to the inter-relatedness of a nurturing social environment and a feeling of self-worth as influencing positive health practices. In particular, women were more likely to practice self breast exam and to obtain and use contraceptives effectively if they had high self-concept levels.

Muhlenkamp and Sayles (1986) in turn designed a study to identify the relationship between the three variables of social support, self-esteem and positive health practices. The study was comprised of a convenience sample of 98 adults from an adult apartment complex in a southwestern urban area.

Three questions were provided to the subjects measuring the three variables of self-esteem, social support and positive health practices. A correlational matrix found that both social support and self-esteem were related to positive health practices at approximately the same level but greater correlation was noted between self-esteem and social support. These results demonstrated an explicit rather than an implied relationship.

Social support and Adjustment to Cancer

Numerous studies identify social support as having a significant effect on a woman's ability to adjust to breast cancer (Woods & Earp, 1978; Northouse, 1981; Bloom, 1982; Hobfoll, 1986). In particular, these studies found social support to modify or buffer the effects of distress, depression and fear of disease reoccurrence.

One such relevant study was completed by Northouse (1988) in which the relationship between social support and adjustment was measured in 50 mastectomy patients at 3 and 30 days post-surgery. Northouse's (1988) found that breast cancer patients with higher level of social support had fewer adjustment problems than patients with lower levels of support. In addition, the level of on-going support was a better predictor of adjustment than the initial levels of support (Northouse, 1988).

Social support has been found to be a predicator of self-care (Cobb, 1979; Hubbard et al., 1984; Muhlenkamp & Sayles, 1986; Hanucharunkul, 1989). Of particular interest was Hanucharunkul's (1989) study of 112 individuals receiving treatment for cervical and head/neck cancer in Bangkok, Thailand. Utilizing Orem's self-care model social support was found to be highly correlated to self-care. In addition, when stage and site of cancer was factored in, social support had a buffering effect on the relationship between stage and site of cancer and self care (Hanucharunkul, 1988).

The two concepts of psychosocial adjustment and self-care are not mutually exclusive. Research has found that adjustment is related to feelings of autonomy, self-confidence and self-esteem. Individuals with greater autonomy, self-confidence, and self-esteem were found to make greater attempts at controlling and modifying their environment (Cobb, 1979; Muhlenkamp & Sayles, 1986). Therefore, efforts to enhance autonomy, self-confidence, and self-esteem can lead to better self-care.

Social support critique

Although the literature is substantial concerning the positive effects of social support, conflicting results and shortcomings are prevalent. In a comprehensive review

of the literature, Wortman (1984) critiqued the conceptual and methodological problems related to social support and the cancer patient. A number of issues were noted:

1. A lack of consensus for the definition and operationalization of “social support.” For example, the literature revealed a range of constructs used in the operation definition, e.g., social class, job satisfaction and insufficient financial resources.

2. Most conclusions about social support constructs are based on correlational data at a single point in time.

3. Data reflect a relationship between social support and health but lacks any significant focus on specific mechanisms.

4. Interventions involving social support resulted in enhanced self-esteem and self-efficacy but interventions were multi-faceted and difficult to assess for efficacy.

Wortman (1984) noted that the intense fear and stigma associated with cancer, caused patients to fear rejection and abandonment by their loved ones. This may explain why interpersonal problems, especially in the form of communication, are focused on in the literature. To illustrate, Ward et al., (1991) focused on communication in cancer patients as the intervening variable after noting lower levels of self-esteem in patients with high levels of social support. They noted multiple reasons that cancer patients had for problems communicating with their significant others. These ranged from feeling hurt by thoughtless comments from friends and relatives to not wanting to discuss their feelings related to diagnosis and treatment (Ward et al., 1991).

In summary, despite a wide range of issues undermining the results of research in social support, Wortman (1984) found it to be a powerful variable and worthy of serious

consideration among cancer researchers.

Hispanics and Social Support

Cohen and Syme (1985) stated that a predictive model of the relationship between social support and well-being includes individual differences in need or desire for such support, as well as the social and environmental context in which support is perceived, mobilized, given and taken. Furthermore, social support takes place in a reciprocal manner (Cohen & Syme, 1985). The structure for the reciprocal exchange is found in "role sets." Role sets are comprised around the interaction of a particular group of people, for example, a family or work group. This view was also asserted in Mishel's uncertainty model in her use of "structure providers." The interactions of a role set provides a "functional link" integrating the roles. In this way life problems that beset one party also affect that person's interactions with other closely related parties who share the role set (Cohen & Syme, 1985).

To some degree, the importance of cultural and reciprocal characteristics of social support could be argued for any family group, but for Hispanic families, this is particularly relevant. The significance of the interdependence of family in Hispanic culture can be exemplified in that the word "privacy." Personal privacy is a concept dear to the hearts of Anglo-Americans, but it has no Spanish translation (Falicov, 1998). A word that has no place in a culture's vocabulary probably is absent from thought and practice. This section will focus on cultural aspects of the Hispanic family as well as the culturally significant issues concerning cancer and illness.

Familismo

“I do not belong to the culture of 911 (there is always a relative I can depend on to rescue me).”

- A Latina client (Falicov, 1998, p. 161).

Sabogal et al., (1987) defined familismo as having a strong identification and attachment of individuals to families (nuclear and extended), and includes strong feelings of loyalty, reciprocity and solidarity among members of the same family. In the family system, this is reflected through what is considered to be the basic social unit of Hispanic culture – the extended family (Keefe et al., 1979; Mindel, 1980; Becerra et al., 1982; Garcia & Zea, 1997; Falicov, 1998; Koss-Chiómo & Vargas, 1999). The extended family can be composed of multi-generations that include cousins, aunts, uncles, grand-parents as well as non-blood related members who take on the rights and obligations of a relative.

There appears to be consensus about the influence and existence of the Hispanic extended family system, yet conflicting data exist. Some researchers in particular feel that with increasing acculturation on each passing generation, the value of the extended family diminishes (Sabogal et al., 1987; Koss-Chióimo & Vargas, 1999).

Vernon and Roberts (1985), in a study comparing 254 Anglos and 181 Mexican-Americans, found no differences in the number of contacts with relatives between the groups. Hood (1993), in data obtained through interviews of elderly Mexican-Americans, found the extended family was a generalization which no longer existed. Evidence for her premise was based on the observation that the extended family was noted by researchers to play a significant role in the care of elderly Hispanics, yet her

sample denied receiving such social support (Hood, 1993).

Addressing these conflicting studies is the research by Sabogal et al. (1987).

Their study considered the effects of acculturation on attitudinal familism in a sample of 452 Hispanics and 227 Anglos. Data included three basic dimensions of familism (family obligations, perceived support from the family, and family as referents) (Sabogal et al., 1987). This finding supported their premise that when considering familism one must distinguish between attitudinal and behavioral components.

The high level of perceived support from family did not change with increasing acculturation. However, family obligations and family as referents diminished with acculturation (Sabogal et al., 1987). Differences between the underlying components of attitude and behavior could have affected the outcome measures of familism. However, the attitudes of Hispanic persons with high levels of acculturation were more familistic than those of white non-Hispanics (Sabogal et al., 1987).

