June 2017

Exploring Nutritional Needs, Roles, and Expectations of Latina Breast Cancer Survivors

Pamela Carolina Birriel
University of South Florida, pguevara@health.usf.edu

Follow this and additional works at: http://scholarcommons.usf.edu/etd

Part of the Public Health Commons

Scholar Commons Citation
http://scholarcommons.usf.edu/etd/6802

This Dissertation is brought to you for free and open access by the Graduate School at Scholar Commons. It has been accepted for inclusion in Graduate Theses and Dissertations by an authorized administrator of Scholar Commons. For more information, please contact scholarcommons@usf.edu.
Exploring Nutritional Needs, Roles, and Expectations
of Latina Breast Cancer Survivors

by

Pamela Carolina Birriel

A dissertation submitted in partial fulfillment
of the requirements for the degree of
Doctor of Philosophy
Department of Community and Family Health
College of Public Health
University of South Florida

Major Professor: Dina Martinez Tyson, Ph.D., M.P.H., M.A.
Julie A. Baldwin, Ph.D.
Carol A. Bryant, Ph.D., M.S.
Cathy D. Meade, Ph.D., R.N., F.A.A.N.
Lauri Wright, Ph.D., R.D.N., L.D./N.

Date of Approval:
June 5, 2017

Keywords: coping, Hispanic, nutrition, social support, survivorship

Copyright © 2017, Pamela C. Birriel
DEDICATION

This dissertation is dedicated to my family. To my parents, Juan and Maria Elena Guevara, the success in my life is immensely due to your unconditional love, support, and understanding. I am truly thankful for the sacrifices that both of you have made for me to pursue and complete my studies in the United States. For everything that you have provided me, I am forever grateful. To my brother, Ronald Guevara, your passion and drive to be a better physician everyday helped me to push through the hardest of times throughout my doctoral program. Your support and advice for as long as I can remember has made me a better student and professional. I strive to be a little bit like you every day.

To my husband, Gabriel Birriel, who has been by my side throughout my entire doctoral program, I honestly could not have done all of this without you. Thank you for your empathy, love, and encouragement through this process; at times, you were my only needed support system. To my father-in-law, Jose Birriel-Caló; mother-in-law, Julia Torres; and brother-in-law, Gian Carlos Birriel, I appreciate your expressions of caring throughout the time that I have known you and especially while I have been in graduate school. Your support is really valued.

Last but not least, I dedicate my dissertation to my family members in Venezuela. My background and our culture are what drive my passion for wanting to reach Latino populations. I will continue to conduct research in the field of public health to better serve and ultimately improve the quality of life of vulnerable communities and families.
ACKNOWLEDGMENTS

Thank you to the members of my doctoral committee, Drs. Martinez Tyson, Baldwin, Bryant, Meade, and Wright; my supervisor, Dr. Jennifer Marshall; my department chair, Dr. Sappenfield; and my doctoral cohort, I could not have gotten through this dissertation process without your knowledge, mentorship, suggestions, and support.

To my major professor, Dr. Martinez Tyson, your dedication and invaluable insights regarding Latinos diagnosed with cancer fueled my interest in also wanting to reduce health disparities among underserved populations. Thank you for being there for me every step of the way. To Dr. Baldwin, thank you for your continuous support throughout my entire doctoral program, especially as I transitioned through advisors and through my journey into candidacy. Your unremitting involvement and guidance all the way from Arizona is truly acknowledged and appreciated. To Dr. Bryant, your extensive experience, leadership, and constructive feedback allowed me to learn, grow, and become a better researcher. I strive to one day accomplish as much as you have professionally and personally. To Dr. Meade, your research expertise centered on culturally tailored cancer education has sincerely impacted my dissertation study to be the best it could be. Your networks through Moffitt Cancer Center eased my recruitment process and ultimately strengthened my data collection methodology. For your genuine guidance, I am grateful. To Dr. Wright, your wealth of knowledge and experience regarding nutrition and dietetic education practices really complemented my research proposal ideas.
Thank you for joining my committee soon after coming to the College of Public Health at the University of South Florida.

To Dr. Jennifer Marshall, your leadership and support have been invaluable throughout the time that we have worked on the Florida Maternal, Infant, and Early Childhood Home Visiting (MIECHV) program evaluation. Our everyday interactions for the last three years enabled me to grow professionally and personally; and your experience, guidance, and understanding allowed me to balance conducting my dissertation research and being Project Coordinator for the Florida MIECHV evaluation. Thank you for providing me the opportunity to be a leader within our evaluation team; this experience has been instrumental throughout my journey to become a better public health professional.

To Dr. Sappenfield, I would like to acknowledge your support through this entire process, as we began our journey in the Department of Community and Family Health together. Thank you for your words of wisdom and recommendations throughout my doctoral program, as well as believing in my passion and skills through job searching. You are a tremendous role model and leader.

To my doctoral cohort, my main support system throughout the doctoral program. Learning and sharing in these experiences with you have been my guiding stars as a doctoral student. Watching your individual growth, accomplishments, and achieved milestones just persuaded me to work that much harder. I am so happy to have met you as we crossed paths in our doctoral program, and I could not be luckier to call you my colleagues and friends.

To Will Forde-Mazrui and Paul Flagg, consultants at the Writing Studio, thank you for your help and support at each of our appointments throughout the spring 2017 semester. Your feedback truly improved my dissertation, and working with you has ultimately strengthened my
academic writing skills. I am grateful to have had the Writing Studio at the University of South Florida as a resource for engaged discussions regarding my dissertation.

Lastly, to the participants of this study, my findings would not have been possible without your willingness to share your experiences with me. Your demonstrated kindness, support, and compassion for my educational goals were priceless gestures. I aim to address your challenges and concerns and help to prevent the cause.
# TABLE OF CONTENTS

<table>
<thead>
<tr>
<th>Section</th>
<th>Page</th>
</tr>
</thead>
<tbody>
<tr>
<td>LIST OF TABLES</td>
<td>iv</td>
</tr>
<tr>
<td>LIST OF FIGURES</td>
<td>v</td>
</tr>
<tr>
<td>ABSTRACT</td>
<td>vi</td>
</tr>
<tr>
<td><strong>CHAPTER ONE: INTRODUCTION</strong></td>
<td>1</td>
</tr>
<tr>
<td>Latinos in the United States</td>
<td>1</td>
</tr>
<tr>
<td>Health Disparities</td>
<td>3</td>
</tr>
<tr>
<td>Cancer Survivorship in the U.S.</td>
<td>4</td>
</tr>
<tr>
<td>Sociocultural Considerations</td>
<td>5</td>
</tr>
<tr>
<td>Statement of the Problem</td>
<td>7</td>
</tr>
<tr>
<td>The Role of the ‘Nutritional Gatekeeper’</td>
<td>9</td>
</tr>
<tr>
<td>Purpose of the Study</td>
<td>10</td>
</tr>
<tr>
<td>Definition of Terms</td>
<td>11</td>
</tr>
<tr>
<td>Organization of Dissertation</td>
<td>13</td>
</tr>
<tr>
<td><strong>CHAPTER TWO: REVIEW OF THE LITERATURE</strong></td>
<td>15</td>
</tr>
<tr>
<td>Introduction</td>
<td>15</td>
</tr>
<tr>
<td>Section I: Breast Cancer in the U.S.</td>
<td>15</td>
</tr>
<tr>
<td>Section II: Risk Factors for Breast Cancer</td>
<td>16</td>
</tr>
<tr>
<td>Dietary Patterns, Body Composition, and Cancer</td>
<td>17</td>
</tr>
<tr>
<td>Section III: The Effect of Cancer Treatment on Quality of Life</td>
<td>18</td>
</tr>
<tr>
<td>Section IV: The Psychosocial Impact of Cancer and its Treatment</td>
<td>20</td>
</tr>
<tr>
<td>Weight Gain Due to Treatment</td>
<td>21</td>
</tr>
<tr>
<td>Section V: Diet and Nutrition after Cancer Treatment: Opportunity for Change</td>
<td>22</td>
</tr>
<tr>
<td>Nutrition Interventions for Cancer Survivors</td>
<td>24</td>
</tr>
<tr>
<td>Section VI: Breast Cancer and Latina Survivors.</td>
<td>25</td>
</tr>
<tr>
<td>Section VII: Theoretical Framework</td>
<td>28</td>
</tr>
<tr>
<td>The Transactional Model of Stress and Coping</td>
<td>28</td>
</tr>
<tr>
<td>Primary and secondary appraisal</td>
<td>29</td>
</tr>
<tr>
<td>Coping efforts</td>
<td>30</td>
</tr>
<tr>
<td>Meaning-based coping</td>
<td>30</td>
</tr>
<tr>
<td>Outcomes of coping</td>
<td>31</td>
</tr>
<tr>
<td>Family and peer support</td>
<td>33</td>
</tr>
<tr>
<td>Conclusion and Next Chapter</td>
<td>35</td>
</tr>
</tbody>
</table>
CHAPTER THREE: METHODS ........................................................................37
  Overview ...............................................................................................37
  Study Setting .........................................................................................39
  Community Engagement .......................................................................39
  Study Sample .........................................................................................41
    Latina Breast Cancer Survivors ..........................................................41
      Sampling strategy ...............................................................................41
      Inclusion criteria ..............................................................................42
      Exclusion criteria .............................................................................43
    Supportive Adults/Caregivers ..............................................................43
      Sampling strategy ...............................................................................43
      Inclusion criteria ..............................................................................43
      Exclusion criteria .............................................................................44
    Key Informants ....................................................................................44
      Sampling strategy ...............................................................................44
      Inclusion criteria ..............................................................................45
      Exclusion criteria .............................................................................45
  Recruitment of Study Participants .........................................................45
  Instrumentation ......................................................................................47
    Interview Guide Development ..............................................................47
    Demographic and Food Security Questionnaire ...................................48
  Data Collection Procedures ..................................................................50
    Semi-Structured Interviews ..................................................................50
    Field Notes and Reflection ...................................................................50
  Data Analysis .........................................................................................51
  Research Ethics ......................................................................................52
    Compensation .....................................................................................53
    Confidentiality ...................................................................................53
    Privacy of Research Subjects ...............................................................54
  Conclusion and Next Chapter ................................................................55

CHAPTER FOUR: RESULTS .......................................................................57
  Overview ...............................................................................................57
  Study Findings .......................................................................................59
    Description of Study Population ..........................................................59
      Latina breast cancer survivors .........................................................59
      Caregivers .......................................................................................60
      Key informants .................................................................................61
    In-Depth Interview Results ..................................................................65
  Specific Aim 1 .......................................................................................65
    Latina Breast Cancer Survivors ..........................................................66
    Caregivers .........................................................................................69
    Key Informants ...................................................................................72
  Specific Aim 2 .......................................................................................76
    Latina Breast Cancer Survivors ..........................................................77
    Caregivers .........................................................................................80
Key Informants .................................................................................................................87
Specific Aim 3 ....................................................................................................................91
Latina Breast Cancer Survivors .......................................................................................91
Caregivers ..........................................................................................................................95
Key Informants ....................................................................................................................99
Conclusion and Next Chapter ..........................................................................................102

CHAPTER FIVE: DISCUSSION ..........................................................................................103
Overview .............................................................................................................................103
Research Summary ...........................................................................................................103
   The Value and Meaning of Nutrition ..............................................................................104
   Factors that Influence Latina Breast Cancer Survivors’ Decisions ...............................106
   The Role of the ‘Nutritional Gatekeeper’ ......................................................................107
   The Influence of Social Support ....................................................................................109
   Gap in Culturally and Linguistically Tailored Information Related to Diet .................110
   The Need for Organizational Support and Assistance .................................................111
Theoretical Framework .....................................................................................................113
   Mediating Processes Related to the Coping Effort .........................................................114
   Moderators: Dispositional Coping Style and Social Support .......................................116
   Outcomes of Coping and Adaptation ............................................................................118
Strengths and Limitations ...............................................................................................119
Implications for Practice, Research, and Education .......................................................120
Conclusions .........................................................................................................................123

REFERENCES ....................................................................................................................125

APPENDICES .....................................................................................................................128
   Appendix A. Interview questions for cancer survivors guided by Model constructs .....148
   Appendix B. Semi-structured interview guide for survivors ..........................................152
   Appendix C. English and Spanish Recruitment Flyers .................................................155
   Appendix D. Interview Protocol: Latina Breast Cancer Survivors .................................157
   Appendix E. Interview Protocol: Caregivers .................................................................176
   Appendix F. Interview Protocol: Key Informants ..........................................................187
   Appendix G. Letters of Support ......................................................................................200
   Appendix H. IRB Letters of Approval .............................................................................207
   Appendix I. Approval for Use of Transactional Model of Stress and Coping Figure ....213

ABOUT THE AUTHOR ......................................................................................................... End Page
LIST OF TABLES

Table 1.1. Stages of Cancer Survivorship ................................................................. 5
Table 1.2. Specific Aims and Research Questions .................................................. 11
Table 2.1. Transactional Model of Stress and Coping Key Constructs ..................... 29
Table 2.2. Types of Social Support .......................................................................... 34
Table 3.1. Pseudonyms Given to Study Participants ................................................ 55
Table 4.1. Characteristics of Interview Participants .................................................. 63
Table 4.2. Key Themes across Participant Groups for Specific Aim 1 ....................... 65
Table 4.3. Key Themes across Participant Groups for Specific Aim 2 ....................... 76
Table 4.4. Key Themes across Participant Groups for Specific Aim 3 ....................... 91
LIST OF FIGURES

Figure 1.1. Proportions of the Latino Population ................................................................. 2

Figure 5.1. Adapted Transactional Model of Stress and Coping ........................................ 114
ABSTRACT

Latina breast cancer survivors, especially those who have undergone chemotherapy, may face major disruptions to their diet and eating habits; and a major concern is their ability to function in daily life roles throughout survivorship. Food and nutrition are suggested to be significant factors that can influence the process of cancer development, yet little research has been done to understand the nutritional needs, roles, and expectations among Latina breast cancer survivors. The purpose of this study was to understand Latina breast cancer survivors’ perceptions of the role of diet and nutrition in helping them cope with the effect of chemotherapy treatment. This study was guided by the Transactional Model of Stress and Coping and employed a qualitative research design. A purposive sample of Latina breast cancer survivors (n=32), caregivers identified by the survivors (n=8), and key informants (n=6) were interviewed in their language of preference (Spanish or English) using a semi-structured, open-ended interview guide that explored how coping with a cancer diagnosis influences cancer survivors and caregivers’ nutritional needs and practices. The data were analyzed using an inductive approach to develop an a priori codebook. Thematic analysis was performed using MAXQDA, and emergent codes were added as appropriate.

The results yielded that Latina breast cancer survivors emphasized the value and meaning of nutrition; this was accomplished by increasing their nutritional awareness to restore health, improve the body’s immunity, and regain/maintain agency and control of their food
consumption. Food provided by friends and family, assistance from nutritional organizations, doctors’ recommendations, and negative chemotherapy side effects influenced Latina breast cancer survivors and caregivers’ decisions about diet and nutrition during and after treatment. Negative chemotherapy side effects and positive support from husbands, family members, and friends affected the role of Latina women as the ‘nutritional gatekeepers’ in the family, since breast cancer diagnosis and treatment disrupt or limit the role of Latinas within the household unit. Findings from the interviews with Latina breast cancer survivors, caregivers, and key informants indicated that cultural expectations among this population shape the kinds of support and assistance that are provided by family members. Lastly, this research study revealed unmet information needs: Latina breast cancer survivors relied on organizational and online nutrition-related resources but identified a gap in culturally and linguistically tailored information related to diet and nutrition following diagnosis. The study concluded that Latina breast cancer survivors and caregivers mentioned no routine dietary assessment for cancer survivors after beginning chemotherapy and during treatment. Additionally, caregivers specified needing instrumental support to better meet the nutritional needs of Latina breast cancer survivors. This study added to our understanding of Latina breast cancer survivors’ unmet needs that could contribute to the creation of future nutrition education programs and interventions most appropriate during cancer survivorship for diagnosed individuals and their caregivers.
CHAPTER ONE:
INTRODUCTION

Latinos in the United States

Latinos are the largest and fastest-growing ethnic minority group in the United States (Siegel, Naishadham, & Jemal, 2012). Data from the 2010 U.S. Census found that 16.3% (50.5 million/308.7 million) of people residing in the nation were of Latino origin, accounting for more than half of the growth in the total U.S. population within the last decade (Ennis, Ríos-Vargas, & Albert, 2011). This considerable growth of the Latino population during the past 10 years is in part due to relatively higher levels of immigration, and the number will continue to increase nationwide (Humes, Jones, & Ramirez, 2011; Juarez, Mayorga, Hurria, & Ferrell, 2013; Pew Hispanic Center, 2010). Although Latinos are usually classified as a single ethnic group, there is heterogeneity among the Latino population regarding cultural and socioeconomic factors (González Burchard et al., 2005). Several factors, such as socioeconomic status and access to healthcare, also contribute significantly to health disparities among the Latino population (Ruiz, Hamann, Mehl, & O’Connor, 2016). In this dissertation research study, the terms Hispanic and Latino are used interchangeably throughout.

The 2010 U.S. Census defines Hispanic or Latino as a person of Cuban, Mexican, Puerto Rican, South or Central American descent, or other Spanish culture or origin regardless of race (Ennis et al., 2011). Overall, large proportions of the Latino population in the United States have
made the nation more ethnically diverse over time (Ennis et al., 2011). In this study, Latinos are defined as a group of people with origins in the countries of South America, Central America, Mexico, and Spanish-speaking Caribbean (e.g., Puerto Rico, Dominican Republic, and Cuba). In the U.S., Florida ranks as the third state with the highest Latino population (4.2 million) following California and Texas (Ennis et al., 2011). The distribution of Latinos also varies from state to state with Florida having a unique population of Latino groups (Ennis et al., 2011). For example, population estimates for 2010 report that more than half (61%) of the Mexican origin population in the U.S. resides in California and Texas; whereas more than two-thirds (68%) of all Cubans live in Florida (Ennis et al., 2011). Figure 1.1 specifies the proportions of the Latino origin population by type in the U.S. (Ennis et al., 2011).

![U.S. Latino Population by Type](image)

**Figure 1.1. Proportions of the Latino Population.**  
*Source: Ennis et al. (2011)*
Health Disparities

Disparities in socioeconomic status and food availability among ethnic minority groups may contribute to differences in household dietary patterns through limited accessibility to food and resources (Devine, Sobal, Bisogni, & Connors, 1999). As Latinos spend more time in the U.S., their eating habits become more like those of non-Hispanic whites, with diets lower in fiber, fruits, and vegetables and higher in fat (Villarruel et al., 2009). Food security means that all individuals have access to enough food at all times, for an active, healthy life. In 2014, an estimated 14% of American households were food insecure at least some time during the year, meaning that their access to adequate food was limited by a lack of money and other resources (Coleman-Jensen, Rabbitt, Gregory, & Singh, 2015). Inadequate access to food disproportionately affects economically and resource-poor individuals resulting in negative health status.

Furthermore, the real median income of Latino households increased by 3.5% between 2012 and 2013, from $39,572 to $40,963, but is still below Asian and non-Hispanic whites real median household incomes (DeNavas-Walt & Proctor, 2014). Data from the 2013 U.S. Census Bureau found that Latinos were the only major demographic group to experience a statistically significant change in their poverty rate and the number of people in poverty (DeNavas-Walt & Proctor, 2014). For Latinos, the poverty rate fell 2.1% from 2012 to 2013, while the number of Latinos in poverty fell from 13.6 million to 12.7 million (DeNavas-Walt & Proctor, 2014). It is important to take into consideration socioeconomic and structural factors, such as race/ethnicity, gender roles within the household, and socioeconomic class as limitations on food choice and food-related behavior for cancer survivors (Dean, Sharkey, Johnson, & St John, 2012).
Cancer Survivorship in the U.S.

Cancer is a major public health problem (Siegel, Naishadham, & Jemal, 2013). In this dissertation study, cancer survivorship is defined as beginning at the time of cancer diagnosis (Brown et al., 2001). In 2012, there were approximately 13.7 million Americans who were cancer survivors (American Cancer Society, 2014a). In 2013, there were more than 1.6 million estimated new cases of invasive cancer that were expected among men and women in the U.S.; the most commonly diagnosed cancer that was expected among women was breast cancer (Siegel et al., 2013). Women are also more likely to develop cancer before the age of 60 years because breast cancer is generally diagnosed at an earlier age (Siegel et al., 2013). In addition, Latinas tend to be diagnosed with breast cancer at younger ages, at more advanced stages of disease, and have lower cancer survival rates (81%) compared to non-Hispanic whites (89%) (Li, Malone, & Daling, 2003; Martinez Tyson, 2008; Siegel et al., 2015). Furthermore, over the past three decades, survival rates for all cancers combined have increased by about 20 to 23 percent among white and black populations, respectively (Siegel, Miller, & Jemal, 2016). Ashing-Giwa et al. (2004) discussed that within the last 20 years there has been an increased interest in the literature regarding cancer survivorship issues; therefore, the need to address survivorship issues (e.g., information needs, changes in roles, and social support expectations) among Latino cancer survivors will aid in closing the health disparity gap (Intercultural Cancer Council, 2006).

The stages of cancer survivorship are not only defined by the experience of the person who was diagnosed with cancer but also by the family members and peers who were affected by the diagnosis (Centers for Disease Control and Prevention & Lance Armstrong Foundation, 2004). Table 1.1 differentiates between the three stages. The target population of this dissertation study is Latina breast cancer survivors currently undergoing (acute stage), or within
their first five years after completing (extended stage), chemotherapy treatment to capture the experiences and information needs of more recently diagnosed women and caregivers.

**Table 1.1. Stages of Cancer Survivorship.**

<table>
<thead>
<tr>
<th>Stage</th>
<th>Description</th>
</tr>
</thead>
<tbody>
<tr>
<td>Acute</td>
<td>Spans from diagnosis to active cancer treatment</td>
</tr>
<tr>
<td>Extended</td>
<td>Begins with remission or completed treatment and through recovery from treatment where the body needs to be restored</td>
</tr>
<tr>
<td>Permanent</td>
<td>Health maintenance to prevent cancer recurrence, second primary tumors, and other preventable nutrition-related diseases</td>
</tr>
</tbody>
</table>

*Sources*: Centers for Disease Control and Prevention and Lance Armstrong Foundation (2004) and Brown et al. (2001)

**Sociocultural Considerations**

Kagawa-Singer, Valdez Dadia, Yu, and Srbone (2010) explain that there is an interaction between biology, culture, ethnicity, and race. These factors may affect behavior or lifestyle practices such as diet and physical activity among diverse populations, thus playing a major role in health promotion and maintenance (Kagawa-Singer, 2001; Kagawa-Singer et al., 2010). Culture is seen as a major component that accounts for disparities in both cancer incidence rates and treatment outcomes (Kagawa-Singer, 2001). Cultural beliefs and behaviors also influence cancer risk factors and form the existential and experiential significance of cancer (Kagawa-Singer, 2001). Operationalizing elements comprised in the measurement of ethnicity include diet choices, availability, and quality, as well as level of adaptation within a specific ethnic group (Kagawa-Singer, 2001). Food plays an important role within the Latino
community. This population’s cultural identity, beliefs, and values influence food practices providing a sense of belonging and ultimate loyalty to their heritage (Kagawa-Singer & Chung, 1994).

Differences in exposure (e.g., history of smoking, alcohol drinking habits, diet), as well as genetic susceptibility, are various factors that also affect an individual’s risk for developing cancer (Siegel et al., 2013). Furthermore, data shows that the development of secondary malignancies, cardiovascular disease, diabetes, and osteoporosis are more common among cancer survivors, which can often be attributed to lifestyle factors (Demark-Wahnefried & Jones, 2008; Hewitt, Rowland, & Yancik, 2003; Parkin, Bray, Ferlay, & Pisani, 2005; Rowland, Mariotto, Aziz, Tesauro, & Feuer, 2004). Researchers assert that lifestyle modifications, such as a healthy diet and weight management, can impact the rate of cancer progression and improve overall cancer survival; yet social relationships may also influence health (Berkman & Glass, 2000; Davies, Batehup, & Thomas, 2011; Murphy & Girot, 2013; Pekmezi & Demark-Wahnefried, 2011). Therefore, improving nutrition, diet, and other lifestyle factors characterize key public health targets among cancer survivors (Murphy & Girot, 2013).

As mentioned previously, the survival rates for cancer (including women diagnosed with breast cancer) have significantly increased due to advances in healthcare (American Cancer Society, 2014a; Ashing-Giwa, Lim, & Gonzalez, 2010; Pekmezi & Demark-Wahnefried, 2011). Also, researchers discuss that social support is an important factor that contributes to the length of cancer survival (Ell, Nishimoto, Mediansky, Mantell, & Hamovitch, 1992; Kelly, 1998; Maunsell, Brisson, & Deschenes, 1995; Spiegel, 2001, 2002). Social support is a mediating pathway that relates to the adjustment and wellbeing of cancer survivorship, where social networks may influence health status (Berkman & Glass, 2000). Berkman and Glass (2000)
found that social support may have the greatest impact on determining the prognosis and survival of chronic disease rather than the onset. More specifically, an increased level of social support is related with improved survival outcomes among women diagnosed with breast cancer (Kroenke, Kubzansky, Schernhammer, Holmes, & Kawachi, 2006; Maunsell et al., 1995; Reynolds & Kaplan, 1990).

Statement of the Problem

There have been advancements in cancer mortality and survival outcomes, but these advances vary considerably among racial and ethnic groups (Siegel et al., 2013; Zebrack, 2009). Breast cancer is the most frequently diagnosed form of cancer in women, as well as the most common among Latinas residing in the United States (American Cancer Society, 2012, 2014a). Hispanic or Latino populations suffer most from disparities in cost and availability to care; communication problems have also been identified as barriers in getting access to needed healthcare services (Ramirez et al., 2005). Although cancer research literature is growing, there is limited knowledge of cancer-related issues and priorities of greatest significance to the Latino population (Ramirez et al., 2005).

Nutrition is an important issue for Latinos (Pérez-Escamilla, 2009). Researchers found that one of the greatest issues for the Latino population in the U.S. is nutrition, which is affected by poor educational attainment, higher poverty, and food insecurity rates (Pérez-Escamilla, 2009; Ramirez et al., 2005). Among survivors in general, the diagnosis of cancer has been identified as a ‘teachable moment’ when a high proportion of individuals want nutritional information and are amenable to making positive health behavior changes (Demark-Wahnefried, Aziz, Rowland, & Pinto, 2005; Humpel, Magee, & Jones, 2007; Lemon, Zapka, & Clemow, 2004; McBride, Clipp,
Peterson, Lipkus, & Demark-Wahnefried, 2000; Toles & Demark-Wahnefried, 2008). Nutrition has also been identified as a very important topic among community-based organizations that serve Latina breast cancer survivors in the Tampa Bay area. Changes in roles at the family level have been found to be more beneficial than solely focusing on the nutritional change in individual behavior (Kaiser, 2006). Researchers also suggest that social roles and relationships within the household context influence food selection and dietary changes that reduce the probability of breast cancer recurrence across the breast cancer survivor population (Beagan & Chapman, 2004a). Despite this knowledge, little research has been done to understand the nutritional needs, changes in roles, and expectations as a result of breast cancer diagnosis and chemotherapy treatment on Latina cancer survivors as caregivers.

Cancer survivors are far more receptive to nutritional counseling than people who do not face immediate health challenges. Brown et al. (2001) state that after a diagnosis of cancer, many survivors are highly motivated to seek information about diet, food safety, physical activity, body weight changes, dietary supplement use, and nutritional complementary therapies. Studies investigating changes in diet among cancer survivors conclude that this population is likely to make lifestyle changes for non-scientific reasons and could benefit from increased communication concerning diet, physical activity, and supplement use with healthcare providers (Maskarinec, Murphy, Shumay, & Kakai, 2001; Patterson et al., 2003).

Available resources in Spanish, including strategic planning materials regarding nutrition, may be preferred by Latino cancer survivors and their caregivers, but there is limited availability of materials already translated into the Spanish language. Brown and colleagues (2001) state that cancer prevention guidelines for nutrition and physical activity have been established by the American Cancer Society but are intended to reduce cancer incidence, not necessarily geared
towards cancer survivors and the different phases of cancer survivorship. Patterson et al. (2003) report that educated patients, individuals undergoing multiple treatments, and females are more likely to adopt new lifestyle practices and roles in response to cancer diagnosis. Previous literature has emphasized the patient’s adjustment to long-term chronic illness, rather than the household members’ adaptation and support to the patient’s recent breast cancer diagnosis (F. M. Lewis, Hammond, & Woods, 1993). Therefore, it is important to understand how the household “actively manages the ways in which it organizes itself and its daily activities to obtain, process, map and alter its environment in response to the mother’s illness” (F. M. Lewis et al., 1993, p. 354). Consequently, their overall population growth, the increasing cancer survivor population, and disparities faced by this ethnic minority, the inclusion of Latinos in current research is crucial (Ashing-Giwa et al., 2010).

The Role of the ‘Nutritional Gatekeeper’

Defined as the person in a home who typically makes the purchasing and preparation decisions related to food, the ‘nutritional gatekeeper’ was first introduced in the 1940s (Lewin, 1943). This leadership role is traditionally inhabited by women who are responsible for the process of food choice and distribution in the home (McIntosh & Zey, 1998; Vidrine et al., 2013). Meal decision-making has also been reported as a shared responsibility among members of Latino households resulting in dietary issues affecting the family, such as poorer quality diets (Arredondo, Elder, Ayala, Slymen, & Campbell, 2006; Kaiser, 2006). The behavior of the ‘nutritional gatekeeper’ has been seen as a multifaceted process involving sociocultural and psychological factors, such as emotions, motives, and attitudes (Gedrich, 2003). Therefore, internal and external factors have an effect on the major role this person plays in monitoring the
nutritional intake of members living within the household (Johnston, 2007; Vidrine et al., 2013). This dissertation research study focuses on women who identified themselves as the ‘nutritional gatekeeper’ in their households.

**Purpose of the Study**

The purpose of this study was to understand Latina breast cancer survivors’ perceptions of the importance of diet and nutrition in helping them cope with cancer treatment and survivorship. The objectives of this dissertation study were accomplished by pursuing the three specific aims that correspond with six research questions presented in Table 1.2. Focusing on women who were currently undergoing or within the first five years post-chemotherapy treatment was important for this research study because the Latina breast cancer survivor may not have been able to physically partake in her usual ‘nutritional gatekeeping’ routine. The inability to continue in her role often occurs due to fatigue among other side effects (National Cancer Institute, 2012a). Additionally, women who have undergone chemotherapy may have faced major disruptions to their diet and nutritional ability of food consumption (e.g., appetite changes, diarrhea, mouth and throat changes, nausea, and vomiting) (National Cancer Institute, 2012a).
Table 1.2. Specific Aims and Research Questions.

<table>
<thead>
<tr>
<th>Specific Aim</th>
<th>Research Question</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. To understand the sociocultural factors that influence the diet of Latina breast cancer survivors.</td>
<td>1.a. How do Latina breast cancer survivors value the meaning of nutrition?</td>
</tr>
<tr>
<td></td>
<td>1.b. What influences Latina breast cancer survivors’ decisions about diet and nutrition during and after chemotherapy?</td>
</tr>
<tr>
<td>2. To explore how Latina breast cancer survivors cope with nutrition-related experiences and changes in roles that may have been prompted by cancer treatment and survivorship.</td>
<td>2.a. How do breast cancer diagnosis and chemotherapy affect the role of Latina women as the ‘nutritional gatekeeper’ in the family?</td>
</tr>
<tr>
<td></td>
<td>2.b. How does family and/or peer support influence Latina breast cancer survivors’ diet and nutrition during and after chemotherapy?</td>
</tr>
<tr>
<td>3. To identify the information needs regarding diet and nutrition among Latina breast cancer survivors.</td>
<td>3.a. What are Latina breast cancer survivors’ informational needs related to diet and nutrition following diagnosis?</td>
</tr>
<tr>
<td></td>
<td>3.b. What nutrition-related resources are available to Latina breast cancer survivors, and how do they access these resources?</td>
</tr>
</tbody>
</table>

Definitions of Terms

The information below provides definitions of terms used throughout this dissertation.

