

EXPLORATION OF THE CULTURAL BELIEFS OF MEXICAN AMERICAN
YOUNG ADULT CHILDHOOD CANCER SURVIVORS AND
THEIR DECISIONS TO ENGAGE IN CANCER
SCREENING BEHAVIORS

by

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Presented to the Faculty of the Graduate School of
The University of Texas at Arlington in Partial Fulfillment
of the Requirements
for the Degree of

DOCTOR OF PHILOSOPHY

THE UNIVERSITY OF TEXAS AT ARLINGTON

December 2010

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ACKNOWLEDGEMENTS

I would like to thank the college of nursing for their support and sincere interest in the higher education of nursing professionals in this community. I would like to formally acknowledge Dr. Mary Lou Bond, Dr. Carolyn Cason, and Dr. Judy Leflore for their guidance, patience and support during my dissertation and defense. You along with the rest of the graduates have displayed a true understanding of what it means to be a nurse scientist, and have well prepared me for this role as I embark on new challenges and professional experiences. I would also like to offer my special thanks to Dr. Andrea Smith who has endured my pain right along with me for the past 6 years working on this labor of love. She has taught me much about nursing and how to be a leader in nursing research. She has provided me with endless suggestions on how to enhance my own nursing and research skills, and the finer ways of enjoying and eating chocolate. Although my parents were not with me physically as I struggled through these past years of completing my higher education, they have always provided me with words of praise, support and their enduring love to me and my efforts to reach for higher grounds. I truly thank my parents and the rest of my family for being there for me. To my Life After Cancer Program staff who supported by dissertation work, I could not have completed this without your support. Lastly, to many of my other colleagues at work who have provided me with statistical and writing support, more chocolate, time to reflect, and often times heard me scream when I just wanted to quit, I thank you for giving me the support I needed to succeed.

November 4, 2010

ABSTRACT

EXPLORATION OF THE CULTURAL BELIEFS IN MEXICAN AMERICAN YOUNG ADULT CHILDHOOD CANCER SURVIVORS AND THEIR DECISIONS TO ENGAGE IN CANCER SCREENING BEHAVIORS

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Gaps in the literature exist exploring the cultural beliefs and the cancer screening practices in Mexican American (MA) young adult childhood cancer survivors (YACCS). Lack of representation of MA in past survivor research is one reason for the gaps in knowledge about the beliefs in MA survivors, and the current study is the beginning of the examination of the cultural beliefs in MA YACCS and how these beliefs influence their decisions about cancer screening. Kleinman's (1978) cultural explanatory model (CEM) approach served as the conceptual framework in which this study was conducted. Survivors were recruited from the investigators institution where survivors receive their follow-up and who met the criteria for participation including being ages 18-39 years, MA, and who are at least 2 years from completion of cancer treatment. Eleven survivors of cancer participated in individual interviews to explore their cultural beliefs like familism, faith, fatalism, modesty and gender roles and their decisions to engage in cancer screening behaviors. The means age of the survivors was 22

years and most had at least a high school education. All of the survivors were treated in the center where they receive follow up care. The cultural beliefs of familism, and faith in God were prevalent in survivors. Family and faith provided the necessary support for survivors during their cancer treatment. Traditional gender roles and modesty were not observed in this group of MA YACCS. Survivors indicated they took responsibility for their health and participate in cancer screening behaviors. Survivors were not fatalistic but had positive expectations for their future. Their family was important, and faith helped them to cope with whatever their future holds. Emergent themes were the illness (cancer), impact of cancer (response to cancer) and cultural stereotyping. Illness for this group of survivors was having had cancer, and the impact of having had cancer had a lasting impression on their lives. Future research is planned to further explore cultural beliefs in a larger sample of MA YACCS to test the CEM identified in this group of survivors, and the participation in cancer screening behaviors.

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CHAPTER 1

INTRODUCTION

The American Cancer Society (ACS) has established cancer-screening guidelines, which may improve cancer survival (ACS, 2009). Childhood cancer survivors may be at greater risk for second cancers due to chemotherapy agents and radiation given as part of cancer treatment. Unfortunately, many survivors do not engage in optimal screening behaviors (Oeffinger et al., 2004; Yeazel et al., 2004).

The Children's Oncology Group (COG) has established evidence-based practice guidelines to direct cancer screening in child, adolescent and young adult cancer survivors (Landier et al., 2004). Unfortunately many Hispanic and Caucasian young adult childhood cancer survivors (YACCS) do not engage in recommended cancer screening behaviors despite receiving information about their individual risk for developing a second or recurrent cancer. There may be factors other than knowledge and perceived risk for developing another cancer, which prevent these individuals from engaging in optimal cancer screening. Cultural beliefs may have an impact on whether individuals choose to engage in cancer screening behaviors. The number of Hispanic children living in North Texas is increasing although stable (Texas Cancer Registry, 2010). Therefore, the number of Hispanic children potentially diagnosed with cancer may also increase.

Little research has been conducted examining the effect of culture and cultural beliefs on participation in cancer screening behaviors in YACCS and specifically Mexican Americans (MAs). At the Cook Children's Medical Center's (CCMC) Hematology & Oncology Program, the number of children presenting to CCMC with cancer has risen over the course of 4 years from 147 in 2005 to 182 in 2008. The number of Hispanics diagnosed in 2008 was 49 (29% of total

diagnosed in 2008) and represented an almost 2-fold increase from 2005 in number of Hispanics diagnosed with cancer.

1.1 Background and Significance

Culture and cultural beliefs may explain why individuals with a previous history of cancer do not engage in cancer screening behaviors (Giger & DavidHizar, 2008; Purnell, 2008). No literature was found which explored the Mexican American (MA) young adult childhood cancer survivors' (YACCS) decisions to engage in cancer screening behaviors. Understanding cultural beliefs is important in order to understand why cancer survivors choose not to engage in cancer screening or to not seek medical attention when ill. It is important to begin examining the cultural beliefs of MAs and specifically young adults and their cancer screening behaviors.

Cultural explanatory models (CEM) have been developed to explain the behaviors of individuals of Hispanic descent and symptoms of diabetes (Luvás, Kay, & Solomons, 1991) and behaviors associated with breast cancer screening (Rajaram & Rashidi, 1998). The researchers compared the CEM of low-income Hispanic women to the biomedical (medical) explanatory model (EM) for chronic diseases like diabetes and breast cancer, respectively. Luvás et al. (1991) reported a disparity between the medical/biological and the EM of the MA women, and these differences may influence how responsive individuals will be in respect to interventions. The medical model was focused on the disease aspect of diabetes, whereas the EM of MA women focused on the economic and family stressors, which they felt triggered the onset of diabetes. Contradictions between the known behaviors, which control diabetes, differed among health professionals and women of Mexican descent. Because of these differences in beliefs of the causes and treatment for diabetes, conflicts between physicians and their Hispanic patients exist in the management of diabetes.

Culture defines who we are and how we act and is engrained in our beliefs and behaviors over time. Health and illness beliefs are influenced by the worldview in which the

particular culture presides, and is further influenced by cultural and social dimensions like religion, kinship, cultural values and beliefs (Leininger, 1978). Cultural beliefs have had an explanatory role in why the Chinese, African Americans (AAs), and MAs chose to or not to engage in cancer screening behaviors (Borrayo & Jenkins, 2001a; 2001b; Eggenberger, Grassley, & Restrepo, 2006; Jones et al., 2007; Lee-Lin et al., 2007; Sobralske, 2006). The meaning attached to the illness or symptoms of the illness are defined by the culture to which the person belongs as well as social and economic factors experienced by individuals in any culture (Kleinman, Eisenberg, & Good, 1978).

Culture influences the health beliefs and practices in the MA population. The constructs of familism, religion, faith (Eggenberger, Grassley, & Restrepo, 2006), machismo (Sobralske, 2006), and modesty (Borrayo & Jenkins, 2001a; Giger & Davidhizar, 2008) have been found to influence the responses of MAs in the face of illness. Additionally, fatalism has been studied in MA men and women regarding cancer-screening practices (Anstheil, 2002; Coronado & Thompson, 2000) and findings indicated that fatalism is a belief like others engrained in the culture, and may influence their decisions to engage in cancer screening behaviors.

With the increase in the number of MAs living in the U.S., and those diagnosed and surviving cancer (Office of Minority Health [OMH], 2009) examination of the cultural beliefs in the MA culture will be important to best understand how beliefs influence cancer screening behaviors.

1.2 Philosophical perspective

The CEM of health and illness was used as the conceptual approach to this study. Kleinman (1978) first conceptualized a CEM out of his personal reading and his longstanding research in the Chinese culture and psychiatric illnesses. A CEM is an attempt to understand health, illness, and healing in a society as a cultural system. Kleinman (1978) suggested that when examining a problem-focused phenomenon in a culture, the meaning, social context, and

behavior norms that are attached to that particular culture should be examined. Further, Kleinman (1978) proposed that culture mediates the internal and external parameters of the medical system, which are cultural systems having similar symbolic, religious, and behavioral norms. The medical system links beliefs about causation, symptoms, and patterns of illness behavior, treatment alternatives, and evaluation of outcomes. For instance, causation of diabetes is a result of pathological changes in the pancreas and there are symptoms that are specific to diabetes such as increased thirst and increased urination. Further, the medical professional expects that individuals will behave in a specific way including seeking medical treatment. Because health and illness, and health care itself are part of the medical cultural system, they must be understood in relation to each other. Any one of these components examined alone would distort comprehensive understanding of the nature of each of these components in the context of health and illness.

Health care explanatory models differ within the health care system. Experiences in the past may predict how individuals perceive, label, validate, and explain their response to the illness (Kleinman, 1978). For example, even among health care staff, each come from a different social background and experiences in health and illness. These different experiences may affect how professionals communicate with families and patients. The practitioners, patients, and family members' models may vary in regards to a particular illness based on social context and values attached (Kleinman, 1978). Conflicts in explanatory models (EM) occur when differences between cultural beliefs exist between patients and providers and result in problems with patient compliance, satisfaction, and use of health care. Therefore, close communication between professionals and patients, as well as respect for cultural differences is warranted.

Kleinman, Eisenberg, & Good (1978) recommend that health professionals ask eight (8) important questions about the illness to understand patients' beliefs and perceptions about their

illness or presenting symptoms. The questions were developed and organized after years of intense clinical work with patients and families (A. Kleinman, personal communication, April 15, 2009). The use of this technique will assist health providers to identify and understand the patient's model of health and illness. The health care system and the professionals within the system will be able to identify the discrepancies that exist between the patient's CEM and the medical model by adapting these questions to the phenomenon of interest. These questions include: "[1] what do you call your problem? [2] What has caused it? [3] Why do you think it started when it did? [4] What does it do to you? [5] How severe is it? [6] What do you fear most about it? [7] What are the chief problems it has caused you? [8] What kind of treatment do you think you should receive" (Kleinman, et al. 1978, p. 256).

Kleinman's (1978) approach to obtain a cultural (emic) perspective about the meaning of cancer to the individual may be feasible for use with survivors. His questions were tailored to ask cancer survivors about their cultural beliefs and cancer. Exploration of the cultural beliefs of MA YACCS using a series of questions like Kleinman et al. (1978) proposed provided the impetus for the development of a CEM to improve participation in cancer screening behaviors in MA YACCSs.

Based on the review of the literature, several cultural beliefs have been identified as having influence in MA men and women in engaging in cancer screening behaviors. No literature was found exploring such beliefs in MA young adult childhood cancer survivors between the ages of 18-39 years.

Family is one of the core values in the MA population, and may serve as the first source of support and medical advice sought by the young adult cancer survivor. The family, which may include extended members, is most often consulted first about a health problem (Zoucha, 2000). Religion also has a strong influence in the MA culture. The belief that God predestines the future and that illness results from bad behaviors is quite prevalent. A belief that

God predestines how one is to live and die may influence cancer screening practices (Reynolds, 2004). Personal factors like gender, age, marital status, social status, generational status and education also may influence cultural beliefs in the MA young adult childhood cancer survivor as noted in review of literature with MA in general. However, personal factors have not been studied in the MA YACCS and their influence on cancer screening behaviors. However personal factors should be measured to evaluate their roles in the beliefs and cancer screening practices in MA YACCS.

The conceptual model used to develop a CEM of the cultural beliefs of young adult MA cancer survivors and why they engage in cancer screening behaviors is presented in Figure 1.1. Demographic factors were explored in how they may have influenced the cancer screening behaviors in MA YACCS.

1.2.1 Definitions of Major Variables

Personal Factors like age now and at time of diagnosis, gender, generational status, education, employment status, marital status, living arrangement, and socioeconomic status are demographic factors that may influence the cancer screening behaviors in MA YACCS.

Demographic Factors:

Age is defined as the number of years since the survivor was born.

Age at diagnosis is defined as the age in months or years the survivor was diagnosed with cancer.

Gender is defined as being either male or female.

Generational Status is defined as: (1) participant born outside the U.S., (2) participant was born in the U.S. and at least one parent born outside the U.S., and (3) participants' parents born in the U.S. (Ahmed et al. 2009).

Education is defined as the number of years of formal schooling acquired by participants of this study

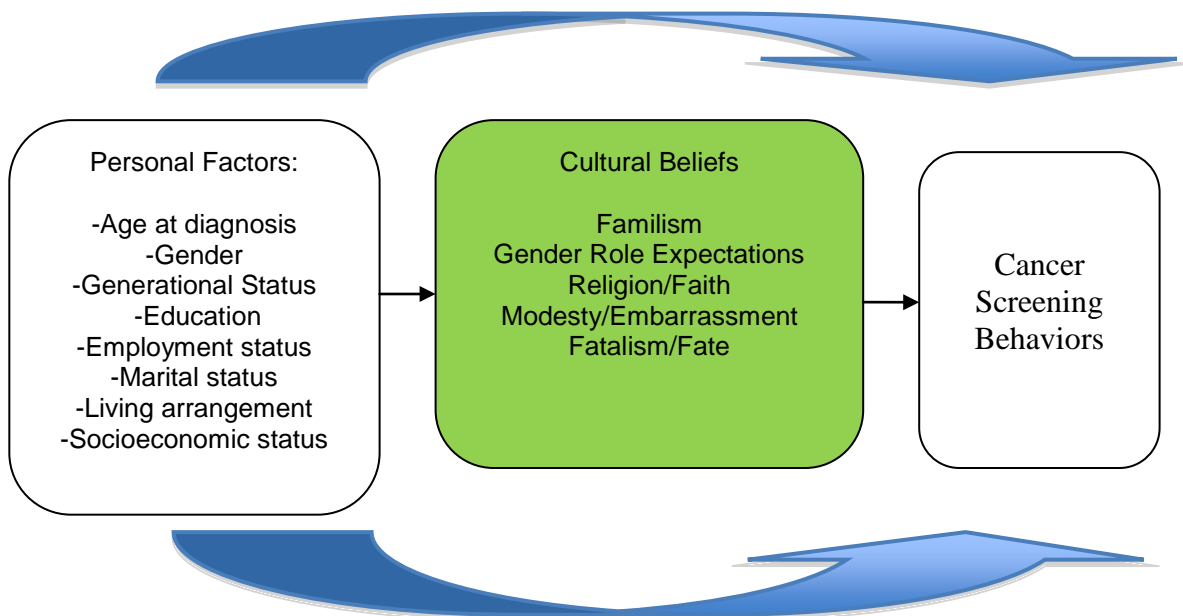


Figure 1.1 Conceptual model. Cultural explanatory model to explore cancer-screening behaviors in Mexican American young adult childhood cancer survivors (Bashore, 2010)

Employment status is defined as working full or part time, unemployed, looking for work, being a student or other.

Marital status is defined as being single, married, living with partner, widowed, divorced, or separated and no longer living as married.

Living arrangement is defined as living with parents, a roommate, a sibling, with another relative, living alone or other.

Socioeconomic status is defined as the total annual income in the single survivor or total family income if married.

Cultural Beliefs are defined as shared meanings and ideas. They are socially constructed and learned, and include patterns of behaviors that are guided by common meanings, ideas and values (Arnett, 2004).

Familism is a core value within the MA culture, and in the most traditional Hispanic individual. Familism will be defined as seeking health care and medical advice from either the immediate or the extended family (Zoucha, 2000).

Gender roles like Machismo is defined as the belief of males in masculinity, strength, and lack of emotion and need to protect these beliefs at all costs (Zoucha & Zamarripa, 2008). Marianismo is defined as the belief that women are self-sacrificing, religious, and pious (Garcia-Bravo, 2009)

Religion is defined as the belief in a higher power like God and the predestination of the future. The religious beliefs in the MA culture include the predestination of their future, and God's divine power over the outcomes of events including medical crises including cancer (Reynolds, 2004).

Modesty/Embarrassment is defined as 'feeling indecent' when exposing one's body during screening or touching one's own body for examination (Borrayo & Jenkins, 2001a).

Fate/Fatalism in MA will be defined as the belief that in the face of a second cancer, death will occur. God predestines the future, and there may be nothing the person can do to change it (Zoucha & Zamarripa, 2008).

Cancer Screening Behaviors are defined as recommended self body examinations including self-testicular and self-breast examinations, checking for moles, and recommended annual clinical cancer screening behaviors including physical examinations, mammography, and colorectal screening if indicated based on treatment.

1.3 Purpose

The purpose of this study was to identify the CEM of MA YACCS and the influence on cancer screening behaviors so that culturally meaningful interventions may be initiated to improve cancer screening in MA YACCS. The specific aims of this study were to: 1) Explore the cultural beliefs like familism, faith/religion, gender roles, modesty/embarrassment, and fate in

MA YACCS; and 2) Explore how these beliefs influence the MA YACCS' decisions to engage in cancer screening behaviors.

1.4 Study Questions

The questions for this study in keeping with the CEM framework were:

1. What does being ill mean to MA YACCS and how do their cultural beliefs influence decisions about seeking medical treatment?
2. What is the role of the MA family (including extended family and friends) in the lives of children diagnosed with and surviving cancer?
3. What is the influence of gender role expectations and decisions to participate in cancer screening behaviors of MA YACCS?
4. What role do religion and faith play in MA YACCS decisions about cancer and cancer screening behaviors?
5. What role does modesty/embarrassment play in the MA YACCS decisions to engage in cancer screening behaviors?
6. Do MA YACCS have fatalistic views of their future if they are diagnosed with another cancer?
7. Do MA YACCS feel they have control over their future?

1.5 Assumptions

The assumption of this study was based on the philosophical approach that Kleinman (1978) proposed as important in gaining access to the cultural beliefs of the culture of interest.

Cultural beliefs influence cancer-screening behaviors.

1.6 Summary

The number of YACCS surviving cancer is growing and concerns over their lack of participation in cancer screening behaviors continue. Cultural beliefs are engrained within the culture in which they preside and include but are not limited to the constructs of familism,

religion/faith, gender roles, fatalism, and modesty and may influence decisions about health and illness. Cultural explanatory models about health and illness may assist health professionals in better understanding how individuals of varying cultures respond to illness like cancer. The conceptual framework for this study was taken from Kleinman's (1978) work in the development of CEM that drives individuals' decision to engage in health practices. Kleinman's work in exploring the CEM in explaining behaviors of individuals as part of a health care system provided the impetus for conducting the exploration of cultural beliefs in MA YACCS about cancer and cancer screening behaviors in a small group of MA YACCS.