The significance of the extended family system, as well as why it is maintained, is due to cultural, political and socio-economic influences. Conditions of poverty common among the majority of the people in immigrant Hispanic groups may foster the maintenance of extended family systems (Mindel & Habenstein, 1976). In the Mexican-American population, 30% live below the poverty level (Garcia & Zea, 1997). As such, poverty may intensify the extended family system by promoting it as a survival safety net (Falicov, 1998). Therefore, if more acculturated Hispanics have diminished reliance on extended families, it may be that their economic circumstances have improved.

Politically, Mindel (1980) noted the heavy reliance on an extended family

network for aid, comfort and friendship is very much related to the degree of access individuals have to larger institutions in society, such as education and health care. Anglos who do not demonstrate this dependence on family are not restricted in their movement to middle class (Mindel, 1980).

Finally, extended family systems are maintained culturally. The kinship ties are maintained because the members receive an enjoyable social experience from them (Mindel, 1980). Mexican-American customs and rituals include such gatherings as baptisms, Saints' days, birthdays, weekly meals at grandparents and weddings, which take on a decidedly festive air (Falicov, 1998; Hansen & Garey, 1998). These events are social in nature and afford enjoyment, as well as social support.

Illness and social support

Psychological illness

In the literature, the effects of the Hispanic extended family system, as it impacts the stress/illness relationship, can best be classified as limited and conflictual. The majority of what is known concerning this relationship comes from a mental rather than a physical illness perspective.

A number of studies found that the Hispanic family system, because of its emphasis on being a large support system, sheltered individual members from stress resulting in decreased mental illness (Keefe et al., 1979; Becerra et al., 1982; Perez-Stable, 1987; Sotomayor, 1991). These establish a beginning acknowledgement of the role that families play in illness outcomes.

Keefe et al. (1979) compared the effects of the family support systems on mental

health (sample = 666 Mexican-Americans and 340 Anglos) to find that Mexican-Americans do not seek out professional psychiatric services as 21% of Anglos, versus 4% of Mexican-Americans, had sought help from mental health workers. In contrast, Cervantes and Castro (1985) cited numerous studies finding "institutional barriers" to use of mental health services for Mexican-Americans. Thus, access versus interest in access is an unresolved issue for researchers.

Physical illness

There is little literature that examines support that Hispanic families offer their members during physical illness. Kagawa-Singer (1987), in her paper on Hispanics and cancer, noted that in ethnic groups with strong family organization, sickness is a time for relatives to display solidarity and love. While Quesada (1976) noted, that because of their culture, Mexican-Americans must care for the ill family member. This view seemed in contrast to Kagawa-Singer (1987) indicating that family support during illness was a duty versus a compassionate act.

Of particular significance was a study by Perez-Stable et al. (1992) (sample = 844 Hispanics in California) on their knowledge and attitudes concerning cancer. Compared to Anglos, the Hispanics were less likely to talk about cancer, more likely to feel uncomfortable touching someone with cancer, more likely to consider cancer a death sentence, more likely to consider cancer as God's punishment, and more likely to believe that there is little one can do to prevent cancer (Perez-Stable et al., 1992). These findings would not seem conducive to a show of support for an individual with cancer in the Hispanic culture. Yet education and acculturation were significant predictors of the

unfavorable attitudes about cancer (Perez-Stable et al., 1992).

Breast Cancer and Hispanics

As in other sections, the availability of literature specifically addressing Hispanics was limited. The following is a review of the significant findings.

Although Hispanic women have a lower incidence of breast cancer than Anglo or African-Americans, the mortality rate is higher (Chavez et al., 1995; Skaer et al., 1996). This may in part explain the findings by the American Cancer Society study finding that Latinos were more afraid of cancer than whites or African-Americans (Perez-Stable et al., 1992). The reason for this difference in ethnic groups is likely multi-factorial and includes a significant number of non-cultural determinants. Skaer et al. (1996) noted that a number of well established factors are known to deter breast cancer screening beyond ethnicity. In particular, increased age, less education, income below poverty level, lack of prevention knowledge and lack of recommendation by care provider (Skaer et al., 1996). Unlike the structural barriers, the influence of cultural beliefs on the use of health services by Latinas is less clear (Chavez et al., 1995).

In an attempt to address the cultural differences, Chavez et al. (1995) studied 39 Mexican-American women to determine their perception of breast cancer risk factors. Using open-ended responses, the study resulted in four themes being noted among this population: physical stress and trauma, behavior and lifestyle choice, breast function, and lack of medical attention.

Physical Stress and Trauma was one of the most pervasive themes as 74% of the Mexican-American women included it as a risk factor for breast cancer. In particular,

29% of this group listed blows and bruises as a factor that would lead to breast cancer in later life. Fondling during normal sexual relations and rough handling during breast feeding from older children were also noted as risk factors (Chavez et al., 1995).

Of the Mexican-American women, 53.9% considered a woman's lifestyle to increase the risk of breast cancer, and behavior and lifestyle choice was an important theme identified. It was particularly noted that destructive behaviors like drugs and alcohol, as well as poor hygiene, constituted risk factors (Chavez et al., 1995).

The third theme was breast functions. In this category, 23% of the Mexican-American women considered problems producing breast milk as a risk factor. Finally, the fourth theme was lack of medical attention. Only 15% of the Mexican-American women considered lack of medical attention as a risk factor for breast cancer (Chavez et al., 1995).

A lack of biomedical information may contribute to Hispanics increased level of risk (Chavez et al., 1995). Supporting this conclusion is a study by Skaer et al. (1996) on 512 Hispanic women utilizing migrant health clinics. In this study, 62% of women 40 years of age or older had ever heard of a mammogram and 38 percent had ever received a mammogram (Skaer et al., 1996). Women who have no information about screening procedures will not access them.

Likewise, in a study by Coe et al., (1994), self-breast exams (BSE) knowledge and practices were considered in a population of 1, 453 Hispanic women. The women were from Phoenix and San Diego. Of particular interest in this study was that, although a majority performed BSE (63%), when questioned about what they could do to prevent

cancer, the majority of the women (93.5 percent in Phoenix and 95.1 percent in San Diego) did not mention BSE (Coe et al., 1994).

Summary

Serving as the foundation of this study is Mishel's "Uncertainty in illness" model. This model is comprised of three major components: antecedents of uncertainty, the process of uncertainty appraisal and coping with uncertainty. Social support plays a significant role in exerting both direct and indirect effects on these three components. As social support, family members input can significantly impact the stress of uncertainty. They can do this by providing actual information or through facilitating the maintenance of denial. In turn, social support effects the individual's illness outcome through self-esteem and self-care. Both Mishel's Uncertainty theory and social support as well as their relationship to the cancer experience have been demonstrated. What is lacking is the generalizability of Mishel's Uncertainty in Illness model and social support studies on a Mexican-American breast cancer population. The literature on social support and its effects on attitudes of illness and cancer in a Mexican-American family is limited and conflictual. But this study will add to our knowledge about Hispanic families' (nuclear, extended) impact on uncertainty due to a cancer diagnosis.

CHAPTER 3

RESEARCH METHODOLOGY

A descriptive secondary analysis of data collected for the Self-Help Intervention Project II (SHIP II) studies will be conducted for this study. The original SHIP study focused on the effects of nursing interventions such as independent study, self-help class, and nurse case manager in meeting the needs of women recently diagnosed and in treatment for breast cancer. The SHIP II studies were conducted with a primary focus on the cancer treatment experiences Anglo-American, African-American, and Mexican-American women. The research design, sample and setting criteria, human subjects protection, data collection instruments, data collection protocol, and data analysis are discussed in this chapter.