**Appraisal support:** Providing information that helps with decision-making and is used for self-evaluation, such as constructive feedback and affirmation (Berkman & Glass, 2000; Heaney & Israel, 2008).
**Breast cancer survivor:** A women diagnosed with breast cancer, current or in the past, who is still living. “Cancer survivorship focuses on the health and life of a person with cancer… beyond the diagnosis and treatment phases… Family members, friends, and caregivers are also considered part of the survivorship experience” (National Cancer Institute, 2016).

**Emotional support:** Providing expressions of empathy, love, trust, caring, sympathy, and understanding (Berkman & Glass, 2000; Heaney & Israel, 2008).

**Health disparity:** A particular type of health difference that is closely linked with social or economic disadvantage (Carter-Pokras & Baquet, 2002). More specifically, “the variation in rates of disease occurrence and disabilities between socioeconomic and/or geographically defined population groups” (National Institutes of Health, 2016).

**Hispanic or Latino/Latina:** A person with origins from the countries of Latin America, including South America, Central America, and Mexico; Spanish-speaking Caribbean, such as Puerto Rico, Dominican Republic, and Cuba; or other Spanish culture regardless of race (Ennis et al., 2011). In this study, the terms Hispanic and Latino/Latina are used interchangeably.

**Informational support:** Providing advice, information, and suggestions that a person can use to address problems (Berkman & Glass, 2000; Heaney & Israel, 2008).

**Instrumental support:** Providing tangible aid, help, and services that directly assist a person in need (Berkman & Glass, 2000; Heaney & Israel, 2008).
**Nutritional gatekeeper:** The person in a household who typically makes the purchasing and preparation decisions related to food (McIntosh & Zey, 1998).

**Role strain:** The tension that individuals experience when he or she struggles with meeting the responsibilities of a specific role in their life (White & Klein, 2008).

**Social support:** A mediating pathway by which aid and assistance are exchanged through social relationships and interpersonal transactions (Berkman & Glass, 2000; Heaney & Israel, 2008). Social support is typically categorized into four broad types of supportive behaviors or domains that include: appraisal, emotional, informational, and instrumental support (Berkman & Glass, 2000; Heaney & Israel, 2008).

**Stressors:** “Demands made by the internal or external environment that upset balance or homeostasis, thus affecting physical and psychological well-being and requiring action to restore balance and equilibrium” (Glanz & Schwartz, 2008, p. 211).

**Organization of Dissertation**

This dissertation is organized into five chapters: *Introduction, Review of the Literature, Methods, Results*, and a final chapter containing *Discussion, Conclusions, and Recommendations*. This *Introduction* chapter describes the nature and purpose of the study and explains the significance of and justification for conducting the study. This chapter also presents the specific aims and research questions addressed by the dissertation study and concludes with the definition of terms used throughout the dissertation.
Chapter Two: Review of the Literature presents a thorough analysis of prior literature related to the research questions of the dissertation. The Review of the Literature chapter focuses on scholarly research conclusions directly pertinent to the specific aims and links the Transactional Model of Stress and Coping to the problem addressed in the dissertation. Chapter Three: Methods includes subsections regarding subjects and setting, instrumentation, data collection procedures, and data analysis. The Methods chapter describes the characteristics of participants of the study, how they were selected, and the setting of the study. The third chapter also presents a thorough description of the instrumentation, steps involved in data collection, and analytic strategies employed.

Chapter Four: Results presents the research findings by providing a summary of the results by specific aims from Latina breast cancer survivors, caregivers, and key informants, respectively. The Results chapter highlights the findings both in the text and accompanying tables in anticipation of more developed discussions, conclusions, and recommendations found in chapter five. Chapter Five: Discussion presents interpretation of findings; connects results with the literature; and closely follows the guiding specific aims, research questions, and theoretical framework articulated in the dissertation. The Discussion chapter includes triangulation of the findings; description of study strengths and limitations; implications for nutrition, oncology, and public health; and conclusions. Finally, lessons learned, suggestions for future research, and recommendations for practice are discussed.
CHAPTER TWO:
REVIEW OF THE LITERATURE

Introduction

This chapter presents a review of the literature directly pertinent to the subject area of interest, where significant literature published is described and summarized. The purpose of this chapter is to focus on research pertaining to breast cancer in the United States. This section is followed by the importance of information relating dietary patterns, body composition, and breast cancer in the Latina population; this is followed by the effect of cancer treatment, diet intervention findings, and household adaptation to breast cancer diagnosis. In addition, the Transactional Model of Stress and Coping (Lazarus & Folkman, 1984) along with the application of social support (Berkman & Glass, 2000) are presented as the theoretical framework that helped guide the design, data collection, and analysis for this dissertation study.

Section I: Breast Cancer in the U.S.

This section focuses on statistics of breast cancer in the United States. According to breast cancer statistics, one out of every eight women in the U.S. will develop breast cancer during her lifetime (National Cancer Institute, 2014c). Breast cancer is the most common form of cancer diagnosis among females, accounting for 41% of all female cancer survivors in the U.S. (Campbell et al., 2012; DeSantis et al., 2014; Siegel et al., 2013). In 2016, approximately
246,660 new breast cancer cases were expected to be diagnosed in women in the U.S., joining the growing number of about 14.5 million total cancer survivors in the nation (American Cancer Society, 2014b, 2016; DeSantis et al., 2014). An increase in screenings and more effective treatments attribute to the detection of cancer in earlier stages; therefore, the number of survivors continues to steadily increase among the cancer population nationwide (American Cancer Society, 2014b; DeSantis et al., 2014; Pekmeziz & Demark-Wahnefried, 2011; Rowland et al., 2004). For this dissertation study, cancer survivors comprise all living persons who have ever received a cancer diagnosis (Aziz & Rowland, 2003; Rowland et al., 2004). As a result, cancer survivorship is quickly evolving as a major public health concern, since the economic impact of cancer is high for both the cancer survivor and society as a whole (Jones & Demark-Wahnefried, 2006; National Cancer Institute, 2014c; Rowland et al., 2004). Short- and long-term treatment consequences for breast cancer survivors are important, as people with cancer are surviving for a longer period. In addition, there may be implications for the individuals and members in their household throughout the process of cancer survivorship (Murphy & Girot, 2013).

Section II: Risk Factors for Breast Cancer

This section focuses on risk factors for breast cancer and also examines the important connection between dietary patterns and body composition as modifiable determinants of cancer risk. More specifically, the section provides justification for why it was necessary to conduct this exploratory research pertaining to the: (a) meaning and value of nutrition and influential factors regarding diet for cancer survivors during and after chemotherapy treatment, and (b) information needs and awareness of available resources related to diet and nutrition.
There are multiple risk factors for breast cancer, some of which are modifiable and some are not. The main risk factors for breast cancer that cannot be modified are being female, of older age, and inherited changes in certain genes (i.e., BRCA1, BRCA2) (National Cancer Institute, 2014b). Due to the high risk for women, they are also more likely to develop cancer before the age of 60 years (Siegel et al., 2013). In addition to non-modifiable factors, modifiable lifestyle behaviors, such as poor dietary intake and obesity, may increase cancer risk (National Cancer Institute, 2014d; Siegel et al., 2013). The National Cancer Institute (2012b) states that being overweight and obesity are associated with an increased risk of postmenopausal breast cancer; however, other studies have found that being overweight and obesity are associated with a reduced risk of breast cancer before menopause (Ballard-Barbash et al., 2009; Roberts, Dive, & Renehan, 2010). The World Cancer Research Fund and American Institute for Cancer Research (2007) ascertain that there is increased evidence to show that food and nutrition are important factors that can modify the process of cancer development.

**Dietary Patterns, Body Composition, and Cancer**

By the 1940s, there was already a link suggested between cancer and food intake; however, it was not until the year 1981 that studies on nutrition and cancer research were reported (Doll & Peto, 1981; Lucchiari, Masiero, & Pravettoni, 2012; Tannenbaum, 1942). “Specific dietary patterns, foods and drinks, and dietary constituents can and do protect against cancer, not only before the process starts, but also afterwards” (World Cancer Research Fund & American Institute for Cancer Research, 2007, p. 46). Chlebowski, Blackburn, and Elashoff (2005) reported on the association between fat intake and survival after being diagnosed with cancer, where there was a 24% relative risk reduction for cancer recurrence in the low-fat diet
group compared with the control group (Ashing-Giwa et al., 2010). Henderson and Henderson (2010) state that nutritional strategies and dietary patterns that consist of higher fiber intake and lower fat intake are vital for breast cancer survivors.

An abnormally high and unhealthy proportion of body fat (i.e., obesity) places women not only at a higher risk for breast cancer but also at a greater risk for other chronic diseases, such as cardiovascular disease, stroke, hypertension, and diabetes (Henderson & Henderson, 2010; National Cancer Institute, 2012b). Lucchiari, Masiero, and Pravettoni (2012) state that “the obesity epidemic, the increasing occurrence of diseases in the world’s population, and the growing awareness of a correlation between chronic diseases and dietary habits have led to an increased interest in nutrition” (p. 2). Lifestyle behaviors regarding diet are crucial for cancer survivors, since considerable weight gain is also a risk factor for the development of several other types of cancers (Bianchini, Kaaks, & Vainio, 2002). Weight gain is common as a result of breast cancer treatment; therefore, avoidance of weight gain should be considered one of the foundations of chronic disease prevention, including cancer, where weight can be controlled partially through nutrition and dietary restrictions (Bianchini et al., 2002; James-Martin, Koczwara, Smith, & Miller, 2014).

Section III: The Effect of Cancer Treatment on Quality of Life

This section examines the influence of cancer diagnosis and treatment on the expectations of the role of women within the family unit to provide justification for exploring: (a) how cancer diagnosis and chemotherapy treatment affected the family structure and role expectations, and (b) who the women sought for support during their transition from breast cancer patients to survivors.
The period following cancer diagnosis and treatment affects the survivor and the family by posing a range of challenges and needs (Anderson, Steele, & Coyle, 2013; Craig, 2007; Humpel et al., 2007). Although breast cancer survivors may often have favorable health outcomes, a major concern among these women is their ability to function in daily life roles after treatment and through their survivorship trajectory (Ashing-Giwa et al., 2004; Bower et al., 2000). Alternatively, Latina breast cancer survivors are more susceptible to poor physical and emotional wellbeing outcomes in comparison to non-Hispanic whites (e.g., higher levels of emotional distress and significant lack of social support) (Ashing-Giwa et al., 2010; Ashing-Giwa, Tejero, Kim, Padilla, & Hellemann, 2007; Juarez et al., 2013; Spencer et al., 1999).

Researchers focusing on ethnic minority women, specifically non-Hispanic black breast cancer survivors, report that diagnosis and treatment result in concerns with body image and challenges in familial and marital relationships (Ashing-Giwa & Ganz, 1997; Ashing-Giwa, Ganz, & Petersen, 1999; Ashing-Giwa et al., 2004). Ashing-Giwa and colleagues (2004) conducted 20 key informant interviews and 11 focus group discussions to explore the impact of cultural and socio-ecological factors on health-related quality of life and psychosocial experiences among breast cancer survivors of various ethnic minority groups. From the focus group discussions, Ashing-Giwa et al. (2004) found that breast cancer survivors experienced fear, anxiety, and more specifically, “concerns about the illness affecting their roles as caregivers and the impact on their families” (p. 417). Additionally, Martinez Tyson (2008) conducted a study with four out of five key informants who discussed the stress and anxiety Latina immigrants with breast cancer experienced. One of the stressors described was that many Latina immigrants could not afford not to work during cancer treatment, and thus endured the side effects of chemotherapy on the job (Martinez Tyson, 2008).
Yanez, Thompson, and Stanton (2011) assert that only a few studies have aimed to understand the quality of life experience among ethnic minority breast cancer survivors, with the exception of Powe et al.’s 2007 study focusing on the non-Hispanic black population. The authors conducted a systematic literature review to compare the quality of life of Latina breast cancer survivors with other racial/ethnic groups (Yanez et al., 2011). A cross-sectional study conducted by Carver, Smith, Petronis, and Antoni (2006) found that Latinas reported significant levels of distress about the future of their families when compared to non-Latinas. Other studies focusing on the quality of life of Latino cancer patients reported that their quality of life was significantly influenced by cultural beliefs and family (Ashing-Giwa et al., 2004; Juarez, Ferrell, & Borneman, 1998a, 1998b).

Section IV: The Psychosocial Impact of Cancer and its Treatment

This section examines the psychological and social impact of cancer and weight gain due to cancer treatment. Cancer survivors experience both short and long-term needs that may influence their sense of wellbeing directly following treatment (Anderson et al., 2013; Institute of Medicine & National Research Council, 2006; Kornblith, 1998). The ‘nutritional gatekeeper’ is the person primarily responsible for cooking in the home (McIntosh & Zey, 1998). Focusing on Latinas who had undergone chemotherapy is important because these women may have faced major disruptions related to food consumption (e.g., appetite changes, diarrhea, mouth and throat changes, nausea, and vomiting) (National Cancer Institute, 2012a). In addition, these women may not have been able to physically partake in their usual role as ‘nutritional gatekeeper’ in their household due to fatigue among other side effects (National Cancer Institute, 2014a). Furthermore, long-term strategies could be aimed at altering health behaviors to reduce the risk
of cancer recurrence and other comorbidities, such as cardiovascular disease (Anderson et al., 2013; McBride et al., 2000).

**Weight Gain Due to Treatment**

Breast cancer survivors commonly experience weight gain as a consequence of cancer treatment (Demark-Wahnefried, Rimer, & Winer, 1997; Harvie, 2010; James-Martin et al., 2014; Vance, Mourtzakis, McCargar, & Hanning, 2011). Weight gain during chemotherapy may be due to steroids that increase appetite, changes in metabolism, hormones depending on the woman’s menopausal status, or other side effects of treatment (Demark-Wahnefried, Winer, & Rimer, 1993; James-Martin et al., 2014; Vance et al., 2011). Weight management is important for cancer survivors, since significant weight gain is a risk factor for the development of various types of cancers and other chronic conditions, such as cardiovascular disease, diabetes, osteoporosis, and functional decline (Bianchini et al., 2002; Demark-Wahnefried & Jones, 2008; James-Martin et al., 2014; Pekmezli & Demark-Wahnefried, 2011; World Cancer Research Fund & American Institute for Cancer Research, 2007). The functional limitations that cancer survivors often experience may affect their daily lives and their family’s (Chang et al., 2004; Chirikos, Russell-Jacobs, & Jacobsen, 2002; Hewitt et al., 2003; Jones & Demark-Wahnefried, 2006; Ramsey, Berry, & Etzioni, 2002).

Cancer survivors report motivation to make lifestyle changes regarding diet and exercise in order to improve their health following diagnosis (Burke Beckjord et al., 2008; Demark-Wahnefried et al., 2005; Demark-Wahnefried, Peterson, McBride, Lipkus, & Clipp, 2000; James-Martin et al., 2014; Kostopoulou & Katsouyanni, 2006). Maskarinec et al. (2001) explored dietary changes among 143 cancer survivors and found that 48% (n=69) of the
interviewed patients modified and maintained their diet after diagnosis, and another 11% (n=16) made temporary dietary modifications. Qualitative analysis revealed multiple reasons for dietary changes — increasing well-being, maintaining health, preventing cancer recurrence, avoiding causes of cancer, eating cancer-preventative foods, taking control, and following advice (Maskarinec et al., 2001). However, researchers suggest that a breast cancer diagnosis is not the only factor that promotes change toward healthy lifestyle behaviors following treatment (Blanchard, Courneya, & Stein, 2008; Campbell et al., 2012).

Section V: Diet and Nutrition after Cancer Treatment: Opportunity for Behavioral Change

This section examines diet intervention findings among newly diagnosed cancer survivors. Researchers assert that the diagnosis of cancer has been identified as a ‘teachable moment’ when a high proportion of cancer survivors want nutrition information and are amenable to making positive health behavior changes (Demark-Wahnefried et al., 2005; Humpel et al., 2007; Lemon et al., 2004; McBride et al., 2000; Toles & Demark-Wahnefried, 2008). Alternatively, studies focusing on health behaviors among both female and male non-Hispanic white cancer survivors found that the diagnosis of cancer could also motivate the families of cancer survivors to make positive lifestyle changes (Humpel et al., 2007; Lemon et al., 2004).

Pekmezi and Demark-Wahnefried (2011) reviewed and compiled guidelines for diet and/or physical activity specific to cancer survivors. Additionally, the authors reviewed randomized controlled trials of lifestyle interventions for adult cancer survivors and described the priorities identified by these articles; the three main result areas described were weight management, dietary patterns, and physical activity (Pekmezi & Demark-Wahnefried, 2011).
Anderson and colleagues (2010) surveyed 288 clinicians regarding their understanding of colorectal cancer survivors’ knowledge about weight management. The authors found 41% of respondents to have a lack of awareness and hesitance of promoting a lifestyle change to their patients (Anderson et al., 2013).

James-Martin, Koczwara, Smith, and Miller (2014) held three focus groups with oncology practitioners, cancer patients, and cancer survivors to determine weight management information needs after beginning chemotherapy. The three key themes that emerged from the qualitative data analysis included: 1) information regarding diet, exercise, and weight management; 2) assessment of diet, exercise, and physical activity; and 3) patient and practitioner recommendations regarding format and timing of information. More specifically, the authors found that there was no routine assessment in place regarding diet and weight management for cancer patients and survivors during treatment (James-Martin et al., 2014).

Jones and Demark-Wahnefried (2006) reviewed and discussed studies relating to health promotion, health behavior change, and delivery preferences for cancer survivors. The authors found that effective weight management interventions that promote nutrition and diet (i.e., energy restriction; balancing fat, protein, and carbohydrate intake) for cancer survivors still need to be developed (Jones & Demark-Wahnefried, 2006). Anderson, Steele, and Coyle (2013) conducted six focus group discussions in the United Kingdom with 20 men and 20 women ages 27-84 regarding their beliefs as well as perceived needs for advice on diet, physical activity, and lifestyle. This study focused on colorectal cancer survivors whose perceived needs immediately following treatment related to a range of psychological and physical challenges including seeking advice on food parameters and weight management (Anderson et al., 2013).
Lewis and colleagues (2012) examined the effect of cancer patients seeking information from media and nonmedical sources (e.g., family/friends); they found improved nutrition, more specifically higher fruit and vegetable consumption, among the cancer patient population that were actively seeking information. Additionally, Metz et al. (2005) conducted a survey with newly diagnosed cancer patients, including breast cancer patients. The results showed that over two-thirds of respondents seek nutritional information following their cancer diagnosis and that family and friends were a common source of retrieval for 31% of respondents (James-Martin et al., 2014; Metz et al., 2005).

**Nutrition Interventions for Cancer Survivors**

Food choice and diet have emerged as fundamental factors in long-term survival planning for patients who have been recently diagnosed with cancer, those who are currently undergoing active treatment, and those who have survived many years after their initial diagnosis and cancer treatment (Lucchiari et al., 2012; Toles & Demark-Wahnefried, 2008). Brown and colleagues (2001) found data most compelling for breast cancer survivors, where the risk of recurrence might be increased by obesity, as well as diets low in fruits and vegetables and high in fat. Murphy and Girot (2013) assert that it is essential for post-treatment cancer survivors to understand how modifications help them recover and improve their quality of life; more specifically, dietary patterns aimed at following healthy lifestyle behavior recommendations. These changes also possibly reduce the risk of cancer recurrence or development of a new form of cancer.

Campbell et al. (2012) conducted a pilot study to measure the outcomes and efficacy of a 24-week diet and exercise intervention in 14 early-stage breast cancer survivors adapted from the
Diabetes Prevention Program Research Group (2002). The authors concluded that older participants attended a greater number of sessions, since family commitments of younger participants may have acted as a barrier to successful weight loss. The difficulties encountered by younger participants related to practical issues, such as an inconvenient time of day and travel distance to the intervention location (Campbell et al., 2012).

The National Cancer Institute (n.d.) shares information regarding research-tested intervention programs, including evidence-based cancer control interventions and program materials. The Complete Health Improvement Program and Eating a Healthy Life Project were designed to build awareness, modify behavior, and provide motivation by promoting healthy dietary habits to markedly reduce risk factors for chronic disease among adults (National Cancer Institute, n.d.). However, there has not been much work done regarding nutrition-related interventions for cancer survivors.

Section VI: Breast Cancer and Latina Survivors

This section focuses on study findings and implications for Latina breast cancer survivors. Latinas have lower incidence of breast cancer when compared to non-Hispanic white or non-Hispanic black populations; nonetheless, breast cancer is still the most commonly diagnosed cancer among Latinas in the U.S. (Ashing-Giwa, Padilla, Bohorquez, Tejero, & Garcia, 2006; Howe et al., 2006; Murtaugh et al., 2008; Siegel et al., 2012; Yanez et al., 2011). Based on cancer cases diagnosed during 2007 to 2009, the lifetime risk that a Latina will develop breast cancer is 9.83% (American Cancer Society, 2012). Ashing-Giwa and colleagues (2006) explain that Latinas with lower socioeconomic status are more likely to be diagnosed with more advanced disease, therefore social status is a correlate of stage diagnosis (Zaloznik, 1997).
Yanez, Thompson, and Stanton (2011) assert that the physical and psychological burden of breast cancer treatment may be greater among Latinas due to being diagnosed at later stages of cancer. Juarez et al. (2013) state that Latina breast cancer survivors may encounter overwhelming post-treatment concerns that are critical to short- and long-term healthcare, including being at a greater risk for developing chronic illnesses due to cancer-related treatment. Common issues identified were comprised of medical care needs, including an increase in cost due to later stage at diagnosis, language barriers to care, psychosocial concerns related to worry about children and burdening the family, and body image anxieties (Ashing-Giwa et al., 2006). Consequently, it is important to understand expectations among the increasing number of Latina cancer survivors directly following chemotherapy treatment (Lopez-Class, Gomez-Duarte, Graves, & Ashing-Giwa, 2012).

Martinez Tyson (2008) used ethnographic methods to understand social support and breast cancer within the social environment and experience of health disparities; participant observation, 28 in-depth interviews, and 60 structured questionnaires were conducted with Latina immigrants diagnosed with breast cancer in West Central Florida. Five key informant interviews with support service providers were also conducted. Results suggested that cultural expectations about gender roles shape what kinds of support and assistance are provided by men and women (Martinez Tyson, 2008). Beliefs about not burdening the family with personal concerns and beliefs that family needs should come before one’s own were negatively associated with social support. While family both in the United States and in their native country were identified as sources of support, they were also identified as sources of stress (Martinez Tyson, 2008).
Juarez, Mayorga, Hurria, and Ferrell (2013) conducted a pilot study to evaluate the transition into survivorship of eight Latina diagnosed with breast cancer participating in a bilingual survivorship education intervention. Family members were permitted to be present during the *Nueva Luz* intervention. Within the Latino families, members were able to speak and/or read in Spanish, English, or both languages; discussions within a specific session focused on family needs among other support issues (Juarez et al., 2013). Through qualitative analysis, Juarez and colleagues (2013) found that integrating the family enabled trust and engaged the women, empowering them to share the educational information learned.

Ashing-Giwa (2005) claims that a method integrating intrapersonal domains to larger social contexts more comprehensively evaluates health-related quality of life in Latina-American breast cancer survivors. The multilevel model approach that incorporates contextual factors is comprehensive in explaining health outcomes and unique challenges faced by Latina cancer survivors (Lopez-Class et al., 2012). Lopez-Class and colleagues (2012) conducted a literature review, which included a final sample of 37 identified studies, to explore all levels of a synthesized contextual and ecological health-related quality of life model targeting Latina-American breast cancer survivors. The authors found studies that focused on the role that members of the household play in the decision-making process at the intrapersonal level, as well as the social support that family members provide at the interpersonal level (Lopez-Class et al., 2012; Maly, Umezawa, Ratliff, & Leake, 2006). Lopez-Class et al. (2012) highlight that there is still a gap to be addressed beyond family influences regarding the paucity of nutrition intervention research for Latina cancer survivors.
Section VII: Theoretical Framework

This section presents the Transactional Model of Stress and Coping (Glanz & Schwartz, 2008; Lazarus & Folkman, 1984) with a focus on social support as the theoretical framework that drove this research study (Berkman & Glass, 2000; Heaney & Israel, 2008). In addition, the section explores changes in roles within the household and the effect of treatment on newly diagnosed Latina breast cancer survivors and their families.

The Transactional Model of Stress and Coping

The Transactional Model of Stress and Coping is an influential theoretical framework related to health (Glanz & Schwartz, 2008; Lazarus & Folkman, 1984) that can be applied to cancer, nutrition, and cancer survivorship. Glanz and Schwartz (2008) state that dating back to the 1960s and 1970s, “stress was considered to be a transactional phenomenon dependent on the meaning of the stimulus to perceivers” (Antonovsky, 1979; Lazarus, 1966). Lazarus and Cohen (1977) define stressors as demands that are made by the environment and interrupt an individual’s equilibrium. Thus, a diagnosis of breast cancer and chemotherapy treatment may act as the stressors affecting the behaviors and health status of the survivor and household members in a variety of ways. This feeling of distress affects the individual’s wellbeing, and changes in behavior are necessary to reestablish one’s balance (Lazarus & Cohen, 1977). Table 2.1 specifies and describes the key constructs within the Transactional Model of Stress and Coping (Glanz & Schwartz, 2008; Lazarus & Folkman, 1984). The constructs from the Transactional Model were used to guide the interview questions and probes asked in this dissertation study. The purpose of utilizing the model was to explore how coping with stress was an influential factor that affected the survivor and identified individuals/caregivers.
Table 2.1. Transactional Model of Stress and Coping Key Constructs.

<table>
<thead>
<tr>
<th>Construct</th>
<th>Description</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Primary appraisal</strong></td>
<td>Evaluation of the significance of a stressor or threatening event as stressful, positive, controllable, challenging, benign, or irrelevant</td>
</tr>
<tr>
<td><strong>Secondary appraisal</strong></td>
<td>Evaluation of the controllability of the stressor and assessment of a person’s coping resources and options</td>
</tr>
<tr>
<td><strong>Coping efforts</strong></td>
<td>Actual functional and emotional strategies used to mediate primary and secondary appraisals</td>
</tr>
<tr>
<td><strong>Problem management</strong></td>
<td>Functional strategies (i.e., problem-focused coping efforts) directed at changing a stressful situation</td>
</tr>
<tr>
<td><strong>Emotional regulation</strong></td>
<td>Strategies (i.e., emotion-focused coping efforts) aimed at changing the way one thinks or feels about a stressful situation</td>
</tr>
<tr>
<td><strong>Meaning-based coping</strong></td>
<td>Coping processes that induce positive emotion, allowing reenactment of problem- or emotion-focused coping</td>
</tr>
<tr>
<td><strong>Outcomes of coping</strong></td>
<td>Adaptation to a stressor (i.e., emotional well-being, functional status, health behaviors) influenced by coping efforts</td>
</tr>
<tr>
<td><strong>Dispositional coping styles</strong></td>
<td>Generalized ways of behaving that can affect a person’s emotional or functional reaction to a stressor; relatively stable across time and situations</td>
</tr>
<tr>
<td><strong>Social support</strong></td>
<td>Mediating factor (e.g., feelings of interconnectedness) affecting emotional distress and health outcomes</td>
</tr>
</tbody>
</table>

Source: (Glanz & Schwartz, 2008; Lazarus & Folkman, 1984)

**Primary and secondary appraisal.** A person’s judgment concerning the significance of chemotherapy treatment could protect against a variety of negative health outcomes; the person would enhance the coping responses through his or her assessment of resources due to the
psychological effects encountered from cancer diagnosis. Patterson and colleagues (2003) conducted telephone interviews with 356 eligible cancer survivors in the state of Washington. The participants were identified through the Cancer Surveillance System and were interviewed regarding changes in diet, physical activity, and supplement use. The psychosocial characteristics assessed in this study included: (1) perceived health status; (2) desire for personal control; and (3) internal locus of control; these were used to predict lifestyle changes after cancer diagnosis (Patterson et al., 2003). More specifically, the lifestyle changes assessed among adults diagnosed with cancer included diet changes, new physical activity, or consumption of new dietary supplements. There was no prediction of lifestyle changes in diet or physical activity, and this could arise from other psychosocial factors such as belief, which may prompt this diet-disease correlation (Patterson et al., 2003).

**Coping efforts.** Depending on the area of concern, individuals may prefer seeking help first from within their informal social networks rather than formal support (Bussing, Koro-Ljungberg, Gary, Mason, & Garvan, 2005; Featherstone & Broadhurst, 2003; Gamoran, Turley, Turner, & Fish, 2012). Conversely, while individuals will often go to a formal provider for guidance when serious concerns arise, they will turn to others for support if that provider is not responsive (Frankenburg, 2002; Sayal, 2006). Among low-income individuals in one study, the most frequently selected sources of help were family, books and videos, telephone helplines, and friends (Keller & McDade, 2000). Several studies found that friends were perceived as most helpful over family for a variety of concerns (Keller & McDade, 2000; Raviv, Raviv, Edelstein-Dolev, & Silberstein, 2003; Rose & Campbell, 2000).

**Meaning-based coping.** “Positive reinterpretation, acceptance, and use of religion and spirituality” are common coping responses to health threats (Glanz & Schwartz, 2008, p. 218).
Stead (2004) highlights that relationships and the process of contextual interactions create shared symbols and meanings among people in a social group which influences human behavior.

Different economic and social contexts affecting an individual’s health and illness experience may influence how the household understands and responds to that individual’s breast cancer progression (Meiklejohn, 2011). For this reason, the theoretical approach of social support was also directly suited to explore how newly diagnosed Latina breast cancer survivors perceived their role within the household structure and responded to their experiences. For example, a cancer survivor who has a high income, social support from family and friends, and sufficient resources at their disposal may experience the disease differently than someone who has a low income, lacks support, and does not have accessibility to such resources (Meiklejohn, 2011).

Socialization is the process by which we acquire symbols, beliefs, and attitudes that are shared by families (White & Klein, 2008). The household culture is composed of commonly shared symbols that can construct meaning of disease; therefore, the members understand the dimension of role expectations, and the rules of different roles are clear as some household members step up for others (White & Klein, 2008). Family beliefs can influence the meaning of breast cancer, and social interactions within the family can facilitate or hinder knowledge that is socially constructed (Grunfeld, Ramirez, Hunter, & Richards, 2002). There is also a link between identity and behavior. With changes in roles, the individuals behave according to the identity and meanings relevant to the situation. Role strain is then taken into account if the cancer survivor within the family does not have sufficient resources to enact a role, especially when there is a change in expectations due to the diagnosis of a chronic illness (White & Klein, 2008).