CHAPTER 2

CRITICAL REVIEW OF RELEVANT LITERATURE

An extensive literature search using multiple databases including MEDLINE, CINAHL, and Sociology as well as the anthropological literature revealed little research examining cultural beliefs about health and illness in young adult Mexican Americans (MA). There was even less research exploring the cancer screening practices specifically in MA young adult childhood cancer survivors (YACCS). Culture and cultural differences may have a huge impact on decisions about health and illness like cancer. Culture, as defined by multiple investigators, lays the foundation for the expected behaviors of individuals who share that culture (Purnell, 2008).

Young adult MAs, like their elders, may hold similar beliefs in the face of illness. Beliefs include familism, machismo, faith/religion, fate or fatalism, modesty and embarrassment (Gonzalez, Owen, & Esperat, 2008; Zoucha & Zamarripa, 2008). Cultural beliefs about health and outcomes of illness may influence why MAs do or do not engage in specific health practices including cancer-screening behaviors. Do MA YACCS make decisions about participation in cancer screening behaviors based on traditional belief systems or because of their past experience with cancer? No research was found exploring other cultural beliefs in MA young adult childhood cancer survivors.

The following review of the literature will first describe; (1) the concept of culture and (2) cultural explanatory models (CEM), and the importance of understanding culture. Following, the review of the literature will provide information on (3) how cultural beliefs and values influence decisions about health and illness in both the African American (AA) and Chinese cultures.

Next, the review will (4) explore cultural beliefs in Hispanic cultures like religion and health beliefs. The review of literature will then (5) explore MA culture and (6) the cultural beliefs and cancer screening. Lastly, the review of literature will discuss (7) the cultural beliefs of young adult MAs and cancer screening practices of MA young adults and YACCS.

2.1 Culture

Culture has been described as complex and includes a set of behavior patterns, values, beliefs, and customs that serve to guide decisions about many aspects of life including health and illness (Giger & Davidhizar, 2008; Purnell, 2008). Purnell (2008) further defines culture as an unconscious act that has powerful influence on decisions about health and illness. The values, traditions, and beliefs that are engrained within a culture are learned from birth and continue throughout the continuum of life. Similarly, Zouha (2000) defined culture as the sum of behavioral patterns socially acquired and transmitted through customs, beliefs, and material objects.

The construct of culture historically comes from the anthropological literature. The anthropological definition of culture is a “totality of all the learned and transmitted behaviors of a particular group of people” (Leininger, 1994, p.20-21). Leininger (1994) states that understanding the cultural perspective of individuals’ behaviors is critical for health professionals like nurses in order to provide culturally appropriate health care.

2.2 Cultural Explanatory Models

Cultural explanatory models (CEM) have been developed in an attempt to explain breast cancer screening specifically and include three key determinants of cancer screening: (1) the influence of cultural beliefs, (2) socioeconomic status, and (3) influence of social networks (Rajaram & Rashidi, 1998). These authors conducted a critical review of the approaches to understanding women’s decisions to participate in breast cancer screening in minority women.

Rajaram & Rashidi (1998) provided support for the use of CEM based on the literature why CEM offer the best approach to study cancer screening in minority women.

In a qualitative study with 20 Mexican immigrant women (Mean_{age} 39 years), McMullen, De Alba, Chavez & Hubbell (2005), explored the CEM of women and cervical cancer. The women in this study believed there is an association of physical trauma and unwise sexual behaviors with infections that lead to cervical cancer. Further, women suggested that God gives people illnesses like cervical cancer because they lived bad lives.

A three-year project was conducted exploring the cultural beliefs about breast and cervical cancer in a group of Latino's in Southern California (Chavez, Hubbell, McMullin, Martinez, & Mishra, 1995). The ethnographic study included interviews with 27 Chicanas (U.S. born MA women), 29 Mexican-born women, & 28 women from El Salvador (all defined as Latinas) living in the U.S. Twenty-seven Anglo women as well as 30 physicians were also interviewed for comparison of cultural beliefs and the medical/biological risk factors for breast and cervical cancer. The Latina immigrants (Mexican-born women, and Salvadorans) generally differed in their rankings of breast cancer risk as a Latina group about the causes of breast when compared to the Anglo women and physicians. The Latina immigrants revealed a high level of agreement, with a correlation coefficient ($r = .84$). The same group of women had disagreement with the biomedical model of physicians and risk factors for breast cancer. Latina immigrants compared with physicians had negative correlated rankings of the risk factors for breast cancer ($r = -.13$ and $r = -.35$), respectively. The Chicana's explanatory model correlated highly with Anglo women's rankings of breast cancer risk ($r = .76$) as well as Mexican women's rankings ($r = .72$) (Chavez et al. 1995).

No agreement existed between Latina immigrants and the physician model for cervical cancer risk rankings. Again, the Mexican and Salvadoran women had high correlations on cervical cancer risk rankings ($r = .83$). Low correlations coefficients were reported for Mexicans

and physicians ($r = .19$) and Salvadorans and physicians ($r = .08$). The Chicanos had rankings of cervical cancer risk factors that correlated with both Anglo women ($r = .85$) and Mexican women ($r = .66$). The two most prominent themes identified as risk factors for breast or cervical cancer in the Latina women (Mexican and Salvadoran) were physical trauma and bad behaviors. Anglo women and physicians beliefs about the causes of breast and cervical cancer were more medically based and included family history, and advancing age (Chavez et al. 1995).

Chavez et al. (1995) described two separate CEMs in how Anglo women, physicians, and Latina immigrants interpret the perceived risk for developing breast and cervical cancer. Anglo women and physicians had basic agreements on causes of both breast and cervical cancer. Similarly, there was agreement about the causes of breast and cervical cancer among the Latina women together as a group including Chicanos, but Chicanos reported beliefs consistent with a more bicultural model (Chavez et al.).

Simon (2006) conducted a review of the cultural beliefs in diverse populations and the variations of cultural beliefs like modesty, shame, fatalism and God's will in regards to breast cancer screening. Culture serves as a lens in which one's life is viewed and lived; and therefore, the CEM may be useful in explaining breast cancer screening. Simon reported that CEMs for breast cancer screening exist in different ethnic groups, and assist in providing adequate and culturally appropriate care. Family values, personal beliefs, and social networks provide a medium for sharing of ideas, attitudes and beliefs about cancer, and cancer screening have influenced cultural beliefs.

2.3 Cultural Beliefs and Health and Illness (ethnic variations)

Cultural beliefs about health and illness play a significant role among many cultures and cancer screening behaviors. African Americans (Hamilton, Powe, Pollard, Lee, & Felton, 2007; Jones et al., 2007) and Chinese-Australian women specifically (Kwok & Sullivan, 2006; Kwok,

Sullivan, & Cant, 2006; Lee-Lin et al., 2007) were studied and how beliefs may influence their decisions about engaging cancer screening behaviors.

2.3.1 African Americans

Spiritual beliefs and faith are important in the AA community. God is viewed as divine and responsible for both physical and spiritual well being. Spiritual beliefs about life and health propose that pain and suffering are to be endured and are inevitable (Campinha-Bacote, 2008; Hamilton et al., 2007; Kinney, Emery, Dudley, & Croyle, 2002). Trust in God and whatever happens is God's will is a strong belief in the AA, and is often misinterpreted as fatalism. Cultural beliefs played a role in the lack of use of health care and the increased use of complimentary and alternative medicine (CAM) to help manage disease in both AA prostate (Hamilton et al.; Jones et al., 2007) and breast cancer survivors (Hamilton, et al.). Jones et al. used a qualitative approach to explore the role of cultural beliefs about CAM in a convenience sample of 14 AA prostate cancer survivors. Participants reported they used their faith in God and prayer to make decisions about treating their disease. Fifty percent of the men reported faith would help heal their disease and that God works through health care providers to make them well. Hamilton et al. also used a qualitative approach to explore spirituality in AA cancer survivors. Twenty-eight older AA women and men diagnosed with breast or prostate cancer, respectively. Women and men were interviewed about what had helped them through the experience. The majority of the respondents indicated a relationship with God and his support throughout the treatment was comforting for them. Men and women reported that it was God's will for them to have cancer, and they would not worry, as God would take care of them. Other respondents indicated that God was with them during treatment, and he worked to heal them through the health professionals. One prostate survivor reported the use of personal prayer and prayers of his family and church to make him well.

Screening practices in AA women at high risk for breast cancer were examined using a survey method (Kinney, Emery, Dudley, & Croyle, 2006). Women were members of AA kindred (K2099) and were identified as having the BRCA1 gene, which is associated with a higher incidence of breast cancer. Fifty-two women ($M_{age} = 37$ years) completed several surveys including the God Locus of Health Control (GLHC) Scale, a 6-item scale measuring beliefs in God as a locus of control. The total range scores possible for the GLHC is 6-36 with internal consistency reliabilities are acceptable with a range from 0.87-0.94. Women indicated a moderate level of GLHC of 26 ($SD = 6.2$, range 7-36). Investigators reported the GLHC was negatively, significantly predictive of clinical breast examinations (CBE) and mammography behaviors ($t = -2.16$, $DF = 40$, $p = .04$) in women over 25 years. God Locus of Health Control was not predictive of breast self-examinations (BSE). On the other hand, logistic regression indicated a higher GLHC was predictive of the decisions of these women to seek out professional breast cancer screening like CBE and mammography (odds ratio = 0.88, 95% CI = .77-1.00, $p = .05$). As part of the study, an investigator-developed item was used to measure fatalism, and specifically addressed hope in event of a breast cancer diagnosis. Unfortunately, the investigator-developed tool has no known reliabilities in measuring fatalism thus limiting its ability to accurately measure fatalism. The findings indicated the majority (86%) did not have fatalistic beliefs about breast cancer, but only 36% reported they complied with clinical breast examination (CBE) and mammography practices.

2.3.1 Chinese

The Chinese have strong beliefs about health and illness and the use of traditional medicine. Individuals alternate between traditional and more modern medicine (Wang & Purnell, 2008). Life is a balance between the Yin and Yang (opposite forces) and is imperative to positive health status. Preventative medicine such as Tai' Chi, is used to maintain balance

between the mental and physical self. According to Wang & Purnell, the Chinese are not fatalistic or fear death. A "long life" is a major symbol displayed on jewelry or other trinkets.

Cultural beliefs, specifically as they relate to cancer screening have been examined in several studies (Kwok, Sullivan, & Cant, 2006; Lee-Lin et al., 2007). Lee-Lin et al. used a cross-sectional correlation study of 100 Chinese women 40 years and older regarding their beliefs about cervical cancer screening. Investigators used modified versions of several tools to measure knowledge, perceived cancer risk, benefits, barriers, perceived cultural barriers, demographic barriers, and participation in cancer screening behaviors. The modified tool for this study had only moderate reliabilities with Cronbach alphas ranging from .054-0.72 limiting the reliability of the results. The findings indicated that women who were less likely to undergo cancer screening had inaccurate knowledge of the causes of cancer and were modest about undergoing screening. Cultural misconceptions of the causes of cervical cancer existed and included poor hygiene, using birth control pills, using an intrauterine device, and having a miscarriage. Purposeful sampling was used in Kwok, Sullivan, & Cant's (2006) study of 20 older Chinese-Australian women and the role of their cultural beliefs about breast cancer screening. Modesty was also a factor that influenced decisions specifically about breast cancer screening. Women held traditional beliefs and taboos about the inappropriateness of having a man other than their husbands examine their breasts. Taboos about touching one's own body also prevented these women from engaging in clinical breast cancer screening.

Using the same sample, Kwok & Sullivan (2006) explored the beliefs about cancer in general in 20 Chinese-Australian women. Several women reported cancer was contagious and that getting cancer is a death sentence. Their explanations of the causes of cancer fell into several categories including lifestyle, stress, genes, and the unknown. Women held both traditional as well as modern beliefs about the causes of cancer. Traditional beliefs included an imbalance between yin and yang. Stress was also reported as a cause of cancer. One woman

reported that her husband's diagnosis of cancer was caused by stress since worried all the time about his cancer diagnosis.

Women in Kwok, Sullivan, & Cant's (2006) study felt that immoral and shameful behaviors such as promiscuity resulted in breast cancer. Similarly, women in Lee-Lin et al's (2007) study reported traditional beliefs about the causes of cancer, and included poor hygiene, use of birth control pills, miscarriages, and frequent sexual relations even with the same man.

2.4 Hispanic Culture

As of July 2008, Hispanics represented over 15% of the total U.S. population and exceed 46,000,000 persons in the U.S. (U.S. Census Bureau, 2009). In 2000, the number of Hispanics exceeded the number of AA and 50% of Mexican Americans (MA) who migrated to the U.S. lives in the Southwest including Texas (Giger & Davidhizar, 2008).

2.4.1 Hispanic Cultural Beliefs

The importance of understanding the cultural beliefs in the Hispanic population is imperative when addressing health issues. The beliefs like respect (*respeto*) and familism (*familismo*) play important roles in the lives of Hispanics (Andres-Hyman, Ortiz, Anez, Paris, & Davison, 2006). One of the most important values of the Hispanic culture is familismo. The family is the center of the lives of Hispanics, and has strong emotional interdependence not just between family members but across generations (Chong, 2002). Hispanic households include the immediate family members, extended family, and close family friends. Families may live in close proximity to other Hispanic families and function interdependently (Organista, 2007). Family and friends serve as support in times of illness.

Torres (2008) reported that many Puerto Rican families travel long distances to comfort and care for ill members of the family. Multiple family members make many health decisions as a group. Cortes (1995) explored familism in two generations of Puerto Ricans using 400 individuals representing intergenerational families. The sample was taken from a large housing

project in New York City. Measures of familism, knowledge of English, and language spoken were obtained using measures with acceptable reliabilities. Other information obtained included migration status and education. Despite these families living in the same home and exposure to similar family beliefs, the level of familism declines with increasing education within the host system (U.S.). For example, hierarchical regression analysis revealed that education was negatively correlated with familism even when gender was entered into the model ($R^2 = -.36$). When gender, language used, English knowledge were entered into the model, only education remained statistically significantly negatively correlated with familism ($R^2 = -.30$, $p = < .01$). With the addition of ethnic self-identify and feelings of closeness added to the model, education only continued to remain statistically significantly negatively correlated with familism ($R^2 = -.29$, $p = < .01$). Puerto Rican children who began education within the U.S. at a younger age were more likely to adhere to more U.S. beliefs than those children who entered the U.S. education system at an older age.

Cultural beliefs like familism are important to understand when exploring the health practices in the Hispanic population. These beliefs are engrained within the culture, and guide the decisions about life, health practices, and specifically cancer screening behaviors.

2.4.2 Religion and Health Beliefs

The roles of religion, spirituality and the use of traditional healing methods have importance not only in every day life of the Hispanic culture, but have strong ties to health and illness (Chong, 2002; Gonzalez, Owen, Esperat 2008; Andres-Hyman et al., 2006; Torres, 2008). Spiritism, as Hispanics living in the Caribbean coin it, takes on two forms: Espiritismo (Mesa Blanca) and Santeria (worship of saints). Mesa Blanca states that life is a test and individuals must maintain good conduct in order to be rewarded in the afterlife. Santeria proposes spirits are assigned to individuals at birth and serve as protectors and guides. Gonzalez, Owen, & Esperat (2008) and Torres (2008) report both Cubans and Puerto Ricans,

respectively, may summon spiritualists to speak with the dead. Santeros may be called upon for treatment of symptoms. These symptoms are often considered by modern medicine as manifestations of mental problems (Torres, 2008).

The Office of Minority Health highlights information specifically about Hispanic culture, and provides a broad picture about the culture (OMH, 2009). One of the beliefs of the Hispanic culture is the belief in luck, fate or external powers like God. It is in God's hands (*Que sea lo que Dios quiera*) is the belief that God has predestined the lives of individuals. Hispanics who are ill may believe they are afflicted with the illness because of wrongdoing and interpret the malady because of bad behavior and as part of God's design. Chong (2002) further suggests that for many Latinos, health and illness may be consequences of God's approval or disapproval of an individual's behavior (p. 27). Seeking the help of God in time of illness is common in Hispanics, and visiting shrines, making promises to God and offering medals may be used to cure illness especially in Catholic Latinos.

2.5 Mexican American Culture

Cultural beliefs about health and illness weigh heavily in MAs' decisions about engaging in health practices (Zoucha & Zamarripa, 2008). Many MAs strive to maintain their cultural uniqueness and traditional beliefs. To best understand the MA culture, one must have an understanding of the cultural beliefs within this population (Gordon, 1994).

According to Gonzalez, Owen, & Esperat (2008), MAs attempt to retain their own cultural beliefs including machismo, respeto, verguenza (shame), and familism that may result in their behaviors in regards to health and illness. Cultural beliefs like familism, machismo (gender role), modesty/embarrassment, and religious beliefs are among the strongest tenets held by the MA and may influence decisions of MA to participate in appropriate medical screening.

Traditional health beliefs are strong in Mexican Americans. A number of MAs engage in the use of folk medicine such as prayer and herbs. Folk medicine practices cross all social classes (Zoucha & Zamarripa, 2008). Although the majority of the population may not ascribe to this belief any longer, in some cases the less educated MA may continue to believe in such techniques (L. Purnell, personal communication, March 1, 2009). Curanderos (or lay healers) are used widely among MAs and the lay healers use a wide array of pharmaceuticals or herbs (more non-traditional medications) to cure 'ailments.'

Curanderos (faith healers) may use prayers to cure illness (OMH, 2009). Divine intervention may be misinterpreted by modern medical practitioners as being passive. However, this belief provides comfort and security to MA. Because God ordains Curanderos, they believe illnesses are part of God's plan. MAs also believe that suffering through illness is seen as part of the plan, which God has set forth for them.

The following section on MA cultural beliefs and health practices will further clarify and delineate these beliefs and how they influence cancer-screening behaviors.

2.6 MA Cultural Beliefs and Health Practices

2.6.1 Familism

Familism (*familismo*) or the belief that family comes first is present in MAs (Zoucha, 2000), and is the first line of support and decision-making. Familism is at the core of the MA family. The family is the focus of social identity and the most valued institution (Gonzalez, Owen, & Esperat, 2008). It is not uncommon to observe multiple generations living together or in close proximity to each other. The immediate and extended families are included in all decisions and all members take pride in helping others in the family. The family often provides the first course of health care prior to engagement in modern medicine. The health care team may need to negotiate with MA patients and their families to consider both the use of modern medicine along with more traditional treatment.

Family extends beyond the immediate family to friends, as well as community members. Families can be quite large and all members share in the nurturing and discipline of the children. Extended families also provide financial and problem solving support when necessary (Gonzalez, Owen, Esperat, 2008). Familism was a major theme noted in a study by Eggenberger, Grassley & Restrepo, (2006). The six elder MA women interviewed stated they relied on their family in times of sickness, and family members were expected to help solve their health problem. Women indicated that their family was involved in meeting their health needs. Decisions about health are present in the comments of the women; "I took care of my mom for nine years before she died; "I talk to my daughters" (referring to health questions); and "my family would help me get to the doctor or the hospital."