Research Design

This study utilized a descriptive, cross-sectional design for a secondary analysis of the SHIP II data obtained on Mexican-American women. A descriptive design was selected to provide data on the household composition (persons living at home with the participant) as an influence on the quality of social support of Mexican-American women diagnosed with breast cancer. Data collected for this study was at baseline (T1). T1 was selected since this data was collected prior to nursing interventions. The nursing interventions would have themselves provided social support, confounding the data results concerning the influence of familial support. In addition, T1 was selected as a period of increased uncertainty concerning illness since this was the time in which the women were beginning to experience side effects from breast cancer treatment. The

specific research questions that this study addressed were:

1. What is the relationship between household composition of Mexican-American women with breast cancer and the quality of social support as measured by the total score on the social support instrument?
2. What is the relationship between household composition of Anglo-American women with breast cancer and the quality of social support as measured by the total score on Mishel's Social Support instrument?
3. What is the relationship between quality of social support and degree of uncertainty about illness among Mexican-American women with breast cancer?
4. What is the relationship between quality of social support and degree of uncertainty about illness among Anglo-American women with breast cancer?

Sample and Setting

The population for this secondary analysis of data consisted of subjects who participated in the SHIP II studies. The SHIP II studies consisted of women age 18 and older who self-identified as Anglo-American, African-American, or Mexican-American. The women who met the secondary study's criteria were referred through oncology treatment clinics and obtained through media advertisements in Arizona, California, and New Mexico. Names of potential subjects were provided to research personnel who in turn invited the subject to participate in the study. These were grouped by self-identified culture and by age (<50 years; ≥ 50 years). Data collected at baseline (T1) was utilized. T1 data were collected on women who had initiated breast cancer treatment but had not received any self-help nursing interventions.

Inclusion criteria for the present study were: 1) self-identity as Mexican-American or Anglo-American woman, 2) age 18 years or older, 3) primary or recurrent breast cancer diagnosis undergoing treatment, and 4) fluent in either English or Spanish. Although women were separated into age groups (<50 years; ≥ 50 years) in the SHIP II study, they were analyzed together for this study. This decision was made, as age was not a variable of interest in the present study.

Sample size estimation. Many assumptions must be made in order to estimate a sample size that will give adequate power for statistical significance (Hulley & Cummings, 1988). It is common in health care research to assume a medium effect size as described for the behavioral sciences in Cohen (1977) at .25. With alpha set at .05, we have the ingredients needed for power analysis. Therefore, an effect size of .25, together with a desired power of .80 and α at .05, a sample size of 192 is required (Kraemer, & Thiemann, 1987). This secondary analysis included 197 Mexican-American women and 99 Anglo-American women.

Human Subjects

This study was limited to voluntary participation. The SHIP II study had been approved and found to be exempt from review by the University of Arizona Human Subjects Committee (Appendix A). Human Subjects approval for the present study can be found in Appendix B. In the SHIP II studies bilingual/bicultural recruiters and data collectors provided both a written and verbal explanation of the study to prospective participants. Potential subjects were informed that participation was voluntary, that they could withdraw at any time, there would be no hazards or costs, questions could be

answered, and that all information would be confidential.

All data was stored in a locked file cabinet within a locked storage room. Only those persons who were members of the research team had access to the data.

Data Collection Instruments

For this secondary analysis, the data from three instruments used in the SHIP II studies were used. These instruments were: Breast Cancer Patient Demographic Data (Appendix C), Social Support Questionnaire (Appendix D), and Mishel's Uncertainty in Illness Scale (Appendix E). Approximate total time to complete the instruments utilized in this study was 20 minutes.

The Mexican-American women, based on preference, were provided with either an English or Spanish version of the instruments. To ensure reliability of translation of English instruments into Spanish a process of "Back-translation" was utilized. McDermott and Palchanes (1994) found Back-translation to effectively reduce the number of translation errors in instruments used for quantitative research. A Cronbach's alpha was run separately for the instruments returned by the Mexican-American and Anglo women in this secondary analysis.

Breast Cancer Patient Demographic Data

This questionnaire consists of a number of demographic variables. Birthplace, age, and who lives in the home will be the data used in this study. The total number of questions utilized from this instrument was 10.

Social Support Questionnaire

This is a 12-question instrument was based on a scale developed by Sarason,

Sarason, Shearin and Pierce (1987). The instrument measures function and quality of social support. Six of the questions measure function through a short answer format. While the remaining six questions measure quality of social support via a six-item Likert scale. Choices range from 1 (very dissatisfied) to 6 (very satisfied). The sum total from the six-item Likert scale measuring quality of social support will be utilized for this study; the higher the total score, the greater the quality of the social support. The internal consistency reliability for Anglo-Americans was .94 and for the Mexican-American women it was .87 utilizing this instrument.

Uncertainty in Illness Scale

This scale was developed by Mishel (1981) to measure subjects' perceived uncertainty in illness. This scale consists of 26 questions which are rated on a Likert scale from 1 (strongly disagree) to 5 (strongly agree). A total uncertainty score pertains to the patient's perception of illness and cues concerning treatment. A higher score indicates a higher degree of uncertainty. The internal consistency reliability for the Anglo-Americans was .88 with the Mexican-American women reporting .81 on this instrument.

Data Collection Protocol

In the SHIP II studies subjects agreed to participate in one of two groups with data to be collected over three separate points in time. The subjects were provided nursing interventions through a nurse case manager (treatment group) or used their own natural learning resources (comparison group). Time one (T1) data was collected at the subjects' initial entrance into the study and utilized in this study. In the SHIP II studies, subjects were provided 1 to 1 ½ hours to complete a booklet of data collection

instruments. The instruments measured a number of variables influencing self-care and illness outcomes in women with breast cancer.

Instruments were completed after instructions were provided according to the subjects' language preference. No names appear on the completed instruments; instead, identification numbers were utilized to protect the anonymity of participants. Completed instruments are kept in a secured area and are only accessible to the principal investigator or her designates. Data were entered into the Statistical Program for the Social Sciences (SPSS), cleaned, and checked for accuracy by research assistants and other project personnel who were specifically trained for that function.

Data Analysis Plan

Data analyses consisted of descriptive statistics and inferential statistical tests. Descriptive statistics were utilized to describe the sample and to answer the specific research question.

Descriptive statistics

Sample characteristics and variables were analyzed using descriptive statistics and measures of central tendency. These included age, marital status, employment status, education, whether or not they have children, where they were born, total monthly family income, and who lives at home with the participant. The latter variable was categorized as 1) live alone, 2) live with husband, 3) live with children, 4) live with other family, 5) live with friends, and 6) live with others. Participants may live with any combination of these. Therefore, this study has calculated both the frequency that the above categories were reported as well as the mean number of categories that women across the sample

reported.

Inferential statistical tests

An alpha level of .05 was used for all statistical tests. Research questions were answered in the following manner.

1. What is the relationship between household composition of Mexican-American women with breast cancer and the quality of social support as measured by the total score on the social support instrument?

Frequencies were calculated for each category of persons who live at home with participants. A new variable was created that represents the mean number of categories of persons who live at home with participants to profile the complexity of the homes of Mexican-American women in this study. Another new variable was created to group those women who reported only the traditional nuclear family composition, ie. husband and children. To categorize women who live with extended family, an additional variable was created that grouped women who lived with husband, children, other family, friends, and/or other. These new variables were compared to the quality of social support reported by participants using the Pearson's Product Moment Correlation.