**Outcomes of coping.** Coping strategies may result in short- and long-term positive or negative adaptation affecting emotional wellbeing, functional status, and health behaviors (Glanz
Latino cultures comprise strong family values, and the women constitute the backbone of caregiving (de Fugueiredo & Turato, 2001; Land & Guada, 2011; Madianos et al., 2004; Magana, 2006; Oliveros, 2007). More specifically, caregiving tasks fall to Latinas because of the strong cultural role expectations (Land & Guada, 2011; Oliveros, 2007). Due to Latinas’ specific cultural practices and beliefs, a breast cancer diagnosis may disrupt and/or limit the woman’s performance in her role within the family or household unit (Buki et al., 2008; Pérez-Stable, Sabogal, Otero-Sabogal, Hiatt, & McPhee, 1992; Ramirez, Suarez, Laufman, Barroso, & Chalela, 2000; Stanton, Revenson, & Tennen, 2007; Victorson, Cella, Wagner, Kramer, & Smith, 2007; Yanez et al., 2011). Beagan and Chapman (2004a) suggest that across the breast cancer survivor population, social roles and relationships within the household context are relevant factors that influence food selection and dietary changes to reduce the probability of breast cancer recurrence.

Ashing-Giwa, Lim, and Gonzalez (2010) measure the relationship between lifestyle changes (e.g., eating healthier) and physical wellbeing (e.g., meeting the family needs) following cancer treatment among European- and Latina-American breast and cervical cancer survivors. Within the health-related quality of life physical wellbeing items, Ashing-Giwa et al. (2010) defined family needs as a variable that may influence cancer survivorship outcomes (Demark-Wahnefried, Pinto, & Gritz, 2006). Among cervical cancer survivors, assessing the physical well-being level of ‘meeting the family needs’ significantly differed by whether survivors positively changed their diet (Ashing-Giwa et al., 2010, pp. 1166-1167). Nápoles-Springer, Ortíz, O’Brien, and Díaz-Méndez (2009) note that “the central role of family for cancer survivors can provide not only a sense of support, but also added concerns for women who do not want to cause any hardships on their families” (Lopez-Class et al., 2012, p. 120).
**Family and peer support.** Social networks refer to the web of relationships that surround individuals, and social support is an important function of those relationships (Glanz, Rimer, & Viswanath, 2008). Families are considered social groups, but they are differentiated from other social groups in a variety of ways (White & Klein, 2008). Individuals are usually born into a family and are part of that family for a lifetime, whereas joining a network of close friends is voluntary (White & Klein, 2008). Families are also intergenerational while other groups may not have such a large age difference; through this intergenerational component, a parent becomes a caregiver to a child, an older sibling may nurture a younger sibling, or a grandparent could take responsibility as a caregiver (White & Klein, 2008). Within the context of surviving breast cancer, a change in family roles as well as strong support, or lack of social support, from family or peers may affect the food-decision making process within the household (Beagan & Chapman, 2004b; Martinez Tyson, 2008).

Families are linked biologically or through marriage, while other relationships may not have that fundamental family tie (White & Klein, 2008). A network of friends could have some family properties, where their beliefs, practices, and social interactions are shared between its members. Therefore, distinctive features of who is considered part of a family may vary across cultural and ethnic groups. Lewis, Hammond, and Woods (1993) state that “families who actively negotiate their experiences as a family and include feedback and flexible responses in their behavior are expected to positively affect the level at which the household is able to function as a unit” (p. 357). The foundation of reciprocity shows how social networks provide support that directly affects the mental, physical, and social well-being of cancer survivors, thereby building upon their social relationships (Glanz et al., 2008). The kinds of social support a person has available to them (e.g., family, friends, social groups, coworkers, and school
networks) can influence individuals’ health-related dietary behaviors in positive or negative ways (Glanz et al., 2008). The types of supportive behaviors account for ways in which individuals develop coping responses that could affect their food practices. Support behaviors can also build connections to organizational and community resources that may empower positive change (Berkman & Glass, 2000; Heaney & Israel, 2008). Table 2.2 specifies and describes the four types of support.

**Table 2.2. Types of Social Support.**

<table>
<thead>
<tr>
<th>Domain</th>
<th>Description</th>
</tr>
</thead>
<tbody>
<tr>
<td>Instrumental</td>
<td>Tangible aids and services that assist a person in need</td>
</tr>
<tr>
<td>Informational</td>
<td>Advice, suggestions, and information that a person can use to address problems</td>
</tr>
<tr>
<td>Emotional</td>
<td>Expressions of empathy, love, trust, and caring</td>
</tr>
<tr>
<td>Appraisal</td>
<td>Information that is used for self-evaluation, such as constructive feedback and affirmation</td>
</tr>
</tbody>
</table>

Sources: Berkman and Glass (2000) and Heaney and Israel (2008)

Bloom, Stewart, Chang, and Banks (2004) conducted a study assessing and comparing quality of life in the social domain by interviewing 185 female breast cancer survivors. In their study, Bloom et al. refer to social wellbeing for early cancer survivors as “the effort to deal with the impact of cancer on individuals, their roles, and relationships” (p. 148). Social factors that were measured and compared at baseline and five years later were:
- Employed at least part-time,
- Married or had partner,
- Children under 18 years of age at home,
- Social network index,
- Sexually active (for women who were married or had partner),
- Sexual problems (for women who were sexually active),
- Emotional support, and
- Patient-physician communication (Bloom et al., 2004).

The study found that these factors affected food practices as the women expressed concern about diet and weight gain in regard to their physical health, and social factors such as resources provided through employment (Bloom et al., 2004). Coreil (2010) mentions that the responsive acts of assistance between individuals and their social support could be classified as having both positive and negative dimensions; therefore, there are many ways to measure perceived social support by taking into account both type and quality of support and considering their social networks, social embeddedness, and social climate.

**Conclusion and Next Chapter**

This chapter provided a review of the literature related to the Latina population, breast cancer, and nutrition. More specifically, it emphasized breast cancer in the United States; risk factors for breast cancer, such as dietary patterns and body composition; and the psychosocial impact of cancer and effect of treatment, such as weight gain, on quality of life. Additionally, opportunities for behavioral change after treatment and diet and nutrition interventions for cancer survivors were highlighted. The guiding theoretical framework, the Transactional Model of
Stress and Coping and application of social support, was also discussed. *Chapter Three: Methods* details the research methodology, which includes recruitment of study participants, the research design, sampling strategy, data collection, and analysis.
CHAPTER THREE:
METHODS

Overview

This chapter outlines the research methods used in the dissertation study. The chapter begins with an overview of the purpose of the study and describes the setting, sampling strategy, and inclusion criteria. This is followed by a description of recruitment of study participants and interview guide development. Qualitative data collection and analysis processes are then discussed in further detail. Recruitment materials and approved informed consent documents are included as appendices. Lastly, research ethics, including cost and time, confidentiality, and privacy of research subjects are discussed.

This dissertation used a cross-sectional study design. Qualitative methods were used to explore Latina breast cancer survivors’ perception of the importance of diet and nutrition in helping them cope with cancer treatment and survivorship. Due to the exploratory nature of this study, qualitative methods were well-suited and appropriate. The study design followed an ethnographic inquiry approach of qualitative research that focused on describing and interpreting Latina breast cancer survivors and caregivers’ experiences surrounding nutrition education and changes in role (Creswell & Maietta, 2002). Interviews with caregivers and key informants were used to achieve triangulation of findings from the Latina breast cancer survivors. Specifically, this study explored the needs and meaning of nutrition for Latina breast cancer survivors, as well
as how changes during/after chemotherapy affected the role of Latinas as ‘nutritional gatekeepers.’ Through this qualitative approach, the goal was to gather descriptions and be able to interpret the targeted cultural, social group through the “learned patterns of behavior, customs, and ways of life” of Latina breast cancer survivors (Miller & Salkind, 2002, p. 158). A factor that needed to be taken into consideration was that flexibility was critical in conducting qualitative interviews (Ulin, Robinson, & Tolley, 2005).

The study also drew from the tenents of community-engaged research, which included informal discussions with key informants who provided invaluable feedback on the questionnaire and interview guide, recruitment assistance, and the opportunity to participate in community events. All components of the dissertation research were reviewed and approved by the Institutional Review Board (IRB) at the University of South Florida in Tampa prior to starting the study (refer to Appendix H). The objectives were accomplished through the following specific aims and research questions:

**Specific Aim 1:** To understand the sociocultural factors that influence the diet of Latina breast cancer survivors. **Research Question 1.a.** How do Latina breast cancer survivors value the meaning of nutrition? **Research Question 1.b.** What influences Latina breast cancer survivors’ decisions about diet and nutrition during and after chemotherapy?

**Specific Aim 2:** To explore how Latina breast cancer survivors cope with nutrition-related experiences and changes in roles that may have been prompted by cancer treatment and survivorship. **Research Question 2.a.** How do breast cancer diagnosis and chemotherapy affect the role of Latina women as the ‘nutritional gatekeeper’ in the family? **Research Question 2.b.** How does family and/or peer support influence Latina breast cancer survivors’ diet and nutrition during and after chemotherapy?
Specific Aim 3: To identify the information needs regarding diet and nutrition among Latina breast cancer survivors. Research Question 3.a. What are Latina breast cancer survivors’ informational needs related to diet and nutrition following diagnosis?

Research Question 3.b. What nutrition-related resources are available to Latina breast cancer survivors, and how do they access these resources?

Study Setting

This dissertation research study involved Latinas living in West Central Florida diagnosed with breast cancer who were willing to participate in an interview. Recruitment and interviews took place in Hillsborough, Pinellas, and Orange counties. The idea of the study originated from conversations with outreach workers and health-provider staff that were involved with Latino cancer support organizations in the Tampa Bay and Orlando-Kissimmee metropolitan areas. Furthermore, West Central Florida has highly recognized comprehensive cancer centers, as well as several cancer institutes and treatment centers in the area.

Community Engagement

The study was informed by the tenents of community-engaged research (Mikesell, Bromley, & Khodyakov, 2013), and informal discussions were conducted with key informants (e.g., providers, health educators, or other stakeholders) that worked closely with Latina cancer survivors. The researcher sought input from community members and experts that were currently involved at some capacity in cancer health promotion through service, science, and partnership via support groups and research institutes or hospitals. Community health workers from cancer support groups and cancer institutes partnered with the researcher throughout the
study: (a) LUNA (Latinos Unidos por un Nuevo Amanecer), a cancer supportive environment, located in Hillsborough and Pinellas counties serves a broader audience; (b) H. Lee Moffitt Cancer Center and Research Institute located on the University of South Florida campus has made a commitment to the prevention and cure of cancer, working in the areas of patient care, research, and education; and (c) St. Joseph’s Cancer Institute is the largest hospital in the Tampa Bay area providing a wide range of services to help cancer patients and their families with the fight against cancer.

Throughout the course of the study, the researcher also attended and participated in community events and visited cancer clinics to engage with Hispanic cancer survivors and share information about the study. The researcher connected with potential study participants through these events, which underlined the importance of cancer health education and health promotion for cancer survivors and family members. Refer to the list below.

- Attended *Creando Conciencia por Reina* (Creating Awareness by Reina) and *El Arcoíris de Emma* (Emma’s Rainbow) “Pink Party” support group gatherings in Orlando, Florida;
- Joined LUNA support group monthly meetings held at Moffitt Cancer Center in Tampa and Morton Plant Hospital in Clearwater, Florida;
- Volunteered at Relay for Life in Casselberry, Florida;
- Distributed study flyers to dieticians and nurses at Tampa General Hospital and at a reconstructive plastic surgery office in Tampa, Florida;
- Shared study information with a health educator at Florida Health — Seminole County;
- Participated as a planning committee member for LUNA Camp Alegría;
- Volunteered at a Faces of Courage Women’s Cancer Retreat; and
- Attended the Latinos and Cancer: Educational Symposium sponsored by Moffitt Cancer Center in Tampa, Florida.

**Study Sample**

Latina breast cancer survivors (n=32), supportive caregivers (n=8), and key informants (n=6) who worked closely with Latina cancer survivors were included in this study sample. The final sample size was determined by theoretical saturation (Guest, Bunce, & Johnson, 2006). In total, 46 interviews were completed from March through December 2016. The following paragraphs will detail the sampling strategy, inclusion, and exclusion criteria for each group.

**Latina Breast Cancer Survivors**

**Sampling strategy.** In this dissertation study, recruited and eligible Latinas self-identified as individuals with origins in the countries of Latin America; more specifically South and Central America, as well as Mexico, Cuba, the Dominican Republic, and Puerto Rico. The goal was to conduct interviews with 25 to 30 Latina breast cancer survivors who self-identified as the ‘nutritional gatekeeper’ within their household. As stated previously, the ‘nutritional gatekeeper’ was defined as the person in a household who typically makes the purchasing and preparation decisions related to food. Purposive and snowball sampling (Bernard & Ryan, 2009) was also used to recruit Latinas who were undergoing — or within their first five years following the completion of — chemotherapy treatment. This dissertation study focused on Latinas who had undergone chemotherapy, as these women may have faced major disruptions related to food consumption. Additionally, these women may not be able to physically fulfill their usual
‘nutritional gatekeeping’ routine due to fatigue, among other side effects of chemotherapy (National Cancer Institute, 2012a).

Initially, this study proposed to recruit Latina breast cancer survivors who were currently undergoing or only one year following the completion of chemotherapy treatment. After the beginning recruitment period, the researcher realized that that eligibility criterion was too narrow making it difficult to find participants within the specific time frame. Therefore, after approval from the doctoral committee, an amendment was submitted and approved by the IRB to expand the eligibility criterion to Latina breast cancer survivors undergoing or who were within the first three years post-chemotherapy treatment (refer to Appendix H). Following another period of recruitment, the extended time frame continued to make it difficult to find eligible participants. After another discussion with the doctoral committee, a second IRB amendment submission was approved that further expanded the eligibility criterion to Latina breast cancer survivors currently undergoing or within the first five years following the completion of chemotherapy treatment (refer to Appendix H).

**Inclusion criteria.** Individuals were screened before enrollment to determine if they met certain requirements to participate in the study (refer to the eligibility form in Appendix D). The final sample of cancer survivors recruited:

- Were at least 18 years of age,
- Had been diagnosed with breast cancer,
- Were currently undergoing or had completed chemotherapy treatment within the last five years,
- Self-identified as the ‘nutritional gatekeeper’ in the household,
- Preferred to speak Spanish in the home, and
Self-identified as being of Latino decent with origins to South or Central America, Mexico, or the Spanish-speaking Caribbean.

**Exclusion criteria.** The following characteristics excluded individuals from participating in the study:

- Individuals under the age of 18,
- Men who were breast cancer survivors,
- Women who had completed chemotherapy over five years ago,
- Women who did not self-identify as a ‘nutritional gatekeeper,’ and
- Women who did not self-identify as Hispanic or Latina.

**Supportive Adults/Caregivers**

**Sampling strategy.** Each eligible Latina breast cancer survivor was asked to identify at least one supportive adult who had either assisted with, or taken over, her role as ‘nutritional gatekeeper.’ The intention was to recruit at least one supportive adult for every Latina interviewed, but identifying the supportive individual/caregiver was not a requirement for participation in this study. The researcher understood that some women may not have had family and/or peer support; therefore survivors may not have been able to identify a caregiver who assisted with the role of ‘nutritional gatekeeper’ following their breast cancer diagnosis and during chemotherapy treatment.

**Inclusion criteria.** Eligible supportive individuals/caregivers needed to be:

- At least 18 years of age,
- Able to speak English or Spanish, and
- Referred by the Latina breast cancer survivor as the supportive individual/caregiver that had assisted in the role of ‘nutritional gatekeeper’ before, during, or after chemotherapy treatment.

**Exclusion criteria.** The following characteristics excluded caregivers from the study:
- Under the age of 18, and
- Not identified by the Latina breast cancer survivor participant as a supportive individual or caregiver.

**Key Informants**

**Sampling strategy.** Providers, health educators, or other stakeholders at least 18 years of age were recruited to participate in the key informant interviews. The intention was to conduct five interviews with stakeholders that worked closely with cancer survivors to get information regarding what the stakeholders identified as issues for this specific population. It was anticipated that recruitment of these key informants would have been difficult with the researcher’s limited access to cancer healthcare providers. The busy schedule of these stakeholders may have also limited their availability to participate in the study; however, key informants who had participated in the initial discussions and review of the data collection materials were more than willing to be interviewed. Although the proposed research study only included informal discussions with key informants, an IRB amendment was submitted to include interviews with them as well. Key informant interviews enabled further triangulation of the data by offering an outsider perspective into the dietary practices and nutritional needs of Latina cancer survivors.
**Inclusion criteria.** Eligible key informants recruited needed to:

- Be at least 18 years of age,
- Speak English or Spanish,
- Identify as a person who worked with cancer survivors, and
- Not have been interviewed as a survivor or caregiver as part of this dissertation study.

**Exclusion criteria.** The following characteristics excluded individuals from participating as key informants:

- Under the age of 18, and
- Having previously participated as part of this research study as a survivor or caregiver.

Eligible key informants participated in the interviews in either English or Spanish. The interviews were conducted in-person by the primary researcher with each of the eligible providers, health educators, or other stakeholders. Key informant interviews gathered a broad range of information about nutritional needs from a diverse group of health professionals who worked with Latino cancer survivors (Ashing-Giwa et al., 2006). Additionally, interviews with these stakeholders provided in-depth knowledge regarding information about diet and nutrition sought by Latina breast cancer survivors. It was also beneficial that triangulation of themes could be captured from conducting these qualitative key informant interviews (Ashing-Giwa et al., 2006). The knowledge gathered from interviews with key informants can inform future research and practice.

**Recruitment of Study Participants**

The two main geographical locations in West Central Florida, which included Tampa Bay and Orlando-Kissimmee, served as the areas for recruitment of the study population.
Recruitment for interviews was done through personal telephone calls, in addition to flyers (refer to Appendix C) posted at different agencies and sites recommended by the key informants. Flyers were distributed at the following community organizations: cancer centers or hospitals where verbal permission was received to distribute flyers; Latino cancer support group organizations; other community venues (e.g., health fairs and outreach events); and other community-based organizations and clinics where the manager or director gave their verbal permission to post flyers. To build rapport, the researcher participated in the planning committee of a bi-annual camp for Latina cancer survivors. This camp provided the opportunity for recruitment of eligible Latina breast cancer survivors, also enabling key informant discussions for feedback on the data collection materials. In addition, through key informant discussions, the researcher received referrals from these contacts to support groups and assistance with recruitment of potential study participants.

Eligible participants across all recruitment points were given information regarding the study prior to enrollment. Prior to data collection, an IRB-approved waiver of informed consent was distributed; participants were informed about the purpose of the study, benefits, risks, and confidentiality in their language of preference (English or Spanish). The waiver was applicable for participants that completed the interview over the phone. Eligible participants who agreed to participate after receiving information regarding the study were invited to attend a scheduled date and time to participate in the semi-structured interview. In addition, Latina breast cancer survivor participants referred the supportive individual/caregiver to be interviewed. All interviews were conducted by the primary researcher in the Tampa Bay and Orlando-Kissimmee areas.
Instrumentation

The questionnaires and interview guides available in English and Spanish were the main instruments used (refer to Appendices D, E, and F). The primary researcher, a bilingual, bicultural individual proficient in qualitative research methods, used the Brislin seven-step translation method to lead translation and back-translation efforts (Lopez, Figueroa, Connor, & Maliski, 2008). The iterative process allowed for instruments to be continually revised with each step of translation. The questionnaire and interview guide were also pilot tested among five Latina breast cancer survivor participants for clarity and understanding (Vázquez-Montilla, Reyes-Blanes, Hyun, & Brovelli, 2000). Minor modifications were incorporated to ensure that all questions were understandable, relevant, and meaningful. In addition, a total of four informal discussions with key informants were conducted during the initial period of data collection. Comments on how to improve the questionnaire and interview questions for the Latina breast cancer survivors and caregivers were addressed. In response to this feedback, an IRB amendment was submitted, and approval was received that incorporated the edits and recommendations from key informants to the data collection materials (refer to Appendix H). Interviews with Latina breast cancer survivors took between 30 and 90 minutes to complete. Interviews with supportive adults/caregivers took between 30 minutes and an hour, and interviews with key informants took between 45 and 75 minutes to complete.

Interview Guide Development

A semi-structured interview guide was developed for Latina breast cancer survivors to explore their perception of the importance of diet and nutrition in helping them cope with cancer treatment and survivorship. Following the initial discussions with key informants during the
beginning period of data collection, edits were made to the format and content of the interview guide (refer to Appendix H for IRB letters of approval). Mirrored interview guides were also developed for the caregivers and key informants (refer to Appendices E and F); therefore, the type of interviews was the same across Latina breast cancer survivors, caregivers, and key informants.

The qualitative interviews used the Transactional Model of Stress and Coping, social support theory, and nutrition literature to guide the development of open-ended questions for survivors, supportive individuals/caregivers, and key informants. Specific constructs from the Transactional Model helped to develop the questions and probes for data collection, as well as emphasize social support concepts to explore perceived instrumental, informational, emotional, and appraisal support (Glanz et al., 2008). Appendix A provides a table that clarifies the constructs from the Transactional Model that were used to address each research question, as well as corresponding interview questions used within the interview guides. Appendix B presents the semi-structured interview guide for the eligible Latina breast cancer survivor participants in the order that the questions and probes were asked.

**Demographic and Food Security Questionnaire**

Self-reported demographic questions and food security questions were asked directly before completing the semi-structured interview guide. Information that was obtained through the close-ended demographic questionnaire included marital status, age, ethnicity, language fluency, educational attainment, employment status, household income, and health insurance status. Additionally, social support factors (e.g., satisfaction with family, peers, and health provider; attending a support group) and food security questions were included. To
quantitatively measure food security among the participants interviewed, the six-item short form of the U.S. household food security survey module was utilized. The six-item food security scale was developed by researchers at the National Center for Health Statistics in collaboration with Abt Associates Inc. and has been shown to identify food-insecure households with reasonably high specificity, sensitivity, and minimal bias compared with the 18-item measure. The six-item food security questions included:

- “The food that (I/we) bought just didn’t last, and (I/we) didn’t have money to get more.” Was that often, sometimes, or never true for (you/your household) in the last 12 months?
- “(I/we) couldn’t afford to eat balanced meals.” Was that often, sometimes, or never true for (you/your household) in the last 12 months?
- In the last 12 months, since last (name of current month), did (you/you or other adults in your household) ever cut the size of your meals or skip meals because there wasn’t enough money for food? Yes or no?
- [If yes above, ask] How often did this happen—almost every month, some months but not every month, or in only one or two months?
- In the last 12 months, did you ever eat less than you felt you should because there wasn’t enough money for food? Yes or no?
- In the last 12 months, were you every hungry but didn’t eat because there wasn’t enough money for food? Yes or no?

The sum of affirmative responses to the six questions in the module determined the household’s raw score on the scale. The food security status was assigned as high (raw score of 0), marginal (raw score of 1), low (raw score of 2-4), or very low (raw score of 5-6).
Data Collection Procedures

Semi-Structured Interviews

Data collection consisted of semi-structured interviews, “recognizing that qualitative methods are particularly useful in the exploration of understudied issues” (Buki et al., 2008, p. 164). Semi-structured interviews “resemble a platica interview, a friendly mutual exchange in the conversational tradition of Latino culture” (Buki et al., 2008, p. 164); this approach offers a culturally salient way to connect the participants and gather insights about their experiences. The primary researcher took notes and digitally audio recorded all interviews in order to preserve the data gathered. All interviews with Latina breast cancer survivors, caregivers, and key informants were conducted individually by the primary researcher, either in-person or over the phone, as preferred by the recruited participant; the first option given to potential participants was that of a face-to-face interview. In-person interviews offered rich insights by capturing peoples’ actual behavior and how it may vary with social context (e.g., changes in roles) (Draper & Swift, 2011).

Field Notes and Reflection

Managing bias and maintaining subjectivity was done with careful documentation through the data collection process (Ulin et al., 2005). An assumption of collecting qualitative data from interviews was that it was “a process of bringing what you want to learn together with what you observe and what participants know and have experienced” (Ulin et al., 2005, p. 103). Conducting the interviews and keeping meticulous field notes was done by the primary researcher (Krueger & Casey, 2009; Ulin et al., 2005). Last, “the conceptual framework,
imprinted in the mind of the interviewer or observer, is a valuable compass, helping to keep a firm grasp on the research’s purpose and main questions and to locate what participants say or do in the emerging picture” (Ulin et al., 2005, p. 104)

**Data Analysis**

Each interview was digitally recorded and transcribed in an abridged manner to capture the essential elements from the interviews. The data analysis was dependent on the participants’ preferred language. The English interviews were transcribed by a professional transcription company, and the Spanish interviews were transcribed by the primary researcher. Additionally, each transcription was simultaneously reviewed with the audio recording and written field notes to ensure accuracy. Field notes were compared to the information found in the transcripts to prevent misinterpretation of the data gathered and provide additional input to the primary researcher. Essentially, the field notes of all of the interviews were reviewed to ensure that data was not missing from the transcripts regarding main themes.

The primary researcher and another bilingual researcher coded ten selected interview transcripts. The coded transcripts were qualitatively analyzed for salient themes using an inductive approach to develop a preliminary codebook. Analysis of qualitative data began with this step of developing the codebook based upon the main questions asked during the interviews. The primary researcher and second coder discussed parent and child codes found throughout the transcripts; more specifically, to make comparisons and coordinate an understanding of the definitions of codes and inclusion/exclusion of transcribed information. This discussion of preliminary codes complemented the development of an *a priori* codebook that was partially
based on theory and review of the literature. Emergent themes throughout the transcripts were also included in the codebook.

Following the discussion between the two coders and development of the codebook, the reviewed transcripts were imported into MAXQDA Qualitative Data Analysis Software for coding to assess inter-coder reliability, along with concordance and discrepancies. The coding was compared where codes agreed on were assigned a “1” and missing codes or codes not matched on were assigned a “0” for the corresponding coder. Percent agreement was assessed using Cohen’s Kappa to find substantial agreement ($k=0.70-0.80$) (Bernard & Ryan, 2009), and discrepancies were reconciled until agreement between coders was achieved throughout the transcripts. Content and thematic analyses were then performed for each transcript until saturation was met. The two coders perceived that saturation was reached early in data collection; moreover, during coding of the transcripts, it became apparent that no new information was emerging after the ten interviews were double coded. Twenty-eight salient themes emerged from the thematic analyses of the qualitative data, and content analyses demonstrated agreement on a majority of salient themes amongst groups. The primary researcher continued to code and analyze all of the transcripts to include the experiences of all of the participants.

**Research Ethics**

Steps were taken to protect the privacy of participants during the conduct of the research. Additionally, participants were provided an incentive for participation in the study. The following sections provide further information regarding compensation, privacy, and confidentiality.
Compensation

Krueger and Casey (2009) discuss that it takes effort and time for participants to share their experiences and knowledge; therefore, the participants must make an investment, where they have to reserve time on their schedule to be at a certain location at a specific time, to take part in an individual interview (Krueger & Casey, 2009). To address potential travel barriers for the participants who preferred in-person interviews, the researcher traveled to them (e.g., their home) to conduct the interview; this resulted in the added benefit that potential participants felt more comfortable being in a familiar place. Additionally, childcare was a barrier, therefore the researcher had coloring books or other distractions that were necessary for participants who had their child present during in-person interviews.

A portion of funding received from the College of Public Health Student Research Scholarship and the Department of Community and Family Health Graduate Research Award was used for participant incentives. Hispanic/Latina breast cancer survivors were provided a $20 Wal-Mart gift card, and caregivers and key informants were provided a $15 Wal-Mart gift card after completion of the questionnaire and interview protocols. Providing an incentive helped for the participants to be available, participate, and ultimately contribute to successful interviews.

Confidentiality

The recorded, compiled, and analyzed information, as well as field notes were stored in the researcher’s password-protected computer in a locked office. The researcher addressed any ethical issues or challenges that arose by being open regarding the research planning, process, and results (Krueger & Casey, 2009). More specifically, the researcher followed a “defensible, systematic and verifiable” analysis protocol (Krueger & Casey, 2009, p. 146). Throughout the
entire period of the development of materials, data collection, and analysis, the researcher continued to seek guidance from the doctoral committee as their experience and comments were essential elements for this dissertation research study.

**Privacy of Research Subjects**

All IRB requirements and ethical standards were enforced at all times to protect participants; they were assured at all data collection points (recruitment, eligibility screening, informed consent process, and during the interview) that efforts were made to secure confidentiality of the information they provided. All data was kept secured in file cabinets within a locked office and maintained on a password-protected computer only accessible with the researcher’s login information. A participant identification was used on all data forms, with every subject in the study assigned a unique identification code that linked the data collection and analysis in the study database. Personal identifiers such as name, address, and phone numbers were kept separate and not linked to information collected from the interviews, with the exception of using the information to call participants to schedule their interview time and for directions on their scheduled interview date. The study identification codes were used throughout data collection and analysis, but their relationship to other identifiers (name, address, and phone number) was stripped from the data.

A reference table that linked study identification with data was kept and stored securely on the password-protected computer. All other databases were free of identifying data. The primary researcher was the only person with access to contact information linked to participant study identification codes. Data will be kept in electronic files on a secured server and locked in filing cabinets for at least five years after the final report has been submitted; data will be
destroyed by permanently deleting electronic files and shredding paper documents. Lastly, individual pseudonyms were assigned to each study participant replacing their actual names for purposes of presenting the results in this dissertation study (refer to Table 3.1). Data will continue to be de-identified and analyzed in aggregate when disseminated in professional and community venues (e.g., journal publications, conference presentations, and cancer support group discussions).

Table 3.1. Pseudonyms Given to Study Participants.

<table>
<thead>
<tr>
<th>Latina Breast Cancer Survivors</th>
<th>Caregivers</th>
<th>Key Informants</th>
</tr>
</thead>
<tbody>
<tr>
<td>Amalia</td>
<td>Granada</td>
<td>Nazareth</td>
</tr>
<tr>
<td>Ana</td>
<td>Gladys</td>
<td>Osiris</td>
</tr>
<tr>
<td>Beatriz</td>
<td>Hilda</td>
<td>Eduardo</td>
</tr>
<tr>
<td>Bruna</td>
<td>Ingrid</td>
<td>Haiza</td>
</tr>
<tr>
<td>Carla</td>
<td>Josefina</td>
<td>Patricia</td>
</tr>
<tr>
<td>Camila</td>
<td>Juliana</td>
<td>Julio</td>
</tr>
<tr>
<td>Damaris</td>
<td>Kathy</td>
<td>Laura</td>
</tr>
<tr>
<td>Diana</td>
<td>Karen</td>
<td>Nilsa</td>
</tr>
<tr>
<td>Elena</td>
<td>Luisa</td>
<td>Rosario</td>
</tr>
<tr>
<td>Fey</td>
<td>Melissa</td>
<td>Xiomara</td>
</tr>
<tr>
<td>Flor</td>
<td>Mariana</td>
<td>Yuri</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Walska</td>
</tr>
</tbody>
</table>

Conclusion and Next Chapter

In summary, this chapter detailed the methodology used in this study. The previous paragraphs illustrate how community engagement and qualitative data collection techniques can be used to explore Latina breast cancer survivors’ perception of the importance of diet and nutrition in helping them cope with cancer treatment and survivorship. The following chapter describes the results and begins with an overview and description of study findings by participant category: Latina breast cancer survivors, caregivers, and key informants. The second section of
the results chapter presents data from the in-depth interviews pertaining to each aim and presented by each participant category. The data describes the sociocultural factors that influence the diet of Latina breast cancer survivors, coping with nutrition-related experiences and changes in roles that may have been prompted by cancer treatment and survivorship, and the need for information regarding diet and nutrition among Latina breast cancer survivors.
CHAPTER FOUR:
RESULTS

Overview

The purpose of the current study was to understand Latina breast cancer survivors’ perceptions of the importance of diet and nutrition in helping them cope with the effect of cancer treatment and survivorship. The Latina breast cancer survivors (n=32) that participated in this study self-identified as the ‘nutritional gatekeepers’ of their households. They were either undergoing or had completing chemotherapy within five years. Study participants openly shared their experiences and were asked to identify one supportive adult (if applicable) to also be interviewed (n=8). Additionally, key informants (n=6) who worked closely with Latina cancer survivors were interviewed to further understand nutrition within the context of cancer survivorship among Latinas and their caregivers.