Another belief is filial piety and adherence to family (parental) values even when they (parents) are not present. Unger et al. (2002) examined substance abuse and cultural values in 211 adolescents in Southern California using measures from the Youth Risk Behavior Surveillance System. Results indicated that the largest positive correlation was between filial piety and familism ($r = .42, p < .05$). Because of the correlation between filial piety and familism, adolescents choose to avoid risk behaviors. Adolescents responded by stating: "after my parents die, I will still live according to their values and rules" (coefficient alpha .671). The findings of this study indicated that cultural values play an important role in decisions about behaviors. Respect for parents and responsibility to the values given to them by their parents guided these adolescents' choices not to engage in risk taking behaviors like using alcohol and smoking.

2.6.2 Gender Roles

Machismo is another cultural belief present in MA men. Machismo is a traditional belief of men and the need to be strong and impervious to illness. Machismo is the cultural belief that men are virile and must maintain this persona despite all else. Women are seen as more

submissive, and are expected to adhere to female gender role expectations (Sobral, 2006; Zouha & Zamarripa, 2008). Machismo was present in all eight MA men in a study, which explored health seeking behaviors (Sobral, 2006). These men, who were 24-73 years of age ($M_{age} = 38$ years), expressed the need to remain manly, and the need to fulfill their obligations as the man of the household. Men worked and provided for their families. The majority reported being ill would be seen as less macho but would only seek medical care if they were experiencing symptoms. More often, these men reported they sought the medical care from their wives or other family members first.

Fernandez et al. (2008) examined 92 Texas-Mexico border MA men and women about colorectal cancer (CRC) screening using a qualitative design. Participants were asked about knowledge, attitudes and beliefs about CRC. The men in this study reported CRC screening a “violation” to their manhood (p. 200). One man in this study reported that CRC screening was an affront to his manhood and insult to his virility to undergo colonoscopies.

Gender roles for women (*Marianismo*) are prevalent in the Hispanic culture. Women are seen as the primary caretaker of their children and husbands. In the face of symptoms, women will not go to be examined for fear of finding a cancer, and the burden it may place on the family (Eggenberger, Grassley, & Restrepo, 2006). Marianism as Steven states (as cited in Rondon, 2003) is the “the good women role is played out by the dutiful mother and wife whose needs are secondary to the family needs (Zouha & Zamarripa, 2008). For women, the family takes priority and seeking health care for one’s own benefit is not seen as a priority in the Hispanic culture. Although gender roles are changing, men remain the authority within the family (Eggenberger, Grassley & Restrepo, 2006).

Mendelson (2003), interviewed MA women about their cultural beliefs and relation to their health practices within the context of their roles in the family. Thirteen women ($M_{age} = 38.23$, $SD = 7.62$) all felt that raising their family to be healthy was very important. In respect to

health practices, the participants varied in how they feed their family and were torn between preparing traditional meals and more healthy meals for their children. Participants reported the use of both home remedies and U. S. medicine to treat their family's illness. Traditional medicine like drinking soups and teas were used to treat illness. The use of healers was not widely used in this sample of women, and the majority stated they would seek the advice of their doctor before their families.

2.6.3 Religion/Faith

Another important cultural belief is religion, faith, and the belief in God. Religion plays an important role in the health practices and beliefs in MAs (Zoucha & Zamarripa, 2008). Fernandez et al. (2008) in their study of men and women in Texas border towns explored the religious beliefs of the participants in regards to colorectal cancer (CRC) screening by asking them about the importance of spirituality and prayer. Participants with a history of cancer reported how prayer helped them overcome pain, and how their belief in God and use of prayer helped them deal with illness like cancer.

Living in the present is the focus of MAs, and God predestines the future so it is needless to worry about the future (Zoucha & Zamarripa, 2008). Gonzalez, Owen & Esperat (2008) report MAs are more likely to ascribe to an external locus of control which support their beliefs in God's divine influence.

Six elder MA women from two senior centers in a large Texas city were interviewed to explore their health beliefs (Eggenberger, Grassley, & Restrepo, 2006). The mean age was 71 years and all of them were born in the United States. Spiritual beliefs were apparent in several comments of the women indicating a strong faith in God and his influence in their lives. "It's all up to God"; and "I pray and then I feel better...I tell it to God and then I feel better." The comments by women indicated an external locus of control. Contrary, the MA women also indicated an internal locus of control as well in regards to their health. "If you don't take care of

yourself ain't anybody else going to do it." (p. 13), and "I made up my mind to lose that fat when I retired. I can do something about it [my health]." The women in Borrayo & Jenkins (2001b) study, punishment from God for wrongdoing (castigo) was also perceived to be cause of disease and religious practices are the only means of curing them. Practices for salvation include prayer, visiting shrines, offering medals or other gifts to the patron saints, and doing well in the face of God.

2.6.4 Shame/Modesty/Embarrassment

Shame, modesty and embarrassment are beliefs that prevent women from undergoing cancer screening. Mexican American women stated they do feel uncomfortable exposing their bodies to men or women (Gonzalez, Owen, & Esperat, 2008). Undergoing cancer screening which requires a doctor to touch a woman's genitals is taboo. Cultural values like modesty is highly valued in MA women and nakedness is avoided (Salazar, 1996). Women are also taught that even touching themselves is taboo.

Borrayo & Jenkins, (2001a) examined cultural beliefs about modesty and cancer screening in 34 MA women ($M_{age} = 62$ years). Participants in this exploratory study reported 'feeling indecent' and exposing one's body during screening or touching one's own body was inappropriate. Beliefs like embarrassment often precluded women from undergoing routine cancer screening (Borrayo & Jenkins, 2001a; Byrd, Chavez & Wilson, 2007). One respondent in Borrayo & Jenkins' (2001a) study stated; "you just don't do that" [touch or expose one's body during breast cancer screening] (p. 541). Women also indicated they mistrusted men to touch them. Other reasons for not going to the doctor and being screened are apparent in this comment; "...The [male] doctor sometimes takes advantage of you so you have to be careful..." (p. 544). This comment indicates the myths Hispanic women have about cancer screening and what actually happens during a doctor's visit and the reasons why many MAs may not engage in clinical breast examinations.

Byrd, Chavez & Wilson (2007) used 13 focus groups of 84 Hispanic women ages 18-61 years to explore the barriers and facilitators of cancer screening. Seventy-three percent (N=62) of the women were young adults. Women in this study reported they were fearful of having a Pap smear, and embarrassed about undergoing cancer screening. The gender of the physician did not matter. This study included a small sample size and also young adult subjects of various Hispanic cultures. However generalization to the MA young adult exclusively may not be possible

2.6.5 Fatalism

Fatalism in the MA population is a religious belief and is the predetermination by God and how individuals will die (Anstheil, 2002). Most women in Borrayo & Jenkins (2001b) study had fatalistic beliefs about breast cancer, which reflected their belief that God predestined people to develop cancer. The authors indicated that belief in a higher power might have religious connotations and be prevalent in women who are highly religious. Whether these fatalistic beliefs serve as barriers to screening is not clear, but the study participants' responses further supported the belief that one's destiny is out of their control.

Coronado & Thompson (2000) examined cancer-screening practices in 158 men using a 104-item interview tool to assess beliefs and attitudes. Researchers reported that the less acculturated rural MA men held fatalistic beliefs about cancer and stated a lack of personal control over their health. Men in this study were primarily older men (> 50 years) and so generalization to young adult MA men may not be possible.

2.6.6 Myths about cancer and cancer screening

Misconceptions like inaccurate knowledge about the causes of disease preclude MAs from engaging in cancer screening practices and general health promotion behaviors (Carpenter & Colwell, 1995). In an examination of the knowledge and the causes of cancer in 112 women who lived in a Texas border town, investigators reported that many women lacked

sufficient knowledge and self-efficacy about engaging in cancer screening. Over half of the women believed that there is no cure for breast cancer and therefore, did not to examine their own breasts. Salazar examined the beliefs of 29 women ($M_{age} = 52.8$ years) about breast cancer screening using the Multiattribute Utility Model, which proposes that individuals choose behaviors which optimize their perceived personal gain given a particular situation. Women reported unless they had symptoms or felt something was wrong, they did not see a reason to engage in cancer screening. Other responses indicated lack of knowledge about the cause of breast cancer. For example, women who breast-fed their babies believed they were not at risk for breast cancer and do not participate in cancer screening.

Women had misconceptions about how cancer develops. Women believed that cancer occurred because of trauma to the breast while others believed that breast feeding causes breast cancer, which may be a form of trauma to the breast (Borrayo & Jenkins, 2001b). The trauma associated with mammography and is a deterrent for women to undergo screening. Touching one's own breasts, breast feeding, and other potential trauma to the breast are also perceived causes of cancer (Borrayo & Jenkins, 2001b). Participants reported that due to lack of symptoms and feeling healthy, they choose to not to engage in cancer screening. Women who believed they had no family risk or did not have symptoms did not engage in screening.

2.7 Mexican American Young Adults and Cancer Screening Practices

No research was found exploring the cultural beliefs in young adult, MA exclusively, or young adult childhood cancer survivors. Arnett (2004) suggested that Latino young adults are more likely to stay at home longer due to the emphasis on family versus self.

2.7.1 Fatalism (Cancer) in Young Adults

Cancer fatalism has been explored in young adults and despite higher education. Male college students like most young adults know little about the risks for testicular cancer, and less about how to perform a self-testicular examination (TSE) (Powe, Ross, Wilkerson, Brooks, &

Cooper, 2007). Cancer may be seen as a disease of the elderly or individuals who have bad habits like smoking, but not in young adults. The results of Powe et al. (2007) study reported barriers to performing TSE among AA college students included perceived risk, lack of testicular cancer knowledge, and higher levels of cancer fatalism.

2.7.2 Fatalism in YACCS

Young adult, female Hodgkin lymphoma survivors' feelings about breast cancer and their risk for getting breast cancer were examined using a qualitative methodology (Bober et al., 2007). Investigators used focus groups and individual interviews with the women about their health perceptions, risk perceptions about cancer, knowledge, and benefits and barriers to cancer screening. Many of the participants lacked knowledge of cancer risk and cancer screening behaviors were minimal.

Bober et al. (2007) reported that women who were engaging in breast cancer screening, reported early identification as a benefit to routine screening. Lack of communication with physicians during annual visits, were stated as barriers and women reported they were not aware of their risk. Lack of concern or ignoring their risk was another barrier, and one participant stated: "I don't want to know anything else that is going to happen to me" (p. 44). Many women were not worried, which may have reflected the general lack of perceived risk and knowledge. Further, many felt helpless in the face of another cancer, and the ideation of fatalistic beliefs was entertained. The investigators suggested that fatalism and the belief that another cancer would be out of these survivors' control, might have explained their lack of screening.

Only one study from the Children's Cancer Survivor Study (CCSS), a cohort of over 14,000 survivors, examined cancer screening in minorities specifically (Castellino et al., 2005). A cross sectional study was conducted using self-reported items. None of the questions

specifically measured fatalism. However, fatalism may have played a role in the small number of Hispanic cancer survivors and lack of cancer screening.

2.8 Personal Factors

Personal factors specifically, and their influence in the decision to engage in cancer screening have not been explored. However, Oeffinger et al. (2004) analyzed data from the Children's Cancer Survivor Study for 9,434 adult survivors to identify the type of medical care the survivors were reported (general physical examination, cancer-related visit, or visit to a cancer center). Using a multivariate model, the authors reported that survivors over 30 years of age compared to survivors less than 29 years at the time of the analysis were less likely to report any follow up examination (OR = 1.56; 95% CI, 1.35-1.81). Other risk factors, important for the current study, for not reporting at least one type of medical visit included being male (OR = 1.65; 95% CI, 1.44-1.88), and the lack of concern for future (OR = 1.57; 95% CI, 1.36-1.82). Not having health insurance was also a risk factor for not reporting at least one medical visit and may have been a proxy measure for unemployment (OR = 2.34; 95% CI, 1.97-2.77).

Survivors who received treatment for high risk diseases like bone tumors, central nervous system (CNS) tumors, Hodgkin's lymphoma and leukemia were less likely to report a cancer-related visit the longer from treatment they were ($p < .001$). From time since diagnoses to 25 years, less than 50% of survivors of CNS tumor survivors, and 40% of Hodgkin's lymphoma survivors, and approximately 20% of leukemia and bone tumors survivors reporting a cancer related visit in a 2-year period. The findings of this retrospective analysis are important because as survivors age, the incidence of many late effects of treatment including second malignancies are increasing (Oeffinger et al. 2004). Ethnicity was not examined and the reported participation in follow up care.

2.9 Summary

The review of literature began with a general overview of culture and how it may impact decisions about health. Culture defines who individuals are, how they act within the family as well as their community at large. Culture and cultural beliefs play a role in decisions about cancer screening in both the Chinese and AA cultures. Cultural beliefs like familism, machismo, and faith strongly predicted the beliefs about life, health and health screening behaviors, and death in Hispanics. Cultural beliefs in Hispanics also played a huge role in family structure and behaviors among family members, and in how decisions were made about health. Faith was strongly suggestive of how decisions were made in respect to illness, and reverence to God and his will. God predestines what will happen in life and to succumb to these beliefs about God, life and death are considered to be in line with the beliefs in the Hispanic culture. Similarly, MAs as well as the general Hispanic culture hold similar beliefs, and the review of literature has revealed these beliefs and how they affect decisions about health and illness.

The young adult MAs has not been widely examined in respect to cultural beliefs, and studies were not found specifically which explored their beliefs about health and illness. Whether these young adults adhere to the traditional beliefs of their elders in time of illness is not known. Cancer can be a terminal disease, and even less is known about the health practices of young adult MA childhood cancer survivors. Whether fatalism is a belief in of itself in the Hispanic culture and more specifically in young adults was not established in studies reviewed in this review of literature.

Currently appropriate measures to examine cultural beliefs and specifically cancer fatalism in young adults are lacking and further validation of current measures is warranted. Cultural explanatory models may provide the impetus to develop more appropriate tools to measure cultural beliefs and cancer screening practices. The construct of fatalism as a cultural belief in the MA young adult, had not been established. Many of these MA young adult

childhood cancer survivors are at risk for second cancers because of their cancer treatment. Cancer screening practices may prevent cancer or detect a second cancer early. This review of literature has identified the gaps in current literature and the culture beliefs in young adult MAs. Further gaps exist in young adult MA childhood cancer survivors and cancer screening behaviors.

The proposed study will begin to fill the gap in current research and how cultural beliefs affects the cancer screening behaviors of MA young adult childhood cancer survivors. It is expected that a CEM can be identified that can be used to explore the cultural beliefs of MA young adult cancer survivors and their decisions to engage in cancer screening practices.

CHAPTER 3

METHODOLOGY AND PROCEDURES

This chapter describes the design used to explore the cultural beliefs and cancer screening behaviors of Mexican American (MA), young adult, childhood, cancer survivors (YACCS). The chapter also describes the setting, sample, and data collection procedures used to obtain an adequate sample size in order to answer the research questions.

3.1 Research Design

A qualitative descriptive design to explore the cultural beliefs of MA YACCS and cancer screening behaviors was used (Sandelowski, 2000). A qualitative approach was best suited to examine phenomena such as cultural beliefs in an unexplored population like MA YACCS. Literature is sparse exploring the cultural beliefs in MA YACCS and little is known why these and other YACCS do not engage in recommended cancer screening behaviors. Knowing and understanding phenomena minimally require knowing the 'facts' about the phenomena (Sandelowski, 2000). Descriptive qualitative research is characterized by presenting the facts in everyday language rather than an abstract framework or interpretive language as used in phenomenology or ethnography. The words of the participants are the data. Data were collected using semi-structured interviews to understand the individuals' perspectives about their cultural beliefs and their participation in recommended cancer screening behaviors. The interview questions are found in Appendix A.

3.2 Sample

Purposeful sampling was done from a large group of over 100 Hispanic YACCS from a cancer survivor database, a cancer registry, and survivors who attended an outpatient hematology and oncology clinic. Purposeful sampling provided the most information-rich data

(Patton, 2002) and was used to obtain the sample for this study. Inclusion criteria into this study were:

1. Self identifies as a MA YACCS
2. 18-39 years of age
3. Diagnosis of cancer as a child or adolescent between the ages of one year and 17.99 years
4. At least two years post therapy.
5. Attends the outpatient cancer center, the formal survivor program or followed peripherally by the cancer treatment center
6. Able to speak and understand English

The LiveStrong Young Adult Alliance (2008) defines young adults (YA) as 18-39.

3.2.1 Definitions

For the purposes of the study, the following definitions were used to formally identify eligible participants:

1. Mexican American was defined as those survivors who identified themselves as MAs.
2. Age was calculated by the date of birth of participants to date of eligibility determination.
3. Two years since completion of therapy as self reported by survivors but then verified by chart review following consent by the participant.

3.3 Setting

Study participants were recruited through a comprehensive cancer center and the survivor program in North Texas where the researcher works. Potentially eligible participants (survivors) were recruited using three methods. Survivors were recruited at the time they presented to the cancer center for their annual survivor appointment or general cancer follow up

visit. Survivors were also identified using the survivor database and cancer registry. Survivors not attending the clinic were sent a flyer (Appendix B) by postal mail describing the study and seeking their participation and were identified by the survivor database or cancer registry. The participants were also recruited using a posted flyer in the clinic (Appendix C). The staff in the survivor program recruited all participants and received returned mailed flyers. Potential participants' names were given to the researcher following their expressed interest in being part of the study.

3.4 Data Collection Methods

3.4.1 Demographic Questions

Demographic questions included: 1) age, 2) age at diagnosis, 3) gender, 4) generational status, 5) diagnosis, 6) employment status, 7) marital status, 8) income, 9) education, 10) living arrangements, and 11) socioeconomic status. The participants independently completed an investigator-developed demographic form (Appendix D).

3.4.2 Interview Questions

The researcher collected all data and used interview questions using Kleinman's eight (8) questions of inquiry about the illness. The study questions, and the variables identified in the review of literature in Chapter 2 were used to explore the cultural beliefs of study participants and their decision to participate in cancer screening behaviors. Several prompting questions were asked in the event further exploration of the particular belief (concept) was necessary. Questions were edited or reworded based on the responses of the participants and appropriateness of the questions to obtain valid responses. If participants required further probing or did not understand the questions, the researcher reworded the question to gain insight into the cultural beliefs of the MA YACCS.

3.5 Procedure

Following IRB approval, recruitment was done at the pediatric cancer center in North Texas where the majority of the potentially eligible participants received their cancer treatment. The researcher used resources such as the cancer registry (registrar), survivor database (program assistant), and other oncology health professionals in the cancer center where the researcher works. A flyer that explained eligibility criteria (Appendix C) was posted in the clinic where other oncology providers such as nurses, nurse practitioners, doctors, social workers, and other general office staff could identify potential participants, and a script (Appendix E) to be used to explain the study. The script presented was also used for the survivor program staff to recruit potential participants.

First, a staff member, working within the survivor program sent out via postal mail flyers to survivors who met eligibility criteria using the survivor database and the cancer registry. A telephone call by one of the survivor program staff was done approximately two (2) weeks following the mailed letters to follow up on the mailed letters. The telephone calls were made to those survivors who did not respond to the mailed flyers and for those mailed flyers that were returned with no forwarding addresses. The staff member of the survivor program addressed questions by the potential participants and then further inquired about their eligibility to be in the study. If the survivor was interested in being in the study, the researcher contacted the participant and arranged a time and place where the audio taped formal written consent (Appendix F) process and data collection took place.