2. What is the relationship between household composition of Anglo-American women with breast cancer and the quality of social support as measured by the total score on the social support instrument?

An identical analysis as described in question 1 was performed on the Anglo-American women. The same variables were created for this group as for the Mexican-American women. Frequencies were also calculated for each category of persons who lived at

home with participants. The results were reported using a Pearson's Product Moment Correlation.

3. What is the relationship between quality of social support and degree of uncertainty about illness among Mexican-American women with breast cancer?

Quality of social support and degree of uncertainty were calculated and reported as frequencies and as total scores. Using Pearson's Product Moment Correlation, these variables were compared to determine significant relationships.

4. What is the relationship between quality of social support and degree of uncertainty about illness among Anglo-American women with breast cancer?

Once again, quality of social support and degree of uncertainty were calculated and reported as frequencies and as total scores. The variables were compared to determine significance of relationship using a Pearson's Product Moment Correlation.

Summary

The research design and methodology for the present study were detailed in this chapter. Included was a discussion of the sampling protocol, inclusion criteria, and data management. Data analyses were presented for each of the three study questions. The next chapter profiles study results.

CHAPTER 4

RESULTS OF DATA ANALYSIS

The results of secondary data analysis of the Self Help Intervention Project II (SHIP II) study examined the relationship between household composition, social support, and uncertainty in illness in Mexican-American and Anglo women with breast cancer. This chapter includes the demographic characteristics of the sample, analysis of the data related to each of the major variables, and the statistical analysis of the research questions. The secondary data analysis was limited to 197 Mexican-American women and 99 Anglo women who completed questionnaires at Time 1 (T1). T1 was comprised of baseline data collected prior to any nursing interventions.

Demographic Characteristics of the Sample

Age, Education, and Income. A convenience sample of 197 Mexican-American women and 99 Anglo women with various stages of breast cancer took part in this study. Table 1 presents the mean, standard deviation, and range of age, education, and income of the Mexican-American women. Table 2 presents the same findings for Anglo women. The ages of the Mexican-American women ranged from 28 to 81 years old ($x = 50.83$, $s.d. = 11.87$). While the Anglo women ranged in age from 28 to 56 years old ($x = 43.38$, $s.d. = 5.67$). Note the difference in years of education and income level between the two groups. Ninety (45.5%) of the Mexican-American women reported completing less than 12 years of school versus 3 (3%) of the Anglo women. While 69 (34%) of the Mexican-American women reported yearly income of less than \$10,000 versus 2 (2%) of the Anglo women.

Table #1. Demographic Characteristics of Mexican-Americans.

Characteristic	Mean (SD)	Inclusive Range (Range)
Age (years)	50.83 (11.87)	28-81 (53)
Completed School (years)	10.79 (4.11)	1-25 (24)
Monthly Income (\$)	1649.30 (1711.66)	0-10000 (10000)

Table #2. Demographic Characteristics of Anglos.

Characteristic	Mean (SD)	Inclusive Range (Range)
Age (years)	43.38 (5.67)	28-56 (28)
Completed School (years)	15.46 (2.87)	10-23 (13)
Monthly Income (\$)	3080.80 (3347.88)	0-30000 (30000)

Household composition. Tables 3 and 4 detail the household composition of Mexican and Anglo-American participants. Note that for both cultural groups, fewer women lived alone and the majority lived with their husband. Most women (approximately 40%) did not report having children presently in the household, however, a few Mexican-Americans (6%) had 4 children in the household. The greatest difference between the two groups appears to be in the “other family” category, with Mexican-Americans (20.8%) having more other family in the household compared to Anglos (4.1%).

Breast cancer stage at diagnosis. Tables 5 and 6 detail the breast cancer stage at diagnosis for Mexican-Americans and Anglo-Americans. Contrary to the literature, both cultural groups appeared to be similar in their stage of breast cancer at diagnosis.

Place of birth. Ninety one (46.1%) of the Mexican-American women identified the United States as their place of birth. While 99 (50.3%) identified Mexico as their birth place. The remaining 7 women (3.6%) marked “other” as their country of origin. In contrast, 92 (92.9%) of the Anglo women indicated the United States as their country of origin, with 6 (6.1%) marking “other” for their country of origin.

Reliability of the Instruments

To calculate the internal consistency reliability of the instruments utilized in this study, a Cronbach’s alpha was calculated for total scores on each instrument for the entire sample. In addition, Cronbach’s alphas were preformed separately by cultural group.

Social support. The social support instrument was internally consistent with Cronbach’s alpha at .89. The instrument had greater internal consistency reliability for

Table #3. Composition of Household of Mexican-Americans.

Composition		<u>n</u>	Percent
Alone		19	9.6
Husband		110	55.8
Children			
	0	77	39.1
	1	47	23.9
	2	36	18.3
	3	25	12.7
	4	6	3.0
	5	4	2.0
	6	0	0.0
	7	1	0.5
	8	1	0.5
Other Family		41	20.8
Friends		8	4.1
Others		15	7.6

Table #4. Composition of Household of Anglos.

Composition		<u>n</u>	Percent
Alone		18	18.4
Husband		63	64.3
Children			
	0	41	41.8
	1	22	22.4
	2	26	26.5
	3	6	6.1
	4	3	3.1
Other Family		4	4.1
Friends		7	7.1
Others		6	6.1

Table #5. Frequency of Stages of Cancer of Mexcian-Americans.

Stage	<u>n</u>	Percent
0	7	3.7
I	39	20.5
IIA	65	34.2
IIB	37	19.5
IIIA	13	6.8
IIIB	10	5.3
IV	19	10.0

Table #6. Frequency of Stages of Cancer of Anglos.

Stage	<u>n</u>	Percent
0	1	1.1
I	26	27.4
IIA	28	29.5
IIB	14	14.7
IIIA	6	6.3
IIIB	5	5.3
IV	15	15.8

Anglos (.94) than for Mexican-Americans (.87).

Mishel's Uncertainty in Illness Scale (MUIS). Cronbach's alpha was .84 for the total sample, which indicates high internal consistency reliability. Once again, internal consistency reliability was higher in Anglo-Americans (.88) than in Mexican-Americans (.81).

Findings Related to the Research Questions

Pearson's product moment correlation coefficients were computed to determine relationships and strength of relationships among the conceptual variables: household composition, social support, and uncertainty of illness. For this study, a correlation coefficient of .70 was considered high (Polit & Hungler, 1999). Correlations of a psychosocial nature, as the ones in this study, are typically in the .10 to .40 range (Polit & Hungler, 1999).

Research Question #1. What is the relationship between household composition of Mexican-American women with breast cancer and the quality of social support as measured by the total score on the social support instrument?

To answer this question, household composition was categorized as live alone ($n=19$, 9%), nuclear family comprised of husband and/or children ($n=114$, 57.8%), and extended family comprised of any combination of husband, children, other family members, and friends ($n=64$, 32.4%). There were no significant differences between these household composition categories and total score on social support for this cultural group.

Research Question #2. What is the relationship between household composition

of Anglo-American women with breast cancer and the quality of social support as measured by the total score on the social support instrument?