The objectives of this dissertation study were accomplished through the following specific aims and research questions:

Specific Aim 1. To understand the sociocultural factors that influence the diet of Latina breast cancer survivors.

Research Question 1.a. How do Latina breast cancer survivors value the meaning of nutrition?
Research Question 1.b. What influences Latina breast cancer survivors’ decisions about diet and nutrition during and after chemotherapy?

Specific Aim 2. To explore how Latina breast cancer survivors cope with nutrition-related experiences and changes in roles that may have been prompted by cancer treatment and survivorship.

Research Question 2.a. How do breast cancer diagnosis and chemotherapy affect the role of Latina women as the ‘nutritional gatekeeper’ in the family?

Research Question 2.b. How does family and/or peer support influence Latina breast cancer survivors’ diet and nutrition during and after chemotherapy?

Specific Aim 3. To identify the information needs regarding diet and nutrition among Latina breast cancer survivors.

Research Question 3.a. What are Latina breast cancer survivors’ informational needs related to diet and nutrition following diagnosis?

Research Question 3.b. What nutrition-related resources are available to Latina breast cancer survivors, and how do they access these resources?

This chapter begins with a description of the characteristics of interview participants and is followed by the findings from the in-depth interviews separated by study aim. Under each aim, study findings are presented by participant category: firstly, Latina breast cancer survivors; followed by the caregivers; and lastly from the key informants.
Study Findings

Description of Study Population

**Latina breast cancer survivors.** From March through December 2016, 32 Latina breast cancer survivors participated in this dissertation research study. Refer to Table 4.1 for a complete description of demographic characteristics for the Latina breast cancer survivor study sample. Twenty-four (24/32, 75.0%) interviews were conducted in Spanish, and eight (8/32, 25.0%) interviews in English. The women interviewed shared their knowledge regarding their cancer diagnosis and chemotherapy treatment experience, informational needs regarding nutrition, and different types of family and/or peer support they received.

More than half (17/32, 53.1%) of the women were between the ages of 40 and 54. Almost a third (9/32, 28.1%) were diagnosed with breast cancer in 2015, about a third (10/32, 31.3%) were diagnosed in 2014, 12.5% (4/32) in 2013, and both a tenth (3/32, 9.4%) diagnosed in 2012 and 2011. Almost three-fourths (23/32, 71.9%) had completed chemotherapy, while about a quarter (9/32, 28.1%) were currently undergoing chemotherapy treatment; less than half (13/32, 40.6%) had also received radiation, and more than half (17/32, 53.1%) had undergone surgery. The women stated that between one and five people (including themselves) lived in their household at the time of the interview. A quarter (8/32, 25.0%) were homemakers, and almost half (15/32, 46.9%) felt that their household income was not enough to meet their needs.

All Latina breast cancer survivor participants responded to the questions regarding food security. Eighteen of the women (18/32, 56.3%) had some sort of gap regarding their food security status based on the sum of affirmative responses (on a scale from zero to six) to the questions. Half of the participants (16/32, 50.0%) scored from two to six on the scale, signifying
either ‘low food security’ or ‘very low food security.’ This implies that half of the participants’ households had significant food security problems. Out of the 32 Latina breast cancer survivors interviewed, half (16/32, 50.0%) reported that ‘often’ and ‘sometimes’ the food bought for the household did not last, and they did not have money to get more. Furthermore, more than half (18/32, 56.3%) acknowledged that they could not afford to eat balanced meals either ‘often’ or ‘sometimes.’ Interestingly, only six of the women (6/32, 18.8%) reported food insecurity in their household by either cutting the size of their meals or skipping meals in the last 12 months due to a lack of money for food. Out of these six women, half explained doing so ‘almost every month,’ while half ‘some months.’ Additionally, more than a third (11/32, 34.4%) of the Latina breast cancer survivor participants experienced eating less than they felt they should in the last 12 months because there was not enough money for food, while less than a quarter (7/32, 21.9%) mentioned being hungry but not eating in the last 12 months because there was not enough money for food. Results demonstrate that many of the survivors felt that their household did not have enough money to purchase sufficient food nor resources to eat nutritious and balanced meals.

**Caregivers.** A total of eight caregivers, who were identified by Latina breast cancer survivors as the people who helped them the most (i.e., following their breast cancer diagnosis and during chemotherapy treatment) participated in the semi-structured interviews. Refer to Table 4.1 for a complete description of demographic characteristics for the caregiver study sample. These caregivers provided support regarding the cancer survivors’ responsibilities related to food in the home. Six (6/8, 75.0%) of the participants were family members of the breast cancer survivors, and two (2/8, 25.0%) caregivers were not blood relatives. Seven (7/8, 87.5%) interviews were conducted in Spanish, and one (1/8, 12.5%) interview in English; five
(5/8, 62.5%) of the interviews were conducted in person, and three (3/8, 37.5%) were conducted over the phone.

More than half (5/8, 62.5%) of the caregivers were female and over 50 years of age (range=19-68; mean=46), and half (4/8, 50.0%) were married. Half (4/8, 50.0%) of the participants had an education level of high school graduate or less. About a third (3/8, 37.5%) were employed full-time and made an average yearly household income of less than $10,000. Consequently, more than half (5/8, 62.5%) perceived their household income as not enough, or barely enough, to get by. The majority (7/8, 87.5%) of the caregivers did not participate in a social support group for various reasons (e.g., lack of opportunity, awareness, distance, and/or time). About a third (3/8, 37.5%) identified their Latino origin as Colombian; half (4/8, 50.0%) had lived on the U.S. mainland between 20 and 30 years.

All eight caregivers that participated in the interviews responded to the food security questions. About 38% (3/8) of the caregivers reported that their households experienced food insecurity. Out of the three participants interviewed for this portion of the study that reported their household status as food insecure in the last 12 months, all of them (3/3) stated that ‘sometimes’ the food bought just did not last, and they did not have money to get more. Additionally, all of them (3/3) mentioned that ‘sometimes’ they could not afford to eat balanced meals (i.e., meals that were varied and nutritious). Lastly, one of the three (1/3) reported in the last 12 months being hungry but not eating because there was not enough money for food. Results indicate that some of the caregivers experienced difficulty providing enough food for their household due to a lack of resources.

Key informants. Six key informant interviews were conducted in person in the Tampa or Orlando area in October 2016: two (2/6, 33.3%) in English and four (4/6, 66.7%) in Spanish.
Half (3/6, 50.0%) of the key informants had full-time employment, and half (3/6, 50.0%) worked part-time. They had been in their current role/position between 11 months and 17 years. Key informants reported working with Latinas who had been diagnosed with all types of cancers (e.g., breast, ovarian, leukemia, and thyroid cancers) regarding counseling and education. Additionally, these key informants mentioned working previously with cancer survivors involving mental health, support groups, economic advising and orientation, and nutrition.

About two-thirds (4/6, 66.7%) of the key informants were between 55 and 64 years of age. Most (5/6, 83.3%) were Hispanic or Latina. All (6/6, 100.0%) of the participants spoke English, and almost all (5/6, 83.3%) spoke Spanish. Almost all (5/6, 83.3%) of the key informants were of Hispanic origin, but all (6/6, 100.0%) had lived in the United States for more than 25 years. About two-thirds (4/6, 66.7%) had attended graduate school, and half (3/6, 50.0%) had an average yearly household income of greater than $80,000; consequently, half (3/6, 50.0%) stated that their household income was sufficient to meet their needs.

All six key informants responded to the questions regarding food security and reported a high food security status by scoring a zero on the six-item scale. Therefore, the status of their households is described as having consistent access to adequate food in the 12 months prior to participating in this research study. Refer to Table 4.1 for a complete description of demographic characteristics for the key informant study sample.
Table 4.1. Characteristics of Interview Participants (N=46).

<table>
<thead>
<tr>
<th>Characteristic</th>
<th>Latina Breast Cancer Survivors</th>
<th>Supportive Caregivers</th>
<th>Key Informants</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>n=32</td>
<td>n=8</td>
<td>n=6</td>
</tr>
<tr>
<td>Gender*</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Male</td>
<td>0 (0)</td>
<td>3 (38)</td>
<td>0 (0)</td>
</tr>
<tr>
<td>Female</td>
<td>32 (100)</td>
<td>5 (63)</td>
<td>6 (100)</td>
</tr>
<tr>
<td>Age*</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>18-24 years</td>
<td>0 (0)</td>
<td>2 (25)</td>
<td>0 (0)</td>
</tr>
<tr>
<td>25-39 years</td>
<td>3 (9)</td>
<td>1 (13)</td>
<td>0 (0)</td>
</tr>
<tr>
<td>40-54 years</td>
<td>17 (53)</td>
<td>1 (13)</td>
<td>2 (33)</td>
</tr>
<tr>
<td>55-69 years</td>
<td>11 (34)</td>
<td>4 (50)</td>
<td>4 (67)</td>
</tr>
<tr>
<td>70-84 years</td>
<td>1 (3)</td>
<td>0 (0)</td>
<td>0 (0)</td>
</tr>
<tr>
<td>Marital status*</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Single</td>
<td>7 (22)</td>
<td>2 (25)</td>
<td>N/A</td>
</tr>
<tr>
<td>Married</td>
<td>17 (53)</td>
<td>4 (50)</td>
<td>N/A</td>
</tr>
<tr>
<td>Separated</td>
<td>0 (0)</td>
<td>0 (0)</td>
<td>N/A</td>
</tr>
<tr>
<td>Divorced</td>
<td>5 (16)</td>
<td>2 (25)</td>
<td>N/A</td>
</tr>
<tr>
<td>Widowed</td>
<td>3 (9)</td>
<td>0 (0)</td>
<td>N/A</td>
</tr>
<tr>
<td>Education*</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Less than high school</td>
<td>1 (3)</td>
<td>1 (13)</td>
<td>0 (0)</td>
</tr>
<tr>
<td>High school graduate</td>
<td>8 (25)</td>
<td>3 (38)</td>
<td>0 (0)</td>
</tr>
<tr>
<td>Some college</td>
<td>6 (19)</td>
<td>1 (13)</td>
<td>2 (33)</td>
</tr>
<tr>
<td>College degree (Associate/Bachelors)</td>
<td>12 (38)</td>
<td>1 (13)</td>
<td>0 (0)</td>
</tr>
<tr>
<td>Graduate school (Masters/Doctorate)</td>
<td>5 (16)</td>
<td>2 (25)</td>
<td>4 (67)</td>
</tr>
<tr>
<td>Employment Status*</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Unemployed</td>
<td>8 (25)</td>
<td>2 (25)</td>
<td>0 (0)</td>
</tr>
<tr>
<td>Homemaker</td>
<td>8 (25)</td>
<td>1 (13)</td>
<td>0 (0)</td>
</tr>
<tr>
<td>Retired</td>
<td>6 (19)</td>
<td>1 (13)</td>
<td>0 (0)</td>
</tr>
<tr>
<td>Part-time</td>
<td>6 (19)</td>
<td>1 (13)</td>
<td>3 (50)</td>
</tr>
<tr>
<td>Full-time</td>
<td>4 (13)</td>
<td>3 (38)</td>
<td>3 (50)</td>
</tr>
<tr>
<td>Average Yearly Household Income*</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Less than $10,000</td>
<td>5 (16)</td>
<td>3 (38)</td>
<td>0 (0)</td>
</tr>
<tr>
<td>$10,000-$39,000</td>
<td>13 (41)</td>
<td>2 (25)</td>
<td>1 (17)</td>
</tr>
<tr>
<td>$40,000-$79,000</td>
<td>4 (13)</td>
<td>1 (13)</td>
<td>2 (33)</td>
</tr>
<tr>
<td>Greater than $80,000</td>
<td>5 (16)</td>
<td>1 (13)</td>
<td>3 (50)</td>
</tr>
<tr>
<td>Prefer not to answer</td>
<td>5 (16)</td>
<td>1 (13)</td>
<td>0 (0)</td>
</tr>
<tr>
<td>Perceived Household Income As...*</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Not enough to get by</td>
<td>15 (47)</td>
<td>1 (13)</td>
<td>0 (0)</td>
</tr>
<tr>
<td>Barely enough to get by</td>
<td>8 (25)</td>
<td>4 (50)</td>
<td>2 (33)</td>
</tr>
<tr>
<td>Sufficient to meet your needs</td>
<td>6 (19)</td>
<td>3 (38)</td>
<td>3 (50)</td>
</tr>
<tr>
<td>More than enough to meet your needs</td>
<td>3 (9)</td>
<td>0 (0)</td>
<td>1 (17)</td>
</tr>
<tr>
<td>Characteristic</td>
<td>Latina Breast Cancer Survivors</td>
<td>Supportive Caregivers</td>
<td>Key Informants</td>
</tr>
<tr>
<td>--------------------------------------</td>
<td>-------------------------------</td>
<td>-----------------------</td>
<td>----------------</td>
</tr>
<tr>
<td></td>
<td>n=32</td>
<td>n=8</td>
<td>n=6</td>
</tr>
<tr>
<td>Participates in a Social Support Group*</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>No</td>
<td>18 (56)</td>
<td>7 (88)</td>
<td>4 (67)</td>
</tr>
<tr>
<td>Yes</td>
<td>14 (44)</td>
<td>1 (13)</td>
<td>2 (33)</td>
</tr>
<tr>
<td>Ethnicity</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Hispanic or Latino(a)</td>
<td>32 (100)</td>
<td>8 (100)</td>
<td>5 (83)</td>
</tr>
<tr>
<td>Non-Hispanic</td>
<td>0 (0)</td>
<td>0 (0)</td>
<td>1 (17)</td>
</tr>
<tr>
<td>Latino Origin*</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Colombian</td>
<td>4 (13)</td>
<td>3 (38)</td>
<td>1 (17)</td>
</tr>
<tr>
<td>Cuban</td>
<td>3 (9)</td>
<td>1 (13)</td>
<td>0 (0)</td>
</tr>
<tr>
<td>Dominican Republic</td>
<td>3 (9)</td>
<td>0 (0)</td>
<td>0 (0)</td>
</tr>
<tr>
<td>Mexican</td>
<td>7 (22)</td>
<td>2 (25)</td>
<td>1 (17)</td>
</tr>
<tr>
<td>Puerto Rican</td>
<td>9 (28)</td>
<td>1 (13)</td>
<td>2 (33)</td>
</tr>
<tr>
<td>Venezuelan</td>
<td>2 (6)</td>
<td>1 (13)</td>
<td>1 (17)</td>
</tr>
<tr>
<td>Other/Not applicable</td>
<td>4 (13)</td>
<td>0 (0)</td>
<td>1 (17)</td>
</tr>
<tr>
<td>Time Living on the U.S. Mainland*</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Under 10 years</td>
<td>5 (16)</td>
<td>1 (13)</td>
<td>0 (0)</td>
</tr>
<tr>
<td>10-19 years</td>
<td>9 (28)</td>
<td>2 (25)</td>
<td>0 (0)</td>
</tr>
<tr>
<td>20-29 years</td>
<td>6 (19)</td>
<td>4 (50)</td>
<td>0 (0)</td>
</tr>
<tr>
<td>Greater than 29 years</td>
<td>12 (38)</td>
<td>1 (13)</td>
<td>6 (100)</td>
</tr>
<tr>
<td>Fluency in Speaking English*</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Not at all</td>
<td>4 (13)</td>
<td>2 (25)</td>
<td>0 (0)</td>
</tr>
<tr>
<td>Not well</td>
<td>10 (31)</td>
<td>5 (63)</td>
<td>1 (17)</td>
</tr>
<tr>
<td>Well</td>
<td>18 (56)</td>
<td>1 (13)</td>
<td>5 (83)</td>
</tr>
<tr>
<td>Fluency in Speaking Spanish*</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Not at all</td>
<td>0 (0)</td>
<td>0 (0)</td>
<td>1 (17)</td>
</tr>
<tr>
<td>Not well</td>
<td>4 (13)</td>
<td>2 (25)</td>
<td>0 (0)</td>
</tr>
<tr>
<td>Well</td>
<td>28 (88)</td>
<td>6 (75)</td>
<td>5 (83)</td>
</tr>
<tr>
<td>Food Security Status*</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>High – 0</td>
<td>14 (44)</td>
<td>4 (50)</td>
<td>6 (100)</td>
</tr>
<tr>
<td>Marginal – 1</td>
<td>2 (6)</td>
<td>1 (13)</td>
<td>0 (0)</td>
</tr>
<tr>
<td>Low – 2-4</td>
<td>10 (31)</td>
<td>3 (38)</td>
<td>0 (0)</td>
</tr>
<tr>
<td>Very low – 5-6</td>
<td>6 (19)</td>
<td>0 (0)</td>
<td>0 (0)</td>
</tr>
</tbody>
</table>

*Percentages do not exactly add up to 100% due to rounding errors
In-Depth Interview Results

Data gathered from the in-depth interviews provide rich information contextualizing the nutritional needs, roles, and expectations of Latinas diagnosed with breast cancer and their caregivers. Results are presented by the most salient themes that emerged by participant category: Latina breast cancer survivors, caregivers, and key informants. Participants were given pseudonyms to protect their identity and preserve their privacy.

Specific Aim 1. To understand the sociocultural factors that influence the diet of Latina breast cancer survivors.

Table 4.2. Key Themes across Participant Groups for Specific Aim 1.

<table>
<thead>
<tr>
<th>Participant Group</th>
<th>Theme</th>
</tr>
</thead>
<tbody>
<tr>
<td>Latina Breast Cancer Survivors</td>
<td>Increased nutritional awareness and the role of nutrition in Latina breast cancer survivors’ health and recovery</td>
</tr>
<tr>
<td></td>
<td>The food provided by friends and family influenced what Latina breast cancer survivors ate and their nutritional decisions</td>
</tr>
<tr>
<td></td>
<td>Latina breast cancer survivors relied on assistance from nutritional organizations</td>
</tr>
<tr>
<td>Caregivers</td>
<td>Caregivers increased their awareness of nutrition and proper dietary habits due to the cancer diagnosis of the Latina breast cancer survivor</td>
</tr>
<tr>
<td></td>
<td>Nutrition is an important factor for caregivers to restore health and improve the body’s immunity</td>
</tr>
<tr>
<td></td>
<td>Caregivers followed doctors’ nutritional recommendations in response to their family members’ breast cancer diagnosis</td>
</tr>
<tr>
<td></td>
<td>The cancer diagnosis of the Latina breast cancer survivor impacted the caregiver’s nutrition</td>
</tr>
</tbody>
</table>
### Participant Group

<table>
<thead>
<tr>
<th>Key Informants</th>
<th>Theme</th>
</tr>
</thead>
<tbody>
<tr>
<td>Latina breast cancer survivors and family members understand the importance of nutrition</td>
<td>Latina breast cancer survivors want to regain and maintain agency and control through nutrition</td>
</tr>
<tr>
<td>Chemotherapy side effects negatively influence the diet and nutrition of Latina breast cancer survivors</td>
<td></td>
</tr>
</tbody>
</table>

**Latina Breast Cancer Survivors**

Study participants were asked a series of questions regarding how the significance of nutrition has changed throughout their journey with cancer. All Latina breast cancer survivors (32/32) interviewed openly shared their insights regarding sociocultural factors that influenced their diet and the significance of nutrition for them. Themes included acknowledging the importance of nutrition for their health, the physical and emotional support from family and friends (influencing what they ate and their nutritional decisions), and relying on assistance from nutritional organizations.

**Increased nutritional awareness and the role of nutrition in Latina breast cancer survivors’ health and recovery.** Many participants (18/32) felt the significance of food changed due to their cancer experience; more specifically, how important food was to them and how important it was to eat healthy after cancer. In addition to stating the importance of nutrition for her as a cancer survivor, Ana stated that “…nutrition will help me get back on my feet.” Latina breast cancer survivors raised their level of health consciousness regarding nutrition after the diagnosis of cancer and the initiation of chemotherapy. All participants (32/32) agreed that nutrition played an important role in their health after cancer and emphasized
their increase in awareness to reduce recurrence. By being more aware of their nutritional intake, the Latina breast cancer survivors shared that knowledge with their family members:

“I try to have my family [learn]. Yes […] but I’m terrified of my daughters having this, or even just getting their period early. It’s very, very scary. […] I turn to the Paleo diet, and they like that. Yeah, I mean, in a perfect world I would love to, you know, eat more vegetables, and cleaner, nutritious. Not sugar or processed foods. That’s the other thing. We try to reduce processed foods… So now I just pray over the food and say, ‘please, don’t let it affect my children.’” (Sofia, survivor)

The food provided by friends and family influenced what Latina breast cancer survivors ate and their nutritional decisions. Some of the study participants (14/32) counted on family and friends to assist with their meals and nutritional decisions (e.g., food purchased, cooked, and/or what Latina breast cancer survivors ate). For example, Sofia, a survivor, shared her experience regarding her family’s influence on what she ate: “We have, like, extended family and wonderful friends. They would buy stuff. Come to the house, cook stuff. So, I didn’t have to worry about it. My husband didn’t have to worry about it.” Nazareth, another survivor, mentioned that family members often played a role in bringing her food: “And it was normally very healthy food. […] I had other aunts and […] friends who would bring me food and stuff. They usually were soups […] salads, healthy stuff.”

Conversations with Latina breast cancer survivors relating to the influence of sociocultural factors also coincided with a discussion about their support system. For example, a survivor mentioned that nutritional support — bringing food — was also part of her social and emotional support:
“I had a routine to spend time with [my aunt] every Sunday, and she always cooked for me when I was there. Like I said, a few friends […] brought me soup a couple of times, different people brought me soup or took me out to eat. So, I did have some support, […] and I did go out to eat several times; probably, because that was part of my social […] support and emotional support, too.” (Nazareth, survivor)

**Latina breast cancer survivors relied on assistance from nutritional organizations.**

Other factors influencing survivors’ (9/32) nutritional decisions included community nutritional support groups or food delivery services, such as ‘Take a Meal’ and ‘Meals on Wheels,’ respectively. The website ‘Take a Meal’ was convenient and efficient for survivors and their friends and family, as expressed by a Latina breast cancer survivor:

“There’s a website called ‘Take a Meal,’ and you sign up, register, and you send it out to different friends and then they’re like, ‘Okay, I’ll cook for them October 17th. Yeah.’ That’s something that you should pass on, too. That website didn’t exist, I don’t think, back then. So just emails like, okay, who’s going to bring this one day? ‘I want to do this one day. Can I come over? Yes or no, or I’ll just drop off the food. I know you don’t want anybody there so I’ll just drop the food and go.’ Yeah, there’s a few of them like that that’s really good.” (Sofia, survivor)

On the other hand, a participant stated that receiving assistance from an outside source like ‘Meals on Wheels’ was not always her preferred choice and that she would still depend on family to bring her food:

“It’s hard. You’re not used to this, so you gotta get used to this change again and have to get used to the ‘Meals on Wheels’… And then my son, sometimes I didn’t like it, then he
would — he says, ‘Don’t worry, I’ll bring you some food.’ I said, ‘Okay.’ If I didn’t eat it, he’ll bring me the food.” (Ana, survivor)

**Caregivers**

Caregivers expressed an increase in awareness of food consumed and health consciousness due to the breast cancer diagnosis of their close family or friend. Similarly, caregivers acknowledged the importance of nutrition for their health and how doctors’ suggestions influenced the meaning of food and significance of nutrition for them and their families. Lastly, there was a focus on financial resources influencing the diet and nutrition of members in the household during and after the chemotherapy treatment of the diagnosed individual.

**Caregivers increased their awareness of nutrition and proper dietary habits due to the cancer diagnosis of the Latina breast cancer survivor.** The caregivers (8/8) shared their perspective on the role that nutrition played as an important health factor within their households and culture. Eduardo, a caregiver, stated why he considered the importance of nutrition: “I see it as a vehicle of energy. Of course you give yourself your desires, but now they are very limited to avoid long-term complications.” A supportive individual discussed a change in soda intake:

“I think it is very important for everyone. Now we don’t eat on the street, it has changed a lot. Before we drank soda, now we drink water; she used to drink soda every day, not now, now there is water everywhere.” (Rosario, caregiver)

Caregivers became more health conscious, as they showed an increased awareness of nutrition and proper dietary habits. Haiza, a caregiver, explained this heightened awareness: “It helped us realize that a lot of the food that we’re eating weren’t as good as we thought they
were. Just because they taste good doesn’t mean they’re good for your health.” Additionally, Nilsa, a caregiver, expressed her motivation for change: “It affected us in not eating too much fried [food], a lot of meat, because we have to take care of [our] health; it is the greatest treasure that God has given us, and we must take care of it.” Caregivers also had a better understanding of portion sizes and balanced meals following the breast cancer diagnosis of their family member or friend. During the interviews, caregivers expressed that their goal was to see their relative healthy. Xiomara, a caregiver, explained that the Latina breast cancer survivor’s diagnosis made her more aware “that we have to give the body the necessary nutrients.”

**Nutrition is an important factor for caregivers to restore health and improve the body’s immunity.** The majority of caregivers (6/8) shared the meaning of food and the importance of nutrition to them and their families. Haiza, a caregiver, defined the meaning of food as “health, like a lifestyle, like a culture.” Eduardo, another caregiver, also specified the meaning of food and nutrition to him: “That is the motor, the instrument of energy that moves our body, and if there is no energy the body stalls, and even to heal there must be good nutrition.”

Caregivers explained that after caring for someone with cancer, the importance of nutrition increased and became more of a focus than it was before. For example, Laura, a caregiver, mentioned an increase in importance regarding nutrition following her family member’s breast cancer diagnosis and chemotherapy: “I learned that the more we take care of ourselves, the better it’ll be for the future.” Supportive individuals understood the meaning of food and nutrition as being important for one’s health to ultimately strengthen their own immune system. Rosario, a caregiver, shared her motivation for changing dietary habits: “That if something happened to us, we would be better nourished, so that the [body’s] defenses would be
better.” Lastly, a supportive individual found the importance in that everything in the human body depends on food and nutrition:

“Basic like milk, proteins, fish, eggs, chicken, lots of fruit and salads; I think that is the most important, with that a person can live very well... That it’d be rich in fruits, vegetables, proteins, and not so much sugar and carbohydrates that is what usually causes diseases, especially when one is older that one suffers from diabetes and hypertension. One should be careful because food is [the] basis for people, combined with a little exercise, helps you to live a little longer and better.”  (Julio, caregiver)

Caregivers followed doctors’ nutritional recommendations in response to their family members’ breast cancer diagnosis. Caregivers (8/8) expressed following doctors’ recommendations in response to the Latinas’ breast cancer diagnosis, where there was an increased consumption of fruits, proteins, and natural smoothies, and reduced consumption of red meat, sugar, and soda. A caregiver explained that differences in consumption occurred for the individual diagnosed:

“She ate what the doctors recommended her, yogurt, she drank a lot, she drank juices, ate a lot of protein... During the treatment, she ate every three hours — that was what the doctor recommended to her — so that her metabolism stayed active. She has gone through it fine despite the illness.” (Julio, caregiver)

Another supportive individual was also influenced by the doctors’ suggestions:

“It’s very important because now, for example, I know that sugar feeds cancer. So we’ve cut off a lot of sugars and carbs as well... The doctor said she can go back to her regular diet. But even still then, now we still try to hold back on certain things that we know now that aren’t really that good that we thought were good.” (Haiza, caregiver)
The cancer diagnosis of the Latina breast cancer survivor impacted the caregiver’s nutrition. Caregivers (14/32) mentioned changing what they ate as a result of the Latinas’ breast cancer diagnosis. For example, Rosario, a caregiver, emphasized that everybody in the household made nutritional changes during the time that the Latina breast cancer survivor was undergoing treatment: “She said we had to eat everything organic.” Supportive individuals shared how the diagnosis of the Latina breast cancer survivor impacted their nutritional habits:

“In the first months, I totally changed my diet and then I changed a little, sometimes I like to eat red meats and I know that it is not good. We know that if we do not take care of how we nourish or feed ourselves, the cancer can come back... I lost a lot of weight because I was no longer consuming things I used to eat, and with the news that you have cancer, you can no longer consume sugar, milk, meat... It continues [to affect me] but I would like to continue with the style, because after the cancer news, sometimes you crave to eat a steak but I know it is not good.” (Xiomara, caregiver)

Another caregiver shared her experience after diagnosis:

“Now we see what the consequences are... No one expects to be told they have cancer, so yeah, it came after... So, I think at that point when they diagnosed [her], I was, like, ‘oh it can never happen to me.’ But I think that opened my eyes a lot to realize that it can, that I need to take more care of myself. Yeah, it did open my eyes a lot.” (Haiza, caregiver)

Key Informants

Key informants also gave their perspectives regarding the significance of nutrition for Latina breast cancer survivors and their families. Key informants were asked:
What is the meaning of food or nutrition to Latinas who have been diagnosed with cancer?

How important is nutrition for the families of those who have been diagnosed?

Key informants provided their insights regarding nutrition as an important factor for the health of survivors and their families, the need for survivors to feel a sense of control over their diet, and how chemotherapy treatment affects the diet and nutrition of survivors.

**Latina breast cancer survivors and family members understand the importance of nutrition.** Almost all key informants (5/6) shared that diagnosed Latinas and their families understand the importance of nutrition. The diagnosed women and their caregivers become interested in what is healthier and more conscious of what is consumed. Tania, a key informant, explained how food is an integral part of the Latina culture; the awareness of what is consumed becomes specially important as a result of cancer diagnosis: “If they are Hispanics, it’s key. The family thinks that if the patient does not eat they say that he/she is going to die.”