Second, for those survivors who attended the outpatient survivor program, the social worker approached the survivors as they presented to the clinic. The social worker discussed the study with the survivors, provided the survivors with consents for review, and answered any questions. If the survivor expressed an interest in being in the study, the researcher answered any further questions the survivor had and then audiotaped the formal consent at the

permission of the participant. Survivors who attended the outpatient clinic for a general follow up visit were to be approached by another health professional other than that researcher and follow the same method of recruitment. The recruitment procedure algorithm is found in Appendix G. The procedure used for data collection is outlined in a flow chart (Appendix H).

3.6 Ethical Considerations

3.6.1 Review Process

Institutional Review Board (IRB) approval of this protocol was obtained from the health care facility where the study was conducted and the University of Texas at Arlington, prior to subject recruitment. The letters of approval for both facilities are found in Appendix I. The informed consent and all data collection forms and semi-structured interview questions are included in the Appendices.

3.6.2 Potential Risks

This study posed only minimal psychological risk and no physical risk to survivors participating in the study. A potential loss of confidentiality occurred due to the maintenance of an audit trail for data collection (Appendix J) and data analysis (Appendix K) along with participant characteristics for data analysis. All of the documents except consents were coded with participants' initials. Further, the personal demographic logs, audit trail for data collection and analysis do not contain the participants' names but only codes that are linked to the signed written consents, which are kept in a separate locked cabinet. All potential risks and benefits of this study were explained to the participants. Some of the interview questions about cancer, reflections of their cancer treatment and need to engage in cancer screening behavior resulted in emotional discomfort in the subjects. The researcher, who has over 17 years experience working in pediatric oncology, listened and watched for verbal cues of anxiety, was able to respond appropriately to the emotional responses of the participants.

3.6.3 Benefits

The primary benefit from participating in this study for the participant was the ability to discuss their cultural beliefs, and be able to tell their story of how cancer affected their lives. The ability to tell their story was mentioned as being very helpful to several survivors. The second benefit from participating in this study was the awareness of the survivor of the importance in engaging in cancer screening behaviors. Investigators can use this information to develop more culturally appropriate interventions to improve cancer screening in the MA YACCS.

3.6.4 Informed Consent

All information collected, as part of this study was kept confidential. All information obtained as part of this study was kept in locked research cabinets in the researcher's office. The consents and all data collection forms were coded and only the researcher was able to link the responses to the signed consents. Both documents were kept in a separate locked location and will be destroyed at the end of the study.

3.7 Data Analysis

Descriptive statistics were used to examine categorical demographic data and presented in percentages and sums. The qualitative data was analyzed using content analysis (Sandelowski, 2000). The researcher transcribed and analyzed all the interviews.

Data obtained from the participants were initially placed in broad categories based on the interview questions found in Appendix A. The information obtained during the interviews was then placed into subcategories of coded information and continued until no new ideas were obtained from participants. Line by line coding was done to identify key ideas (phrases) from the quotes of the participants. Field notes were kept along side the transcribed information to capture key phrases and ideas. The field notes and ideas were then organized into themes based on ongoing analysis of subsequent interviews.

The analysis of this study was done in the context of a cultural explanatory model (CEM) of MA YACCS and their participation in cancer screening behaviors. An anthropologist with extensive expertise in both the Hispanic culture and qualitative researcher independently coded five of the interviews. Once the experienced researcher coded the interviews, she and the researcher worked together to reach a consensus on the themes that best represent the cultural beliefs of the survivors and cancer screening behaviors.

3.7.1 Assumptions of the analysis

Qualitative descriptive design (Sandelowski, 2000)

1. presents the data (facts) in the everyday language used by the participant (MA YACCS).
2. collects as much information as necessary to capture the essence of the phenomenon.
3. offers a summary of the phenomenon in everyday terms.
4. presents the language used by participants as the vehicle of communication (MA YACCS quotes) and not the interpretation of the data by the researcher.
5. entails interpretation of results in greater consensus among researchers.

3.7.2 Rigor and credibility of analysis

The rigor and credibility of qualitative analysis is the outcome of the ongoing verification of the data received. Rigor in qualitative research was established in this study by use of audit trails (Appendix K) and evaluation of the interviews by both the researcher and an expert in qualitative research (Morse, Barrett, Mayan, Olson, & Spiers, 2002). Strategies used by researchers include responsiveness to participants, methodological coherences, theoretical sampling, and adequacy in sampling, active analytical stances, and saturation of the data (Morse et al. 2002). Verification of the data is the process of checking, and making sure trustworthiness is established (Guba and Lincoln, 1982). The focus in this study was to

determine credibility, transferability, dependability, and confirmability of the data. These strategies included:

1. Confirmation of important ideas was done throughout the data collection to ensure accurate interpretation of what was said by the participants. An independent staff member transcribed two interviews for accuracy of the transcription.
2. An anthropologist and expert in qualitative research coded and validated five interviews and then met with the researcher to derive at a consensus about the interviews.
3. An audit trail was kept as a means of validating the research process so others can replicate the process (Appendix K).
4. Journal writing served to keep the PI objective throughout the research process. The journal was used to document any biases or assumptions the researcher may have about the participants' feelings during and following the interviews.
5. The researcher's dissertation chair, experienced in working with the MA, reviewed all decisions, conjectures and made suggestions for future research.

3.8 Summary

A qualitative descriptive design study was used to explore the relationships between personal variables, cancer fatalism and cancer screening behaviors among an ethnically diverse sample of young adult childhood cancer survivors. Institutional review board approval was obtained prior to approaching any potential participants in this study. Potential participants were recruited from a North Texas Pediatric Oncology Center, and the respective cancer survivor program and general oncology population of survivors.

Data analysis was conducted using content analysis and descriptive demographic data analyzed using SPSS 14.0. Interviews continued until saturation of the themes were identified and an independent expert in qualitative analysis worked with the researcher to analyze five of the interviews for reliability of findings. The researchers worked together to derive an agreement on the themes identified from the individual interviews.

All data was kept confidential and a data collection and data analysis audit trail were kept in order for replication of the procedure and data analysis.

CHAPTER 4

FINDINGS

The thematic findings of this study were organized based on the constructs of the Cultural Explanatory Model (CEM); *Cultural Beliefs and Cancer Screening Behaviors in Mexican American Young Adult Childhood Cancer Survivors* shown in figure 1 (p. 7): (1) familism, (2) gender role expectations, (3) religion/faith, (4) modesty/embarrassment (examinations), and (5) fatalism(future). The chapter begins with a description of the characteristics of the participants. Following this section, the themes identified within the constructs of the CEM are presented as exemplar quotes. Emergent themes identified from the analysis of the data provided by the participants are also presented.

4.1 Sample Characteristics

One hundred and one young adult childhood cancer survivors were initially identified as potentially eligible for participation in this study using the survivor database. Ninety-nine were initially identified as Hispanic. Two of the potentially eligible survivors were Guatemalan and removed from the mailing list. The postal mailed recruitment flyers were mailed to the potentially eligible participants. Only 15 individuals responded to follow up telephone calls that were made 2-3 weeks following no response to mailed flyers. Eleven of these 15 provided informed consent and completed interviews. One young adult scheduled an appointment but did not show up and was unable to be contacted following the missed interview. Two other survivors who indicated interest in being in the study, by either phone or email, were not able to be reached attempts at contacting them for consent.

Three of the interviews were completed by phone at the request of the survivor. Two of the Mexican American (MA) young adult childhood cancer survivors (YACCS) were in college and not able to come to the cancer center, and the other lived several hours away.

The MA YACCS were interviewed using the CEM and questions based on Kleinman's model to identify cultural explanations for the beliefs in the survivors (Kleinman, 1978). The constructs of the model were addressed with each series of questions, and the responses of the survivors provided the data to further construct the CEM in MA YACCS.

The interviews were done either in the comprehensive survivor center, the researcher's office, or by telephone. The Interviews were conducted with English speaking MA YACCS. The interviews and the informed consent process were audio taped. Each interview took from 35-65 minutes. Participants received a small compensation of \$15.00 (gift card) in appreciation for their time in completing the demographic data form and participation in the interviews.

Sampling was done until no new ideas about the cultural beliefs and their influence on cancer screening behaviors were identified (Liamputtong & Ezzy, 2005). Saturation sampling and redundancy of themes criteria were met following the completion of 11 survivors' interviews. A table of the demographic characteristics of the subjects can be found in Appendix L. As part of the qualitative descriptive approach, an independent person in the survivor program reviewed the first two interviews for accuracy of transcription of the data (words spoken by participant).

Table 4.1 displays the age, gender, generational and educational status of the participants. The current age of the participants ranged from 18 – 36 years ($M = 22.7$, $SD = 5.9$). The average income was less than \$20,000 for seven (63.6%) participants. Marital status, living arrangement, employment status and income are found in Table 4.2

The mean age at diagnosis of the participants was 7 months - 17 years ($M = 8.6$ years, $SD = 5.9$), and six (54.5%) were diagnosed with Acute Lymphoblastic Leukemia. Table 4.3 displays the diagnoses and the age at diagnosis for the participants in this study.

Table 4.1. Age, Gender, Generational and Educational Status of Participants (N=11)

Characteristics	Frequency	Percent
Age		
18	4	36.4%
20	2	18.1%
22	1	9.1%
24	1	9.1%
26	1	9.1%
30	1	9.1%
36	1	9.1%
Gender		
Male	6	54.5%
Female	5	45.4%
Generational Status		
Born outside of the U.S.	1	9.1%
Born in the U.S. and at least one parent born outside the U.S.	6	54.5%
Born in U.S. with both parents born in the U.S.	4	36.4%
Education		
<High School	2	18%
High School Graduate	2	18%
Some College	5	46%
College Degree	2	18%

Table 4.2. Marital Status, Living Arrangement, Employment Status Income of Participants

Marital Status	Frequency	Percentage
Single	5	46%
Married	3	27%
Living with Partner (Significant other)	3	27%
Living Arrangement		
Live with Spouse/Partner	5	46%
Live with Parents	3	27%
Live with Roommate (friend)	1	1%
Live Alone	2	2%
Employment Status		
>30 hr/week	3	27%
< 30 hr/week	3	27%
Unemployed (looking)	1	9%
Student (not working)	3	27%
Other (homemaker)	1	9%
Income		
<20,000	7	64%
20,001-30,999	2	18%
40,000-50,999	1	9%
60,000-70,999	1	9%

Table 4.3. Diagnosis and Age of Diagnosis of Participants

Characteristics	Frequency	Percent
Diagnosis		
Acute Lymphoblastic Leukemia	6	54.5%
Acute Myeloid Leukemia	1	9.1%
Hodgkin's Lymphoma	1	9.1%
Non Hodgkin's Lymphoma	1	9.1%
Germ Cell Tumor	1	9.1%
Other	1	9.1%
Age at diagnosis		
7 months-3 years	4	36.4%
4 years-10 years	3	27.2%
13 year – 17 years	4	36.4%

4.2 Themes

The cultural explanatory model (CEM) of the Mexican American (MA) young adult childhood cancer survivors (YACCS) provided the conceptual model for analysis of the data. Results from the interviews are presented based on concepts within the model formed by the responses of the survivors. Emergent themes from the interviews are presented separately from the CEM. Quotes from the survivors serve as the data to support the themes and are provided with each respondent's subject number.

4.2.1 Family Importance in Medical Decision-making

Familism (*familismo*) is defined in Chapter 1 as seeking health care and advice from either the immediate or the extended family (Zoucha, 2000). Family for many MAs is the focus of social identity and the most valued institution (Giger & Davidhizar, 2008). Multiple

generations of MA family often live together or in close proximity. Family members may be included in all decisions and all members take pride in helping others in the family, the use of medical care may not be sought until much later. Survivors' comments provided support for the importance of their families' advice and support when medical attention was needed. One young adult male stated, "Family used to come and bring me to the hospital and they still today and they still come with me." "We are a close family...always together we always have family time and it always has been like that as long as I can remember" (Subject 6). Another young adult female echoed this "My mother...always has been very supportive" (Subject 1). Survivors indicated their families were supportive during both their first experience with cancer and in the event they become ill again.

4.2.1.1 Supportive

Most of the MA YACCS talked about how supportive their families were during their cancer therapy and now as responsible young adults. "My mom helped me a lot. She did everything, everyone saw she never left" (Subject 3). This young adult talked a lot about how her mother was always there for her throughout her treatment and now as a young adult with her own child. She also talked about her brother and sister and how they fought when they were younger, but when she needed them during her treatment, they were there for her. In the same context, she also talked about her boyfriend who became a real friend throughout her therapy. "I had a boyfriend. He came up every single day he was a big part and he is still my best friend now" (Subject 3).

Another young adult talked about how her mother was her sole support system and how much of a strain it had been on her mother and father. "...but ah I remember um I remember guess the struggle my mom went through." "My dad was in Mexico and he worked for the phone company so he could not come here..." (Subject 11). Despite her father's inability to be there, he sent money from Mexico to help support his family whenever he could.

“We all go to my mom...” was voiced by one survivor who talked throughout the interview about her mother and how she comforts her and reassures her when she or her siblings worry. She (her mother) makes her feel comforted and more at ease (Subject 10). Another young adult male talked about his family and how his family helps each other. “We are really close so when someone is sick we try to help them out now” (Subject 8).

One young adult male talked about his family’s closeness. He discussed his need for their support when he has to come back for his check ups. He prefers the support of his family because he continues to be very worried about coming back to the clinic fearing the worst (Subject 6).

Even with her own current health issues, one young adult female talked about how she and her sister take care of and support her mother who undergoes dialysis twice weekly. “...we just try to support her and be there for her...” She remembers how much having her mother there for her meant to her when she went through cancer twice. “My mother...always has been very supportive” (Subject 1). Another young married female (Subject 3) talked about the role of her new family that included her husband now and the decision she would make if she were to get ill again. “I mean yes it would be a family discussion with my husband um but ultimately I would do it all over again and he knows that he would want me to fight just like I did before and we talked about that.”

4.2.1.2 “We Talk Together” (Communication)

The MA YACCS indicated they and their families spend time talking about health decisions or to whom they seek conversation for answers to questions about health. The majority would seek medical attention or at least contact the health care system for advice. However, the family was consulted for assistance about what decisions the YACCS should consider when medical attention was needed.

“...family talks about it, and regards to just trying to make sure we are all on top you know of an illness...” (Subject 1).

“All the adults sit down and talk about it calmly and we decide whatever is best for the person that’s all.” “...we all as a family we work together it’s something I didn’t used to have. It’s nice, I like it” (Subject 4).

“...and so it is definitely like you know the adults, aunts and uncles would try to come to a consensus what the best choice was...” (Subject 5).

“...because we have a couple of nurses in the family then we usually guess kinda get some guidance from them” (Subject 7).

Two of these young adults were very well educated and currently in higher education. One commented, “I guess the decision I would make would be probably be at the advice of the medical staff (that) would be much more important to me...” (Subject 5). His comments indicated that he believes the advice of medical staff is more important in helping him make decisions about his health. He also went on to say if he were to be diagnosed again with cancer, “I would like I would definitely call my parents and let them know um that would be pretty soon after I left the doctor.” Even though he is very untraditional in his thinking about health and illness, this young adult would still discuss his diagnosis with his parents.

4.2.2 Gender Role Expectations

Gender roles within the MA population are described as follows. Machismo is the belief in the masculinity and lack of emotion in the male MA (Zoucha & Zamarripa, 2008). Marianism is the belief that women are religious, self-sacrificing and pious (Garcia-Bravo, 2009). The expectations for gender roles among these survivors were most apparent in male participants, who talked about the expectations of them as males within the family. At least two female survivors talked about their roles as females within the family and they like being mothers taking care of their children. Neither of the survivors would ignore their own health needs despite being a MA mother. None of the comments indicated machismo or marianism as described in the literature, but more indicated their perceptions of their gender roles within the family.

One young adult male expressed his responsibility to fulfill the female role. "I cook and clean the house...wife is always busy working...at night...don't see each other" (Subject 7). Several others had expectations for being successful in life commented, "...take advantage of that the second chances...become somebody with my life" "...she (Mother) wants us to go to school and learn everyday and becoming somebody in life" (Subject 6).

Two other males talked about their role as males to be successful in life or to provide for their future families.

"Well myself is to be someone who is successful in life and to be able to hold myself and put a roof over my family one day" (Subject 2).

"my father walked...from Mexico...started working with him on the roofs since I was 12...have every opportunity to be more successful living here...finishing school" (Subject 9).

A young adult female spoke about her role as a MA female and now as a mother. She spoke very fondly of her own mother and her mother took care of her while she was young reported, "I am the one who changes them, feeds them, bathes, everything that they need" (Subject 3). Another commented "...I have to for myself and my daughter, go to college and make the best out of life you know, as my mom could not..." (Subject 4). One of the young adult males commented about how he felt pressured as a MA YACCS to be successful because his father came here to the U.S. with nothing, and had higher expectations for his son. Whether these expectations are real or perceived, they were engrained in this young man's psyche (Subject 9).

"...when he came over and walked the desert and all that..." "I feel more pressure he managed to do that worked over here with one set of clothes and a couple of vessels in his pockets and learned to speak and write English..." "...I have kept in my head till now and am sure I will keep it for..."

"I will keep I forever that he can do that being born in Mexico coming over here and doing and I have every opportunity to be 10 times more successful living here being born here living, finishing school." "I feel a little trapped and under pressure because I

feel wow I need to have full-time job that is fine I feel I should over do myself and over do what my dad has done.”

4.2.3 Religion/Faith

The cultural belief surrounding religion may be defined as a belief in a higher power such as God and the predestination of the future. Many MAs hold the belief that God holds our future in his hand and God controls the outcomes of events like illness (Reynolds, 2004). However, fatalism as a religious belief was noted in the literature (Borrayo & Jenkins, 2001b; Giger & Davidhizar, 2008) but was not identified in this group of survivors. Most of the survivors had prayed in the past for their health or continued to use prayer as a means of coping with illness. The survivors also suggested that God as a higher power has influence in their lives.

4.2.3.1 Faith as Coping

For several of the MA YACCS, prayer is an integral part of their lives. The survivors used prayer for coping. The survivors mentioned their parents and family used prayer not only as part of their faith but in face of illness. “I believe in God and believe in the power of prayer.” One young adult female with lung problems because of her treatment for cancer, strongly believes in prayer and its redeeming feature. “I have a strong belief in the power of prayer.” “...I mean I believe in miracles.” “...you know I pray about... and you know I will pray a lot, usually things have come out in my favor” (Subject 1). For another young adult female, prayer is used not only to support others, but also if she was diagnosed with cancer again. “...I would pray about it you know I would pray and pray and for sure I would take treatment again...” (Subject 4).

One young adult male talked about his mother and her faith in prayer. He talked about how when the pope died on the same day as he had scans, “...she prayed to him about it too if he (the survivor) were to come out OK and out of all of this OK and then she would promise to

do this and my dad promised to do all that.” “So I mean I also prayed and everything I could and just be a different person when I be out of this” (Subject 2).

One Other MA YACCS used prayer as part of her daily faith in God and used it for guidance.