To answer this question, household composition was categorized as live alone ($n=18$, 18.12%), nuclear family comprised of husband, and/or children ($n=65$, 65.7%), and extended family comprised of husband, and/or children, and other family members or friends ($n=15$, 15.2%). No significant differences were found on categories of household composition and social support except that Anglos who live alone were significantly different from those with extended family on total social support scores. Surprisingly, those who lived alone had a positive correlation ($r=.28$) and those with extended family in the household had a negative correlation ($r=-.28$) with total social support scores, $p<.01$.

Research Question #3. What is the relationship between quality of social support and degree of uncertainty about illness among Mexican-American women with breast cancer?

The mean score for social support for Mexican-Americans was 34 (± 3.0), with a range of 14-36. Social support categories were low (6-15; $n=1$, 0.5%), medium (16-25; $n=4$, 2%), and high (26-36; $n=190$, 96.4%). Note that the mean social support score for this cultural group fell into the high social support category.

Total mean score on the uncertainty scale for Mexican-Americans was 61.6(± 12.2). Range possible for uncertainty was 26-130 with higher scores indicating greater uncertainty about illness. Frequencies for scores were not computed, however for interpretation, low to medium uncertainty was from 26-78 and 79-130 was medium to

high uncertainty. Mexican-Americans fell into the low to medium uncertainty category. Although social support and uncertainty about illness had a high negative correlation, this relationship was not significant.

Research Question #4. What is the relationship between quality of social support and degree of uncertainty about illness among Anglo-American women with breast cancer?

The mean score for social support for Anglo-Americans was $33.6(\pm 2.9)$, with a range of 9-36. Social support categories were low 6-15; $\underline{n}=2$, 2%), medium (16-25; $\underline{n}=6$, 6.1%), and high (26-36; $\underline{n}=90$, 91%). Note that the mean social support score for this cultural group fell into the high social support category.

Total mean score on the uncertainty scale for Anglo-Americans was $56.5(\pm 13.2)$. Range possible for uncertainty was 26-130 with higher scores indicating greater uncertainty about illness. Frequencies for scores were not computed, however for interpretation, low to medium uncertainty was from 26-78 and 79-130 was medium to high uncertainty. Anglo-Americans fell into the low to medium uncertainty category. The relationship between social support and uncertainty in Anglo-Americans approached significance, $r=-.186$, $p=.067$.

Summary

The results of data analysis were presented in this chapter. Demographic characteristics of the sample, reliability of the instruments, and statistical analysis of the research questions were addressed. Results were presented by cultural group, and these results will be discussed in Chapter 5.

CHAPTER 5

DISCUSSION, CONCLUSION, AND RECOMMENDATIONS

This chapter will present discussion of the findings as they relate to the conceptual framework. Limitations of the study, implications for nursing practice, and recommendations for further study will also be presented.

Findings Related to the Conceptual Framework

The purpose of this secondary analysis was to describe the relationships, if any, among household composition, quality of social support, and uncertainty about illness in both Mexican-American and Anglo women with breast cancer.

Household Composition

In Mishel's Uncertainty in Illness Model, family is considered a source of social support. As an antecedent of uncertainty, family support as a structure provider would modulate the meaning and outcome of an illness event. Traditionally, the Mexican-American women in this study would have been considered to benefit individually from greater social support because of a large extended family network. No statistical significance was found to support this finding in this study.

Curiously, significant findings were noted in the Anglo women concerning household composition and quality of social support. The findings were not consistent, however, with the conceptual framework for this study. It was the Anglo women who lived alone which indicated a significantly higher degree of social support. While the Anglo women who were living as part of an extended family indicated significantly lower total social support scores. Since the results for the social support instrument

demonstrated a non-normal distribution, then a more appropriate inferential statistic would have been Spearman's rho.

These results may highlight what researchers in the literature have found to be the negative aspects of family as a source of social support. The families of cancer patients, much like the patient themselves, are faced with uncertainty resulting in role and communication disturbances (Vess et al., 1985; Woods et al., 1989). This creates a state of stress between the cancer patient and those who are expected to be supportive. Wortman (1984) noted that "...a large percentage of breast cancer patients reported such negative reactions as being misunderstood, avoided, or feared" (p. 2346).

Woods et al. (1989) noted that because family members are expected to provide support for an ill member, their lack of support is evaluated very negatively by the patient. In contrast, support from friends is not expected and thus evaluated very favorably. So it could be hypothesized that the women who live alone received a higher quality of social support from various individuals than the women who relied on live-in family members.

Uncertainty in Illness

The degree of uncertainty in illness is influenced by the individual's social support network. This social support network can encompass a multitude of sources, including but not limited to individuals from inside and outside the family, such as doctors, nurses, and clergy. The relationship of total score in quality of social support and total score on uncertainty in illness for both the Mexican-American women and the Anglo women was not significant.

Limitations of the Study

Three main limitations of this secondary analysis of SHIP II data were noted. The first limitation concerns the sample size of the two groups. The sample size estimation for this study indicated that a population of 192 was required to provide adequate statistical power. Although the Mexican-American women met this requirement ($n = 197$) the Anglo women ($n = 99$) did not. The insufficient sample size of the Anglo women with breast cancer may have affected the outcome – limiting the generalizability of this study.

The second limitation concerns the high total score on the social support instrument reported by both groups in this study. A frequency distribution was calculated for the scores on the social support instrument. The social support sum scores were divided into 3 categories: 1) low social support (range 6-15), 2) medium social support (range 16-25), and 3) high social support (range 26-36). Ninety-six percent of the Mexican-American women reported high social support while 91% of the Anglo-American women reported high social support scores (see tables 7 and 8).

In addition, the format and wording of this instrument may have skewed the findings. For example, this questionnaire requires the respondent to first list the people by name whom can be really counted on, then to rate those people in the following question (see Appendix D). The format predisposes the respondent to favorably rate those people who were previously listed, excluding those who would provide inadequate social support.

Finally, the third limitation of this study was that T1 data only was analyzed. As

Table #7. Mexican-American Group of Total Social Support Scale

	Frequency	Percent	Valid Percent	Cumulative Percent
Valid 1.00	1	.5	.5	.5
2.00	4	2.0	2.1	2.6
3.00	190	96.4	97.4	100.0
Total	195	99.0	100.0	
Missing System	2	1.0		
Total	197	100.0		

Table #8. Anglo-American Group of Total Social Support Scale

	Frequency	Percent	Valid Percent	Cumulative Percent
Valid 1.00	2	2.0	2.0	2.0
2.00	6	6.1	6.1	8.2
3.00	90	90.9	91.8	100.0
Total	98	99.0	100.0	
Missing System	1	1.0		
Total	99	100.0		

previously reported, T1 data was selected in order to eliminate confounding influence from nursing interventions. However, it has been noted that social support is not a stagnate variable with its level of influence changing over time (Northouse, 1988).

Recommendations for Further Study

1. Conduct a study on Mexican-American women with breast cancer in which a social support instrument measures the various types of social support, i.e., functional, instrumental, quality, etc. provided to the respondent.
2. Comparison of data on Mexican-American women with breast cancer to Anglo women on T1 (baseline) and T2 (30 days) and relation of social support and uncertainty in illness.
3. Comparison of data on Mexican-American women with breast cancer to a matched group of Anglo women in terms of age, income, and education in regards to social support and uncertainty in illness.

Implications for Nursing

Mexican-American women with breast cancer represent an overlooked research population in this country. This is reflected in the proportionally higher mortality rate suffered by this group. Thus, it is essential for the profession of nursing to consider Mexican-American women with breast cancer when doing research.