Two key informants (2/6) highlighted the link between food and cancer. Teresa, a key informant, stated, “Since we do not know where breast cancer comes from, we think that [it comes] from how we feed ourselves because of how bad we do it, that’s why we learn to take better care of ourselves.” Another participant emphasized the importance of nutrition as it relates to the family:

“It’s very important [in] preventing diagnosis, and I know cancer is not hereditary, but [...] some cancers can run in families. So, if you are controlling your environment and trying not to expose yourself to things that promote the development of cancer, nutrition we know is one of them. So, I think it becomes very important... So, mothers, for example, want to make sure [...] okay, I have this [...] we’ve got to eat well and everybody needs to eat this way.” (Zoraida, key informant)
Latina breast cancer survivors want to regain and maintain agency and control through nutrition. A few key informants (3/6) focused on influence and control in that Latina breast cancer survivors have a sense of agency, and nutrition is one way to control their health. Uraima, a key informant, shared that even as Latina breast cancer survivors and their caregivers find nutrition to be important and listen and participate in the talks, the problem is keeping control over their diet. Patricia, a key informant, stated that women “grab [their] power back,” by continuing as much as possible in the role as ‘nutritional gatekeeper.’ An informant reflected on the meaning of food or nutrition within the population of cancer survivors that she works with:

“I haven’t thought about that. I think when people have cancer food becomes another burden. Sometimes it’s, ‘I have to eat. I don’t feel like eating. I don’t want to eat, but I have to eat.’ And it is a lot of times a source of arguments in the family because now the patient is being poked, X-rayed, all these other things that are being ordered for them, and food remains the one thing they have control over... So, that’s the thing that they tend to, like, cling to. And now, ‘I’m going to eat what I want to eat, when I want to eat.’ And it takes a lot of convincing, and a lot of this is what’s going to help you sometimes. Many times, you get that, ‘I just can’t, I just can’t, I just can’t.’ You know, more than nutrition, it has to do with control.” (Zoraida, key informant)

Chemotherapy side effects negatively influence the diet and nutrition of Latina breast cancer survivors. All key informants (6/6) shared that the side effects of chemotherapy influence Latina breast cancer survivors’ decisions about diet and nutrition. Waleska, a key informant, stated that women may experience nausea, vomiting, stomach pain, and fatigue. On the other hand, some of the women that she has worked with did not share their food-related
problems caused by chemotherapy side effects. At the beginning of treatment, side effects are unpredictable, but she emphasized how the smell of food can affect her patients. Another participant went into more detail regarding chemotherapy side effects experienced:

“If you are going through — where in their population [food and nutrition] may be a comfort item and that it is a family-based meal, that when they’re going through chemotherapy, which has the greatest change in their daily habits, that even the smell of cooking food will make someone sick. And the portion size on a plate will make someone sick. So, if someone comes in with a full plate of ropa vieja and the rice and the yucca, that’s gonna make someone who’s going through chemotherapy ill... And even the smell of the food — they can say, ‘Hey, listen, I'm really hungry.’ Somebody goes in the kitchen and starts to cook. By the time that food is finished, they’re vomiting. And so there’s — that has a lot to do with [...] — what you do.” (Patricia, key informant)

A few key informants (3/6) mentioned how chemotherapy side effects depend on the dosage, sessions, medicines, and length of treatment. After treatment, the body tends to return to normal. An informant stated specific side effects that are caused by chemotherapy in general:

“Depends on the type of cancer and depends on the type of treatment that they can experience dysgeusia. That is like the alteration of the taste. Food doesn’t taste good, or tastes different, or has a metallic taste. They can experience xerostomia. That is a really dry mouth. Decreased intake, just anorexia, no appetite whatsoever. They could experience nausea and vomiting. Sometimes diarrhea and constipation from the opioids, the painkillers they have to take. Sometimes it’s just fatigue. ‘I’m just too tired to go do anything,’ and that’s when the family becomes very important. You know, they have some support. If they are too tired to make their meals, is there somebody that can bring it to
them? Is there somebody that can prepare meals for them? ... So, there are other things. They can have difficulty swallowing. They can have just pain swallowing, or, you know, serious enough where it’s actually going into their lungs, so then they’re not allowed to eat at that point.” (Zoraida, key informant)

Specific Aim 2. To explore how Latina breast cancer survivors cope with nutrition-related experiences and changes in roles that may have been prompted by cancer treatment and survivorship.

Table 4.3. Key Themes across Participant Groups for Specific Aim 2.

<table>
<thead>
<tr>
<th>Participant Group</th>
<th>Theme</th>
</tr>
</thead>
<tbody>
<tr>
<td>Latina Breast Cancer Survivors</td>
<td>Chemotherapy side effects drastically changed the role of the Latina breast cancer survivor as the ‘nutritional gatekeeper’</td>
</tr>
<tr>
<td></td>
<td>Husbands and family members step into the role of ‘nutritional gatekeeper’</td>
</tr>
<tr>
<td></td>
<td>Exercise, music, and religion alleviate nutrition-related challenges due to chemotherapy for Latina breast cancer survivors</td>
</tr>
<tr>
<td>Caregivers</td>
<td>Caregivers needed support to manage the Latina breast cancer survivors’ side effects of chemotherapy</td>
</tr>
<tr>
<td></td>
<td>Latinas’ breast cancer diagnosis and treatment lead to personal growth in caregivers</td>
</tr>
<tr>
<td></td>
<td>Family members and peers fulfill the ‘nutritional gatekeeping’ role</td>
</tr>
<tr>
<td></td>
<td>Caregivers used religion as a coping mechanism to support changes in the household due to cancer treatment and survivorship</td>
</tr>
<tr>
<td></td>
<td>Family, peers, and hospital provided financial support</td>
</tr>
<tr>
<td>Participant Group</td>
<td>Theme</td>
</tr>
<tr>
<td>-------------------</td>
<td>----------------------------------------------------------------------</td>
</tr>
<tr>
<td>Key Informants</td>
<td>A difference in eating habits caused by chemotherapy negatively affects Latina cancer survivors’ households</td>
</tr>
<tr>
<td></td>
<td>Latina breast cancer survivors continue in their role as ‘nutritional gatekeepers’</td>
</tr>
<tr>
<td></td>
<td>Key informants give credit to family members and friends in helping with cooking responsibilities</td>
</tr>
</tbody>
</table>

**Latina Breast Cancer Survivors**

All Latina breast cancer survivors (32/32) shared their insights regarding the influence of family and peer support on their diet and nutrition. Latina breast cancer survivors dealt with the changes in their life and nutritional habits in various ways. Traditionally, Latinas are the ‘nutritional gatekeeper’ in their families; therefore, the side effects of chemotherapy created a shift in traditional household roles in most of the families of the women interviewed. Different support systems, such as friends and family, allowed the participants to deal with the changes in their lives and influenced their nutritional decisions. The women also reflected on using exercise, music, and religion to manage the physical and/or mental situations in their daily lives while dealing with chemotherapy treatment.

The women mentioned that, since diagnosis, their family and friends provided positive support. Many of the Latina breast cancer survivors (24/32) found that the amount of support from family, friends, and caregivers was sufficient to meet their physical and emotional needs. A few (3/32) mentioned that their needs were not met or that there was a lack of support because their mother and friends lived far away or they felt they needed additional care. Similarly, more than a third (22/32) found that the amount of support from their health provider and/or doctor was sufficient to meet their physical and emotional health needs.
Chemotherapy side effects drastically changed the role of the Latina breast cancer survivor as the ‘nutritional gatekeeper.’ All Latina breast cancer survivors (32/32) mentioned how breast cancer diagnosis and chemotherapy affected their role as the ‘nutritional gatekeeper’ in the family by others cooking or providing meals. The traditional role that Latina women fulfilled in the kitchen changed drastically due to the side effects of chemotherapy. Participants (23/32) shared the different side effects encountered from chemotherapy, such as weakness, sensitivity to heat, and tiredness, among others. Upon attempting to cook normally, a Latina breast cancer survivor stated:

“… I try to cook. But immediately, as soon as the heat gets me, I have to stop. So I have to sit down and wait, and so I normally do the breakfast because it’s fast. But, the dinner, my husband does it.” (Juliana, survivor)

Ana, a survivor, mentioned altering her routine due to treatment when asked about differences between cooking pre-treatment and during chemotherapy: “I’m not cooking. I have no strength in my hands… I used them one time, to make angel food cake. But I can’t because everything falls out of my hands, so my son don’t want me cooking.” Many (23/32) of the study participants’ role as the household ‘nutritional gatekeeper’ changed during and after chemotherapy, indicating that chemotherapy had limited their abilities to make decisions in their kitchen and regarding their meals.

Husbands and family members step into the role of ‘nutritional gatekeeper.’

Chemotherapy changed the role of Latinas in the kitchen (32/32), often shifting the ‘nutritional gatekeeping’ role to husbands or other family members and changing the entire households’ diet. For example, when asked about any changes in household roles, Vanesa, a survivor, stated, “Well, my husband cooked a little more... I think my husband knew I would do less. I just didn’t..."
have the energy.” Other family members also fulfilled the role of ‘nutritional gatekeeper’ as mentioned by Sofia, a survivor: “That would be, of course, family. My mom. His mom. His aunts. My husband.”

The physical and emotional support Latina breast cancer survivors received played an important role regarding nutritional decisions while coping chemotherapy. While some families were supportive, other family members did not fulfill the ‘nutritional gatekeeping’ role. Lack of support from the spouse negatively influenced the nutrition of the cancer patient. One Latina breast cancer survivor claimed that her spouse’s schedule and lack of support influenced her nutrition:

“Yeah. I don’t buy the right stuff. I don’t know what to buy… I didn’t get much support from my husband other than the cooking… There were times I remember my husband was working two jobs, and my son didn’t know how to cook. I would wait for him. It was 9:00, he would come, and I was, like, starving.” (Juliana, survivor)

Not all survivors (6/32) experienced positive support from their family members regarding changing roles in the household, and this shift in roles caused family stress and strain:

“Well, it’s awful. My husband did not take it well at all because he was mad that he had to do everything ‘cause I used to do everything in the house. It was a lot of stress. A lot of stress.” (Juliana, survivor)

Exercise, music, and religion alleviate nutrition-related challenges due to chemotherapy for Latina breast cancer survivors. In order to cope with the negative side effects of chemotherapy, Latina breast cancer survivors used non-traditional positive support systems:
“I tried to keep myself busy. I walked a lot. I didn’t work because my work is emotionally — can be emotionally draining, and I was not in a good place emotionally to work at that time. So, you know, I did a lot of coloring. You know, spending time with family. I did go to a few yoga classes at the hospital, a few classes for cancer patients, exercise classes.

How did I deal with it? I cried a lot.” (Nazareth, survivor)

The survivors shared how they cope with nutrition-related challenges and changes in household roles that may have been prompted by cancer treatment and survivorship. Some participants (5/32) mentioned music as a coping mechanism, while almost a third (9/32) mentioned religion as an additional alternative form of support. Along with the mention of exercise, music, religion, and resources available to cancer patients, another Latina breast cancer survivor recalled counseling as her method of coping with the difficulties of chemotherapy treatment:

“You know, I was in that breast and ovarian cancer group at [the hospital]. I saw the social worker at [the hospital], and so we talked a lot about it, and that it’s normal. It’s, you know, it’s true. The fact is it puts a burden on your caregiver, and friends, and family, but knowing that they do it, because they love you, and for us women that’s often hard, because we’re usually the ones doing a lot.” (Vanesa, survivor)

Caregivers

Caregivers also provided their perspectives to understand how Latina breast cancer survivors cope with nutrition-related experiences and changes in the ‘nutritional gatekeeping’ role. Themes regarding changes in role and family and/or peer support included: coping with the chemotherapy side effects of the Latina breast cancer survivor; caregivers experiencing personal growth; family members and peers fulfilling the ‘nutritional gatekeeping’ role; caregivers
experiencing little-to-no nutrition change due to the survivor’s chemotherapy treatment; caregivers lacking support from other family members; utilizing religion as a coping mechanism; and caregivers receiving financial support from family, peers, and the hospital.

**Caregivers needed support to manage the Latina breast cancer survivors’ side effects of chemotherapy.** Caregivers (3/8) discussed how they managed physical and/or emotional problems in their daily life as a response to dealing with changes in role due to their loved ones’ breast cancer diagnosis and chemotherapy treatment. Eduardo, a caregiver, realized his usefulness came from his military experience, which taught him to cope with certain situations and accept responsibility for what needs to be done. Another supportive individual shared her method of coping as burning written entries that allowed her to release internal emotions:

> “There would be sometimes where I’d be [awake], like, until 1:00 in the morning that I would just be writing down what I felt, and then I’d burn it. It sounds weird, but it really did help me a lot... Like if I was stressed, I would just sit there and write how I felt. If I felt a certain way, I would write it out... It was all internal, really. And I think that’s what helped me mature a lot... I think I burned the ones where I would just — there were times I would be writing and I was crying so bad. But I think, yeah, I burned all the ones that I felt like I don’t even want to read those again. This is bad... It was like write it out, throw it away, write it out, throw it away, throw it away, throw it away.” (Haiza, caregiver)

There was also a single discussion from a caregiver (1/8) who did not receive emotional or physical support from other family members. She shared her frustration as caregiver regarding a lack of support from others to help her address problems when asked who provided constructive feedback and affirmation:
“Nobody. I don’t want to sound selfish, but nobody, really. I think at this point — you could say of this whole journey, nobody. Personally, I’m the one. It’s kind of sad. It’s not sad. Like to me I don’t know what to say because my [family members] are like, ‘I just appreciate everything you do — and I just wish I really would have been there.’ And I’m, like, why are you wishing it when you had the chance to be there?” (Haiza, caregiver)

Latinas’ breast cancer diagnosis and treatment lead to personal growth in caregivers. Caregivers (4/8) reflected on their personal growth following the breast cancer diagnosis of their loved ones. They felt that being there as a caregiver during and after chemotherapy treatment affected them and their families. One caregiver felt that she matured tremendously by going through the process:

“It was hard. It was really hard... It united us. We never realized that something like this had to happen for us to become so united. It made us mature a lot... And it makes you realize that you need to be more grateful for things and that you should realize what you have around you and who you have around you and be more thankful for things. So it just opened your eyes completely, and your world changes like a whole 360. It’s not easy at all... Sometimes I would feel like it was a duty, but at the same time I was, like, this is my chance to pay her back for all the times she took care of me. So really it wasn’t really like I felt like it was an obligation. There are still sometimes that I get stressed out. But at the same time, I’m, like, I need to understand her, too. She’s older, and she needs help... You’ve just got to mature sometimes and realize the world isn’t always revolving around you... You’ve got to open your eyes from one day to another and be, like, I’ve got to step up and do this. It was hard. It was really hard.” (Haiza, caregiver)
Nilsa felt that being a caregiver was difficult because she believed that when children undergo something it is like the parents are undergoing it themselves. Additionally, Rosario, a caregiver, shared that she saw it as an opportunity to learn about one’s own health.

**Family members and peers fulfill the ‘nutritional gatekeeping’ role.** All caregivers (8/8) stated how roles in the kitchen changed where they, as well as others (i.e., daughter, sister, grandson, aunt, cousin, member of the church, friend), would take care of meals so that the Latina breast cancer survivor would not have to be near the heat of the stove or oven:

“I would always make something that I knew she could eat and that we could all eat… She couldn’t get near the stove. She probably wouldn’t even have energy sometimes to even get up out of bed… So yeah, I would cook or her sisters would cook or we would all cook together. We would all kind of do it together.” (Haiza, caregiver)

A few caregivers interviewed (3/8) mentioned that routines stayed the same but that the food they were eating changed. Eduardo, a caregiver, shared that towards the beginning of the Latina’s cancer diagnosis and treatment process, friends would bring prepared meals every day. He stated how that group of individuals alleviated the need for them to cook. A caregiver shared her experience in how the roles in the kitchen and expectations from the family changed while the individual was undergoing chemotherapy:

“Yes and no. Just a bit ‘cause I lived in another state, and I moved to over here. She wanted to continue her routine of us not to have to take care of her, and we tried to not invade her space… She has more conscious than us; sometimes we’d eat on the street and when we’d get back home, we’d know there’d be at least a smoothie, and she would tell us to drink it.” (Rosario, caregiver)
Julio, a caregiver, stated that he shared cooking responsibilities with his family member. Even if routines did change, most of the supportive individuals (5/8) mentioned that routines would go back to how they used to be following the completion of chemotherapy treatment.

While roles in the kitchen and the resulting food consumption changed for the majority of those interviewed, there were exceptions. For example, two caregivers (2/8) mentioned that chemotherapy only had a minor impact on the nutrition habits of the Latina breast cancer survivors undergoing treatment. A caregiver shared the minor changes that occurred in their household:

“We did not change too much. We added the things that she should eat at the time. There were no extreme changes; the only thing was that before to the juice we added sugar, and now we drink it without sugar. The food was, like, the same; the only thing is that she started to eat more fruits.” (Laura, caregiver)

Another supportive individual shared that the diagnosis and treatment of the Latina breast cancer survivor residing in the home did not affect the family:

“It has not changed; she has always fed herself correctly. Fortunately, this process practically did not affect her at all; she has a good appetite. Here we cook for everybody, and she eats the same... I think that in relation to eating, she has changed a little bit, as she has had to do what the doctors tell her, but basically, it’s the same... It did not cause any effect, since what the doctor recommended her was what we have always eaten.”

(Julio, caregiver)

Caregivers found satisfaction and fulfillment in being able to help. Laura and Nilsa, both caregivers, expressed that they would not only assist with cooking but would take care of other household duties (i.e., cleaning, childcare). They also accompanied the diagnosed
individual to chemotherapy appointments. Xiomara and Rosario, both caregivers, stated that they and other family members would help the Latina breast cancer survivors cook. Nilsa stated what she would cook for the diagnosed individual and how others would provide support: “I would cook what she would like, vegetables with chicken, soups, very healthy food; I would make her natural smoothies... Well, we’re a very united family, and my sisters would invite her over to eat at their houses when she felt well.” Xiomara mentioned that, as roles in the kitchen were modified, she felt a great sense of satisfaction in being able to help, and other caregivers (4/8) expressed the same sentiment. Lastly, Rosario shared how demonstrating this support did not cause any problems in the household but instead would make them feel good.

**Caregivers made sacrifices and adjustments by fulfilling the ‘nutritional gatekeeping’ role.** Caregivers (5/8) mentioned that they would compromise their food preferences and cooking habits to support the Latina breast cancer survivors undergoing chemotherapy. A caregiver shared her perspective on supportive sacrifices that she was making:

“*When they started giving her a certain diet, I live with her so she sees people that are helping her, the sacrifice maybe won’t be as hard for her. So, it’s, like, we changed our diets so she wouldn’t feel bad... Like, for example, they wouldn’t let her eat any raw vegetables or any raw foods, and we like shrimp and stuff like that. We were, like, she can’t eat it so we shouldn’t eat it so she won’t feel bad. So, we would hold back on certain things and not eat them.*” (Haiza, caregiver)

One caregiver (1/8) expressed concern as a different supportive family member also suffered from a chronic disease:

“At times, yes, because we’re human, but I say it was for good. It was a school where we learned a lot of things there... When my [supportive family member felt] good she [did]
everything in the kitchen, but between my husband and I we [prepared] the food when she [did] not feel well, as she suffers from Crohn’s.” (Xiomara, caregiver)

Caregivers used religion as a coping mechanism to support changes in the household due to cancer treatment and survivorship. Caregivers (4/8) reflected on how God, religion, or prayer helped them through the diagnosis and treatment of the Latina breast cancer survivor. Haiza, a caregiver, mentioned praying a lot; Xiomara, another caregiver, expressed receiving support from God to help her address problems; and Eduardo, also a caregiver, stated that becoming closer to God was the instrumental support that he needed. An identified individual also stated that God provided her support and would help her make decisions:

“Emotional support is given to me by God... The one who gives us everything — God. I am a Christian person... I didn’t receive advice or suggestions from anyone; the suggestions I received from the Lord... The Lord is the one who is with us and is the one who helps us in all problems, he is the one who gives one strength to go forward, struggling to continue.” (Nilsa, caregiver)

Family, peers, and hospital provided financial support. Caregivers (4/8) stated that finances or money facilitated the chemotherapy treatment necessary for the diagnosed individual. Haiza, a caregiver, mentioned that financially all other family members helped. Xiomara, another caregiver, shared that the treatment negatively affected their household finances. Xiomara claimed that financial support was provided by close family and friends because they wanted the Latina breast cancer survivor to be able to return to her home country completely healthy. A caregiver explained how financial resources impacted the eating habits of his household:
“Well, some changes were made to eat healthier and eliminate as much as possible the things that are toxic or harmful to [one’s] health. Some things taste good but are not good for [one’s] health... The concern is to maintain it and have the resources to maintain it, because I am retiring within five years and when that time comes there will be a very marked transition of how we are eating now.”  (Eduardo, caregiver)

Julio, a caregiver, specified that they did not need other resources or services, due to the financial support provided by the hospital: “Thank God we did not need it. She only receives from the hospital for her treatment. Of the rest has not been necessary, the hospital gave her a card for medicines and everything is covered.”

**Key Informants**

Key informants’ knowledge was important to understand how Latina breast cancer survivors cope with nutrition-related experiences and changes in roles prompted by cancer treatment and survivorship; they shared their insights as stakeholders who provide guidance regarding nutrition to Latina cancer survivors. Key informants mentioned negative nutritional responses among Latina women as the ‘nutritional gatekeeper’ in the family due to their breast cancer diagnosis and chemotherapy treatment. Additionally, it was found that Latina women tend to continue to fulfill the ‘nutritional gatekeeping’ role even if they receive family or peer support during and after chemotherapy.

**A difference in eating habits caused by chemotherapy negatively affects Latina cancer survivors’ households.** Key informants (3/6) mentioned negative forms of coping that Latina cancer survivors use to adapt to a new family dynamic. Waleska, a key informant, shared how Latina cancer survivors deal with difficulties experienced during treatment, rather than
following nutritional advice: “Sometimes they don’t eat; they take medications; often they make natural remedies.” Tania, a key informant, stated that a change in meals and nutrition negatively affects Hispanic families where members tend to embrace sadness; furthermore, a difference in eating habits caused by chemotherapy creates tension causing issues or problems in the household. Other family members feel that they should not need to change their eating habits. Also, Uraima, a key informant, stated, “The concern [regarding diet and nutrition] exists with or without cancer for many people, if you have cancer that concern is greater.” Lastly, a key informant shared how the Latina breast cancer survivor undergoing chemotherapy affects nutrition among household members:

“Each person is affected differently, all of the members are going to suffer or react in one way or another. There are many that try to inform themselves to support the patient, there are others who get mad and do not accept it. Regarding the food, is very individual at the family level. But I also think of the ages of the family members may be that they make positive changes, especially in the younger ones, have become more aware since I got sick; the older ones — we have another dynamic, the way we see life.” (Uraima, key informant)

**Latina breast cancer survivors continue in their role as ‘nutritional gatekeepers.’** A few key informants interviewed (3/6) addressed how Latina women feel the need to maintain the ‘nutritional gatekeeping’ role regardless of their breast cancer diagnosis and chemotherapy treatment. Key informants (2/6) stated that the patients continue to do most of the cooking while in treatment with some help from daughters if there are any in the family:

“If they have a young girl in the household, she may take up for her mother. I think that they’re really woman-driven kitchens in a lot of the Hispanic households. The man works
outside the house, and the woman works in the house, and transitioning that — if it’s just a husband and wife, transitioning him, he’ll do it out of survival, or she might have to get someone in the extended family to provide meals. Depends on the level of machismo.”

(Patricia, key informant)

Another key informant shared the same sentiment regarding survivors continuing to fulfill the ‘nutritional gatekeeping’ role:

“The expectations change a little, but they continue to do the duties because if they have small children that is the motor that keeps them wanting to take care of their family... They feel strong, I know women who are working while they have their chemo... Most of them, they return to their normal routine, there are people who plan and before going to treatment prepare all the meals.” (Waleska, key informant)

Additionally, through “...their sense of commitment to their family, the support from the family, from the club, and their desire for survival,” Waleska states that Latina breast cancer survivors maintain their role in the kitchen. Similarly, another key informant shared:

“There are cases that when the patient has to receive chemotherapy for the rest of her life; it is very critical — she is always taking medication and is drugged. Instead, there are other cases that we feel bad a few days, but then we go back to our routine... They have their routine; what one wants is to have their life, and if that means I have to cook, to cooking it is.” (Uraima, key informant)

Lastly, Patricia, a key informant believed that Latina breast cancer survivors often do not give themselves enough time to heal. She believed that survivors feel a need to take back their ‘nutritional gatekeeping’ role too quickly:
“Powerless, guilty that they’re not — especially in the Hispanic community, there is — the matriarch of the family keeps the family together. She keeps the household together. She is the caretaker, and now she feels like her role in the household is no longer valued, because now she’s an invalid. And there’s tremendous guilt to that, a core guilt of, ‘I need to.’ ...And they push themselves too hard. They go back to work too early. They try to take on the household chores again too early, creating a relapse. So, a lot of times they will push too quickly after surgery and they get infection. And I always say, ‘Slow down. Heal once.’ And, they’re like, ‘No. There’s too much to do.’” (Patricia, key informant)

Key informants give credit to family members and friends in helping with cooking responsibilities. Uraima, Tania, and Teresa, all key informants, gave credit to husbands, extended family members, church groups, and friends in assisting with cooking and the responsibilities in the kitchen. Teresa, a key informant, emphasized collaboration regarding the roles and expectations within the household: “One has to learn to receive the help of the people who are giving it to you, to leave [behind] the Super Woman syndrome.” A key informant, summarized her perspective from working with Hispanic families:

“I think it’s hard for Latinos to be taken care of. Don’t you think? That’s what I find. We’re used to, like, you’re the mother, you’re my wife — you are the one who takes care of all of these things regardless of anything else that is happening. So, I think it’s hard for them to ask for help... I think they just find themselves doing it. You know, forcing themselves to do it. And cooking might make them more nauseous, and they might eat even less, or you know... I think they just try to push through.” (Zoraida, key informant)
Specific Aim 3. To identify the information needs regarding diet and nutrition among Latina breast cancer survivors.

Table 4.4. Key Themes across Participant Groups for Specific Aim 3.

<table>
<thead>
<tr>
<th>Participant Group</th>
<th>Theme</th>
</tr>
</thead>
<tbody>
<tr>
<td>Latina Breast Cancer Survivors</td>
<td>Latina breast cancer survivors relied on organizational and online nutrition-related resources</td>
</tr>
<tr>
<td></td>
<td>Latina breast cancer survivors identify a gap in culturally tailored nutritional information</td>
</tr>
<tr>
<td></td>
<td>Nutritional improvements needed for hospital meals throughout treatment for Latina breast cancer survivors</td>
</tr>
<tr>
<td>Caregivers</td>
<td>Caregivers needed instrumental support to better meet the nutritional needs of Latina breast cancer survivors</td>
</tr>
<tr>
<td></td>
<td>Caregivers felt that there was insufficient diet and nutrition information for Latina breast cancer survivors</td>
</tr>
<tr>
<td></td>
<td>Caregivers preferred nutritional information in a culturally competent format</td>
</tr>
<tr>
<td>Key Informants</td>
<td>Latina cancer survivors and caregivers need culturally and linguistically tailored nutritional information</td>
</tr>
<tr>
<td></td>
<td>Latina breast cancer survivors request specific dietary information and meal plans</td>
</tr>
</tbody>
</table>

**Latina Breast Cancer Survivors**

The Latina breast cancer survivor participants stated that they received informational and instrumental support related to their diagnosis and treatment. However, the women still identified information needs regarding diet and nutrition. The survivors interviewed identified a gap in culturally tailored nutritional information available for them as Latina breast cancer
survivors. Additionally, the women found that nutritional improvements were necessary for the hospital meals that were provided throughout treatment. Participants also mentioned a level of knowledge concerning resources and/or services that were available to them during or after chemotherapy treatment. The women provided insight into awareness, provision, and accessibility of nutrition-related resources.

**Latina breast cancer survivors relied on organizational and online nutrition-related resources.** Latina breast cancer survivors (14/32) received nutrition-related information from healthcare providers and/or professional services. Hospital services utilized included workshops and supplemental written materials; Sofia, a survivor, discussed the resource that she received: “I think they gave me a little cancer book, and there’s probably like a chapter on nutrition in there.” Additionally, another Latina breast cancer survivor stated:

“I found more information [...] and [felt] more educated when it was the conference — the breast cancer conference, and I know they were in downtown, a hotel there where I think I found more information there, ‘cause they have more booklets, they have more speakers, they were actually talking to us. [At the hospital] — that was the class that I went [to] ...” (Melissa, survivor)

One participant had practical experience with nutrition-related preparation of meals in the cancer center she attended:

“I met with a nutritionist every time I was there, and at lunchtime everybody who was getting chemotherapy would come into a demonstration kitchen where we would learn how to cook, and they would give us the recipe. Then we’d eat together what we cooked. So, it was there that I got what they call ‘integrative oncology.’ It’s marrying the
integrative medicine with the traditional cancer treatment. That is where I learned it.”

(Vanesa, survivor)

Latina breast cancer survivors (9/32) also mentioned the availability of other nutrition-related resources aside from healthcare professionals. Churches and organizations like ‘Meals on Wheels’ and ‘Take a Meal’ provided the survivors with nutritional support. Although there were some participants that originally claimed that there were no resources that they were aware of, they later mentioned accessing online nutrition-based resources. Many participants, such as Sofia, a survivor, used the Internet to access information on nutrition and fill that information void: “I hit the library and doctor Google... I used to always type in you know, cancer holistic, or cancer alternative medicine, and then you get lots of resources that way.” She also mentioned being careful of misinformation that they found online:

“...Of course, you had to be careful because not all of it is whatever, right. But there was a documentary that was on Oprah Winfrey prior to me getting cancer, and so when I got cancer that’s how I remember ‘Crazy, Sexy Cancer’ as the title.” (Sofia, survivor)

While most of the participants found the Internet helpful, Melissa, a survivor, shared that she was unsure of who to turn to when she could not find what she was looking for on the Internet:

“...But when I have questions, I'm like 'Who do I go to?'”

Latina breast cancer survivors identify a gap in culturally tailored nutritional information. All Latina breast cancer survivor participants said there was a need for culturally appropriate nutritional information before, during, and after chemotherapy for them. As survivors mentioned informational resources available to them, they specified a lack of information in Spanish, as well as culturally appropriate information specific to the Hispanic culture. Participants (9/32) mentioned the need for providers to create resources for the Latino
community, as much of the information available clearly showcases the gap in nutritional information:

“So, a lot of the books that I bought and things I saw were very geared to Anglo-Sax and White people. I would say that truly I have yet to see a cookbook out there, and I’ve got some of the best out there that are geared and written for our culture. The most important part would be speaking to me and our history, whether it’s a brochure, whether it’s a flyer, whether it’s a book talking about our culture, and the importance of our culture, and how we were raised, and what we eat, and it would’ve been — I’m just using this for an example — my story. The five women, and talking about the five women, and how, and why; I mean on my mother’s side there’s five of us who’ve gotten breast cancer and why it’s important for us from a healthier nutritional perspective to eat healthy, and talk about it in cultural terms.” (Vanesa, survivor)

Several participants (9/32) suggested that further clarification on what is or is not recommended to eat would be helpful during and after chemotherapy:

“I guess more about balanced meals, because what I call a balanced meal may not be — I’m not a nutritionist, never really seen one, so something about more balanced and what things to avoid that, you know, have too much sugar...” (Nazareth, survivor)

Survivors appeared to be unaware of culturally specific nutrition-related resources for them through the processes of cancer diagnosis and chemotherapy treatment. For example, Juliana, a survivor, claimed: “Yeah. I don’t buy the right stuff. I don’t know what to buy.” Participants mentioned the need to fill the void through different uses of social media and written or verbal routes.
Nutritional improvements needed for hospital meals throughout treatment for Latina breast cancer survivors. Latina breast cancer survivors (5/32) also mentioned that the hospital needed to provide more nutritious meals to them:

“[Hospitals] should have said ‘Here’s a list: this is the kinds of foods you’ll eat because you’ll heal’ — not eat whatever you want. When you go to the hospital to have your surgeries, I declined the food. I made my husband go to — I don’t know where it was — but to get me food that I knew was nutritious. Because the hospital gives you crap food. Crap. Fried. Greasy. Non-nutritious.” (Sofia, survivor)

Caregivers

Caregivers (6/8) received informational support from family members and doctors. Family members provided advice and suggestions to help address problems, and doctors provided guidance regarding nutritional support during the treatment of the Latina breast cancer survivor.