“...my mom would pray and even I would pray every night. Even when my older sister was taking off, I would pray because my faith would be God would take care of us.” “...I would pray if something happens that um that bad or if I make a decision that is not right I would be like wow why did I make that decision but my faith is believing in God...” (Subject 10).

However, another MA young adult male stated prayer did not play a role in his daily routine, but was important during his cancer treatment as a child and would be again if he were to become ill again.

“I prayed all the time during, carried the pillow around with me that had a rosary around it.” “Would be same as before, I guess I would pray” (Subject 8).

One of the survivors believes in God. However, he indicated the lack of influence of his faith in his daily life. When asked about whether faith played a role in his decisions about being treated for cancer again if it were to return, he commented. “Probably not too big of a role much for me but my mother would definitely light a candle at the church or something it’s more religious like that um and I am sure my extended family would keep me in their prayers like but um for me personally not too big of role” (Subject 5).

4.2.3.2 God’s Omnipotence

The belief that God holds the key to their future and their past was widely present in many of the MA YACCS. Several of them hold true to their religion and faith that God is forever influential in their lives.

“God doesn’t punish but he makes us learn lessons. I mean when I, before I was sick, I wanted to do my own thing.” “I think of it oh God has it in his hands and all I can do is just continue on the right path and right road of goodness and just continue being myself” (Subject 2).

“...I do ask God for signs give me a sign if I should but I think I would because I would I am not sure if the second you will survive it or not but I, I think anything is possible if God wants it to be possible” (Subject 4).

“...you don't really need to go to church to talk to God and as long you know right from wrong and have good faith he says you will be alright...” (Subject 7).

“...and I guess some people think if someone dies then it's God's fault or why is God punishing them, but it goes back to everything happens for a reason and God's knows what he is doing...” (Subject 10).

One MA young adult male spoke about God's will “...if you believe you continue what you are doing what you do, there is no reason for you to ever have cancer again. I mean if I think when I had cancer it was a test for me. It was something put in my pathway that I had to get over...” (Subject 2). He also talked about God's strong presence in his life not just when he was diagnosed but in how he lives his life and thinks about his future. “I think of it oh God has it in his hands and all I can do is just continue on the right path and right road of goodness and just continue being myself.”

4.2.4. Responsibility for Examinations

Modesty/embarrassment was defined as a feeling of indecency when exposing one's body during evaluations or touching one's own body (Borrayo & Jenkins, 2001a). Cultural values like modesty are highly valued in MA women and nakedness is avoided (Salazar, 1996). Women are taught that even touching themselves is taboo. However, almost all the MA YACCS respondents did not identify modesty. This finding may be due to information provided to them about the importance of self-examinations for maintaining their health. Only one female survivor commented about her distrust in male physicians and concern over being touched by a male. “I feel comfortable when it's a female but when it's a male, I feel really uncomfortable.” “...I don't like them rubbing my shoulder, or cause I watch a lot of TV...” “There's been doctors that they slip a drug and abuse on that.” However, the majority of survivors reported they took the need to undergo cancer screening as a responsibility for maintaining good health.

4.2.4.1 Responsibility

The majority of the survivors indicated they needed to undergo examinations, and took the need for annual professional and monthly self-evaluations as a responsibility. Survivors may have felt this way because of their experience of cancer, and the need to undergo extensive evaluations and ongoing examinations as part of the cancer treatment routine. Responsibility for managing their health including examinations is noted in the following comments by many survivors.

“...it’s more of a just let’s do it. It’s kinda...” “It’s something you have to do. I have to do it. I mean that’s what you gotta do you gotta do it.” “I don’t feel any weird way...in any sexual.” “I try to be very very careful about that. I try to look around for lumps on my neck, and try to see around for any lumps on my body” (Subject 2).

“...so it never bothered me in that way.” “None of that bothered me I was doing it to get my son here safely and healthy so none of that bothers me” (Subject 3).

“Um why I mean I guess if it is in the shower anyway it is just like I am washing myself down there anyway I might as well kind of check um I guess since I am in the shower it is not bad” (Subject 5).

“Well I am actually check myself or I have my wife check for moles or any of that stuff whenever I guess when I take a shower I have her check me out once in a while” (Subject 7).

“Me, I actually don’t have a problem with it.” “...have gotten comfortable with it now I know at first I was caught off guard because I didn’t know if that would help.” “At least I don’t really think about it much I guess part of the process.” (Subject 8).

“...I see no part in being hard to come back it’s easy for me to so and I find it easy as a professional or a doctor...” “...So I have no problem with it that is part of the scheduled appointment procedure and I don’t find nothing hard with it. It’s something I feel something the doctors feel that is something that needs to be taken care if feel just as strongly that it needs to be I need to check myself and everything” (Subject 9).

“When I have to do it I see more as something I have to get done something if that is worst thing that you have to do to make sure you are OK well it is not all that bad” (Subject 11).

Not only did one young adult female feel it was her responsibility to undergo examinations, she also talked about her cancer screening evaluations making her feel grounded. She made many comments about how getting her examinations make her feel grounded and humble, and it is a side of her that only the oncology professional know. "I guess it makes me feel grounded. When I come here it's like I guess it's just a private part of me you know and who I really am, I don't deny it but I guess opening up a raw part of me..." (Subject 11).

Overall, the survivors took the need for examinations and cancer screening seriously and as a responsibility bestowed upon them because of their history. Having had cancer and needing to watch out for it again was a concern for all of them, and a responsibility to get examined by oncology professionals.

4.2.5 Future (Life After Cancer)

Survivors in this study, although not fatalistic, talked about God's will and their feelings that "if it was meant to be, it will happen". Further, when talking about the future, many of them discussed being in control over some of their lives but not everything. Most survivors believed they were going to be successful in life and were very positive about their future despite questioning whether they did or did not have control over the outcome. The notion of ambiguity was apparent in several comments of survivors and their perceptions of control over many aspects of their lives, but not in others.

4.2.5.1 Control over Future

One young adult male who is highly educated talked a little about control. "I don't feel totally in control of that. I think there are environmental factors that cause mutations which can then lead to cancer but I generally try to like do what I can like you like exercising, not smoking..." (Subject 5). He also went on to talk about his control over his success. "Um Yea I have I pretty good control over my future um my parents have always been supportive of my,

you know when I feel I wanted to do something they would do whatever they could financially and being emotionally supportive for whatever I wanted to do..." (Subject 5). Other MA YACCS talked further about their futures and success.

"See it has being successful going on trips and doing things with family and now an engineer but now into nanography. "...I do have control over and being successful. I see other people who have nice things so that motivates me to be successful" (Subject 7).

"I see myself being successful. I put that goal up on me and I want to be able to be a person who can take care of his family and be responsible..." (Subject 2).

"Control yes yet under pressure. I have control over it because of pressure like I said before about my dad I feel I am rushing it because I want to get the that point, but I have control knowing there's steps to take... "(Being Successful in life was topic of discussion) (Subject 9).

4.2.5.2 Optimism for Future

Survivors talked about getting through it again to be there and being optimistic about the future. A young adult male with nieces and nephews talked about wanting to be there for them. "...I want to be there when they have their first birthday or their graduation..." (Subject 6). "I guess if I was diagnosed again and had to get the treatment, I would do it all over again. I would do it all over again." Others talked about the future, the support of their families, and how positive the future will be.

"...I would probably try it one more time since it was effective one time I would have strong faith in it working again..." (Subject 9). "I know my whole family would be supportive you know my brother and my sister both financially and everything."

"That scared me and stuff like and I would honestly do what I needed to do to stay alive" (Subject 10).

"Oh my future I think it is going to be a great one...Not to be selfish um and to take in everything I went thru." "I want to be a nurse...I was with a nurse every single day" (Subject 3).

“Main focus is to be normal is what I think I want. Normal is I guess is a college graduate, working just doing anything I guess do whatever my goals are set” (Subject 8).

For a couple of survivors, getting informed, and dealing with it responsibly would be essential if diagnosed with cancer again.

“...I mean it is something I would have to deal with and that if it comes up and is not something you want to push aside and go on with your life.” (Subject 5).

“...I would do is research the cancer I had and the treatment and um the best place to go and what had to be done” (Subject 11). “...I would actually go to the doctors and hear all the medical terms and not be lost.”

4.2.5.3 Ambiguity/Uncertainty

The survivors were overall very positive about their future. Despite being optimistic about the future, several of the MA YACCS indicated a sense of ambiguity about their future. One young woman talked about her need to be successful, but was uncertain of whether she would ever achieve her goals. “Well I used to see it clearly but now I on a more personal level, I am kind of lost I still haven’t lost vision of that dream I had when I was 12 what I wanted to do...” (Subject 11). Another survivor was not sure if she had control or not. “ ...I do have control, but mostly I do have control, but to say if I were to get cancer I would not have control any more” (Subject 4). For two others, concern over actually getting ill again and concern of what will happen. “I see my future with concerns just concerned and um...” “I do get concerned in regards to my health and the future, especially my lungs” (Subject 1). “Honestly, I do think it may come back again. I don’t know why I just feeling that the next doctor’s appt they may tell me that I might need surgery...” “...it frightens me it scare me it really scares me because man life is real good” (Subject 6).

4.3 Emergent Themes

Three emergent themes, illness (cancer [limiting]), the impact of cancer (responses to cancer), and perceptions of cultural stereotyping were identified. These concepts were not in the conceptual model driving the study but were prevalent in this population of MA YACCS.

4.3.1 Illness (The Cancer)

Most survivors spoke very colorfully about what illness meant to them, with the majority of them equating illness to cancer and the worst experience of their lives. Having had cancer was still very much part of the illness trajectory for the majority of the survivors. Some survivors talked about the limitations placed on them because of their cancer. Only one young adult female who had a recurrence of her disease as an older adolescent, and now suffers from lung disease, described her concerns over her respiratory status. All others talked about their cancer experience which defined what illness means to them and how being ill affected their lives at that time.

4.3.1.1 Cancer as Limiting

Cancer for some meant being held down or limited in what they were able to or would be able to do if diagnosed again with cancer. Two young adults provided vivid pictures when discussing illness and cancer. One young man portrayed illness (cancer) as analogous to a wolf. It could limit your life and your ability to lead a normal life. Cancer is like a wolf and it like many illnesses can creep up on you when you least expect it. "You must live a good life." "It's like a wolf like a hungry wolf like after almost just every day and then just creeping up on you like I ..." (Subject 2). Similarly, one young adult female thought she knew what illness was but then she was diagnosed with cancer. "I thought it was a cold and to me a cold is nothing" "...didn't think much about them until I was diagnosed and that is when I was wow this is sick, but now looking back now we were very sick, we had cancer" (Subject 3). Other survivors mentioned comments specifically about the limiting effects of cancer.

“Not being able to do something but more like saying that I cannot do this at all.”
“...or I can’t do just do what I want but I just felt that something was holding me down ...
“(Subject 2).

“I guess not being able to go out and do thing. ...having to stay away from everything and of course we are Mexican American family where I mean I had to stay away from my nieces and nephews” (Subject 7).

“...I hate being sick it is something I can’t stand when I think I will not be able to do anything...” (Subject 8).

For other MA YACCS illness (cancer) was the worst experience in their lives and brought back memories of how hard and scary it is (cancer).

“Scary to me and it is actually something that I get scared” (Subject 1).

“Um it was not fun it wasn’t. The poking, the needles um the pain all the time. Losing your hair” (Subject 4).

“You know the little hall the sky bridge I can’t stand the smell of the hospital over everything I can’t stand it...” (Subject 4).

“I was thinking the worst case scenarios if I would live or anything like that.” “...seeing my parents I had a brother, my mom had 3 sons, the oldest one is alive and the middle one he passed away due to a brain tumor...” “...my mom and dad, they already lost a child.” “I think the worst part I think of it just will it come back...” (Subject 8).

4.3.2 *Impact of Cancer (Response to Cancer)*

Similar to illness and cancer, the impact of having had cancer had a profound impact on many of the lives of the participants. They talked about their past, their future, and concerns they have about their health and lives in general. The impact that cancer had on the lives of these young adults is depicted in the following comments.

“...see my future with concerns just concerned and um...” (Subject 1).
“...I do get concerned in regards to my health and the future, especially my lungs.”

“Well that is easy to answer. I mean having cancer again” (Subject 2).
“...not being able to have kids because of what they told me. From not being able to reproduce.” “Um, I believe I would survive. Um I have faith um that I would that I would

get through it with my family.” “Cause, I am my children’s mother and it is important to be with them” (Subject 3).

“...occasionally I get scared...having a relapse or...another type of cancer” (Subject 7).

“...I have learned that needles shots don’t hurt. It is a scary thought for me to this day still to go to the hospital because it makes me really uncomfortable because it brings back memories...” “...vague memories of people running around and seeing nurses and me being scared and that was the really that most comes out is the scaredness.” “...I used to get nightmares about the back sticks...that brought back memories because that brought back memories...” (Subject 10).

“...and like really and my body reacts differently than someone else would get a normal cold. You know I just feel like I am dying. ““...it brings back the reality that you know it even thought it’s not coming it left a permanent effect on my life” (Subject 11).

Cancer’s impact not only influenced the beliefs about health and illness in the survivors, but at least for one of them, it meant a change in life’s goals as well.

“When I was in high school I worked really hard to be in the ROTC. ...I had gotten a scholarship and um and I went to sign into the core and I guess I was going to be a student and then serve my year in the military. Um and they didn’t accept me and that was extremely crushing to me “(Subject 11).

“...why I guess that at the time I was kind of resentful that I had gone through it cause I worked really hard and now it kind of threw me for a loop.” “..what was the point of surviving cancer if I can’t do what I want to do with the rest of my life.”

The impact of having had cancer and now having to watch out for it again was echoed by one survivor in the following comment; “Watch out for it I take it real serious that’s why I follow up on checkup” (Subject 9). “...I look out for myself and my kids I look for sign I try to take care of it.”

4.3.3 Perceptions of Cultural Stereotyping

Four of the MA YACCS felt culturally stereotyped. The survivors reported they felt that society has stereotypical expectations of them as MAs.

“People tend to make jokes on me it’s ah. Like I work in a place where I am the only Hispanic there so...we are not taken seriously in places like maybe the way I dress or just who I am” (Subject 2).

“...I feel that like now that a lot of people expect from you like Mexican Americans to live, throw their lives away. You just be lazy and not going to school and dropping out of school...” (Subject 4).

“...people judging you first for what other people had done.”...they judged me. Probably I dropped out of school and why don't I go to school any more” (Subject 6).

“The only time I am reminded I am Hispanic when we would be around my mom's friends when I was younger. It is more of that “let's help out the poor Hispanic family get treatment for her child.” I was feeling separated I just feeling I was not being view like every one else...” (Subject 11).

4.4 Summary

The MA YACCS observed traditional cultural beliefs when talking about their experience of having cancer. All of the survivors received cancer treatment in the United States (U.S.), and have spent much of their formative years in the U.S. However, survivors indicated by their comments that they held traditional beliefs such as the importance of family and faith when it came to health and illness. The survivors provided information about their culture and traditional beliefs about health and illness. The survivors' beliefs provided support, comfort and coping in response to illness like cancer.

All survivors talked about their families and how supportive and comforting their families are when they were ill. The family is important to this group of survivors but not in the more traditional Hispanic approach and adherence to faith healers, curanderos or folk remedies. The majority of the MA YACCS talked about their faith and how strong their faith was not just during their cancer treatment, and also now even in their daily lives. Faith was used as a coping mechanism for a number of survivors, and prayer specifically provided them with comfort and hope. One female survivor talked about her belief in miracles and if she prayed hard enough, a miracle would happen.

Gender roles, modesty and embarrassment were not identified in this group of survivors. All of the MA YACCS acknowledged their responsibility to stay healthy and reported

engaging in cancer screening behaviors such as coming back for clinic appointments or performing self-body examinations. Survivors in this study were very positive about their future despite occasional worry about their health. Three of the survivors are in college and several others are working towards application for a college education to have a better life than had had before.

Two of the three emergent themes; illness (limiting, the cancer) and impact of cancer (responses to cancer) were presented by the quotes of the survivors as well as their having had cancer at a young age. The survivors talked vividly about having had cancer and how limiting and painful at times the experience was to them. The impact of having had cancer in these survivors had both a negative and positive effect on their lives. Most survivors believed that they are more motivated than they may have been in the past, such as being nurse or being successful as many of them indicated. It is also not surprising given the intensity of the cancer treatment for several of the survivors to have concerns about their future and be cognizant of the potential for late effects because of their cancer treatment. The responses to having had cancer in this sample of MA YACCS also indicated a need for undergoing cancer screening like coming back to the treating oncology center. The survivors suggested the importance of cancer screening in order to stay healthy and identify problems early.

The third emergent theme of cultural stereotyping was identified in the quotes by this group of MA YACCS. The survivors' responses to the question about what it is like to be a MA man or women was meant to gain knowledge about their experience as a MA YACCS and expected responses were to be about their culture. Four of the 11 survivors reported perceptions about cultural discrimination or stereotyping and felt that others judged them for being MA. Two of the four talked about expectations of society that they were lazy, quit school and not wanting to make something of life. The perceived societal expectation may have served as an impetus for them to want to be even more successful in life.

CHAPTER 5 DISCUSSION

5.1 Introduction

This chapter will discuss the findings of this study compared and contrasted with the cultural beliefs identified in other Mexican American (MA) populations. The findings suggest that the cultural beliefs in MA young adult childhood cancer survivors (YACCS) may influence their participation in cancer screening behaviors.

5.2 Interpretation

The findings in this study formed a new explanatory model in MA YACCS. The study provided information about cultural beliefs which were important in a small group of MA YACCS, and how their cancer experience has impacted their lives.

5.2.1 Family Importance in Medical Decision Making

Families played an important role in the lives of the survivors throughout their treatment, and continue to play a role as the survivors became young adults. The importance of familial support was also present in a study exploring the meaning of surviving cancer in Hispanic adolescent and emerging young adult cancer survivors (Jones et al. 2010). Survivors in Jones et al. (2010) study talked about the support their families provided during treatment and that somebody was always with them during treatment. Mothers in particular were the most important member for a couple of the survivors while they were going through treatment. Survivors in the current study, who are mothers now, talked about their own responsibility as parents to be there for their children.

Literature suggests that the family in MA culture is a community of support and problem solving (Gonzalez, Owen, Esparet, 2008). Torres (2008) reported that family members talked and made decisions together regarding treatment. For many MA YACCS, the family played a role in decisions about their health. One young man in graduate school commented he would seek medical advice but stated that he would then contact his parents to let them know. Respect for the family (parents) was obvious in this sample of MA YACCS. The family, parents, siblings, mothers and grandparents were important for nurturing, and providing support during the cancer treatment and in the event of recurrence.

5.2.2 Gender Roles Expectations

Interestingly, Machismo and Marianism described in the literature (Zoucha & Zamarripa, 2008), were not widely evident among study participants. Most of the young adult males reported that expectations of them as a MA male are to be successful in life and to support their families. None of the male MA YACCS indicated they are impervious to illness. Professional check ups and self-body examinations were a little uncomfortable, but all males indicated examinations were a responsibility they took seriously. Two of the males talked about their families' involvement in their cancer treatment, and if they were diagnosed again with cancer, either their wives or their parents would need to help take care of them.