Regrettably, this study did not provide any clear answers to much needed questions regarding this population. However, this secondary analysis highlighted what is considered to be significant variables for Mexican-American women suffering from

breast cancer. The influence which social support has on uncertainty in illness for Mexican-American women could unlock the door to needed nursing interventions. Nurses could target interventions which would include and enhance the social support available to these women, altering the negative trajectory of illness in this population.

Summary

This chapter presented a discussion of the results of this secondary analysis. The findings concerning household composition, quality of social support, and uncertainty in illness in Mexican-American and Anglo women with breast cancer were not reflective of the literature, and were largely insignificant. As discussed, shortcomings in this secondary analysis could have accounted for the insignificant results. It is hoped, however, that this study highlighted the critical need for nursing research and interventions in Mexican-American women suffering from breast cancer.

APPENDIX A

PROJECT SHIP II HUMAN SUBJECTS APPROVAL

Human Subject Committee



1690 N. Warren (Bldg. 52681)
Tucson, Arizona 85724
(602) 626-6721 or 626-7575

26 February 1990

Carrie Jo Braden, Ph.D., R.N.
College of Nursing, 109A
Arizona Health Sciences Center

RE: HSC 1890.27 NURSE INTERVENTIONS PROMOTING SELF HELP RESPONSE TO CANCER

Dear Dr. Braden:

We received your 26 February 1990 memorandum, revised consent form, and poster for your above referenced project. The procedures to be followed in this study pose no more than minimal risk to participating subjects. Regulations issued by the U.S. Department of Health and Human Services (45 CFR Part 46.110(b)) authorize approval of this type project through the expedited review procedures, with the condition(s) that subjects' anonymity be maintained. Although full Committee review is not required, a brief summary of the project procedures is submitted to the Committee for their endorsement and/or comment, if any, after administrative approval is granted. This project is approved for one year effective 26 February 1990.

The Human Subjects Committee (Institutional Review Board) of the University of Arizona has a current assurance of compliance, number H-1233, which is on file with the Department of Health and Human Services and covers this activity.

Approval is granted with the understanding that no changes or additions will be made in study personnel, to the procedures followed or to the consent form(s) used (copies of which we have on file) without the knowledge and approval of the Human Subjects Committee and your College or Departmental Review Committee. Any research related physical or psychological harm to any subject must also be reported to each committee.

A university policy requires that all signed subject consent forms be kept in a permanent file in an area designated for that purpose by the Department Head or comparable authority. This will assure their accessibility in the event that university officials require the information and the principal investigator is unavailable for some reason.

Sincerely yours,

A handwritten signature in dark ink, appearing to read "Milan Novak".

Milan Novak, M.D., Ph.D.
Chairman
Human Subjects Committee

HN/MS

cc: Departmental/College Review Committee

APPENDIX B
HUMAN SUBJECTS APPROVAL



cts Committee

0 March 2000

Helen Fleischman, Master's Candidate
/o Judith Berg, Ph.D.
College of Nursing
O BOX 210203

**RE: FAMILIAL SUPPORT AND UNCERTAINTY IN A MEXICAN-AMERICAN
BREAST CANCER POPULATION**

Dear Ms. Fleischman:

We received documents concerning your above cited project. This project involves secondary analysis of existing data which is to be supplied without individual identifiers (letter from Carrie Jo Braden, Ph.D., PI of primary study, granting use of data submitted for review). Therefore, regulations published by the U.S. Department of Health and Human Services [45 CFR Part 46.101(b) (4)] exempt this type of research from review by our Committee.

Thank you for informing us of your work. If you have any questions concerning the above, please contact this office.

Sincerely,

A handwritten signature in cursive script that reads "David G. Johnson, M.D.".

David G. Johnson, M.D.
Chairman
Human Subjects Committee

GJ/js
: Departmental/College Review Committee

APPENDIX C

BREAST CANCER PATIENT DEMOGRAPHIC DATA

ID# _____

BREAST CANCER PATIENT DEMOGRAPHIC DATA

Answer all of the following questions.

Age: _____ Date of Birth: _____
Month Day Year

Address: _____
Street

_____ Town/City State Zip Code

Date of Interview: _____

Interviewer: _____

MARITAL STATUS: (Check One)

- _____ Married
- _____ Living with partner
- _____ more than 6 months
- _____ Separate
- _____ Divorced
- _____ Widowed
- _____ Never married

Ethnic Group:

- _____ White _____ Af-Am
- _____ Mex-Am _____ Nat-Am

EMPLOYMENT STATUS

If you are not working now, check one:

- _____ On medical leave from P/T job
- _____ On medical leave from F/T job
- _____ Retired
- _____ Unemployed

What kind of work do you do (or did you do) and for how long?

Type of Work	Full Time (yes or no)	Part Time (how many hours per week)	Length of Time (number of years)
_____	_____	_____	_____
_____	_____	_____	_____
_____	_____	_____	_____

ID# _____

EDUCATION

How many years of school have you completed? _____

CHILDREN

Do you have any children? YES _____ NO _____

If Yes, how many children do you have? What are their ages?

<u>Name</u>	<u>Age</u>	<u>Name</u>	<u>Age</u>
_____	_____	_____	_____
_____	_____	_____	_____
_____	_____	_____	_____

WHO LIVES AT HOME WITH YOU? (Check all that apply)

<input type="checkbox"/> Live alone	<input type="checkbox"/> Other family (Relationship)
<input type="checkbox"/> Husband	<input type="checkbox"/> Friend(s)
<input type="checkbox"/> Children (number)	<input type="checkbox"/> Other

WHERE WERE YOU BORN? (Check one)

<input type="checkbox"/> (1) North Carolina	
<input type="checkbox"/> (2) Arizona	
<input type="checkbox"/> (3) Elsewhere in the U.S.	(Name state) _____
<input type="checkbox"/> (4) Mexico	(Name state) _____
<input type="checkbox"/> (5) Other	(please specify) _____

INCOME

What is your monthly family income after taxes (take-home pay) from all sources (job, pension, social security, veteran's benefits, etc.)?

\$ _____

How many people live on this family income (it provides at least half of their income)?

APPENDIX D

SOCIAL SUPPORT QUESTIONNAIRE

ID# _____

The following questions ask about people around you who provide help or support. Each question has two parts. For the first part, list all the people you know, excluding yourself, whom you can count on for help or support in the manner described. Give the person's initials, their relationship to you (see example). Do not list more than one person next to each of the numbers beneath the question. If you have had no support for a question, check the words "No One." Do not list more than nine persons per question.

For the second part, circle how satisfied you are with the overall support you have. If you have had no support for a question, still rate your level of satisfaction.

Please answer all questions as best you can. All your responses will be kept confidential.

Example

Who do you know you can trust with information that could get you in trouble?

No One

1) T.N. (brother)	4) T.R. (father)	7)
2) L.M. (friend)	5) S.C. (employer)	8)
3) R.S. (friend)	6)	9)

How satisfied are you with the support you have?