Caregivers needed instrumental support to better meet the nutritional needs of Latina breast cancer survivors. Caregivers (4/8) stated receiving instrumental support that directly assisted the person in need. One caregiver expressed getting all their questions answered by the doctors:

“Yeah. They diagnosed her, and the next day or around those days, that’s when they sent us to the cancer place. And from there, it was just like ‘help, help, help, help, help.’ Everything was happening so fast and at a good pace… They would explain [the information] to me, and then I would explain [it] to her. […] I’d just rather know [the information] because I’m with her all the time. So, I would be like tell me first, and then
I’ll tell her... And then we would write [it] down, too. So, I think that’s why we were so hands-on with her during her treatment because, like, any little concern we would have we would write it down. Then when we’d go to the doctor every week, we’d ask him [about our concerns].” (Haiza, caregiver)

Julio and Rosario, both caregivers, explained only receiving this instrumental support from the hospital. Alternatively, Eduardo, a caregiver, shared that the type of information received was not in-depth: “They simply gave her a handbook of what to eat and not eat; that if she ate the wrong thing there could be a percentage of incidence that she could fall into cancer again.”

Several caregivers (4/8) stated that they were not aware of any nutrition-related resources.

**Caregivers felt that there was insufficient diet and nutrition information for Latina breast cancer survivors.** All caregivers (8/8) stated that they received an inadequate amount of information regarding what the Latina breast cancer survivor should eat. Julio, a caregiver, expressed wanting to know more detailed information: “Which are the most important foods that we should consume in the diet, the way that would be most correct to consume it?” Haiza, a caregiver, also mentioned wanting further information: “Like maybe more details... Regarding how to feed myself. More details into how to maintain a diet.” A caregiver stated wanting to be better informed by the nutritionist:

“The diets are given to lose [weight], not to nourish, there is not a focus on better quality of life that you can do this to later make comparisons of people who have eaten all junk and the others who have eaten everything natural. In [my home country] there are people who last more than a hundred years, and it was due to the factor of eating a healthy diet; it was the determining factor and managing stress aside from poor diet.” (Eduardo, caregiver)
Lastly, a caregiver, stated the need for clarification on provided information:

“To know at what time one should eat the types of foods, for example, at what time to eat the proteins, the flour, what would be the most convenient time... To know what diet she should follow... To know what to do after she does not have the disease... For them to give it to us in brochures to put it into practice, because if they provide it orally, afterwards you do not remember.” (Laura, caregiver)

**Caregivers preferred nutritional information in a culturally competent format.**

Caregivers (3/8) had preferences regarding the best way for them to receive needed information.

A supportive individual expressed the need for bilingual information:

“That people are bilingual and that the literature be in Spanish... When diagnosed, it is good to start there, and after the operation, because there are two tools that can give more strength to the patient and the family that will be fighting with the patient... I would like pre-operation phase one [to be] counseling and nutritional [information], phase two [to be] post-operation [information] that is at [the] group level... Interactive is good because you can ask questions, you can hear different experiences that you do not know, and you learn them, and you say that it should work. I did not know that. If it is a video, not everyone has the capacity of learning; instead in the interactive, there are all who have the ability to contribute and receive.” (Eduardo, caregiver)

Nilsa, a caregiver, stated her preferred format of information: “Brochures... At any time that information is welcome, even [if] they are healthy because you never know — only God knows.”

She also preferred a written-format that would include innovative cooking ideas:

“To provide it written, and that they would explain how to do it... Through talks that would be explained to me better, because if I saw it on the Internet, I did not know if I
was doing it well... To have some guide as to how we needed to prepare the meals...

*Different types of food, not vegetables, meat, chicken. How to make the meals, because everything is based on vision, to be more creative in the way to prepare vegetables.*”

(Nilsa, caregiver)

A couple of caregivers (2/8) did agree that they received enough nutritional resources in Spanish. Julio mentioned being referred to nutrition-related resources by the social worker, as the Latina breast cancer survivor did not qualify for any other services:

“They gave me all the information I needed... What type of diet, how should she eat? ... The hospital has provided us with all the information. They always give us materials, and they give them to us in Spanish. They give us the telephones. If we have any doubts we can call the doctors, the nurses, the social workers... Books, brochures, in addition to the [bulletin board] — I had seen this survey that you are doing — there are [flyers] in English and Spanish, and we always took it in Spanish because it is easier for us... They wanted to give it to me and explain it to us, and we tell her that we read them at home. She has participated in other surveys, before treatment and during treatment. In the hospital, there is a library where there is everything. What happens is that we never go. The girl told us that whenever we wanted to go there it was all at our disposal.” (Julio, caregiver)

Haiza, a caregiver, also mentioned that they were given nutrition-related resources by providers:

“They would tell us, they would give us papers, pamphlets, different diets. If she didn’t like one, she could try another. So, they were really hands-on... We got it in both. But mostly Spanish.”
Key Informants

Key informants received requests on a weekly basis for nutritional information specific for Latina cancer survivors that they work with. More specifically, key informants shared the need to adapt nutritional information to be more culturally and linguistically tailored for Latina cancer survivors and caregivers. Additionally, the key informant participants mentioned the need to explain the “why and how” regarding what Latina cancer survivors should eat, as it is important for the patients to understand the dietary recommendations that are provided.

Latinas cancer survivors and caregivers need culturally and linguistically tailored nutritional information. Key informants (6/6) shared their knowledge regarding the need to make nutritional information that is culturally specific available to Latina breast cancer survivors and their caregivers. Key informants mentioned the need for doctors and nurses to disseminate culturally and linguistically tailored nutritional information:

“That’s what...would be most beneficial, is to write a pamphlet that would take what normal cooking is right now and say, ‘Okay, well, so you want the yucca.’ We don’t need to pour oil over it with the garlic. We might be able to do an abridged version with margarine or with chicken stock, or something like that. [...] They’re not gonna change their cultural eating.” (Patricia, key informant)

Additionally, key informants believed that nutritional recommendations need to be thoroughly explained because survivors find the “why and how” to be important. Key informants shared their perspective on nutritional information that would be most beneficial to Latina cancer survivors in terms of diagnosis and treatment side effects:

“I think they should know from the beginning [...] what’s going to happen with chemo. Their specific treatment. Does this one [cause] anorexia, or does this one give you
diarrhea? Because then you can tailor it. Why are you getting the diarrhea? Is it the treatment or is it something else? An infection? Do we need to remove the fiber from your diet while you’re in treatment and just increase fluids? […] So, I think if they know what the side effects are, we can work better with them… The problem a lot of times is not only the doctors may have said it, but I think once they hear cancer, there’s this ‘oh!’ And then nothing else gets in. So, when it’s happening they’re struggling […] It’s like, what do I do? How do I handle this? Did anybody tell me this? And again, the language. We have interpreters here, which is a huge privilege. […] They might not feel like they can ask for it, or they don’t know how to ask for it. They can’t communicate with the nurse that is the one that is seeing them weekly in the infusion center. So, I think that becomes another barrier. How do I ask for this? How do I say I need help? …Plus sometimes it’s, like, diarrhea, and stuff like that. They don’t want to be telling the world that you know, this is what’s happening.” (Zoraida, key informant)

**Latina breast cancer survivors request specific dietary information and meal plans.**

From the perspective of the key informant participants (4/6), the concerns expressed by Latina breast cancer survivors included foods that cause cancer, foods that can cure cancer, and details regarding what they need to eat. For example, one key informant shared detailed information regarding advice and supplements that Latina breast cancer survivors want regarding their diet and nutrition:

“They want to know what to eat. Like I said, sometimes they believe that […] either what they ate gave them the cancer, or what they can eat is going to cure them. So, normally those are the biggest things. We get a lot of requests for, you know, I need to talk to somebody. Or they have heard about [a remedy from] the neighbor [who] told them that
cherry juice was the first thing in the morning that they should take. Or [...] they want you to give them some supplements from I-don’t-know-where that [...] might help. So, they have questions about them.” (Zoraida, key informant)

Key informants (2/6) also mentioned meal plans as a type of diet and nutrition information that Latina cancer survivors requested from them as stakeholders who work with that specific population:

“They want a meal plan all the time. Which I keep telling them that doesn’t work. You know, they want me to tell them you’re going to have one egg with one cup of coffee. Then you’re going to have one slice of bread. Like first, I can’t make them because everybody is different. I can tell you eat eggs and you don’t like eggs — well that didn’t work for you. So, I try to teach them so they can make their own [meal plan], but many times that’s the biggest barrier. They want it done for them. They don’t want to do the work. Well, I don’t know. I’m telling you. I’m showing you. I have all my food models. I have everything. [...] But, when I have to educate a patient [offsite], you cannot bring all that stuff. And plus, they’re sick so it’s kind of hard to get their mind into ‘I need to learn all these things’ when they’re, you know, still very sick.” (Zoraida, key informant)

Another key informant mentioned the lack of classes on nutritional information for cancer survivors:

“And the doctors don’t have the time, God bless ‘em. They just don’t have the time to sit down and do what I call ‘Lamaze for cancer.’ We need organizations to do that, where we say, ‘This is what’s gonna happen.’ Your doctor can’t sit down — just like your ob-gyn says, ‘Oh, you’re pregnant. There’s a class on Wednesday at the hospital. They’re
gonna tell you all about it 'cause I don’t have the time to tell you.’ And there’s nothing for cancer like that.” (Patricia, key informant)

Conclusion and Next Chapter

Results from the semi-structured, open-ended interview guides provided an understanding of how cancer diagnosis and chemotherapy was an influential factor that affected the nutritional practices of survivors and their caregivers. Insight from Latina breast cancer survivors (n=32), caregivers (n=8), and key informants (n=6) situated the experiences of Latina breast cancer survivors and their caregivers. Chapter 5: Discussion incorporates the results and their relationship to the reviewed literature; it provides a synthesis of the study findings and connections between the perspectives of Latina breast cancer survivors, supportive individuals/caregivers, and key informants, followed by recommendations and conclusions.
CHAPTER FIVE:

DISCUSSION

Overview

This chapter discusses the results and connections between the perspectives of Latina breast cancer survivors, supportive individuals/caregivers, and key informants. The discussion situates the findings within the literature and describes implications for research and practice. The chapter is organized into the following sections: research summary, findings within the Transactional Model of Stress and Coping framework, strengths and limitations, implications for research and practice, and conclusions.

Research Summary

This dissertation study used a cross-sectional design. Qualitative methods were used to explore Latina breast cancer survivors’ perceptions of the importance of diet and nutrition in helping them cope with chemotherapy treatment and survivorship. Study participants included Latina breast cancer survivors, supportive caregivers, and key informants (i.e., providers, health educators, or other stakeholders who worked closely with Latina cancer survivors). Latina breast cancer survivors consisted of women who were undergoing chemotherapy or were within five years of completing chemotherapy treatment; they shared their experiences and were asked to
identify one supportive adult (i.e., caregiver) who could also be interviewed.¹ Latina breast cancer survivors identified caregivers who helped them the most regarding the responsibilities related to food in the home. Key informants also shared their perspectives and understanding regarding what Latina breast cancer survivors and caregivers identified as nutritional issues and informational needs. The open-ended interview questions provided insight on diet, nutrition, management practices, and changes in roles or routines among this population. A qualitative approach with data collected from Latina breast cancer survivors, their caregivers, and key informants achieved a greater depth of investigation and exploration for this research, which was crucial to contextualizing the findings (Greene, Caracelli, & Graham, 1989; Johnson & Onwuegbuzie, 2004).

The Value and Meaning of Nutrition

Latina breast cancer survivors emphasized the value and meaning of nutrition by increasing their nutritional awareness to restore health, improve the body’s immunity, and regain/maintain agency and control of their food consumption. Kagawa-Singer (2001) found that diet choices, availability, quality, and culture comprised the meaning of nutrition within a specific ethnic group; the literature illustrates that cultural beliefs and behaviors influence cancer risk factors and constitute the significance of nutrition. Similarly, in this dissertation study, key informants mentioned that both Latina breast cancer survivors and family members understood the importance of nutrition. Latina breast cancer survivors reported motivation to make lifestyle changes regarding diet in order to improve their health following diagnosis. Much like Maskarinec et al.’s (2001) qualitative study claimed, this dissertation research also found multiple reasons for dietary changes, including an increase in well-being, maintenance of health,  

¹ If Latina breast cancer survivor participants did not identify a caregiver, it did not exclude them from the study.
prevention of cancer recurrence, avoidance of causes of cancer, consumption of cancer-
preventative foods, continuance of control, and adherence to advice. Similarly, the literature has
found that cancer survivors make temporary dietary modifications and maintain their diet after
diagnosis (Burke Beckjord et al., 2008; Demark-Wahnefried et al., 2005; Demark-Wahnefried et
al., 2000; James-Martin et al., 2014; Kostopoulou & Katsouyanni, 2006). However, other
researchers suggest that a breast cancer diagnosis is not the only factor that promotes change
toward healthy lifestyle behaviors following treatment (Blanchard et al., 2008; Campbell et al.,
2012).

Latina breast cancer survivors identified an increase in nutritional awareness regarding
their health and recovery, while caregivers also increased their awareness of nutrition and proper
dietary habits due to the cancer diagnosis of the Latina breast cancer survivor. The literature
specifies that lifestyle behaviors regarding diet are crucial for cancer survivors, as researchers
found that weight gain is a common result of breast cancer treatment that can be controlled
partially through nutrition and dietary restrictions (Bianchini et al., 2002; James-Martin et al.,
2014). It is essential for post-treatment cancer survivors to understand how modifications in
their dietary patterns — aimed at following healthy lifestyle behavior recommendations — help
them recover and improve their quality of life (Murphy & Girot, 2013). In addition to weight
management and recovery, the caregivers interviewed stated that nutrition was an important
factor in restoring health and improving the body’s immunity.
Factors that Influence Latina Breast Cancer Survivors’ Decisions about Diet and Nutrition During and After Treatment

Food provided by friends and family, assistance from nutritional organizations, doctors’ recommendations, and negative chemotherapy side effects influence Latina breast cancer survivors’ decisions about diet and nutrition during and after treatment. The literature explains that supportive behaviors account for ways in which individuals develop coping responses that affect their food practices (Glanz et al., 2008). Conversations with Latina breast cancer survivors relating to the influence of sociocultural factors coincided with discussions about their support systems; survivors claimed that friends and family influenced their health-related dietary behaviors in positive ways. Latina breast cancer survivors mentioned that nutritional support — others bringing food — was part of their social and emotional support. Researchers have found that supportive behaviors also build connections to organizational and community resources that empower positive change (Berkman & Glass, 2000; Heaney & Israel, 2008).

There were similarities among the salient themes by participant categories within the first aim. Latina breast cancer survivors found that the food provided by family and friends influenced what they ate and their nutritional decisions. Similarly, the cancer diagnosis of the Latina breast cancer survivors impacted the caregivers’ nutrition. Even though similarities were found, there was a salient theme within the first aim that was found to crossover participant categories into the second aim. Key informants stated that the side effects of chemotherapy treatment (i.e., loss of appetite, loss of taste, nausea, vomiting, and fatigue) negatively influenced Latina breast cancer survivors’ decisions about diet and nutrition. Key informants tied chemotherapy side effects with the first aim, while Latina breast cancer survivors linked chemotherapy side effects with drastically changing their role as the ‘nutritional gatekeeper’
within the second aim; therefore, salient themes not only overlapped participant categories within each aim, but themes were also found to crossover the different research questions within the study.

**The Role of the ‘Nutritional Gatekeeper’**

Negative chemotherapy side effects and positive support from husbands, family members, and friends affect the role of Latina women as the ‘nutritional gatekeeper’ in the family following breast cancer diagnosis and chemotherapy treatment. The stages of cancer survivorship are not only defined by the experience of the person who was diagnosed with cancer but also by the family members and peers who were affected by the diagnosis (Centers for Disease Control and Prevention & Lance Armstrong Foundation, 2004). In order to contextualize how diagnosis and treatment affect the role of Latina women as ‘nutritional gatekeepers,’ it was important to include the input from Latina breast cancer survivors and caregivers, as well as the perspective of key informants. The literature explains that the leadership role of ‘nutritional gatekeeper’ is traditionally inhabited by women who are responsible for the process of food choice and distribution in the home (McIntosh & Zey, 1998; Vidrine et al., 2013). Furthermore, meal decision-making more generally has been reported to be a shared responsibility among members of Latino households (Arredondo et al., 2006; Kaiser, 2006). As a result, findings show that Latina breast cancer survivors maintain their role in the kitchen through a sense of commitment to and support from their families. Caregivers within this study found satisfaction and fulfillment in being able to help with cooking, as well as assisting with other household duties, such as cleaning and childcare, and accompanying the diagnosed individual to chemotherapy appointments. This research helped to clarify the role of
women as the ‘nutritional gatekeeper,’ as well as what kinds of support are perceived as most and least helpful throughout and following the chemotherapy treatment process and cancer survival.

The period following cancer diagnosis and treatment affects the survivor and the family by posing a range of challenges and needs (Anderson et al., 2013; Craig, 2007; Humpel et al., 2007). Research has found that although breast cancer survivors may often have favorable health outcomes, a major concern among these women is their ability to function in daily life roles after treatment and through their survivorship trajectory (Ashing-Giwa et al., 2004; Bower et al., 2000). Much like Ashing-Giwa et al. (2004) and Bower et al. (2000), this dissertation study found that the ability to function in daily life was a major concern following diagnosis. Latina breast cancer survivors specified that husbands and family members stepped into the role of ‘nutritional gatekeeper,’ while caregivers also stated that family members and peers fulfilled the ‘nutritional gatekeeping’ role. Correspondingly, key informants mentioned that Latina breast cancer survivors continued in their role as ‘nutritional gatekeepers,’ while also giving credit to family members and friends for helping with cooking responsibilities. Caregivers mentioned making sacrifices and adjustments in order to fulfill the ‘nutritional gatekeeping’ role and needing support to manage the Latina breast cancer survivor’s side effects of chemotherapy; nonetheless, caregivers still felt satisfied and fulfilled with being able to help, which led to a sense of personal growth. In order to triangulate the data, the second aim required the perspectives of key informants, Latina breast cancer survivors, and supportive adults/caregivers identified by the survivors who had stepped into that ‘nutritional gatekeeping’ role during this period of time.
The Influence of Social Support

Breast cancer diagnosis and treatment disrupt or limit the role of Latinas within the family or household unit. Research has found that beliefs about not burdening the family with personal concerns and that family needs should come before one’s own were negatively associated with social support (Martinez Tyson, 2008). Similarly, findings from the interviews within this study with Latina breast cancer survivors, caregivers, and key informants indicate that cultural expectations among this population shape the kinds of support and assistance that are provided by family members. This research sought to explore the post-diagnosis shift in household dynamics with regards to nutritional responsibility and found that the eating habits of family members influence Latina breast cancer survivors’ diet and nutrition during and after chemotherapy treatment. These findings align with Beagan and Chapman’s (2004a) statement that across the breast cancer survivor population, social roles and relationships within the household context influence food selection and dietary changes to reduce the probability of breast cancer recurrence (Buki et al., 2008; Pérez-Stable et al., 1992; Ramirez et al., 2000; Stanton et al., 2007; Victorson et al., 2007; Yanez et al., 2011).

The multidimensional construct of social support (Berkman & Glass, 2000; Heaney & Israel, 2008) provided an understanding of what the caregivers did to help fulfill the obligation of ‘nutritional gatekeeper,’ as well as what was not helpful to the Latina breast cancer survivors throughout treatment and within the first five years following chemotherapy. Key informants mentioned that a difference in eating habits caused by chemotherapy negatively affects Latina cancer survivors’ households. While Glanz and Schwartz (2008) specified the use of religion as a common coping response to health threats, the results of this dissertation study show that Latina breast cancer survivors also use exercise and music, in addition to religion to alleviate
both nutrition-related challenges and health threats of chemotherapy. Additionally, caregivers used religion as a coping mechanism to support the Latina’s cancer treatment and survivorship. Specific constructs from the Transactional Model of Stress and Coping (Lazarus & Folkman, 1984) were integrated in this research, where social support was identified as a moderating coping style. The concept of social support enabled an understanding of how perceived instrumental, informational, emotional, and appraisal support are potent factors in mediating distress (Glanz & Schwartz, 2008; Heaney & Israel, 2008).

**Gap in Culturally and Linguistically Tailored Information Related to Diet**

Researchers have found that the perceived needs of cancer survivors immediately following treatment relate to a range of psychological and physical challenges including seeking advice on food parameters and weight management (Anderson et al., 2013). Within the literature, researchers discuss studies relating to health promotion, behavioral change, and delivery preferences for cancer survivors, yet effective weight management interventions that promote nutrition and diet for cancer survivors still need to be developed (Jones & Demark-Wahnefried, 2006; Koutoukidis, Beeken, Lopes, Knobf, & Lanceley, 2016). Interviews with Latina breast cancer survivors found that, in addition to the promotion of nutrition and diet highlighted by Anderson et al. (2013) and Koutoukidis et al. (2016), there is a major lack of information that is culturally and linguistically tailored to Latinas. Latina breast cancer survivors request dietary information and meal plans but identify that there is a lack of information related to diet and nutrition following diagnosis. Both survivors and caregivers specified seeking information regarding nutrition and dietary habits as a result of breast cancer diagnosis and chemotherapy treatment geared toward their population.
Current compiled guidelines for diet and physical activity are mostly specific for English-literate cancer survivors (Pekmezi & Demark-Wahnefried, 2011). Qualitative findings from oncology practitioners and cancer survivors that have emerged in the literature include key themes regarding diet, exercise, weight management, and physical activity information needs, as well as patient and practitioner recommendations regarding format and timing of information (James-Martin et al., 2014). Even though some information is available in Spanish, caregivers within this research felt that there was insufficient diet and nutrition information for Latina breast cancer survivors and preferred nutritional information in a culturally competent format. Key informants also recognized that Latina cancer survivors and caregivers need culturally and linguistically tailored nutritional information. Researchers state that “language and ethnic discordance of Latino patients and their health professionals and the need to provide complex cancer information in lower literacy formats were identified by health professionals and telephone specialists as current challenges limiting the effectiveness of cancer information exchange” (Kaplan et al., 2016, pp. 7-8). Rather than providing lower-literacy formatted information, findings from this research study revealed the need for information in the Spanish language. The literature specifies that strong relationships characterized by good communication between healthcare providers and minority patients are important in vulnerable populations (Sheppard, Williams, & Richardson, 2004; Sheppard, Williams, Wang, Shavers, & Mandelblatt, 2014; Sheppard, Zambrana, & O'Malley, 2004).

The Need for Organizational Support and Assistance

Latina breast cancer survivors relied on organizational and online nutrition-related resources, as well as the nutritional information received from healthcare providers and hospitals.
While results from the literature show that newly diagnosed cancer patients, including breast cancer patients, seek nutritional information from family and friends following their cancer diagnosis (James-Martin et al., 2014; Metz et al., 2005), this study found that Latina breast cancer survivors depended on organizational and Internet nutrition-related resources. Additionally, several studies show that friends were perceived as most helpful over family for a variety of concerns (Keller & McDade, 2000; Raviv et al., 2003; Rose & Campbell, 2000). Consequently, researchers have examined the effect of cancer patients seeking information from media and nonmedical sources (e.g., family and/or friends); they found improved nutrition, more specifically higher fruit and vegetable consumption, among the cancer patient population that were actively seeking information (N. Lewis et al., 2012).

This dissertation study also inquired about the availability of resources that Latina breast cancer survivors, caregivers, and key informants identified related to diet and nutrition. Depending on the area of concern, the literature explains that individuals may prefer seeking help first from within their informal social networks rather than formal support (Bussing et al., 2005; Featherstone & Broadhurst, 2003; Gamoran et al., 2012). While individuals will often go to a formal provider for guidance when serious concerns arise, they will turn to others for support if that provider is not responsive (Frankenburg, 2002; Sayal, 2006). Researchers have also found that the most frequently selected sources of help were family, books and videos, telephone helplines, and friends (Keller & McDade, 2000). This research more specifically focused on the availability of resources for Latina breast cancer survivors in their language of preference and whether or not they were aware of available resources. Latina breast cancer survivors and caregivers specified receiving nutritional information from healthcare providers and hospitals, though they were likely to consult online resources. Consequently, the results
highlighted the need for inclusion of food assistance services, as well as provision of better education for other Latinas that are diagnosed with breast cancer and their caregivers through the future development of a nutrition information or education program.

**Theoretical Framework**

In order to explore how coping with stress is an influential factor that affects survivors and caregivers, constructs from the Transactional Model of Stress and Coping were used (Lazarus & Folkman, 1984). Some of the key concepts from the framework include: primary appraisal, secondary appraisal, coping effort, meaning-based coping, and coping outcomes (Glanz & Schwartz, 2008; Lazarus & Folkman, 1984). Coping with the stressful event of breast cancer diagnosis and chemotherapy treatment also takes into account role strain, which is defined as the difficulties that survivors and caregivers experience in meeting the responsibilities of the ‘nutritional gatekeeping’ role in the household. This study focused on the constructs following the stressor, more specifically on (1) the mediating processes related to the coping effort (i.e., problem management and emotional control) and meaning-based coping (e.g., spiritual beliefs); (2) moderators regarding dispositional coping style, social support, and information seeking; and (3) the outcomes of coping described as adaptation to the stressor (Glanz & Schwartz, 2008; Lazarus & Folkman, 1984). Figure 5.1 illustrates findings from this dissertation research and how the concepts interact with one another based on the Transactional Model (Glanz & Schwartz, 2008). More specifically, following the stressor of breast cancer diagnosis, the moderators of dispositional coping style (i.e., information-seeking behaviors) and social support (i.e., family and friends assisting with ‘nutritional gatekeeping’ responsibilities) led to the mediating processes of meaning-based coping (i.e., using religion and prayer and feeling a sense
of empowerment and control) and coping efforts (i.e., increasing nutritional awareness and modifying the ‘nutritional gatekeeping’ role) that enabled the outcomes of adaptation (i.e., difficulties lessened through dietary control and learning to ask for and receive help). The following section regarding main findings is described as pertaining to the literature and tied to the framework constructs addressed in this study.

![Adapted Transactional Model of Stress and Coping.](image)

**Figure 5.1.** Adapted Transactional Model of Stress and Coping.²

**Mediating Processes Related to the Coping Effort**

Latina breast cancer survivors increased their nutritional awareness and modified their behavior regarding the ‘nutritional gatekeeping’ role within the household to provide a sense of

---

control over their dietary habits. The literature explains that primary and secondary appraisal is an individual’s perception of a stressful event and ability to change, manage, cope, and/or adapt to the situation (Glanz & Schwartz, 2008; Lazarus & Folkman, 1984). In order to contextualize the effect of breast cancer diagnosis and chemotherapy treatment as a stressor on nutritional needs and expectations, it was important to understand how Latina breast cancer survivors’ coping strategies facilitated their evaluation of a health threat. Problem-focused coping and emotion-focused strategies are used in the Transactional Model to adapt to the stressful situation; the two dimensions within the construct of coping efforts are mediators affected by coping strategies (Glanz & Schwartz, 2008; Lazarus & Folkman, 1984).

Latina breast cancer survivors and caregivers reappraised the stressful situation of chemotherapy in a meaningful way for the diagnosed individual. These included positive alterations of their diet and nutrition by following the recommendations from doctors, as well as the use of religion and prayer as support. Similarly, researchers have found that positive reinterpretation and the use of religion and spirituality are common coping responses to a health threat, such as a cancer diagnosis (Carver et al., 1993; Glanz & Schwartz, 2008). Furthermore, studies that use this framework discuss that spirituality among cancer patients lessens the emotional distress associated with the disease, which is conceptualized as a form of emotion-focused coping (Dunkel-Schetter, Feinstein, Taylor, & Falke, 1992; Laubmeier, Zakowski, & Bair, 2004). Meaning-based coping strategies, such as feeling a sense of empowerment and control, allowed Latina breast cancer survivors in this study to adapt the way they think about cancer diagnosis and chemotherapy treatment. These efforts “are most adaptive when the stressor is changeable or when this strategy is used in conjunction with problem-focused coping strategies” (Glanz & Schwartz, 2008, p. 217). In order to understand what influences Latina
breast cancer survivors’ decision about diet and nutrition during and after chemotherapy, it was important to realize that the revised goal of the study population was to ultimately avoid cancer recurrence. Studies within the literature that focused on the quality of life of Latino cancer patients reported that their quality of life was significantly influenced by cultural beliefs and family (Ashing-Giwa et al., 2004; Juarez et al., 1998a, 1998b). Utilizing a qualitative approach enabled an understanding of the reappraisal of events and assessment of spiritual beliefs as a result of breast cancer diagnosis and chemotherapy treatment on Latina cancer survivors as ‘nutritional gatekeepers’ and family and/or peers as their caregivers.

**Moderators: Dispositional Coping Style and Social Support**

An important dimension within this dissertation study was the role expectations from both the Latina breast cancer survivor and caregiver, since there were shifts in the performance of roles within the household as the woman transitioned from breast cancer patient to survivor. Latina breast cancer survivors identified a supportive adult that stepped up to fill the role of ‘nutritional gatekeeper’ during the period of time following diagnosis and during/after chemotherapy treatment. Caregivers were not limited to family members but also included individuals, such as friends and employees. There were participants that did not identify a supportive individual, as they felt that they did not have anybody that helped them with decisions related to food. Researchers explain that coping and social support highlight the importance, process, and content of social relationships (Calvo, 2005; Mailick & Vigilante, 1997); therefore, emphasizing the individual’s understanding and participation was crucial to conducting interviews with Latina breast cancer survivors, caregivers, and key informants.
In order to contextualize how norms, routines, and patterns of practice developed within the specific contexts of Latina cancer survivors and caregivers, factors explored comprised individual characteristics and the interactions between the cancer survivors and family and/or peers (Meiklejohn, 2011). The positive effects of coping and social support came in several forms; informational and instrumental support came from information seeking behaviors that resulted in advice and suggestions, as well as tangible assistance for Latina breast cancer survivors as the ‘nutritional gatekeepers.’ Instrumental support led to Latina breast cancer survivors and their caregivers feeling a sense of empowerment and control. Seeking information and increasing their own knowledge permitted a change and adaptation to the stressor. Through the three perspectives of survivors, caregivers, and informants, their responses facilitated a comprehension of Latina breast cancer survivors’ information needs related to diet and nutrition following diagnosis. Additionally, instrumental support, or lack thereof, enabled an identification of nutrition-related resources that are available to Latina breast cancer survivors and their procedures for accessing these resources.

The Transactional Model of Stress and Coping distinguishes between emotion-focused coping, which regulates the emotional response to the problem, and problem-focused coping, which manages or alters the problem causing the distress (Laubmeier et al., 2004; Lazarus & Folkman, 1984). Emotional and appraisal support for Latina breast cancer survivors came from family members and friends providing empathy, love, and affirmation. Similarly, results from another qualitative study confirmed the relevance of family — who Latina breast cancer survivors considered to be one of the most important sources of social support (Martinez Tyson, 2008). Focusing on these moderators emphasized that breast cancer diagnosis and chemotherapy
treatment causes a change in roles or routines among household members where Latina women are the ‘nutritional gatekeepers’ in the family.

**Outcomes of Coping and Adaptation**

Difficulties faced by Latina breast cancer survivors relate to cooking for women who identify as the ‘nutritional gatekeeper’ in the household. The literature explains that cancer survivors experience both short and long-term needs that influence their sense of wellbeing directly following treatment (Anderson et al., 2013; Institute of Medicine & National Research Council, 2006; Kornblith, 1998). The results from this research provide insight into how breast cancer diagnosis and chemotherapy treatment affect the ‘nutritional gatekeeper’ in the household. Key informants mentioned various forms of coping that Latina cancer survivors use to adapt to a new family dynamic; these entailed moderators and outcomes as a result of the diagnosis where Latinas needed to accept the need to ask and receive help. Following diagnosis, and especially during treatment, Latina breast cancer survivors and caregivers compromise a way to manage the changes in diet and nutrition within the household.