Marianism was also not evident among most female survivors. The review of literature reported that Marianism is the belief among women they are only caretakers in the home, and their health is not important (Eggenberger, Grassley, & Restrepo, 2006). Only one of the females indicated she would put her child's and her family's health before her own. On the other hand, she stated she would not ignore her need for medical care (Subject 3). Another young mother talked about her fiancé's family. She talked about how traditional they were about women working outside the home. She was not going to let her career goals be dismissed (Subject 10). This survivor's beliefs about women and work may be untraditional because a

Caucasian couple adopted her when she was very young. She was raised in a home where traditional Hispanic beliefs were not observed.

5.2.3 Religion/Faith

Faith in the MA YACCS in this study was prevalent. All of the survivors have faith in God. The use of prayer played a role in their lives now and when they were treated for cancer. Unlike the literature (Chong, 2002, Giger & Davidhizar, 2008), survivors did not necessarily ascribe to traditional healing methods. Several survivors talked about their parents lighting a candle, and used prayer in times of illness.

The Office of Minority Health (OMH, 2009) highlighted cultural information about MA and the belief in fatalism as it pertains to God's will or his omnipotence. Several survivors in the current study indicated that God has ultimate control over their lives including their future. However, these survivors would make every effort to be successful in life. Similarly, Latino adolescent survivors in Jones et al. (2010) indicated that God and faith played integral roles during their cancer therapy. One of them suggested that if you lead a good life, good things would happen to you. Others in Jones et al. study indicated that you do have control over the decisions you make about your health and it is these on which the outcome may be based.

5.2.4 Responsibility for Examinations

Modesty and embarrassment were cited in the literature to influence decision of many Hispanic women and being examined for cancer (Borrayo & Jenkins, 2003a, 2003b). The MA YACCS in this study did not suggest they were modest or embarrassed when undergoing physical examinations, but just uneasy at times. They also did not indicate they felt indecent or dirty when touching themselves to do self-body examination, and all of them accepted the responsibility to participate in cancer screening. A couple of survivors stated they felt a little uneasy. One survivor expressed her concern over the professional misconduct of male physicians. During cancer treatment, the MA YACCS were subjected to a number of bodily

examinations and painful procedures. The experiences of the survivors may have accounted for the lack of modesty and embarrassment and historical gender role expectations. Childhood cancer survivors may undergo multiple evaluations including bone marrow aspirations and biopsies, lumbar puncture (spinal taps), testicular and full body examinations at the beginning the cancer treatment to investigate the presence of widespread disease. Throughout their treatment, survivors were subjected to the same evaluations like biopsies, needle pokes as was done during the diagnostic phase of cancer therapy. Because of the repetitive evaluations during cancer, the notion of having to undergo continued bodily examinations, may have accounted for the lack of modesty in this population of MA YACCS.

The survivors did not made excuses for not coming into the clinic for annual visit. Survivors however, indicated there are reasons, which make it hard to come back including bad memories, the blood tests (the results), hearing bad news, and seeing the bald headed children currently undergoing cancer treatment. This group of MA YACCS reported they did engage in cancer screening behaviors including self body examinations as well, which is in contrast to what many survivors report when they present to their cancer visits. The MA YACCSs in this study may not be representative of what the researcher observed in clinical practice, and may not be representative of all YACCSs.

5.2.5 Future (Life After Cancer)

Fatalism was defined in the African American population that God is divine and suffering is part of life (Campinha-Bacote, 2008; Hamilton et al. 2007). Suffering is part of life and must be endured as noted in the literature was not a belief of the MA YACCS. Survivors stated they would do what they needed to stay healthy and that they had control over their future in regards to both decisions about their health and success. A couple of the survivors commented they may have control over their health, but if they were to become ill, control would be in God's hands. One female indicated that fate might play a role in her future as it did in her

past by the comment; “everything happens for a reason.” She made this comment several times throughout the interview to suggest that her cancer happened for a reason. She also reported meeting her biological mother and that happened for a reason. Another male YACCS in the current study believed his cancer may have happened because of Divine intervention when he failed to be an obedient son. He talked a lot about the time preceding his cancer diagnosis. He reported how he became ill after he failed to listen to his mother. He did suggest that he would do what it takes to get well in the event of another cancer or illness whatever the cause. Many of the participants in Jones et al.’s (2010) study also talked about cancer happening for a reason and changed them forever.

Survivors in the current study reported optimism for their future as well as concerns about their health. The majority believed they would be successful in life, however. Survivors talked about how great their future would be, and they wanted to be successful in whatever they set out to accomplish.

Survivors were treated in a tertiary medical facility in the United States (U.S.) in a pediatric focused center where cancer was treated according to clinical trials known to be successful. Because many of the survivors in this study are followed either in the cancer center or in local community facilities, they may be knowledgeable about the likelihood of surviving cancer. The survivors may be more aware of current treatment options if they were to be diagnosed again with cancer. The knowledge of potentially surviving another cancer may have accounted for the lack of fatalism in the study participants.

5.2.6 Emergent Themes

A few of the survivors discussed cultural stereotyping. A number of the young males talked about society’s perception that they are lazy, and would not be successful. One young adult (YA) female perceived that people assume you did not finish high school and that you as a MA would live by the government. She reported she wanted to make something of her life and

provide food on the table for her daughter (Subject 4). This particular survivor is having financial difficulties and currently receives federal funding. Possible reasons for her perception may in the way she feels she was treated within the health care system, and that she is on a federally funded program. The other male YACCSs are living with their parents, and based on the researcher's knowledge do not have financial difficulties or issues with access to medical care. Current literature suggests that many Latino students attending a predominantly all white school are experiencing cultural stereotyping (Marx, 2008). Marx reported that white teachers described Latino students as being capable of doing schoolwork but stated Latino students did not care about doing well. Further, Marx (2008) reported white teachers commented that Latino students just liked life as it is and that Latino students are lazy and don't care.

In the current study, male survivors talked also about parental expectations to be successful in life and to hold your head high. One of the YA males talked a little about his father who came here from Mexico with nothing, and had higher expectations for his own son (Subject 9) to be successful in life. Possibly, the drive to be successful and staying healthy through the participation in cancer screening may have influenced survivors' need to prove others wrong. The drive for success may also have served as the impetus for participants in this study to be responsible for their health.

Two of the three emergent themes identified in this study were illness (the cancer) and the impact of cancer (responses to cancer). These two themes may be expected responses in any young adult who has survived cancer that was diagnosed when they were a child. All but one survivor talked about having had cancer as the worst illness experience in their life. One YA male portrayed his cancer as a hungry wolf, "it's like a wolf like a hungry wolf" (Subject 2). Cancer was a limiting experience emerged in this comment, "...having to stay away from everything and of course we are MA family where I mean I had to stay away from my nieces and nephews" (Subject 6).

Similarly, Yi & Zebrack's (2010) study examined the portraits of cancer of young adult cancer survivors (YACSS). The experience of cancer for those survivors was portrayed as being a time of losses, missed experiences, and bad memories. In the MA YACCS survivors in this study, the impact of cancer brought thoughts of fear to many survivors. "I do get concerned in regards to my health and the future, especially my lungs" was mentioned by a YA female survivor who now has lung problems because of her cancer treatment (Subject 1). Others commented, "...it brings back the reality that you know it even though it's not coming it left a permanent effect on my life" (Subject 11). Another survivor talked about her fears of needles, pain, and the smell of the hospital. She along with another YA female talked a lot about how nervous and scared they were when they had to come back for visits. Just seeing the nurses, the smells and potential bad news worried them around the time of their appointments.

The potential risk for cancer returning is another fear survivors talked about if cancer recurred. Another late effect of therapy is the potential risk for sterility. One YA male talked about the potential late effects of his cancer treatment and not being able to have children. He remembered the doctor telling him and his parents this news when he was diagnosed. Being able to reproduce was important to him.

5.3 Limitations

The limitations of the current study included a small number of survivors from one institution as participants in this study. The majority of survivors who participated in this study were treated on large clinical trials known to be effective in treating childhood malignancies. The survivors and their families recognized the benefit of having been treated on a clinical trial, and may have influenced their decisions to participate in this study. Additionally, the survivors in this study reported they participated in cancer screening and may be vastly different compared to nonrespondents, who may not be engaging in cancer screening behaviors.

Further, survivors in this study are MAs and findings can only be generalized to MA YACCS who have been treated in a U.S. cancer treatment center. This study was conducted at a single pediatric oncology center, and the findings may not be generalized to other MA YACCS in other settings. Further, the researcher is Caucasian and not Hispanic and the responses of the survivors may have been influenced by the cultural differences

5.4 Conclusions

The findings of this study provided information important to understand the cultural beliefs in a population of MA YACCS. The cultural beliefs about their family, faith, having a positive future, and the responsibility for health mentioned by survivors may have influenced their decisions to engage in cancer screening.

Family and faith were important in the lives of the survivors. The family provided influence in their decision to engage in cancer screening. The family was always there for the survivors during their therapy. Survivors came to the clinic weekly to biweekly for a long time and a parent would have taken them to the clinic or hospital for therapy and provided care for the ill child at home. Survivors also mentioned that their families continued to be an integral part of their lives, even though many of them have become independent, emerging young adults. At least two of the survivors who have intimate partners, but they continue to live with their parents. One of the survivors is living with the parents of her partner for financial reasons, but she did talk about how nice it was to have a family to help her. The other survivor living with her parents may be for other reasons not provided. The review of the literature indicated that in Puerto Rican (Torres, 2008) and in many MA (Gonzales, Owen, & Esperat, 2008) cultures, family members may support and provide comfort during illness. The presence of a baby is a blessed event and most Hispanic families provide support to the new mother.

A small number of the current MA YACCS bring their families with them during cancer screening visits. The researcher's clinical experience is that the majority of MA YACCS come to

survivor visits with at least one parent. Having the support of parents during the cancer screening visits may provide comfort, but also may indicate the need for a parent (family member) to be present during the survivor visits. At least one survivor talked about his fears of returning to the clinic and worrying about if the doctor was going to tell him his cancer returned. He always has either one of his parents or his older sibling drive him to the clinic because he gets so nervous coming back.

Faith in God, prayer, and a belief that God is a part of their lives may have also influenced several survivors' decisions to engage in cancer screening behaviors. For many of them, faith and prayer played a role in their surviving cancer. Prayer was used throughout the survivors' cancer experience. Prayer continued to be a useful coping mechanism. Although, the religious beliefs and traditions of the survivors were not captured as part of this study, most survivors indicated they were currently or had been Catholic during childhood. Adherence to the religion and the beliefs of the Catholic faith was a source of tension in one survivor. She (subject 11) talked about how she and her family believed their religion had too literal of an interpretation that God heals. Her parents purposefully left the church to seek medical support to cure her and believed that God worked through medical physicians to heal cancer.

Most of the survivors indicated a positive approach to survivorship despite concerns about the future. Survivors were not only concerned about their health but also being successful. Success in vocational achievements, as a husband or wife was mentioned throughout the interviews. Fatalism was not present in this group of MA YACCS. Several survivors indicated ambiguity and uncertainty about their future, and all survivors recognized a lack of total control over their futures. They were realistic in their expectations about the future, but remained positive about both being successful in life and surviving cancer again. Most YACCS in the researcher's practice are very positive about their future. The majority of survivors are optimistic about their future because both professional staff and family have

provided them with skills to succeed. Further, a large number of these survivors and others were treated on clinical trials with known efficacy in treating cancer. Survivors are educated about prevention and early detection of a second cancer. The prognosis for cancer diagnosed early may make a difference. Therefore, in the event the survivors experience a recurrence, there is hope for survival.

Survivors took the responsibility of examinations and especially cancer screening behaviors responsibly. The survivors are taught when they come to the survivor program about the ill effects of cancer treatment. They are all taught the importance of maintaining good health and engaging in healthy lifestyle behaviors. Healthy behaviors include eating healthy, exercising, and not smoking. Further, all of them experienced multiple examinations, which may have accounted for their lack of modesty. A couple of the survivors talked about their scars, and that they embraced the changes in their body. The changes signified the battle had had been through and survived.

Emergent themes were identified based on the responses of the survivors. The emergent themes were prevalent among several survivors. The concept of illness was compared to having had cancer to most of the survivors. This finding was not surprising due to the age the survivors were diagnosed with cancer. The mean age at diagnosis for this sample of survivors was 8.6 years. Having had cancer during childhood, may have defined who the survivors are since at least one year of their lives may have been spent in the hospital and isolated from their peers. A large number of the survivors were diagnosed with acute leukemia, which requires at least two and one half years of therapy, and required hospitalizations for the administration of chemotherapy. The survivors' responses to questions about illness revealed that MA YACCSs in this study used their cancer as a reference for illness and what it means to them. Being held down, limited in what they can do, and the worst experience ever are what having had cancer meant to them.

Childhood is a time for physical, emotional, and social development. Disruptions in school attendance and social events occurred during a crucial time in the lives of these MA YACCS because of cancer. Having an illness like cancer may be the worst experience that could ever happen to a school-age child because of the isolation from friends. In the researcher's experience, a vast number of children and adolescents with cancer and survivors express feelings of depression, isolation from their peers, and experienced losses of what was supposed to be a normal childhood or adolescence.

The impact of having had cancer for survivors in this study had both a positive and negative lasting effect in their lives. Having had cancer had a negative impact in a couple of the survivors. One survivor talked about how she had to change her goals because her history of having had cancer resulted in rejection from the armed services. She also talked about having concerns about her health and getting ill again. She believes her immune system is weaker and that she gets ill more often.

The survivors who mentioned being fearful of hearing bad news, and who hated the smells the clinic brought back to them are common. The researcher's experience with other survivors is that their senses and emotional arousal are sensitive after cancer treatment. Not only do many of them report noxious smells in the clinic but also some may report nausea or sense of anxiety turning into the parking garage. Several survivors had even mentioned that when they saw the blue roof of the hospital, they became anxious. Even though coming back to the clinic for checkups brought back some bad memories for survivors, most reported they do like to see some of the nurses and doctors who took care of them.

Most survivors indicated a wish to have careers where they have the opportunity to give back to others. Survivors talked about staff like child life specialists, nurses, social workers, pharmacists, and radiology technicians within pediatric care centers. The survivors would talk about how helpful, supportive and fun child life specialists were be when they were children and

made the whole cancer experience more bearable. The survivors' comments in this study and those, whom the researcher has been involved in, may have indicated the wish to give back to those professionals who made their cancer experience tolerable. One of the survivors mentioned he remembered the fun he had in the playroom while waiting to see the doctor. He also talked about how sad he becomes not knowing if the children in the playroom when he comes back to the clinic will survive.

The cultural explanatory model (CEM) of the MA YACCS as conceptualized in chapter 1 was modified after the interviews were analyzed as part of this study. However, important cultural beliefs like family, faith, were identified as important to MA YACCS and having meaning in their lives. The survivors' beliefs had an influence in their decisions to engage in cancer screening. Survivors in this study also reported that they were optimistic about their future and were not fatalistic. The survivors took responsibility for their health and did report engaging in cancer screening.

Last, the impact of the cancer experience may have been mediated by the cultural beliefs of the MA YACCS in this study. Having close families and strong faith along with a positive outlook on life in general may have influenced how survivors approached cancer-screening behaviors. The cultural beliefs of family, using faith as a coping mechanism, and having an optimistic future may have reduced the negative impact that cancer had for survivors in this study.

It is not clear how personal factors in this group of survivors may have influenced their decision to engage in cancer screening. The mean age at diagnosis was 8.6 years, and a large number of survivors were diagnosed with leukemia requiring at least two years of therapy. These two personal factors may have impacted their response to having had cancer and were placed within the CEM. Marital status, living arrangement, socioeconomic status and education did not appear to influence the decision of this group of survivors to engage in cancer

screening. However, this was a qualitative study with only 11 participants, and a larger sample of survivors would be necessary to examine personal factors and their influence on cancer screening behaviors in MA YACCS.

The CEM in MA YACCS identified based on responses of survivors in this study is found in Figure 1.2.

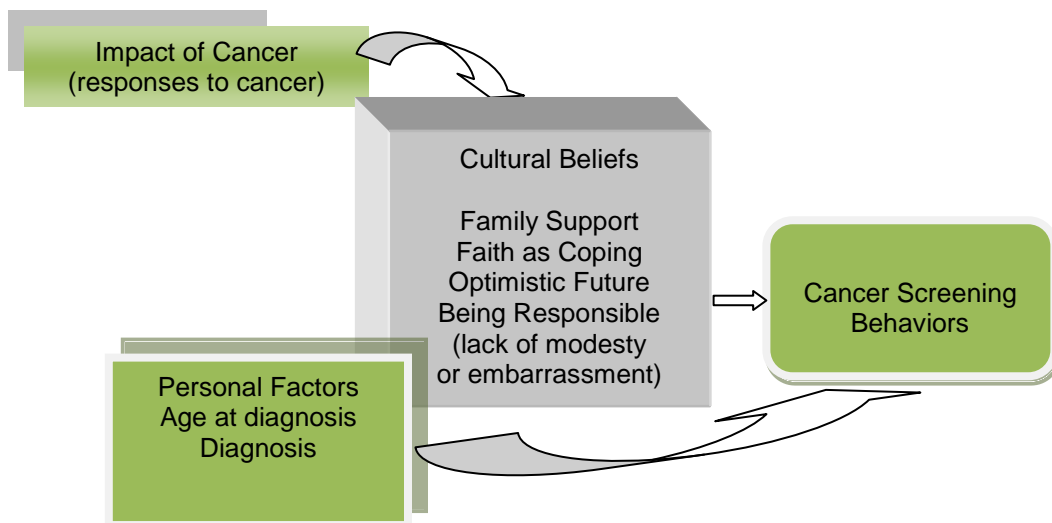


Figure 5.1: CEM for Mexican American Young Adult Childhood Cancer Survivors

The experience of cancer had a profound impact in the lives of this small group of MA YACCS. Using a similar methodology with a larger sample across multiple clinical settings may yield more rich information about MA YACCS. Personal factors should be explored and their influence in MA YACCS decisions to engage in cancer screening behaviors. Second, future research is needed to test the CEM in MA YACCS using a quantitative methodology in a much larger sample to determine if the CEM holds as a model to explain the cancer screening behaviors in MA YACCS.

Survivors talked about how important their families were during the cancer treatment and how important it is for the survivors to stay healthy for their children and other relative.. Future research should be conducted using the family of the MA YACCS as an impetus to

engage in health practices may be useful in influencing the cancer screening practices in MA YACCS.

Health professionals like nurses are in an excellent position to address the cultural beliefs in MA YACCS. Particularly nurses need to explore how these beliefs influence the decision in this underserved population of YACCS to engage in cancer screening. The Children's Oncology Group guidelines exist for all health care professionals to use when addressing the cancer screening needs of cancer survivors. Culturally sensitive interventions may improve cancer screening in the MA YACCS. Interventions may use a family-centered approach to cancer screening to ensure MA YACCS engage in necessary cancer focused follow-up care.

5.5 Summary

The experience of cancer defined what illness meant to the survivors in this study. Cultural beliefs such as family (*familismo*), faith, and optimism for the future may have mediated the impact of having had cancer. The cultural beliefs may also have directly influenced their decisions to engage in cancer screening practices.