Very Satisfied	Fairly Satisfied	A Little Satisfied	A Little Dissatisfied	Fairly Dissatisfied	Very Dissatisfied
6	5	4	3	2	1

1. Whom can you really count on to be dependable when you need help?

No One

1)	4)	7)
2)	5)	8)
3)	6)	9)

2. How satisfied are you with the help you got?

Very Satisfied	Fairly Satisfied	A Little Satisfied	A Little Dissatisfied	Fairly Dissatisfied	Very Dissatisfied
6	5	4	3	2	1

3. Who can you really count on to help you feel more relaxed when you are under pressure or tense?

No One

1)	4)	7)
2)	5)	8)
3)	6)	9)

4. How satisfied are you with the support you have?

Very Satisfied	Fairly Satisfied	A Little Satisfied	A Little Dissatisfied	Fairly Dissatisfied	Very Dissatisfied
6	5	4	3	2	1

5. Who accepts you totally, including both your worst and your best points?

No One

1)	4)	7)
2)	5)	8)
3)	6)	9)

6. How satisfied are you with this support?

Very Satisfied	Fairly Satisfied	A Little Satisfied	A Little Dissatisfied	Fairly Dissatisfied	Very Dissatisfied
6	5	4	3	2	1

7. Whom can you really count on to care about you, regardless of what is happening to you?

No One

1)	4)	7)
2)	5)	8)
3)	6)	9)

8. How satisfied are you with this support?

Very Satisfied	Fairly Satisfied	A Little Satisfied	A Little Dissatisfied	Fairly Dissatisfied	Very Dissatisfied
6	5	4	3	2	1

9. Whom can you really count on to help you feel better when you are feeling generally down-in-the-dumps?

No One

1)	4)	7)
2)	5)	8)
3)	6)	9)

10. How satisfied are you with your support?

Very Satisfied	Fairly Satisfied	A Little Satisfied	A Little Dissatisfied	Fairly Dissatisfied	Very Dissatisfied
6	5	4	3	2	1

11. Whom can you count on to console you when you are very upset?

No One

1)	4)	7)
2)	5)	8)
3)	6)	9)

12. How satisfied are you with this support?

Very Satisfied	Fairly Satisfied	A Little Satisfied	A Little Dissatisfied	Fairly Dissatisfied	Very Dissatisfied
6	5	4	3	2	1

APPENDIX E

MISHEL'S UNCERTAINTY IN ILLNESS SCALE

ID# _____

This section of questions is about what your life is like since your diagnosis.

A person who has a serious illness may feel unsure or uncertain about many things related to the sickness. These next questions will help us find out about the things you are unsure about or things you don't know or fully understand. Read and think about each of the statements below. Circle the number of the answer that matches how you are feeling today.

	Strongly Agree	Agree	Undecided	Disagree	Strongly Disagree
1. I don't know what is wrong with me.	5	4	3	2	1
2. I have a lot of questions without answers.	5	4	3	2	1
3. I don't know if I am getting better or worse.	5	4	3	2	1
4. I don't know how bad my pain will be.	5	4	3	2	1
5. I do not understand what they have told me about my illness.	5	4	3	2	1
6. I understand why I am getting this instrument.	5	4	3	2	1
7. When I have pain, I know what this means about my sickness.	5	4	3	2	1
8. The doctors say things to me that are confusing.	5	4	3	2	1
9. My treatment is too hard for me to figure out.	5	4	3	2	1
10. It is hard to know if the treatments or medications are helping me.	5	4	3	2	1
11. I cannot plan for the future, because I don't know when my sickness will change.	5	4	3	2	1
12. I don't know how to manage my symptoms.	5	4	3	2	1
13. I have been told different things about what is wrong with me.	5	4	3	2	1
14. I do not know what is going to happen to me.	5	4	3	2	1
15. I don't know if this treatment will work.	5	4	3	2	1
16. I do not know how to care for myself.	5	4	3	2	1
17. Most of the time I know what will happen with my sickness.	5	4	3	2	1
18. Because of my treatment, I never know how I will feel day-to-day.	5	4	3	2	1

ID# _____

	Strongly Agree	Agree	Undecided	Disagree	Strongly Disagree
19. I'm certain they will not find anything else wrong with me.	5	4	3	2	1
20. The treatment I am receiving has helped other people before.	5	4	3	2	1
21. They have not told me exactly what is wrong with me.	5	4	3	2	1
22. I know the times when I will feel better or worse.	5	4	3	2	1
23. My health problem is clearly known and will not change.	5	4	3	2	1
24. I can depend on the nurses to be there when I need them.	5	4	3	2	1
25. I know how serious my illness is.	5	4	3	2	1
26. The doctors and nurses use words that I can understand.	5	4	3	2	1

References

- Becerra, R.M., Karno, M., & Escobar, J.I. (Eds.). (1982). Mental health and hispanic americans: Clinical perspectives. New York: Grune & Stratton.
- Berkman, L.F. & Syme, S.L. (1979). Social networks, host resistance, and mortality: A nine-year follow-up study of alameda county residents. American Journal of Epidemiology, 109(2), 186-204.
- Bloom, J.R. (1982). Social support, accommodation to stress and adjustment to breast cancer. Social Sciences and Medicine, 16, 1329-1338.
- Braden, C.J. (1990). Learned self-help response to chronic illness experience: A test of three alternative learning theories. Scholarly Inquiry for Nursing Practice: An International Journal, 4(1), 23-40.
- Castro, F.G., Furth, P. & Karlow, H. (1984). The health beliefs of mexican, mexican american and anglo american women. Hispanic Journal of Behavioral Sciences, 6(4), 365-383.
- Cervantes, R.C. & Castro, F.G. (1985). Stress, coping, and mexican american mental health: A systematic review. Hispanic Journal of Behavioral Sciences, 7(1), 1-73.
- Chandler, C.R. (1979). Traditionalism in a modern setting: A comparison of anglo- and mexican-american value orientations. Human Organization, 38(2), 153-159.
- Chavez, L.R., Hubbell, F.A., McMullin, J.M., Martinez, R.G., & Mishra, S.I. (1995). Structure and meaning in models of breast and cervical cancer risk factors: A comparison of perceptions among latinass, anglo women, and physicians. Medical Anthropology Quarterly, 9(1), 40-74.

Cobb, S. (1976). Social support as a moderator of life stress. Psychosomatic Medicine, 38, 300-314.

Coe, K., Harmon, M.P., Castro, F.G., Campbell, N., Mayer, J.A., & Elder, J.P. (1994). Breast self-examination: Knowledge and practices of hispanic women in two southwestern metropolitan areas. Journal of Community Health, 19(6), 433-449.

Cohen, J. (1977). Statistical power analysis for the behavioral sciences. New York: Academic Press, Inc.

Cohen, S. & Syme, S.L. (Eds.). (1985). Social support and health. New York: Academic Press, Inc.

Cooper, J.P. (1996). Culturally appropriate care: Optional or imperative. Advanced Practice Nursing Quarterly, 2(2), 1-6.

Dean, A. & Lin, N. (1977). The stress-buffering role of social support: Problems and prospects for systematic investigation. The Journal of Nervous and Mental Disease, 165(6), 403-415.

Falicov, C.J. (1998). Latino families in therapy: A guide to multicultural practice. New York: The Guilford Press.

Friedman, M.M. (1998). Family nursing: Research, theory, and practice. Stamford, CT: Appleton & Lange.

García, J.G. & Zea, M.C. (Eds.). (1997). Psychological interventions and research with latino populations. Boston: Allyn and Bacon.

Germino, B.B., Mishel, M.H., Belyea, M., Harris, L., Ware, A., & Mohler, J. (1998). Uncertainty in prostate cancer: Ethnic and family patterns. Cancer Practice, 6(2), 107

113.