Previous research has emphasized the patient’s adjustment to long-term chronic illness, rather than the household members’ adaptation and support to the patient’s recent breast cancer diagnosis (F. M. Lewis et al., 1993). This dissertation study explored the changes in roles among household members through the application of the coping outcomes construct, also known as adaptation. Literature findings show that the operationalizing elements comprised in the measurement of ethnicity include diet choices, availability, and quality, as well as level of adaptation within a specific ethnic group (Kagawa-Singer, 2001). Further exploration is still
needed to gain an understanding of how different types of cancer diagnosis and treatments affect the nutritional needs and role of both men and women.

**Strengths and Limitations**

Purposive sampling was used to select participants that were rich sources of data in order to address the specific research questions within this dissertation (Draper & Swift, 2011). Convenience and snowball sampling were also employed and worked well in trying to reach vulnerable and hard-to-reach populations, such as locating Latina breast cancer survivors that fit the research parameters of this study (Draper & Swift, 2011). Additionally, the central role of the researcher was taken into account, as reflexivity was recommended to enhance the credibility of the qualitative data after the data was collected (Draper & Swift, 2011). This dissertation research thoroughly reached the different stages of in-depth interviews with recruited participants by creating a natural involvement, encouraging conversational competence, showing understanding, getting facts and basic descriptions, asking difficult questions, maintaining emotional detachment, and closing while maintaining contact (Ulin et al., 2005).

Theoretically generalizable qualitative research does not require large or statistically representative samples (Draper & Swift, 2011); however, a limitation that may have affected generalizability of findings was that recruitment may have unintentionally targeted current members of breast cancer support groups (Ashing-Giwa et al., 2006). Therefore, the subjective experiences of the participants recruited for this research and captured through the interviews may not reflect the experiences of other minority cancer survivors (Buki et al., 2008). Another limitation was that interview participants were only recruited in West Central Florida, which was
geographically limiting. This population in this area may have different beliefs about food preparation and nutrition.

To address these limitations, an open-ended format was used for the interview guides “to clarify and probe emerging information and allow insights to emerge” (Buki et al., 2008, p. 164). Another advantage was that the interviews were conducted in either English or Spanish. Recorded interviews also captured quotes that were transcribed; theoretical domains were addressed and major themes captured from conducting these bilingual qualitative semi-structured interviews (Ashing-Giwa et al., 2006). Lastly, it was beneficial that the participants were all within the same initial stages of cancer survival (acute and extended), which improved recall of their recent experiences and overcame “limitations imposed by a cross-sectional design” (Buki et al., 2008, p. 167).

**Implications for Practice, Research, and Education**

The World Cancer Research Fund and American Institute for Cancer Research (2007) ascertain that there is increased evidence to show that food and nutrition are important factors that can modify the process of cancer development. Sociocultural factors (e.g., beliefs and attitudes) that influence the diet of Latina breast cancer survivors and their caregivers provided an important understanding regarding the meaning and value of nutrition and the factors that influence their diet post-chemotherapy treatment. These findings may differ from research on the perceptions of nutrition changes and nutritional information needs among Anglo-Saxon and African-American survivors. Consequently, this study has implications for public health, as well as recommendations for oncology providers and nutritionists that provide services to Latina breast cancer survivors and their caregivers. Findings contribute to a gap in the literature
regarding the nutritional needs, changes in roles, and social support expectations among newly
diagnosed Latina breast cancer survivors undergoing, or immediately following, chemotherapy
treatment.

Modifiable lifestyle behaviors, such as diet, are strongly linked to improved health
outcomes, a decreased risk of chronic disease, and an increase in the quality of life in cancer
survivors (Kushi et al., 2012; Spees et al., 2016; Wiseman, 2008). Educational interventions for
adult cancer survivors with access to harvesting fresh produce at an urban garden have resulted
in significant improvements aligning with current dietary intake recommendations for cancer
prevention and survivorship (Spees et al., 2016). As cancer patients experience greater survival
rates, self-management strategies related to nutrition and diet post-treatment need to be taken
into consideration (Anderson et al., 2013). This dissertation study explored if Latina breast
cancer survivors are provided information that they want and what was helpful for them and their
caregivers going forward. Consequently, caregivers specified needing instrumental support to
better meet the nutritional needs of Latina breast cancer survivors. Thus, to improve post-
chemotherapy treatment lifestyle changes, it is important to integrate the family, as well as other
members living in the household. This study has implications for public health research in that it
adds to the paucity of research of Latinas and survivorship, as well as our understanding of how
women’s expectations, practices, and roles alter. In identifying information needs and awareness
of available resources among Latina breast cancer survivors, caregivers, and key informants,
findings clarified a gap in culturally and linguistically tailored nutritional information that could
contribute to the creation of a future nutrition education program or intervention most
appropriate during cancer survivorship for this specific population.
This dissertation research study identifies unmet information needs and lack of knowledge regarding nutrition-related resources that provide an opportunity for health professionals and support providers to intervene. The education level of patients affects their understanding of vital food and nutrition information pertinent for them as cancer survivors. Similarly, education level and lack of knowledge affect the caregivers’ understanding of the cancer diagnosis and implications. Findings from this study suggest several recommendations for oncology providers, nurse practitioners, and nutritionists that provide services to Latina cancer patients:

- Schedule a meeting with the Latina cancer patient and caregiver following diagnosis to understand the family or peer dynamic that will enable/hinder support for the patient. This will provide an understanding of changes in roles and family and/or peer support as a response to the Latina cancer patient’s recent diagnosis.

- Ask the Latina cancer patient and caregiver about specific nutritional information needs that take into account cultural and linguistic requests. This effort will identify their nutrition information needs and current awareness of available resources regarding diet and nutrition.

- Provide information on how treatment may alter food consumption, nutritional habits, and the ‘nutritional gatekeeping’ role prior to the patient starting treatment. This will enable an increase in instrumental knowledge for the patient and caregiver that prepares them for changes that may be prompted by treatment.

- Continue to provide culturally and linguistically tailored nutritional information to the patient and caregiver during and after treatment. This effort will diminish stress and improve coping with nutritional changes due to treatment.
Establish a routine dietary assessment for Latina cancer patients after beginning chemotherapy and during treatment. Tracking this information allows the patient to feel a sense of control through nutrition.

Include the caregiver in all aspects of providing nutritional information and suggestions through the diagnosis, treatment, and post-treatment process; therefore, provide advice for improving dietary habits following treatment for the patient and caregiver.

Include food assistance services to meet the need for organizational support.

Conclusions

This dissertation provided an understanding of the value and meaning of nutrition for Latina breast cancer survivors that brought to light the factors that influence their diet. A life event affecting the woman, such as being diagnosed with cancer, caused changes in expectations, identities, and behaviors within the household unit, including changes in role among the family members in the household. As Martinez Tyson (2008) states, “Breast cancer not only affects individuals, it impacts their social relationships, finances, work, and social roles” (p. 207).

Influences, changes in roles, and perceived social support of Latina breast cancer survivors contributed to their concerns related to being the ‘nutritional gatekeeper’ in the household during the initial (acute and extended) phases of cancer survival. Therefore, challenges encountered due to chemotherapy side effects, as well as the changes in roles within a household occurred as a result of the ‘nutritional gatekeeper’ being diagnosed and treated for breast cancer. This research targeted Latina breast cancer survivors who identified as the ‘nutritional gatekeeper’ in the family because it was important to explore nutritional information needs and how the cooking roles have changed within her household during and post-chemotherapy treatment. By
understanding the connection between diet and cancer survivorship among this population who was undergoing, or had recently completed, chemotherapy treatment, this dissertation research informed on the ideal teachable moment to provide health information.
REFERENCES


Calvo, A. (2005). *Social construction of cervical cancer screening among women in Panama City, Panama*. (Doctor of Philosophy Disseration), University of South Florida, Tampa, FL.


Gamoran, Adam, Turley, Ruth N. López, Turner, Alyn, & Fish, Rachel. (2012). Differences between Hispanic and non-Hispanic families in social capital and child development:
First-year findings from an experimental study. *Research in Social Stratification and Mobility, 30*(1), 97-112. doi: 10.1016/j.rssm.2011.08.001


136


Li, C. I., Malone, K. E., & Daling, J. R. (2003). Differences in breast cancer stage, treatment, and survival by race and ethnicity. *Archives of Internal Medicine, 163*(1), 49-56. doi: 10.1001/archinte.163.1.49


Meiklejohn, J. A. (2011). *The role of physical activity in the lives of people with lymphoedema following cancer treatment: A social constructionist study.* (Masters by Research), Queensland University of Technology.


APPENDICES
Appendix A. Interview questions for cancer survivors guided by constructs from the Transactional Model.

Aim 1. To understand the sociocultural factors that influence the diet of Latina breast cancer survivors.

<table>
<thead>
<tr>
<th>Research Question</th>
<th>Model Construct</th>
<th>Interview Question</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>RQ 1.a.</strong> How do Latina breast cancer survivors value the meaning of nutrition?</td>
<td>[Context question]</td>
<td>Describe the type/style of cooking in your house and the types of foods that you and your family eat.</td>
</tr>
<tr>
<td></td>
<td><em>Meaning-based coping</em></td>
<td>What is the meaning of food/nutrition to you?</td>
</tr>
<tr>
<td><strong>RQ 1.b.</strong> What influences Latina breast cancer survivors’ decision about diet and nutrition during and after chemotherapy?</td>
<td><em>Coping effort</em></td>
<td>What were some of the difficulties that you experienced during treatment?</td>
</tr>
<tr>
<td></td>
<td><em>Outcomes of coping</em></td>
<td></td>
</tr>
<tr>
<td></td>
<td><em>Coping effort</em></td>
<td>How did you deal with some of the difficulties that you experienced?</td>
</tr>
<tr>
<td></td>
<td><em>Dispositional coping style</em></td>
<td>What did you do to manage these?</td>
</tr>
</tbody>
</table>
Aim 2. To explore how Latina breast cancer survivors cope with nutrition-related experiences and changes in roles that may have been prompted by cancer treatment and survivorship.

<table>
<thead>
<tr>
<th>Research Question</th>
<th>Model Construct</th>
<th>Interview Question</th>
</tr>
</thead>
</table>
| **RQ 2.a.** How do breast cancer diagnosis and chemotherapy affect the role of Latina women as the ‘nutritional gatekeeper’ in the family? | Coping effort  
Dispositional coping style | What motivated you to change your dietary habits? Or how have you maintained what you eat? |
| | Dispositional coping style  
Outcomes of coping | How did the foods you eat and your type/style of cooking change? |
| | Meaning-based coping  
Dispositional coping style | Do you have any concerns about your diet/nutrition? |
| | Dispositional coping style  
Coping effort | How did your role in the kitchen change during treatment? |
| | Outcome of coping  
Dispositional coping style | Do you and your family/household members eat the same foods? |
| **RQ 2.b.** How does family and/or peer support influence Latina breast cancer survivors’ diet and nutrition during and after chemotherapy? | Social support  
Dispositional coping style  
Coping effort | Who did most of the cooking while you were in treatment? |
| | Social support | Since diagnosis, what types of support have you received? |
Aim 3. To identify the information needs regarding diet and nutrition among Latina breast cancer survivors.

<table>
<thead>
<tr>
<th>Research Question</th>
<th>Model Construct</th>
<th>Interview Question</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>RQ 3.a.</strong> What are Latina breast cancer survivors’ informational needs related to diet and nutrition following diagnosis?</td>
<td><em>Information seeking</em></td>
<td>What information related to diet and nutrition do you want?</td>
</tr>
</tbody>
</table>
| | *Coping effort*  
*Information seeking* | Thinking back to when you were undergoing treatment, what kind of information would have been helpful? |
| **RQ 3.b.** What nutrition-related resources are available to Latina breast cancer survivors, and how do they access these resources? | *Information seeking* | What sorts of nutrition-related resources are you aware of? |
| | *Coping effort*  
*Information seeking* | What is the best way to get the information that you want and would be helpful to you? |
Appendix B. Semi-structured interview guide for Latina breast cancer survivor eligible participants.

<table>
<thead>
<tr>
<th>Interview Question</th>
<th>Model Construct Addressed</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>1. Describe the type/style of cooking in your house and the types of foods that you and your family eat.</strong>&lt;br&gt; <em>Probe:</em> Describe some of the typical dishes you cook.</td>
<td><strong>Context question</strong></td>
</tr>
<tr>
<td><strong>2. What is the meaning of food/nutrition to you?</strong>&lt;br&gt; <em>Probe:</em> How did the meaning of food and nutrition change after cancer diagnosis and treatment?&lt;br&gt; <em>Probe:</em> Now as a cancer survivor, how important is nutrition for you?</td>
<td><strong>Meaning-based coping</strong></td>
</tr>
<tr>
<td><strong>TRANSITION STATEMENT</strong></td>
<td></td>
</tr>
<tr>
<td><strong>3. What were some of the difficulties that you experienced during treatment?</strong>&lt;br&gt; <em>Probe:</em> Loss of appetite, nausea, taste, vomiting, fatigue, etc.?&lt;br&gt; □ For how long?&lt;br&gt; □ Are you still experiencing any of these?</td>
<td><strong>Coping effort/Outcomes of coping</strong></td>
</tr>
<tr>
<td><strong>4. You mention _________________ (summarize response to question 3), how did you deal with these? What did you do to manage _________________ (summarize response to question 4).</strong></td>
<td><strong>Coping effort/Disposition coping style</strong></td>
</tr>
<tr>
<td><strong>5. How did the foods you eat and your type/style of cooking change?</strong>&lt;br&gt; <em>Probe:</em> Differences from during/after treatment?&lt;br&gt; <em>Probe:</em> What impact did treatment have on how you cook and what your family/household eats?&lt;br&gt; <em>Probe:</em> What do you do differently?&lt;br&gt; <em>Probe:</em> What are you more aware of now?&lt;br&gt; <em>Probe:</em> Did these changes affect what your family/household ate during this time?</td>
<td><strong>Disposition coping style/Outcomes of coping</strong></td>
</tr>
</tbody>
</table>
6. You mention ________________ (summarize response to question 5).
   - If foods/cooking practices have changed: **What motivated you to change your dietary habits?**
   - If foods/cooking practices have not changed: **How have you maintained what you eat?**

7. Do you have any concerns about your diet/nutrition?
   * **Probe:** What do you consider a healthy diet?
     - Describe a healthy diet for you?
     * **Probe:** What challenges have you encountered to maintain a healthy diet?

   **TRANSITION STATEMENT**

8. What information related to diet and nutrition do you want?

9. Thinking back to when you were undergoing treatment, what kind of information would have been helpful?
   * **Probe:** What information were you provided related to diet and nutrition?
     - Who provided it?
     - How was it provided (e.g., in Spanish, written, spoken, video-format, etc.)?
   * **Probe:** How was the information explained that was provided to you?

10. What sorts of nutrition-related resources are you aware of?
   * **Probe:** Were you aware of these during treatment? Now?
   * **Probe:** When did you learn about them? How? From who?

11. You mention ________________ (summarize responses to questions 8 and 9). **What is the best way to get this information to you?**
   * **Probe:** Through a ‘charla,’ Internet, text, support groups, etc.?
   * **Probe:** When would this information have been the most helpful to you?

   **TRANSITION STATEMENT**

153
12. **How did your role in the kitchen change during treatment?**
   - *Probe:* How did the roles and expectations from your family/household change during this time?
   - *Probe:* How did this make you feel?
     - *If a negative feeling is expressed:* How did you cope? What did you do?
     - *If a positive feeling is expressed:* What helped you? Who helped you?

13. **Who did most of the cooking while you were in treatment?**
   - *Probe:* Did you still cook?
   - *Probe:* Did others cook for you?
     - How did this make you feel?
     - Did this cause any issues or problems in your house?
   - *Probe:* Who does most of the cooking now?

14. **Do you and your family/household members eat the same foods?**
   - *Probe:* If no, what are the differences?
     - Have these differences caused any problems or tension?

**TRANSITION STATEMENT**

15. **Since diagnosis, what types of support have you received?**
   - *Probe:* Who has provided you advice and suggestions to help you address problems?
     - How has that person provided you this informational support?
   - *Probe:* What referrals and services have you used?
     - What else would have been helpful?
   - *Probe:* Who has provided you empathy, love, and/or trust?
     - How has that person provided you this emotional support?
   - *Probe:* Who has provided you constructive feedback and affirmation?
     - How has that person provided you this support?
We are looking for Latina women 18 years of age or older...

Who have been diagnosed with breast cancer...

And have received chemotherapy within the last 5 years!

ARE YOU A LATINA BREAST CANCER SURVIVOR?

We are interested in learning about your experiences & about the importance of diet & nutrition!

Receive a $20 Wal-Mart gift card for participating in this research study.

To schedule your interview, or for more information please contact:

PAMELA BIRRIEL
813.541.5504
pguevara@health.usf.edu
Available in English/Spanish!

USF IRB #Pro22937
¿ERES UNA LATINA SOBREVIVIENTE DE CANCER DE MAMA/SENO?

¡Estamos interesadas en aprender acerca de sus experiencias y sobre la importancia de la dieta y nutrición!

Reciba una tarjeta de regalo de $20 para Wal-Mart por participar en este estudio de investigación.

¡Estamos buscando mujeres Latinas de 18 años de edad o mayores...

Que han sido diagnosticadas con cáncer de mama/seno...

Y hayan recibido quimioterapia en los últimos 5 años!

Para programar su entrevista, o para obtener más información comuníquese con:

PAMELA BIRRIEL
813.541.5504
pguevara@health.usf.edu
¡Se habla español/inglés!

USF IRB #Pro22937
Appendix D. Interview Protocol: Latina Breast Cancer Survivors

Dear participant,

Researchers at the University of South Florida (USF) study many topics. To do this, they need the help of people who agree to take part in a research study. Currently, there is a research study taking place that is called: *Exploring Nutritional Needs, Roles, and Expectations of Hispanic/Latina Breast Cancer Survivors*. The person who is in charge of this research study is Pamela C. Birriel. This person is the Principal Investigator. Mrs. Birriel is a doctoral candidate in the Department of Community and Family Health at the College of Public Health at the University of South Florida.

Participants are being asked to take part in this research study to help the researchers at USF better understand how their thoughts, their background as a Hispanic/Latina woman, their environment, and their experience with cancer has impacted the role of diet and nutrition in helping them cope with the effect of cancer treatment and survivorship. The purpose of this study is to learn from the participants’ experience with cancer. The researchers hope that their responses will add to the understanding of unmet needs that could contribute to the development of future nutrition education programs, interventions, and/or services that could provide support for Hispanic/Latina breast cancer survivors.

About 30 women who are Hispanic/Latina breast cancer survivors will participate in this study. This study will take place in the Tampa Bay Area and in counties around Orlando, Florida. Participants who are eligible and take part in this study will be asked to participate in an interview. During the interview, participants will be asked a few questions about themselves, coping with their cancer experience, their nutrition practices, and forms of support. This interview will take about one hour of their time, and they can take a break during this interview at any time. There is no cost to take part in this study. Hispanic/Latina breast cancer survivors who complete the questionnaire and interview protocols will get a $20.00 Wal-Mart gift card incentive after completing the interview to thank them for their time.

If you have any questions about this study, you can contact the investigator: Pamela C. Birriel (Spanish/English) at 813-541-5504 or through email at pguevara@health.usf.edu. If you have question about the rights of research participants, please contact the USF Institutional Review Board at 813-974-5638.

Sincerely,
Study Eligibility/Pre-Screening Script (English)

Introduction:
Hello, my name is Pamela Birriel. I am a doctoral candidate in the Department of Community and Family Health at the College of Public Health at the University of South Florida. I am conducting a research study to gain a better understanding regarding Hispanic/Latina breast cancer survivors’ perceptions of the importance of diet and nutrition in helping them cope with the effect of chemotherapy treatment and survivorship. You are being asked to participate because your responses can add to the understanding of unmet needs that could contribute to the development of future nutrition education programs, interventions, and/or services that could provide support for Hispanic/Latina breast cancer survivors. Are you interested in learning more about this study?

If No:  Thank you for your time. Please contact me at 813-541-5504 or through email at pguevara@health.usf.edu, if you change your mind about being a participant in this study.

If Yes, Request to Administer Eligibility Form A:
Before you can enroll in the study, I need to ask you a few questions to determine if you meet certain requirements to participate. All information discussed will be confidential. You may refuse to answer any question and stop this interview at anytime. I will begin with the questions. Would you like to continue? [If Yes, Administer Eligibility Form A]

If No:  Thank you for your time. Please contact me at 813-541-5504 or through email at pguevara@health.usf.edu, if you change your mind about being a participant in this study.

If Participant Does Not Meet Eligibility Criteria: I regret to inform you that you do not meet the requirements to participate in this study. The information you have provided me today will be kept confidential. And, I do want to thank you for contacting me and expressing interest in this project.

If Participant Meets Eligibility Criteria: You meet the requirements to participate in this study. Would you like to be scheduled to participate in the interview?

If No:  Thank you for your time. The information I have collected from you today will be kept confidential. Please contact me at 813-541-5504 or pguevara@health.usf.edu, if you change your mind about being a participant in this study.
If Yes, Administer Eligibility Form B:
May I get your name, telephone number (home and cell), physical address, and email address? How would you prefer to be contacted? What date and time would work best with your schedule? Would you prefer for the interview to take place in-person or over the phone? Also, I just have a few questions regarding a supportive individual that has helped you the most regarding your responsibilities for the decisions related to food in the home. May I ask you those questions at this time?
[If Yes, Continue Administering Eligibility Form B]

Thank you for volunteering to participate in this study, and I will talk to you on [Scheduled Date] at [Scheduled Time] for approximately 45 minutes to an hour where you will be provided more information and asked to give verbal permission on a consent form.

Do you have questions for me at this time? If you later decide you have any questions, please contact me at 813-541-5504 or through email at pguevara@health.usf.edu. Thank you.
Eligibility Form

Instructions: Please answer the questions below. This information will not be shared with anyone.

1. What is your age? ________

   NOTE: Is the participant 18 years of age or older?
   ☐ Yes, continue to question #2
   ☐ No, not eligible, STOP

2. Are you Hispanic or Latina?
   ☐ Yes
   ☐ No

   NOTE: Does the participant identify herself with origins from the countries of South America, Central America, Mexico, and/or Spanish-speaking Caribbean (e.g., Puerto Rico, Dominican Republic, or Cuba)?
   ☐ Yes, continue to question #3
   ☐ No, not eligible, STOP

3. When were you diagnosed with breast cancer? (Month and year is okay; we do not need the exact date).

   _________/_________/___________

   NOTE: Has the participant been diagnosed with breast cancer?
   ☐ Yes, continue to question #4
   ☐ No, not eligible, STOP

4. What cancer treatments did you receive or are still receiving? (Check all that apply.)

   ☐ Chemotherapy
   ☐ Radiation therapy
   ☐ Surgery (Specify type):
     ☐ Mastectomy
     ☐ Other (Specify): __________
   ☐ Hormone replacement therapy
   ☐ Other (Specify): __________

   NOTE: Did the participant receive or is still receiving chemotherapy treatment?
   ☐ Yes, continue to question #5
   ☐ No, not eligible, STOP
5. Have you completed chemotherapy treatment?

☐ No…
   When do you plan to have your last session?
   ________/_______/_______

☐ Yes…
   When was your last session?
   ________/_______/_______

   NOTE: Does the participant still need to receive chemotherapy, or has she completed chemotherapy treatment within the last five years?

☐ Yes to either, continue to question #6
☐ No, not eligible, STOP

6. Do you speak Spanish in your home?

☐ Yes
☐ No

   NOTE: Does the participant speak Spanish in the home?

☐ Yes, continue to question #7
☐ No, not eligible, STOP

7. Are you the person in the household who typically makes the decisions related to food?

☐ Yes…
   What are you responsible for?
   ○ Purchasing the food
   ○ Preparing the meals
   ○ Distribution/serving of portions

☐ No

   NOTE: Are two of the three options selected?

☐ Yes, PARTICIPANT IS ELEGIBLE!
☐ No, not eligible, STOP

8. How many people live in your household (including yourself)? _________

   NOTE: For quota sampling purposes only.

☐ Does not live alone
☐ Lives alone

** PLEASE COMPLETE THE CONTACT INFORMATION FORM! **
Contact Information Form

Instructions: Please answer the questions below. This information will not be shared with anyone.

The participant IS ELEGIBLE!

First Name: ______________________________ Last Name: ___________________

Telephone: (__________)__________ - __________________________

Physical Address: __________________________________________________________
Apartment Number: _________________ City: ___________________________
State: _____________________________ Zip Code: _________________________
Email: _____________________________@____________________________________

Best time to contact: ________________________________ (make appointment)

9. Who would you identify as a supportive individual that has helped you the most (i.e., following your breast cancer diagnosis and during chemotherapy treatment) regarding your responsibilities for the decisions related to food in the home?  

NOTE: Has the participant identified a supportive individual?

☐ Yes, continue to question #2
☐ No, STOP

10. Is he/she 18 years of age or older?

☐ Yes
☐ No

NOTE: Is the identified supportive individual 18 years of age or older?

☐ Yes, continue to question #3
☐ No, identified individual is not eligible, STOP
11. May you please provide him/her my contact information, so that I am able to do a brief interview with them regarding his/her experience?

- Yes
- No

**NOTE:** Follow-up with survivor in a week if researcher has not been contacted by the identified supportive individual.

- Yes, **IDENTIFIED INDIVIDUAL IS ELIGIBLE!**
- No, **identified individual not eligible,** STOP

12. Does the identified supportive individual live in your household?

- Yes
- No

**NOTE:** For quota sampling purposes only.

- Yes, *lives with survivor*
- No, *does not live with survivor*

**READY TO ADMINISTER QUESTIONNAIRE FORM!**
Verbal Informed Consent
Breast Cancer Survivor

Researchers at the University of South Florida (USF) study many topics. To do this, we need the help of people who agree to take part in a research study. We are asking you to participate in the research study that is called: Exploring Nutritional Needs, Roles, and Expectations of Hispanic/Latina Breast Cancer Survivors.

Who is doing this study?
The person who is in charge of this research study is Pamela C. Birriel. This person is the Principal Investigator. She is being guided in this research by Dr. Martinez Tyson. Mrs. Birriel is a doctoral candidate and Dr. Martinez Tyson is an assistant professor within the same Department of Community and Family Health at the College of Public Health at the University of South Florida.

Why are you being asked to take part?
You are being asked to participate because you have been identified as someone who is Hispanic/Latina and have been diagnosed with breast cancer. You are asked to take part in this research study to help us better understand how your thoughts, your background as a Hispanic/Latina woman, your environment, and your experience with cancer has impacted the role of diet and nutrition in helping you cope with the effect of cancer treatment and survivorship.

What is the purpose of the study?
The purpose of this study is to learn from your experience with cancer. We hope that your responses will add to our understanding of your unmet needs that could contribute to the development of future nutrition education programs, interventions, and/or services that could provide support for other Hispanic/Latina breast cancer survivors.

What are the study procedures?
If you take part in this study, you will be asked to complete a questionnaire and an interview.

- During the questionnaire and interview, you will answer a few questions about yourself, coping with your cancer experience, your nutrition practices, and forms of support.
- The questionnaire and interview will take about 1 hour of your time, and you can take a break at any time. There are no right or wrong answers. Remember we want to learn from you.

We will digitally audio record during the questionnaire and interview to not miss any of the comments and ideas that are shared. You do not have to share anything you do not want to. Everything you say here will be kept confidential. Your name will not be linked to any of the comments that you make or information you share with us. The Principal Investigator and the person professionally transcribing the audio will be the only individuals with access to the recording. Your information will not be identifiable. The recording and transcript will be permanently deleted and shredded, respectively, five years after the final report is submitted to the USF Institutional Review Board.
What is the total number of participants?
The total number of participants is 60. At least 30 women who are Hispanic/Latina breast cancer survivors will participate in this study. This study will take place in the Tampa Bay Area and in counties around Orlando, Florida.

Is there voluntary participation/withdrawal?
You should only take part in this study if you want to volunteer and should not feel that there is any pressure to take part in the study. You are free to participate in this research or withdraw at any time. There will be no penalty or loss of benefits you are entitled to receive if you stop taking part in this study. Decision to participate or not to participate will not affect your relationship to any support group, health clinic, or social organization.

What are the benefits and risks or discomfort from participating in this study?
There may be no direct benefit to you by participating in this study. This research is considered to be of minimal risk. However, you may feel uncomfortable talking about your feelings and your cancer experience. If you feel this study has caused discomfort in any way, please tell the person in charge of this study.

What are the costs and compensation from participating in this study?
There is NO cost to take part in this study. You will get a $20.00 Wal-Mart gift card incentive after completing the interview to thank you for your time.

Will your information be kept private and confidential?
We must keep your study records as confidential as possible. We may publish what we learn from this study. If we do, we will not let anyone know your name. We will not publish anything else that would let people know who you are. However, certain people may need to see your study records. By law, anyone who looks at your records must keep them completely confidential. The only people who will be allowed to see these records are:

- The research team, including the Principal Investigator, the Advising Professor, and all other research staff.
- Certain government and university people who need to know more about the study. For example, individuals who provide oversight on this study may need to look at your records. This is done to make sure that we are doing the study the right way. They also need to make sure that we are protecting your rights and your safety. These include:
  - The University of South Florida Institutional Review Board (IRB) and the staff that work for the IRB. Other individuals who work for USF that provide other kinds of oversight may also need to look at your records.
  - The Department of Health and Human Services (DHHS).

You can get the answers to your questions, concerns, or complaints
If you have any questions about this study, you can contact the investigator: Pamela C. Birriel (Spanish/English) at 813-541-5504 or through email at pguevara@health.usf.edu. If you have question about your rights as a research participant, please contact the USF IRB at 813-974-5638.
If you agree to participate in this study, you will provide verbal permission to do so. Also, participating in this interview will let us know that you agree to take part in this study.

Would you like to participate in this study? □ Yes □ No

Date of consent: ________/________/_______  Time of consent: ______:______ AM / PM

Statement of Person Obtaining Informed Consent
I have carefully explained to the person taking part in the study what he or she can expect from their participation. I confirm that this research subject speaks the language that was used to explain this research. This research subject has provided legally effective verbal informed consent.