Family for all survivors played an important role in the lives of the survivors. Faith in a higher power like God provided comfort for survivors as they went through treatment. Faith was used as a coping mechanism during treatment and continues to be a driving force in their lives. Survivors talked about how positive their futures are, and may be due to various reasons including family and a strong faith. Survivors talked about being responsible for their health and were not modest or embarrassed about having to undergo cancer screening. Fatalism, modesty/embarrassment, and typical gender roles like Machismo and Marianism were not present in survivors in the current study.

Further exploration of the CEM formed in this study using larger and more diverse sample sizes may yield findings that provide support for the CEM formed in this study in MA

YACCSs. Testing of the CEM identified in this study will be necessary to enhance cancer-screening practices in all MA YACCS. Enhancing recommended cancer screening in all YACCS is a paramount concern and future research efforts should focus on improving the participation in cancer screening.

APPENDIX A
INTERVIEW QUESTIONS

Interview Questions

What did you learn about health and illness in your family?

Tell me about your experience as a child with cancer if you can remember?

What is being ill mean to you and how do you think it will affect your life?

Tell me how you feel about having had cancer and now having to watch out for it again?

What would you do if you found something wrong (lump) (in your body)?

Who lives in your house now?

Tell me more about your family and how you interact?
(Especially when someone is ill)

How are decisions about medical treatment made in your family?

Who was involved in your care when you had cancer as a child?

Who in your family makes decisions about things including medical treatment (including cancer screening)?

How will decisions be made if someone in your family was diagnosed with cancer? (What would those decisions be?)

Talk about your experience as a MA woman/man?

What are the expectations of you as a wife/husband? Mother/father? Woman/man in the family?

How do you fit staying healthy into your lifestyle? Cancer screening?

Tell me about the last time you were very ill?

Tell me how you managed you home and family during that time?

Tell me about you felt about being ill and taking care of your family?

Talk to me about how you took care of yourself?

How did you go about making decisions to get treatment?

Talk to be about what you would do if the illness were cancer?

Tell me about your religion and your faith?

How strong is your faith when a cancer diagnosis occurs in your family?

How do you use your faith to make decision about medical treatment?

Interview Questions

Tell me about how your religion and faith support your decisions to participate in cancer screening?

In regards to your faith, what decisions do you feel you would make if you had cancer again?

Tell me about your last physical examination?

Tell me about how you feel about your body?

How did you feel when the nurse or doctor asked you to take off your clothes?

Tell me how you feel then the doctor or nurse touches your body to do an examination?

Talk about your experience in doing self body examinations?

How does that make you feel to have to touch yourself?

What would you do if you found something wrong when checking your body? (or if the doctor or nurse finds something wrong)

Tell me how you see your future?

Discuss with me whether you feel you have control over your future and life in general?

What about the future frightens you the most?

Tell me what you think will happen if you are diagnosed with cancer again?

Do you believe you have control over whether you get another cancer?

What do you think about getting checked (screened) for cancer as a survivor?

What will make you decide whether to get treated or not for cancer again?

Is there anything else that you would like to share with me?

Thanks so much for your time and willingness to share your thoughts with me.

APPENDIX B

PARTICIPANT RECRUITMENT FLYER

TO: SURVIVOR

Lisa Bashore is a doctoral nursing student at the University of Texas and a nurse practitioner in the Life After Cancer Program at Cook Children's Medical Center. She is doing a research study to:

BETTER UNDERSTAND THE CULTURAL BELIEFS OF MEXICAN AMERICAN YOUNG ADULT CHILDHOOD CANCER SURVIVORS ABOUT CANCER AND IF THEY ENGAGE IN CANCER SCREENING BEHAVIORS

If you are:

- MEXICAN AMERICAN**
- BETWEEN AGES OF 18-39 YEARS OF AGE**
- DIAGNOSED BEFORE YOU WERE 18 YEARS OF AGE**
- 2 YEARS FROM THE END OF CANCER TREATMENT**
- ENGLISH SPEAKING ONLY**

Please contact the Life After Cancer Program and ask for Laurie Bailey at 682-885-2125 or Jan Finch at 682-885-2164 for more information and so they can answer any of your questions

One of them will contact you about 2 weeks after we send these flyers to you to follow up just in case it is difficult for you to call our clinic.

Thank you

APPENDIX C
PROFESSIONAL RECRUITMENT FLYER

**LISA BASHORE IS CONDUCTING A STUDY TO
BETTER UNDERSTAND THE CULTURAL BELIEFS OF MEXICAN AMERICAN (MA)
YOUNG ADULT CHILDHOOD CANCER SURVIVORS ABOUT CANCER AND CANCER
SCREENING BEHAVIORS**

Any cancer survivor who meets the following criteria is eligible to be in the study

MEXICAN AMERICAN

BETWEEN AGES OF 18-39 YEARS OF AGE

2 YEARS FROM COMPLETING CANCER TREATMENT (diagnosed before age 18 years)

ENGLISH SPEAKING ONLY

**CALL LISA BASHORE AT
682-885-2125 or page 817-669-6749
Thank you**

APPENDIX D
DEMOGRAPHIC DATA FORM

DEMOGRAPHIC DATA FORM

<p>___ Age</p>	<p>___ Age at Diagnosis:</p>	<p>Gender ___ Male (1) ___ Female (0)</p>
<p>Diagnosis:</p> <p>___ ALL (1) ___ AML (2) ___ CNS tumor (3) ___ Hodgkin's disease (4) ___ NHL (5) ___ Bone tumor (6) ___ Wilms' Tumor (7) ___ Germ Cell tumor (8) (testicle/ovary) ___ Rhabdomyosarcoma (9) ___ Other (10)</p>	<p>Employment Status:</p> <p>___ Fulltime (> 30 hrs/week) (1) ___ Part time (<30 hrs/week) (2) ___ Caring for other (not pd) (3) ___ Unemployed (looking for job) (4) ___ Unable to work due to disability (5) ___ Retired (6) ___ Student (7) ___ Other-Specify (8)</p>	<p>Marital Status:</p> <p>___ Single (1) ___ Married (2) ___ Living with partner (3) ___ Widowed (4) ___ Divorced (5) ___ Separate/no longer living as married (6)</p>
<p>Income:</p> <p>___ <\$20,000 (1) ___ \$20,001-30,999 (2) ___ \$40,001-50,999 (3) ___ \$60,001-70,999 (4) ___ \$80,000-90,999 (5) ___ >\$100,000 (6)</p>	<p>Education:</p> <p>___ < High School (1) ___ Some High School (2) ___ High School Graduate (3) ___ Some College (4) ___ College Degree (5) ___ Graduate Degree (6) ___ Higher degree (7)</p>	<p>Living Arrangement:</p> <p>___ Live with partner/spouse (1) ___ Live with parents (2) ___ Live with roommate (3) ___ Live with sibling (4) ___ Live with other relative (5) ___ Live alone (6) ___ Other (7)</p>
<p>Generation Status:</p> <p>___ First Generation (born outside the USA) (1) ___ Second Generation (born in the USA with at least one residential parent born outside the USA) (2) ___ Later Generations (born in the USA with residential parents born in the USA) (3)</p>		

APPENDIX E
SCRIPT FOR RECRUITMENT BY PROFESSIONAL

SCRIPT FOR RECRUITMENT

“One of our staff, Lisa Bashore, a doctoral nursing student at UTA is conducting a research study of Mexican American young adults who are survivors of childhood cancer. She is interested in learning more about the cultural beliefs of these young adults who have survived cancer, and how these beliefs affect cancer-screening behaviors.

I am asking you as I believe you may be eligible (meet certain criteria) to be in the study.

This study includes answering a couple of personal questions about your diagnosis, age, education, etc, and then Lisa will ask you a list of questions about your beliefs and cancer screening behaviors (like breast or testicular exams).

I will give you a copy of the consent for you to look over. If you are interested in being part of this study, I will have Lisa come and talk to you more.

If you have questions I cannot answer, I will have Lisa come and talk with you as well.

Thank you for your consideration in being part of this research study.

Do you have any questions right now about this research study?”

APPENDIX F
CONSENT

Research Consent and Authorization Form

Title of Research: EXPLORATION OF THE CULTURAL BELIEFS IN MEXICAN AMERICAN YOUNG ADULT CHILDHOOD CANCER SURVIVORS AND THEIR DECISIONS TO ENGAGE IN CANCER SCREENING BEHAVIORS

CCHCS Department: Hematology and Oncology Outpatient Center
Sponsor: None
Research Team: Principal Investigator: Lisa Bashore, MS, RN, CPNP, CPON, Doctoral Nursing Student, at The University of Texas at Arlington

Other Investigators: None

Telephone #: 682-885-2125

Why is this study being done?


The purpose of this study is to identify (learn more about) the cultural beliefs of Mexican American (MA) young adult childhood cancer survivors (YACCS) and the influence of these beliefs on cancer screening practices. Cancer screening practices are health practices like examining your breasts, going to the doctor for special tests, and checking your skin for moles or other signs of skin cancer.

Cultural beliefs may include values you hold about your family, your faith, and your role in your family, how much control you feel you have over your life, and how shy you are about going to the doctor. The researcher wants to learn more about the beliefs of survivors of different cultures to better take care of you and your family.

What will happen in this study?

If you attend the outpatient clinic in the Hematology and Oncology Department for follow up medical care (as part of your medical care) related to being a cancer survivor, you may be invited to take part in this research study. A staff member of the Hematology/Oncology clinic may tell you a little bit about this study and ask if you are interested in participating. If you decide that you would like to take part in this research study, the staff member will notify the Principal Investigator (PI, the person who will be conducting this research study) may come and talk to you (or call you by telephone). The PI will then tell you more about this research study and will be able to answer any questions that you may have.

If you would like to participate in this research study, the PI will ask you to sign this consent form. It may be necessary to review your medical chart (record) to further determine if you are eligible to take part in this study. If your medical chart does need to be reviewed, certain information will be reviewed such as when you were diagnosed (when your doctor determined your medical condition) with cancer, and the number of

 **IRB NUMBER: 2009-084**
IRB APPROVAL DATE: 1/20/2010
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years it has been since you completed treatment. However, your medical chart will not be reviewed until you have signed this consent form (which gives the PI approval to do so).

The PI and you will agree on a time and place to have you complete a personal demographic form (current age, age when you had cancer, diagnosis, gender, marital status, education and employment status, living arrangement, and what family members including yourself were born inside the United States). The interviews will be done in either the comprehensive survivor center, located in Suite 220, 7th Avenue or the PI's office that is located at Suite 230, 750 Building, 8th Avenue, just one block from the cancer center, Fort Worth, TX. Directions to the PI's office will be made available to you if you need directions. The interviews will be done in English. The interviews will be audio taped (tape recorded) beginning with this consent form and will continue to be audio taped (tape recorded) until the end of the interview so the PI can listen to the tape to be sure she correctly documents the information you say. Each interview will take from 60-90 minutes. All participants will receive a small compensation of \$10.00 in the form of a gift card in appreciation for their time in completing the demographic data form and participation in the interviews.

How long will I be in this study?

Your participation will last about 1 hour to 1.5 hours depending upon how much information you want to share with the PI.

Are there any risks associated with taking part in this study?

The risks that can be identified specifically with this research are:

- Some of the questions the PI will ask may cause you to become emotional. The PI has 16 years of experience as a pediatric oncology nurse and is able to address the feelings you may have.
- If the PI is unable to help you with these feelings, the PI will refer you to a clinical therapist or counselor who works with the PI in the Hematology and Oncology department. These persons are trained (educated) to help people with their feelings and emotions. Your medical insurance company may be billed for services for counseling done by the clinical therapist or counselor.
- There is always a risk of loss of confidentiality associated with participating in a research study. All information pertaining to your participation in this research will be kept in a locked file cabinet in the PI's office within the Hematology and Oncology Department of Cook Children's Medical Center. The researcher involved in this study will take every precaution necessary to ensure that your privacy is protected.

Are there any benefits?

The benefits of participating in this study include the following:

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- You may or may not receive any direct benefit from participating in this research study.
- It is possible that the information learned from this research study could help researcher learn more about the specific cultural beliefs of MA YACCS and other YACCS and how these beliefs influence decisions about engaging in health behaviors like cancer screening and could possibly help others in the future who have similar beliefs and other health behaviors.

What are the alternatives to taking part in this study?

You can choose not to participate in this research. You can withdraw from the study at any time. Refusing to participate or withdrawing from this study will involve no penalty or loss of benefits to which you are otherwise entitled. Your refusal will not affect the quality of health care that you receive from Cook Children's Health Care System or your legal rights.

Are there any costs associated with taking part in this study?

There are no costs associated with this study except costs of travel to the PI's office if you choose to do the interviews there, but you will be given a small stipend for your time for participating. However, you or your insurance company will continue to be responsible for any standard (regular) medical care that you may need. Standard medical care is considered to be regular medical care that is necessary to treat your health condition, which you would need regardless of whether or not you take part in this study.

It is unlikely that you will be injured because of taking part in this study. However, if you are, Cook Children's Health Care System has not set aside any funds to compensate (pay) you in case you are injured because of taking part in the study.

In the case of injury or illness resulting from the research, emergency medical treatment is available. However, you or your insurance company will be responsible for the costs associated with any emergency medical treatment that is necessary. In the event that you need continuing medical care and/or hospitalization as a result of injury or illness resulting from the research, you or your insurance company will be responsible for the costs associated with such treatment.

Will my records be kept confidential?

The Health Insurance Portability and Accountability Act (HIPAA) limits the use and disclosure (sharing) of your private Protected Health Information (PHI). PHI includes any information about your physical or mental health, your health care, or payment for your health care. Among other information, PHI may include your:

- Name
- Birth date
- County of residence
- Zip Code

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- Gender
- Race/Ethnicity
- Diagnosis
- Diagnosis Date
- Disease Status

What other information will be used or shared?

If you give permission, the researcher could use or share any private information (PHI) related to this research from your medical records and test results. In addition to the list above, this could also include:

- History and diagnosis of your disease
- Current and previous treatments you received
- Other medical conditions that may affect your treatment
- Laboratory, radiology and pathology test results
- Follow-up information about your general health
- Status of your disease and late effects from treatments received
- Radiographs and/or photographs as needed to determine disease status

Who will receive my information?

If you give permission, the researcher may use or share your private information (PHI) for the research described above. They may also use your information to develop new procedures or commercial products.

CCHCS will try to protect your private information. However, an absolute guarantee is not possible. For example, the law may require that certain information be given to the courts or the health department.

Depending on the study, your private information (PHI) may be shared with several groups, including the research sponsor, inspectors who check the research, and government agencies. These could include:

- The CCHCS Institutional Review Board (IRB) – a designated team of people who ensure that the rights of research participants are respected
- The University of Texas at Arlington
- The CCHCS Legal and Compliance Departments
- The Federal Office for Human Research Protections (OHRP)

The researcher will report the findings in scientific journals or meetings, but the researcher will not identify you in their reports. The researcher will try to keep your information confidential, but this cannot be guaranteed. The government does not require everyone who might see or receive your information to keep it confidential, so it might not remain private.

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What else should I know?

- The choice to give permission (authorization) for CCHCS researcher to use or share (disclose) your private information (PHI) is voluntary. No one can force you to give permission. However, you must give permission if you want to be in the research. Sharing the information includes sending it to the sponsor.
- CCHCS will keep all patient information private in accordance with Federal law. However, once your information has been shared, CCHCS cannot guarantee that it will remain protected.
- If you refuse to give permission, you can still get standard (regular), non-research health care from CCHCS.
- By signing this form, you are allowing CCHCS, the University of Texas at Arlington, and the Principal Investigator, Lisa Bashore, MS, RN, CPNP, CPON to use and/or disclose your PHI for the purposes of the research.

Can I cancel my permission?

- You have the right at any time to cancel (withdraw) permission for the researcher to use or share your private information (PHI).
- To cancel permission, you must write to the Principal Investigator, Lisa Bashore at 682-885-2125 or the CCHCS Privacy Officer, David Lancaster, at 801 Seventh Avenue, Fort Worth, TX, 76104.
- If you cancel permission, you can no longer be in this research study. You should discuss this with your doctor and the research team because we will need to stop your participation in a manner that is safest for you.
- If you cancel permission, you can still receive standard, non-research treatment for your health condition at CCHCS.

How long can my information be used or shared?

- Unless you cancel your permission in writing, the CCHCS researcher can continue to use or share your information indefinitely.
- If you cancel permission, information that was already used or shared (disclosed) before you withdrew will not be affected. This includes information that was already sent to the sponsor. However, the researcher cannot use your information for anything new, and cannot share it any more or send anything more to the sponsor.

What are my rights as a research participant?

You have the right to find out about the release of your Protected Health Information (PHI). You have the right to withdraw your participation in the research at any and all levels at any time. You have the right to have all your questions and concerns addressed and answered to the best of our ability.

You have the right to any new information that becomes available during your participation in this research that may affect your health or willingness to continue in the research.

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What are my responsibilities as a research participant?

The researcher will monitor you closely while you are in this research. The researcher will watch for any problems that may require additional medical care. It is your responsibility to do the following:

- Ask questions about anything you do not understand.
- Keep appointments.
- Follow instructions
- Let the researcher know if your telephone number changes

Who do I call if I have questions about this study?

If you have questions about this research study, please contact the Principal Investigator, Ms. Lisa Bashore (the researcher who is conducting this study) at 682-885-2125. If you have questions about the risks of this study or are injured, please contact the Principal Investigator, Ms Lisa Bashore at 682 885-2125.

Who do I call if I have questions about my rights as a research participant?

If you have questions regarding rights as a research participant, you can contact the Cook Children's Health Care System Institutional Review Board Chairperson at 685-885-1764.

STATEMENT OF CONSENT and AUTHORIZATION

Your signature below means that you want (consent) to take part in this research. It also means that you give permission for (authorize) the CCHCS researcher to use and share (disclose) any of your Protected Health Information (PHI) that is related to this research.

You should not sign this form until you have had the opportunity to read it (or have it read to you) and have all your questions and concerns answered. You should not sign this form unless you have made a free and voluntary choice to be in the research and to give permission for your PHI to be used and shared.

Participating in the research and giving permission for CCHCS researcher to use and share your PHI are voluntary. Refusing to participate or to give your permission will not result in any loss of benefits to which you are otherwise entitled. You will still be able to get standard, non-research health care from CCHCS.

You may withdraw from the research or cancel permission for your PHI to be used or shared at any time. Withdrawing from the research or cancelling your permission will not result in any loss of benefits to which you are otherwise entitled. You will still be able to get standard, non-research health care from CCHCS.

Your signature below means:

- You have read the information above (or it has been read to you)

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- You have received answers to your questions at this time
- You have freely decided to participate in this research
- You have freely given permission for CCHCS researcher to use or share your Protected Health Information for the purposes of this research.
- You are not giving up any of your legal rights.

You will be given a copy of this consent form to keep.