Hansen, K.V. & Garey, A.I. (Eds.). (1998). Families in the u.s.: Kinship and domestic politics. Philadelphia: Temple University Press.

Hanucharurnkul, S. (1989). Predictors of self-care in cancer patients receiving radiotherapy. Cancer Nursing, 12(1), 21-27.

Hilton, B.A. (1988). The phenomenon of uncertainty in women with breast cancer. Issues in Mental Health Nursing, 9, 217-238.

Hobfoll, S. (Ed.). (1986). Stress, social support and women. New York: Hemisphere Publishing Corp.

Hood, J.C. (Ed.). (1993). Men, work, and family. Newburg Park: Sage.

Hubbard, P., Muhlenkamp, A.F., & Brown, N. (1984). The relationship between social support and self-care practices. Nursing Research, 33(5), 266-270.

Hulley, S. & Cummings, S. (Eds.). (1988). Designing clinical research. Baltimore: Williams & Wilkins.

Kagawa-Singer, M. (1987). Ethnic perspectives of cancer nursing: Hispanic and japanese americans. Oncology Nursing Forum, 14(3), 59-65.

Keefe, S.E., Padilla, A.M., & Carlos, M.L. (1979). The mexican-american extended family as an emotional support system. Human Organization, 38(2), 144-152.

Kosko, D.A. & Flaskerud, J.H. (1986). Mexican american, nurse practitioner, and lay control group beliefs about cancer and treatment of chest pain. Nursing Research, 36(4), 226-231.

Koss-Chioino, J.D. & Vargas, L.A. (1999). Working with latino youth: Culture.

development, and context. San Francisco: Jossey-Bass.

Kraemer, H. & Thiemann, S. (1987). How many subjects? Statistical power analysis in research. Newbury Park, CA: Sage Publications.

Leininger, M. (1995). Transcultural nursing: Concepts, theories, research and practices. New York: McGraw-Hill.

Loveys, B.J. & Klaich, K. (1991). Breast cancer: Demands of illness. Oncology Nursing Forum, 18(1), 75-80.

McDermott, M.A. & Palchanes, K. (1994). A literature review of the critical elements in translation theory. Image: Journal of Nursing Scholarship, 26(2), 113-117.

Mindel, C.H. & Habenstein, R.W. (Eds.). (1976). Ethnic families in america: Patterns and variations. New York: Elsevier.

Mindel, C.H. (1980). Extended familism among urban mexican americans, anglos, and blacks. Hispanic Journal of Behavioral Sciences, 2(1), 21-34.

Mishel, M.H. (1981). The measurement of uncertainty in illness. Nursing Research, 30, 258-263.

Mishel, M.H., Hostetter, T., King, B., & Graham, V. (1984). Predictors of psychosocial adjustment in patients newly diagnosed with gynecological cancer. Cancer Nursing, 7, 291-299.

Mishel, M.H. & Braden, C.J. (1987). Uncertainty a mediator between support and adjustment. Western Journal of Nursing Research, 9(1), 43-57.

Mishel, M.H. (1988). Uncertainty in illness. Image: Journal of Nursing Scholarship, 20(4), 225-232.

Mishel, M.H. & Braden, C.J. (1988). Finding meaning: Antecedents of uncertainty in illness. Nursing Research, 37(2), 98-104.

Mishel, M.H. (1990). Reconceptualization of the uncertainty in illness theory. Image: Journal of Nursing Scholarship, 22(4), 256-262.

Modiano, M. (1995). Breast and cervical cancer in hispanic women. Medical Anthropology Quarterly, 9(1), 75-76.

Muhlenkamp, A.F. & Sayles, J.A. (1986). Self-esteem, social support, and positive health practices. Nursing Research, 35(6), 334-338.

Northouse, L.L. (1981). Mastectomy patients and the fear of cancer recurrence. Cancer Nursing, 4, 213-220.

Northouse, L.L. (1988). Social support in patients' and husbands' adjustment to breast cancer. Nursing Research, 37(2), 91-95.

Pedersen, P. (Ed.). (1985). Handbook of cross-cultural counseling and therapy. Westport, CT: Greenwood Press.

Pérez-Stable, E.J. (1987). Issues in latino health care. Western Journal of Medicine, 146(2), 213-218.

Pérez-Stable, E.J., Sabogal, F., Otero-Sabogal, R., Hiatt, R.A., & McPhee, S.J. (1992). Misconceptions about cancer among latinos and anglos. Journal of American Medical Association, 268(22), 3219-3223.

Polit, D.F. & Hungler, B.P. (1999). Nursing research: Principles and methods (6th ed.). Philadelphia: Lippincott.

Quesada, G.M. (1976). Language and communication barriers for health delivery to a

minority group. Social Science & Medicine, 10, 323-327.

Sabogal, F., Marín, G., & Otero-Sabogal, R. (1987). Hispanic familism and acculturation: What changes and what doesn't? Hispanic Journal of Behavioral Sciences, 9(4), 397-412.

Sarason, I.G., Sarason, B.R., Shearin, E.N., & Pierce, G.R. (1987). A brief measure of social support: Practical and theoretical implications. Journal of Social and Personal Relationships, 4, 497-510.

Skaer, T.L., Robison, L.M., Sclar, D.A., & Harding, G.H. (1996). Cancer-screening determinants among hispanic women using migrant health clinics. Journal of Health Care for the Poor and Underserved, 7(4), 338-354.

Smith, L.S. (1998). Concept analysis: Cultural competence. Journal of Cultural Diversity, 5(1), 4-10.

Sotomayor, M. (Ed.). (1991). Empowering Hispanic Families: A Critical Issue for the '90's. Milwaukee: Family Service America.

Spiegel, D. (1990). Facilitating emotional coping during treatment. Cancer, 66, 1422-1426.

Vernon, S.W. & Roberts, R.E. (1985). A comparison of anglos and mexican americans on selected measures of social support. Hispanic Journal of Behavioral Sciences, 7(4), 381-399.

Vess, J.D., Moreland, J.R., & Schwebel, A.I. (1985). An empirical assessment of the effects of cancer on family role functioning. Journal of Psychosocial Oncology, 3(1), 1-16.

Villarreal, A.M. (1995). Culturally competent nursing research: Are we there yet? Pediatric Nursing, 1(4), 18-26.

Vinokur, A.D., Threatt, B.A., Caplan, R.D., & Zimmerman, B.L. (1989). Physical and psychosocial functioning and adjustment to breast cancer: Long-term follow-up of a screening population. Cancer, 63, 394-405.

Ward, S., Leventhal, H., Easterling, D., Luchterhand, C., & Love, R. (1991). Social support, self-esteem, and communication in patients receiving chemotherapy. Journal of Psychosocial Oncology, 9(1), 95-116.

Wong, C.A. & Bramwell, L. (1992). Uncertainty and anxiety after mastectomy for breast cancer. Cancer Nursing, 15(5), 363-371.

Woods, N.F. & Earp, J.A. (1978). Women with cured breast cancer. Nursing Research, 27, 279-285.

Woods, N.F., Lewis, F.M., & Ellison, E.S. (1989). Living with cancer: Family experiences. Cancer Nursing, 12(1), 28-33.

Wortman, C.B. (1984). Social support and the cancer patient: Conceptual and methodologic issues. Cancer, 53, 2339-2359.