Signatures

Name of patient _____ Date _____

Printed name _____

And Signature _____ Date _____
of legally authorized representative or guardian

Printed name _____

And Signature _____ Date _____
of person obtaining consent

Printed name _____

And Signature _____ Date _____
of witness

Use of witness applicable Use of witness not applicable

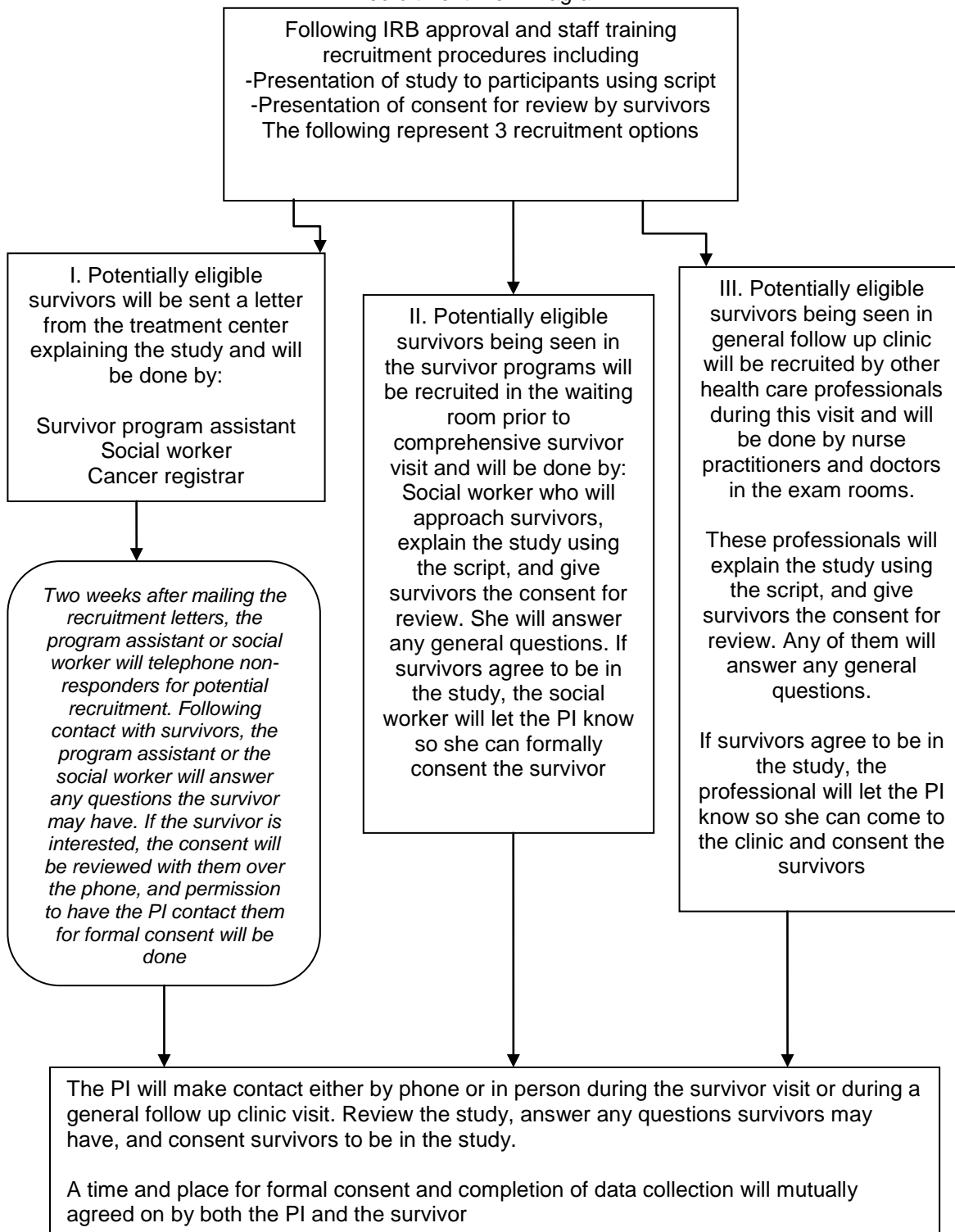
***Please note that the signature of the witness indicates that this person is an impartial third party and observed the consent process (which included the discussion between the investigator(s) and the participant) as well as the signature of the participant. Please note that a witness must be present when consent is obtained from a Non-English speaker or if the participant is illiterate. Otherwise, a witness to the consent process is not required.**

NOTE: Informed consent must be obtained in language understandable to the subject. This requires use of either (I) a full, translated informed consent document approved by the CCHCS IRB, or (II) a translated, IRB-approved "short form" and a translator for the consent process.

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IRB EXPIRATION DATE: 1/18/2011

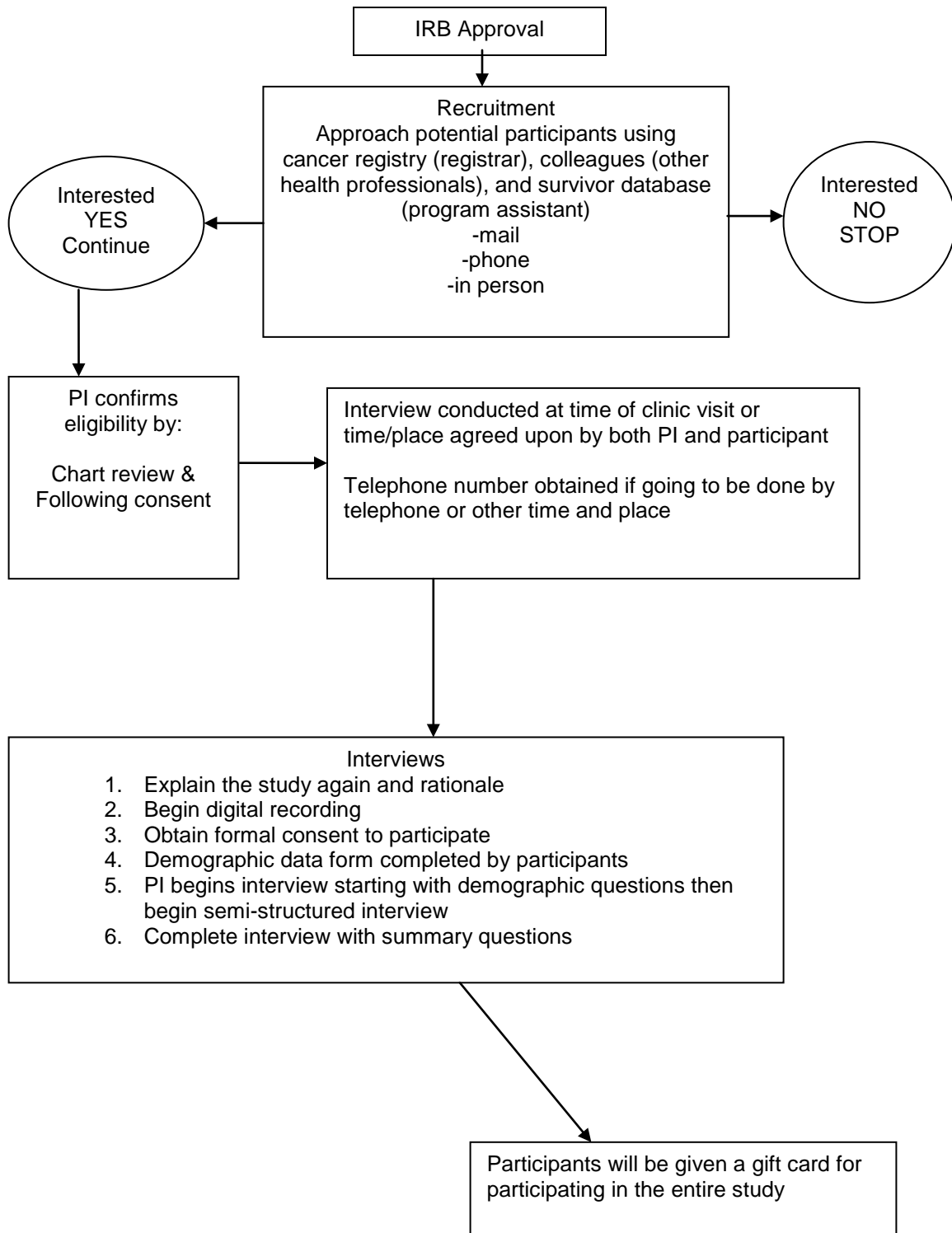
APPENDIX G
RECRUITMENT FLOW DIAGRAM

Recruitment Flow Diagram



APPENDIX H
PROCEDURE FLOW DIAGRAM

Procedure Flow Diagram



APPENDIX I

APPROVAL LETTERS

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Cook Children's Health Care System Institutional Review Board Initial, New Research IRB Approval

Principal Investigator: Lisa M Bashore, CPNP
Title of Research Study: Exploration of the Cultural Beliefs in Mexican American Young Adult Childhood Cancer Survivors and Their Decisions to Engage in Cancer Screening Behaviors
IRB Number: 2009-064
Study Number: Cultural Beliefs MA YACCS
IRIS Submission Reference Number: 002339
Date: January 20, 2010

Dear Dr. Lisa M Bashore,

The above entitled research study was approved by the Cook Children's Health Care System Institutional Review Board (CCHCS IRB) Chairperson on 1/20/2010. This research study has been approved for the following time period:

Initial Approval Period: 1/20/2010 - 1/19/2011

Please note that this final approval letter includes approval of the following: protocol, interview questions, recruitment flyer for professionals, recruitment script for professionals, postal mailed recruitment flyers, demographic data form, personal journal, and revised consent form dated 1/20/10.

The research may not continue beyond the end of the approval period, as indicated by the expiration date above. In order for the research to continue beyond that date, the IRB must first conduct continuing review and designate a new approval period.

The IRB will send you a continuing review notice 90, 60 and 45 days via the iMedRIS system before the expiration date listed above. If the continuing review information is not submitted, completely filled out, received, reviewed and approved by the IRB before the end of the expiration date above, enrollment of new subjects in the research must cease until IRB approval can be obtained. Continued involvement in the research of previously enrolled subjects may not continue unless explicitly approved by the IRB to prevent harm to subjects.

The research was approved by the following method:

Expedited Review; this study meets expedited categories 6 which is defined as: "Collection of data from voice, video, digital or image

Initial New Research Approval Letter
IRB Number: 2009-064
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CookChildren's.

recordings made for research purposes". This study also meets expedited category 7a which is defined as "Research on individual or group characteristics of behavior" and 7b which is defined as "Research which employs surveys, interviews, oral history, focus groups, program evaluation, quality assurance methodologies," etc.

The research may be conducted at the following research sites:

Cook Children's Health Care System; In addition the IRB is agreeable to the Principal Investigator (PI) conducting interviews for this study in the subject's home, but understands that the PI will try and coordinate the study visit at the same time that the subject has a follow-up appointment at Cook Children's.

Enrollment of the following number and type of research subjects may commence:

Number of Subjects Approved: 12
Authorized Types of Subjects: Adults between the ages of 18 and 39

Informed consent is required as follows:

Written, informed consent, which includes a consent document signed by the subject or the subject's legally authorized representative. Please note that written informed consent must be obtained prior to conducting any study-related procedures, including screening activities.

The IRB emphasizes the following requirements in granting approval for this research project:

- 1) Any changes, modifications, or amendments to any facet of the research must be reviewed and approved by the IRB before these changes may be initiated.
- 2) All serious adverse events and unanticipated problems involving risks to subjects or others must be reported to the IRB according to CCHCS IRB policy requirements (please consult the CCHCS IRB Policy and Procedure Manual for specific definitions and reporting time-frames and requirements).
- 3) All research-related records and documentation may be inspected by the IRB and/or Compliance office for the purposes of ensuring compliance with CCHCS IRB policies and procedures and Federal regulations governing the protection of human subjects. The IRB has the right and authority to suspend or terminate its approval if CCHCS and Federal requirements are not strictly adhered to by all study personnel.
- 4) All consent forms and records related to this research should be kept for a period of three years following completion of the study.

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- 5) Copies of consent forms containing genetic testing information should not be filed with the subject's medical record without the subject's explicit consent to do so.
- 6) Investigators should keep the original, executed copy of the consent and/or assent forms for this study. These documents should be filed with the research records associated with this study.
- 7) A copy of the consent and/or assent form should be given to each participant in this study.

If you have any questions or concerns about these requirements or this letter, please contact the IRB Office at 682-885-5990 or andrea.keane@cookchildrens.org. The IRB thanks you for your continued commitment to the protection of human subjects in Cook Children's research.



Signature, IRB Staff Member:

Signature applied by Andrea Keane on 01/20/2010 04:22:43 PM CST



February 5, 2010

Lisa Marie Bashore
Dr. Mary Bond
Nursing
The University of Texas at Arlington
Box 19407

Office of Research
Administration
Box 19100
102 E. Border St., Suite 314
Arlington, Texas
76019-0100

T 817.272.3723
F 817.272.1111

<http://www.utdallas.edu/research>

Research@UT-Arlington

<http://www.utdallas.edu/irb>

Re: UT Arlington Institutional Review Board
Acknowledgement of Approved Research Activity

Project Title: *Exploration of the Cultural Beliefs of Mexican American Young Adult
Childhood Cancer survivors and Their Decisions to Engage in Cancer
Screening Behaviors*

UT Arlington IRB No: 2010-0229

Cook Children's IRB No: 2009-064

Dear Lisa Marie Bashore,

The UT Arlington Office of Research Administration and the UT Arlington Institutional Review Board are pleased to acknowledge your participation in the "*Cognitive Exploration of the Cultural Beliefs of Mexican American Young Adult Childhood Cancer survivors and Their Decisions to Engage in Cancer Screening Behaviors*" protocol.

The Cook Children's Institutional Review Board is noted as the IRB of record for the project, last approved on January 20, 2010. You will not be required to submit a protocol for UT Arlington IRB approval, however, this acknowledgment will be scheduled for annual continuing review in February 2011.

Please be advised that you will be responsible for forwarding to the Office of Research Administration, Regulatory Services, at minimum, a copy of the approval letter forwarded to you upon each continuation review period, modification approval or adverse event acknowledgment as documentation of assertion that the project remains in compliance with all applicable mandates, assurances and institution policies and procedures. In the conduct of cooperative research projects, each institution is responsible for safeguarding the rights and welfare of human subjects and for complying with 45 CFR 46 and 46.114.

In agreement with the IRB of record, this project is approved as follows:

Review: Expedited Review
Number of Subjects: 12

LA/Heath

APPENDIX J

AUDIT TRAIL – DATA COLLECTION

Audit Trail - Data Collection

	A	B	C	D	E	F	G	H
	Code #	Date of 1 st Contact Phone	Interview Date	Site	Person/ Phone	Interviewer	Confirm Consent	Reasons Not done
1	LO	3/10/10	3/10/10	Office	Person	Researcher	Yes	
2	EO	3/16/10	3/19/10	Office	Person	Researcher	Yes	
3	AH	3/16/10	3/27/10	Office	Person	Researcher	Yes	
4	RLL	3/16/10	3/31/10	Office	Person	Researcher	Yes	
5	LC	3/16/10 4/6/10	4/22/10	Phone	Phone	Researcher	Yes	
6	JP	3/16/10	4/25/10	Office	Person	Researcher	Yes	
7	JN	3/16/10 4/8/10	4/29/10	Phone	Phone	Researcher	Yes	
8	KC	3/16/10	5/20/10	Phone	Phone	Researcher	Yes	
9	ER	3/16/10	5/28/10	Office	Person	Researcher	Yes	
10	EB	3/16/10	6/7/10	Office	Person	Researcher	Yes	
11	RD	3/16/10	6/17/10	Clinic	Person	Researcher	Yes	
-	ML						Not done	N/A phone x3
-	AA						Not done	No response x 3 to calls/email
-	JE	3/27/10	4/2010				Not done	Changed appt. no response to calls

APPENDIX K
AUDIT TRAIL – DATA ANALYSIS

Audit Trail Data Analysis

Code #	Interview Date	Site	Phone/ In person	Interviewer	Transcription	Verifier	Analysis	Independent. Coder
1	3/10/10	OFFICE	PERSON	Researcher	Researcher	J.F	Researcher	
2	3/19/10	OFFICE	PERSON	Researcher	Researcher	J.F.	Researcher	S.L
3	3/27/10	OFFICE	PERSON	Researcher	Researcher		Researcher	
4	3/31/10	OFFICE	PERSON	Researcher	Researcher		Researcher	
5	4/22/10	PHONE	PHONE	Researcher	Researcher		Researcher	
6	4/25/10	OFFICE	PERSON	Researcher	Researcher		Researcher	
7	4/29/10	PHONE	PHONE	Researcher	Researcher		Researcher	S.L.
8	5/20/10	PHONE	PHONE	Researcher	Researcher		Researcher	
9	5/28/10	OFFICE	PERSON	Researcher	Researcher		Researcher	S.L.
10	6/7/10	OFFICE	PERSON	Researcher	Researcher		Researcher	S.L.
11	6/17/10	OFFICE	PERSON	Researcher	Researcher		Researcher	S.L

APPENDIX L
CHARACTERISTICS OF PARTICIPANTS

Characteristics of Participants

Initials	Age	Age @ Diagnosis	Sex	Dx	Education	Work	Marital status	SES	Generation
LO	36	10-20yrs	F	HL	High School	Fulltime	Single	\$60-70k	2
EO	18	14 yrs	M	NHL	High School	Part time	Single	<20k	2
AH	18	17 yrs	F	AML	High School	Other	Married	\$20-30k	3
RRL	18	10 yrs	F	ALL	High School	Student	Lives with partner	<\$20k	2
LC	26	< 0.7 yrs	M	GCT	College Degree	Student	Single	<\$20k	2
JP	18	3 yrs	M	LCH	High School	Fulltime	Single	<\$20k	2
JN	30	16 yrs	M	ALL	Some College	Part time	Married	\$40-60k	3
KC	22	13 yrs	M	ALL	Some College	Part time	Single	<\$20k	3
ER	19	5.6 yrs	M	ALL	High School	Fulltime	Lives with partner	\$20-30k	2
EB	18	2.8 yrs	F	ALL	High School	Student	Lives with partner	<\$20k	3
RD	26	3 yrs	F	ALL	Some College	Not Working	Married	<\$20k	1

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BIOGRAPHICAL INFORMATION

The researcher has been a pediatric nurse for 16 years of which 15 of them have been spent specializing in pediatric oncology. She has expertise as an advanced practice nurse in the evaluation and management of pediatric, adolescent and young adults with and who have survived cancer. The experience has influenced her decision to pursue higher education and the PhD degree. Her experience in working with this diverse population, including Mexican American young adult childhood cancer survivors as young adults and their health practices have inspired her to examine these practices as part of her dissertation work. Specifically, she is interested in improving survival in survivors at risk by encouraging their adherence to recommended cancer screening behaviors.

With nine years of experience and expertise in survivorship in this population, the researcher has the necessary skills to conduct interviews with young adult childhood cancer survivors and their cancer screening behaviors. The researcher has served as the PI on two nursing research studies one of which was directed at increasing the health behaviors in older adolescent and young adult cancer survivors. She also has served on several research projects both institutional and multiple-site collaborative research studies over the course of her career. She has co-authored several publications and education programs all of which contribute to the knowledge of childhood cancer survivorship and improving the lives of these survivors.

Her future goals are to continue in her role as clinician and researcher in a childhood, adolescent and young adult cancer survivor program, and to work with colleagues to improve the survival of young adults of all ethnicities diagnosed and treated for cancer.