_________________________________________  __________________________  __________
Signature of Person Obtaining Verbal Informed Consent  Printed Name of Person Obtaining Informed Consent  Date
I would like to start by asking a few brief questions about your background…

1. What is your marital status?
   - Single, never married
   - Separated
   - Divorced
   - Married/living with your partner
   - Widowed

2. Date of birth: ________/_______/_______ (MM/DD/YYYY)

3. In what country were you born? ____________________________

4. What is your Hispanic origin (e.g., Puerto Rican)? ____________________________

5. If you were born outside of the U.S. or you were born in Puerto Rico, how long have you lived on the U.S. mainland? ____________________________

6. How well do you speak English?
   - Well
   - Not well
   - Not at all

7. How well do you speak Spanish?
   - Well
   - Not well
   - Not at all

8. Please circle the highest year of school completed:
   - 1 2 3 4 5 6 (primary)
   - 7 8 9 10 11 12 (high school or vocational school)
   - 13 14 15 16 (college/university)
   - 17 18 19 20 21 22 23+ (graduate school)
9. What is your current employment status?
   - Full-time
   - Part-time
   - Retired
   - Homemaker
   - Unemployed – looking for work
   - Unemployed – through disability
   - Prefer not to answer
   - Other (please specify): ______________________________

10. If you work, what type of work do you do now? ______________________________
    - N/A

11. What type of work have you done in the past? ______________________________

12. What is your average yearly household income?
   - Less than $10,000
   - $10,000 – $39,999
   - $40,000 – $79,999
   - Greater than $80,000
   - Prefer not to answer

13. Is your household income…?
   - Not enough to get by
   - Barely enough to get by
   - Sufficient to meet your needs
   - More than enough to meet your needs

14. Do you have health insurance or any type of government insurance (e.g., Medicaid)? (Do not include free care from a hospital or clinic)
   - Yes
   - No
   If no, do you pay your medical bills out-of-pocket or receive free healthcare from a hospital or clinic?
   - Yes
   - No
Now, I would like to ask you a few questions about your breast cancer diagnosis…

15. What stage of breast cancer were you first diagnosed with (e.g., Stage I or II)? ______

16. Where did you seek or obtain chemotherapy treatment for your breast cancer diagnosis?
   - [ ] In the U.S.
   - [ ] At your home country or outside of the U.S.
   - [ ] Or both

17. What supplements have you taken or are still taking? ___________________________  [ ] N/A

Now, I would like to ask you some questions about the support you receive from family members, friends, or others…

18. Who is your primary caregiver? (i.e., husband, daughter, friend, nursing/home assistance from a governmental or private agency, no one): _______________________________

19. Is the amount of support from your family, friends, and caregivers sufficient to meet your physical and emotional health needs?
   - [ ] Yes
   - [ ] No, why not? _______________________________

20. Is the amount of support from your health provider/doctor sufficient to meet your physical and emotional health needs?
   - [ ] Yes
   - [ ] No, why not? _______________________________

21. Do you participate in social support groups?
   - [ ] No, why not? _______________________________
   - [ ] Yes, which group(s)? _______________________________
Now, these next questions are about the food eaten in your household in the last 12 months, since __________ (current month) of last year and whether you were able to afford the food you need.

I am going to read you two statements that people have made about their food situation. For these statements, please tell me whether the statement was often true, sometimes true, or never true for you/your household in the last 12 months—that is, since last __________ (name of current month).

22. The food that I/we bought just didn’t last, and I/we didn’t have money to get more.  
   Was that often, sometimes, or never true for you/your household in the last 12 months?  
   - Often true  
   - Sometimes true  
   - Never true  
   - Don’t know or refused

23. I/we couldn’t afford to eat balanced meals.  
   Was that often, sometimes, or never true for you/your household in the last 12 months?  
   - Often true  
   - Sometimes true  
   - Never true  
   - Don’t know or refused

24. In the last 12 months, since last __________ (name of current month), did you or other adults in your household ever cut the size of your meals or skip meals because there wasn’t enough money for food?  
   - Yes  
   - No (skip #25)  
   - Don’t know (skip #25)

25. [IF YES ABOVE, ASK] How often did this happen—almost every month, some months, or in only 1 or 2 months?  
   - Almost every month  
   - Some months  
   - Only 1 or 2 months  
   - Don’t know
26. In the last 12 months, did you ever eat less than you felt you should because there wasn’t enough money for food?

- Yes
- No
- Don’t know

27. In the last 12 months, were you ever hungry but didn’t eat because there wasn’t enough money for food?

- Yes
- No
- Don’t know
Now, I would like to ask you some questions about food and your cancer experience…

1a. Describe the style of cooking in your home.  
   *Probe:* How do you cook your foods?  
1b. What types of foods do you and your family eat?  
   *Probe:* Describe some of the typical dishes you cook.

2. What is the meaning of food/nutrition to you?  
   *Probe:* How did the meaning of food and nutrition change after your cancer diagnosis and/or chemotherapy?  
   *Probe:* Now as a cancer survivor, how important is nutrition for you?

3. What were/are some of the difficulties that you experienced during treatment?  
   *Probe:* Loss of appetite, loss of taste, nausea, vomiting, fatigue, etc.?  
   - For how long?  
   - Are you still suffering from any of these?

4. You mention __________________ (summarize response to question 3), how did you deal with these?

5. How did the meals you eat and your style of cooking change?  
   *Probe:* Differences from during/after chemotherapy?  
   *Probe:* What impact did chemotherapy have on how you cook and what your family/household eats?  
   *Probe:* What do you do differently?  
   *Probe:* What are you more aware of now?  
   *Probe:* Did these changes affect what your family/household ate during this time?
6. You mention ____________________ (summarize response to question 5).
   - If meals and cooking practices have changed: What motivated you to change your dietary habits?
   - If meals and cooking practices have not changed: How have you maintained your dietary habits?

7. Do you have any concerns about your diet/nutrition?
   Probe: What do you consider a healthy diet?
   - Describe a healthy diet for you.
   Probe: What challenges have you encountered to maintain a healthy diet?

Thank you. Now, I would like to get your opinion about information that is helpful to you as a Latina cancer survivor…

8. What information related to diet and nutrition do you want?

9. What kind of information would have been helpful when you were undergoing chemotherapy?
   Probe: What information were you provided related to diet and nutrition?
   - Who provided it?
   - How was it provided (e.g., in Spanish, written, spoken, video-format, etc.)?
   Probe: How was the information explained that was provided to you?

10. What sorts of nutrition-related resources are you aware of?
    Probe: Were you aware of these during treatment? Now?
    Probe: When did you learn about them? How? From who?

11. You mention ____________________ (summarize responses to questions 8 and 9). What is the best way to receive this information?
    Probe: Through a ‘charla,’ Internet, text, support groups, etc.?
    Probe: When would this information have been the most helpful to you?
Thanks. I would like to ask you a few questions about your role in the household and the decisions regarding meals and food…

12. How did your role in the kitchen change during treatment?
   Probe: How did the roles and expectations from your family/household change during this time?
   Probe: How did this make you feel?
   - If a negative feeling is expressed: How did you cope? What did you do?
   - If a positive feeling is expressed: What helped you? Who helped you?

13. Who did most of the cooking while you were in treatment?
   Probe: Did you still cook?
   Probe: Did others cook for you?
   - How did this make you feel?
   - Did this cause any issues or problems in your house?
   Probe: Who does most of the cooking now?

14. Do you and your family/household members eat the same foods?
   Probe: If no, what are the differences?
   - Have these differences caused any problems or tension?

Thank you. Lastly, I would like to ask you about support that you have or have not received…
15. Since diagnosis, what type of support have you received?
   
   Probe: Who has provided you advice and suggestions to help you address problems?
   □ How has that person provided you this information?
   
   Probe: What resources and services have you used?
   □ What else would have been helpful?
   
   Probe: Who has provided you empathy, love, and/or trust?
   □ How has that person provided you this emotional support?
   
   Probe: Who has provided you constructive feedback and affirmation?
   □ How has that person provided you this support?

16. We are now done with this interview. Is there anything else you would like to add or anything I may have missed?
Appendix E. Interview Protocol: Caregivers

Verbal Informed Consent
Supportive Individual

Researchers at the University of South Florida (USF) study many topics. To do this, we need the help of people who agree to take part in a research study. We are asking you to participate in the research study that is called: Exploring Nutritional Needs, Roles, and Expectations of Hispanic/Latina Breast Cancer Survivors.

Who is doing this study?
The person who is in charge of this research study is Pamela C. Birriel. This person is the Principal Investigator. She is being guided in this research by Dr. Martinez Tyson. Mrs. Birriel is a doctoral candidate and Dr. Martinez Tyson is an assistant professor within the same Department of Community and Family Health at the College of Public Health at the University of South Florida.

Why are you being asked to take part?
You are being asked to participate because you have been identified as a supportive individual that has helped [name of survivor] the most regarding the responsibilities for the decisions related to food in the home. You are asked to take part in this research study to help us better understand how your thoughts, your experiences, and your environment has impacted the role of diet and nutrition in helping the survivor cope with the effect of cancer treatment and survivorship.

What is the purpose of the study?
The purpose of this study is to learn from your experience with the survivor. We hope that your responses will add to our understanding of unmet needs that could contribute to the development of future nutrition education programs, interventions, and/or services that could provide support for other Hispanic/Latina breast cancer survivors.

What are the study procedures?
If you take part in this study, you will be asked to complete a questionnaire and an interview.
- During the questionnaire and interview, you will answer a few questions about yourself, the effect of the survivor’s cancer experience on you, your nutrition practices, and forms of support.
- This questionnaire and interview will take about 45 minutes of your time, and you can take a break at any time. There are no right or wrong answers. Remember we want to learn from you.

We will digitally audio record during the questionnaire and interview to not miss any of the comments and ideas that are shared. You do not have to share anything you do not want to. Everything you say here will be kept confidential. Your name will not be linked to any of the comments that you make or information you share with us. The Principal Investigator and the person professionally transcribing the audio will be the only individuals with access to the recording. Your information will not be identifiable. The recording and transcript will be
permanently deleted and shredded, respectively, five years after the final report is submitted to the USF Institutional Review Board.

What is the total number of participants?
The total number of participants is 60. At least 30 women who are Hispanic/Latina breast cancer survivors will participate in this study. Some of these women may identify supportive individuals to also interview. This study will take place in the Tampa Bay Area and in counties around Orlando, Florida.

Is there voluntary participation/withdrawal?
You should only take part in this study if you want to volunteer and should not feel that there is any pressure to take part in the study. You are free to participate in this research or withdraw at any time. There will be no penalty or loss of benefits you are entitled to receive if you stop taking part in this study. Decision to participate or not to participate will not affect your relationship or the survivor's relationship to any support group, health clinic, or social organization.

What are the benefits and risks or discomfort from participating in this study?
There may be no direct benefit to you by participating in this study. This research is considered to be of minimal risk. However, you may feel uncomfortable talking about your feelings and/or your experience. If you feel this study has caused discomfort in any way, please tell the person in charge of this study.

What are the costs and compensation from participating in this study?
There is NO cost to take part in this study. You will get a $15.00 Wal-Mart gift card incentive after completing the interview to thank you for your time.

Will your information be kept private and confidential?
We must keep your study records as confidential as possible. We may publish what we learn from this study. If we do, we will not let anyone know your name. We will not publish anything else that would let people know who you are. However, certain people may need to see your study records. By law, anyone who looks at your records must keep them completely confidential. The only people who will be allowed to see these records are:

- The research team, including the Principal Investigator, the Advising Professor, and all other research staff.
- Certain government and university people who need to know more about the study. For example, individuals who provide oversight on this study may need to look at your records. This is done to make sure that we are doing the study in the right way. They also need to make sure that we are protecting your rights and your safety. These include:
  - The University of South Florida Institutional Review Board (IRB) and the staff that work for the IRB. Other individuals who work for USF that provide other kinds of oversight may also need to look at your records.
  - The Department of Health and Human Services (DHHS).
You can get the answers to your questions, concerns, or complaints
If you have any questions about this study, you can contact the investigator: Pamela C. Birriel (Spanish/English) at 813-541-5504 or through email at pguevara@health.usf.edu. If you have question about your rights as a research participant, please contact the USF IRB at 813-974-5638.

If you agree to participate in this study, you will provide verbal permission to do so. Also, participating in this interview will let us know that you agree to take part in this study.

Would you like to participate in this study? □ Yes □ No

Date of consent: ________/_______/_______ Time of consent: ______:______ AM / PM

Statement of Person Obtaining Informed Consent
I have carefully explained to the person taking part in the study what he or she can expect from their participation. I confirm that this research subject speaks the language that was used to explain this research. This research subject has provided legally effective verbal informed consent.

_________________________________  ___________________________  _______
Signature of Person Obtaining  Printed Name of Person  Date
Verbal Informed Consent  Obtaining Informed Consent
I would like to start by asking a few brief questions about your background...

1. What is your marital status?
   - Single, never married
   - Separated
   - Divorced
   - Married/living with your partner
   - Widowed

2. Date of birth: ________/_______/_______ (MM/DD/YYYY)

3. In what country were you born? _________________________________

4. What is your Hispanic origin (e.g., Puerto Rican)? _________________________________

5. If you were born outside of the U.S. or you were born in Puerto Rico, how long have you lived on the U.S. mainland? _________________________________

6. How well do you speak English?
   - Well
   - Not well
   - Not at all

7. How well do you speak Spanish?
   - Well
   - Not well
   - Not at all

8. Please circle the highest year of school completed:
   - 1 2 3 4 5 6 (primary)
   - 7 8 9 10 11 12 (high school or vocational school)
   - 13 14 15 16 (college/university)
   - 17 18 19 20 21 22 23+ (graduate school)
9. What is your current employment status?
   - Full-time
   - Homemaker
   - Prefer not to answer
   - Part-time
   - Unemployed – looking for work
   - Other (please specify):
   - Retired
   - Unemployed – through disability
   - N/A

10. If you work, what type of work do you do now? ________________________________  N/A

11. What type of work have you done in the past? ________________________________

12. What is your average yearly household income?
   - Less than $10,000
   - $10,000 – $39,999
   - $40,000 – $79,999
   - Greater than $80,000
   - Prefer not to answer

13. Is your household income…?
   - Not enough to get by
   - Barely enough to get by
   - Sufficient to meet your needs
   - More than enough to meet your needs

14. Do you have health insurance or any type of government insurance (e.g., Medicaid)? (Do not include free care from a hospital or clinic)
   - No, pay out-of-pocket or have no means to pay for healthcare
   - Yes

15. Do you participate in social support groups?
   - No, why not? ________________________________
   - Yes, which group(s)? ________________________________
Now, these next questions are about the food eaten in your household in the last 12 months, since _________ (current month) of last year and whether you were able to afford the food you need.

I am going to read you two statements that people have made about their food situation. For these statements, please tell me whether the statement was often true, sometimes true, or never true for you/your household in the last 12 months—that is, since last _________ (name of current month).

16. The food that I/we bought just didn’t last, and I/we didn’t have money to get more.

   *Was that often, sometimes, or never true for you/your household in the last 12 months?*
   - [ ] Often true
   - [ ] Sometimes true
   - [ ] Never true
   - [ ] Don’t know or refused

17. I/we couldn’t afford to eat balanced meals.

   *Was that often, sometimes, or never true for you/your household in the last 12 months?*
   - [ ] Often true
   - [ ] Sometimes true
   - [ ] Never true
   - [ ] Don’t know or refused

18. In the last 12 months, since last _________ (name of current month), did you or other adults in your household ever cut the size of your meals or skip meals because there wasn’t enough money for food?

   - [ ] Yes
   - [ ] No (skip #19)
   - [ ] Don’t know (skip #19)

19. [IF YES ABOVE, ASK] How often did this happen—almost every month, some months but not every month, or in only 1 or 2 months?

   - [ ] Almost every month
   - [ ] Some months but not every month
   - [ ] Only 1 or 2 months
   - [ ] Don’t know
20. **In the last 12 months, did you ever eat less than you felt you should because there wasn’t enough money for food?**

- Yes
- No
- Don’t know

21. **In the last 12 months, were you ever hungry but didn’t eat because there wasn’t enough money for food?**

- Yes
- No
- Don’t know
Now, I would like to ask you some questions about food and the effect of ____________________
(insert survivor’s name) cancer treatment on you/your family…

1a. Describe the style of cooking in your home.
   Probe: How do you cook your foods?

1b. What types of foods do you and your family eat?
   Probe: Describe some of the typical dishes you cook.

2. What is the meaning of food/nutrition to you?
   Probe: How did the meaning of food and nutrition change after ____________________
   (insert survivor’s name) cancer diagnosis and/or chemotherapy?
   Probe: Now, how important is nutrition for you/your family?

3. How did ____________________ (insert survivor’s name) treatment affect you/your family?
   Probe: How did that affect what you/your family ate and yours/their nutrition?
   □ Does it continue to affect you/your family? How?

4. You mention ____________________ (summarize response to question 3), how did you deal
   with these?

5. How did the meals you eat and the style of cooking change?
   Probe: Differences from during/after ____________________ (insert survivor’s name)
   chemotherapy?
   Probe: What impact did ____________________ (insert survivor’s name) chemotherapy
   have on how you cook and what your family/household eats?
   Probe: What do you do differently?
   Probe: What are you more aware of now?
   Probe: Did these changes affect what your family/household ate during this time?
6. You mention ____________________ (summarize response to question 5).
   - If meals and cooking practices have changed: What motivated you to change your dietary habits?
   - If meals and cooking practices have not changed: How have you maintained your dietary habits?

7. Do you have any concerns about your diet/nutrition?
   Probe: What do you consider a healthy diet?
     - Describe a healthy diet for you.
   Probe: What challenges have you encountered to maintain a healthy diet?

Thank you. Now, I would like to get your opinion about information that is helpful to you…

8. What information related to diet and nutrition do you want?
   Probe: What about information in terms of the current situation of _________________
   (insert survivor’s name) cancer diagnosis and chemotherapy treatment?

9. What kind of information would have been helpful when ____________________ (insert survivor’s name) was undergoing chemotherapy?
   Probe: What information were you/your family provided related to diet and nutrition?
     - Who provided it?
     - How was it provided (e.g., in Spanish, written, spoken, video-format, etc.)?
   Probe: How was the information explained that was provided to you/your family?

10. What sorts of nutrition-related resources are you aware of?
    Probe: Were you aware of these during _________________ (insert survivor’s name) treatment? Now?
     Probe: When did you learn about them? How? From who?
11. You mention ____________________ (summarize responses to questions 8 and 9). **What is the best way to receive this information?**
   
   *Probe*: Through a ‘charla,’ Internet, text, support groups, etc.?
   
   *Probe*: When would this information have been the most helpful to you/your family?

Thanks. I would like to ask you a few questions about your role in the household and the decisions regarding meals and food…

12. **How did your role in the kitchen change during ________________ (insert survivor’s name) treatment?**
   
   *Probe*: How did the roles and expectations from your family/household change during this time?
   
   *Probe*: How did this make you feel?
   
   - If a negative feeling is expressed: How did you cope? What did you do?
   - If a positive feeling is expressed: What helped you? Who helped you?

13. **Who did most of the cooking while ________________ (insert survivor’s name) was in treatment?**
   
   *Probe*: Did ________________ (insert survivor’s name)/you still cook?
   
   *Probe*: Did others in your family/household cook?
   
   - How did this make you feel?
   - Did this cause any issues or problems in your house?
   
   *Probe*: Who does most of the cooking now?

14. **Do you and your family/household members eat the same foods?**
   
   *Probe*: If no, what are the differences?
   
   - Have these differences caused any problems or tension?

Thank you. Lastly, I would like to ask you about support that you have or have not received…
15. Since _________________ (insert survivor’s name) diagnosis, what type of support have you received?

   *Probe:* Who has provided you advice and suggestions to help you address problems?
   - How has that person provided you this information?

   *Probe:* What resources and services have you used?
   - What else would have been helpful?

   *Probe:* Who has provided you empathy, love, and/or trust?
   - How has that person provided you this emotional support?

   *Probe:* Who has provided you constructive feedback and affirmation?
   - How has that person provided you this support?

16. We are now done with this interview. Is there anything else you would like to add or anything I may have missed?
Appendix F. Interview Protocol: Key Informants

Eligibility Form
Key Informant

Instructions: Please answer the questions below. This information will not be shared with anyone.

1. What is your age? __________
   NOTE: Is the participant 18 years of age or older?
   □ Yes, continue to question #2
   □ No, not eligible, STOP

2. Do you speak English and/or Spanish?
   □ English
   □ Spanish
   □ No
   NOTE: Does the participant speak either of the languages?
   □ Yes, continue to question #3
   □ No, not eligible, STOP

3. Do you currently work with cancer survivors?
   □ Yes… What population specifically?
   ________________________________
   □ No… Have you worked with them in the past?
   □ No
   □ Yes, specify:
   ________________________________
   NOTE: Does the participant currently work with cancer survivors or has done so in the past?
   □ Yes to either, continue to question #4
   □ No, not eligible, STOP

4. Have you been interviewed as a survivor or identified supportive individual as part of this study?
   □ Yes
   □ No
   NOTE: Has the participant been interviewed already as part of this study?
   □ No, PARTICIPANT IS ELEGIBLE!
   □ Yes, not eligible, STOP
** PLEASE COMPLETE
CONTACT INFORMATION! **

The participant IS ELEGIBLE as a key informant!

First Name: ___________________________ Last Name: ___________________

Job Title: ___________________________________________________________
Company/Organization: ______________________________________________

Telephone: (__________)_________ - ______________________

Physical Address: ___________________________________________________
Suite Number: __________________ City: _____________________________
State: ___________________________ Zip Code: _______________________
Email: ___________________________@_______________________________

Best time to contact: ___________________________ (make appointment)

_______________________________________________________________

Attach business card below, if applicable.

** READY TO ADMINISTER
QUESTIONNAIRE FORM! **
Researchers at the University of South Florida (USF) study many topics. To do this, we need the help of people who agree to take part in a research study. We are asking you to participate in the research study that is called: *Exploring Nutritional Needs, Roles, and Expectations of Hispanic/Latina Breast Cancer Survivors.*

**Who is doing this study?**
The person who is in charge of this research study is Pamela C. Birriel. This person is the Principal Investigator. She is being guided in this research by Dr. Martinez Tyson. Mrs. Birriel is a doctoral candidate and Dr. Martinez Tyson is an assistant professor within the same Department of Community and Family Health at the College of Public Health at the University of South Florida.

**Why are you being asked to take part?**
You are being asked to participate as a key informant because you have been identified as an expert in the field that currently works to transform cancer care through service, science, and partnership. As we gather a broad range of information about nutritional needs from a diverse group of health professionals who work with Hispanic/Latino cancer survivors, you are asked to take part to help us better understand the role of diet and nutrition in helping survivors cope with the effect of cancer treatment and survivorship.

**What is the purpose of the study?**
The purpose of this study is to learn from the perspectives of cancer survivors, identified supportive individuals, and key informants. We hope that your responses will add to our understanding of unmet needs that could contribute to the development of future nutrition education programs, interventions, and/or services that could provide support for other Hispanic/Latina breast cancer survivors.

**What are the study procedures?**
If you take part in this study, you will be asked to complete a questionnaire and an interview.

- During the questionnaire and interview, you will answer a few questions about yourself, your work with cancer survivors, as well as your knowledge on their nutrition practices and forms of support.
- This questionnaire and interview will take about 30 minutes of your time, and you can take a break at any time. There are no right or wrong answers. Remember we want to learn from you.

We will digitally audio record during the questionnaire and interview to not miss any of the comments and ideas that are shared. You do not have to share anything you do not want to. Everything you say here will be kept confidential. Your name will not be linked to any of the comments that you make or information you share with us. The Principal Investigator and the person professionally transcribing the audio will be the only individuals with access to the recording. Your information will not be identifiable. The recording and transcript will be
permanently deleted and shredded, respectively, five years after the final report is submitted to the USF Institutional Review Board.

**What is the total number of participants?**
The total number of participants is 60. At least 30 women who are Hispanic/Latina breast cancer survivors will participate in this study. Some of these women may identify supportive individuals to also interview, and we will receive the perspective of key informants that work in the field. This study will take place in the Tampa Bay Area and in counties around Orlando, Florida.

**Is there voluntary participation/withdrawal?**
You should only take part in this study if you want to volunteer and should not feel that there is any pressure to take part in the study. You are free to participate in this research or withdraw at any time. There will be no penalty or loss of benefits you are entitled to receive if you stop taking part in this study. Decision to participate or not to participate will not affect your relationship to any support group, health clinic, or social organization.

**What are the benefits and risks or discomfort from participating in this study?**
There may be no direct benefit to you by participating in this study. This research is considered to be of minimal risk. If you feel this study has caused discomfort in any way, please tell the person in charge of this study.

**What are the costs and compensation from participating in this study?**
There is NO cost to take part in this study. You will get a $15.00 Wal-Mart gift card incentive after completing the interview to thank you for your time.

**Will your information be kept private and confidential?**
We must keep your study records as confidential as possible. We may publish what we learn from this study. If we do, we will not let anyone know your name. We will not publish anything else that would let people know who you are. However, certain people may need to see your study records. By law, anyone who looks at your records must keep them completely confidential. The only people who will be allowed to see these records are:

- The research team, including the Principal Investigator, the Advising Professor, and all other research staff.
- Certain government and university people who need to know more about the study. For example, individuals who provide oversight on this study may need to look at your records. This is done to make sure that we are doing the study in the right way. They also need to make sure that we are protecting your rights and your safety. These include:
  - The University of South Florida Institutional Review Board (IRB) and the staff that work for the IRB. Other individuals who work for USF that provide other kinds of oversight may also need to look at your records.
  - The Department of Health and Human Services (DHHS).
You can get the answers to your questions, concerns, or complaints
If you have any questions about this study, you can contact the investigator: Pamela C. Birriel (Spanish/English) at 813-541-5504 or through email at pguevara@health.usf.edu. If you have question about your rights as a research participant, please contact the USF IRB at 813-974-5638.

If you agree to participate in this study, you will provide verbal permission to do so. Also, participating in this interview will let us know that you agree to take part in this study.

Would you like to participate in this study? □ Yes □ No

Date of consent: _____/_____/______ Time of consent: _____:____ AM / PM

Statement of Person Obtaining Informed Consent
I have carefully explained to the person taking part in the study what he or she can expect from their participation. I confirm that this research subject speaks the language that was used to explain this research. This research subject has provided legally effective verbal informed consent.

__________________________  ___________________________  _____/_____/______
Signature of Person Obtaining  Printed Name of Person  Date
Verbal Informed Consent

Obtaining Informed Consent
I would like to start by asking a few brief questions about your background…

1. Date of birth: __________/__________/__________ (MM/DD/YYYY)

2. What is your race (please select all that apply)?
   - White
   - Black
   - Asian
   - Pacific Island or Alaska Native
   - Other (please specify): ________________________________
   - Prefer not to answer

3. Are you Hispanic?
   - No
   - Yes, what is your Hispanic origin (e.g., Puerto Rican)? ________________________________

4. In what country were you born? ________________________________

5. If you were born outside of the U.S. or you were born in Puerto Rico, how long have you lived on the U.S. mainland? ________________________________

6. How well do you speak English?
   - Well
   - Not well
   - Not at all

7. How well do you speak Spanish?
   - Well
   - Not well
   - Not at all

8. Please circle the highest year of school completed:
   - 1 2 3 4 5 6 (primary)
   - 7 8 9 10 11 12 (high school or vocational school)
   - 13 14 15 16 (college/university)
   - 17 18 19 20 21 22 23+ (graduate school)
9. What is your current employment status?
   - Full-time
   - Homemaker
   - Prefer not to answer
   - Part-time
   - Unemployed – looking for work
   - Other (please specify):
   - Retired
   - Unemployed – through disability

10. If you currently work with cancer survivors, what type of work do you do now?
     ____________________________________________
     - N/A

11. How long have you worked in your current role?
     ________________________________
     - N/A

12. Do you live in the county/community in which you currently work?
   - No
   - Yes, how long have you lived there?
     ________________________________

13. What type of work have you done in the past with cancer survivors?
     ________________________________
     - N/A

14. What is your average yearly household income?
   - Less than $10,000
   - $10,000 – $39,999
   - $40,000 – $79,999
   - Greater than $80,000
   - Prefer not to answer

15. Is your household income…?
   - Not enough to get by
   - Barely enough to get by
   - Sufficient to meet your needs
   - More than enough to meet your needs

16. Do you participate in social support groups?
   - No, why not?
   - Yes, which group(s)?

193
Now, these next questions are about the food eaten in your household in the last 12 months, since ________ (current month) of last year and whether you were able to afford the food you need.

I am going to read you two statements that people have made about their food situation. For these statements, please tell me whether the statement was often true, sometimes true, or never true for you/your household in the last 12 months—that is, since last ________ (name of current month).

17. The food that I/we bought just didn’t last, and I/we didn’t have money to get more.

Was that often, sometimes, or never true for you/your household in the last 12 months?

- Often true
- Sometimes true
- Never true
- Don’t know or refused

18. I/we couldn’t afford to eat balanced meals.

Was that often, sometimes, or never true for you/your household in the last 12 months?

- Often true
- Sometimes true
- Never true
- Don’t know or refused

19. In the last 12 months, since last ________ (name of current month), did you or other adults in your household ever cut the size of your meals or skip meals because there wasn’t enough money for food?

- Yes
- No (skip #20)
- Don’t know (skip #20)

20. [IF YES ABOVE, ASK] How often did this happen—almost every month, some months but not every month, or in only 1 or 2 months?

- Almost every month
- Some months but not every month
- Only 1 or 2 months
- Don’t know
21. In the last 12 months, did you ever eat less than you felt you should because there wasn’t enough money for food?
   - Yes
   - No
   - Don’t know

22. In the last 12 months, were you ever hungry but didn’t eat because there wasn’t enough money for food?
   - Yes
   - No
   - Don’t know
Interview Questions – Key Informant

1a. Describe the style of cooking of Latinos who have diagnosed with cancer.
   Probe: How do they cook their foods?
1b. What types of foods do these Latino families eat?
   Probe: Describe some of the typical dishes they eat.

2. What is the meaning of food/nutrition to people who have been diagnosed with cancer?
   Probe: How did the meaning of food and nutrition change for these people after cancer diagnosis and/or chemotherapy?
   Probe: Now, how important is nutrition for these families?

3. What were/are some of the difficulties that people diagnosed with cancer experience during treatment?
   Probe: Loss of appetite, loss of taste, nausea, vomiting, fatigue, etc.?
   ○ For how long?

4. How does the survivor’s treatment affect the family?
   Probe: How does that affect what the family eats and their nutrition?

5. You mention __________________ (summarize responses to questions 3 and 4), how did they deal with these?
6. How did the meals they eat and the style of cooking change for people diagnosed with cancer?
   
   *Probe*: Differences from during/after chemotherapy?  
   *Probe*: What impact did chemotherapy have on how they cook and what the families/households eat?  
   *Probe*: What do they do differently?  
   *Probe*: What are they more aware of now?  
   *Probe*: Do these changes affect what the families/households eat during this time?

7. You mention ________________ (summarize response to question 6).
   
   - If meals and cooking practices have changed: **What motivates them to change their dietary habits?**  
   - If meals and cooking practices have not changed: **How do they maintain their dietary habits?**

8. Do people diagnosed with cancer have any concerns about their diet/nutrition?
   
   *Probe*: What do they consider a healthy diet?
   - Describe a healthy diet for them.  
   *Probe*: What challenges have they encountered to maintain a healthy diet?

   
   **Thank you. Now, I would like to get your opinion about information that is helpful to Latinas diagnosed with breast cancer...**

9. What information related to diet and nutrition do they want?
   
   *Probe*: What about information in terms of the current situation of cancer diagnosis and chemotherapy treatment?
10. **What kind of information would be helpful when they are undergoing chemotherapy?**

   *Probe:* What information do you provide related to diet and nutrition?
   - When do you provide it?
   - How do you provide it (e.g., in Spanish, written, spoken, video-format, etc.)?
   *Probe:* How do you explain the information that you provide to people diagnosed with cancer and/or their families?

11. **You mention __________________** (summarize responses to questions 9 and 10). **What is the best way to provide this information?**

   *Probe:* Through a ‘charla,’ Internet, text, support groups, etc.?
   *Probe:* When would this information have been the most helpful to them/their families?

12. **What sorts of nutrition-related resources are you aware of for Latinas diagnosed with breast cancer?**

   *Probe:* Are they aware of these during treatment? How? From whom?
   *Probe:* Do you provide information about these resources? When they are diagnosed? During treatment?

   **Thanks. I would like to ask you a few questions about the role in the household and the decisions regarding meals and food…**

13. **How does their role in the kitchen change during treatment for Latinas diagnosed with breast cancer?**

   *Probe:* How does the roles and expectations from their families/households change during this time?
   *Probe:* How does this make them feel?
   - If a *negative* feeling is expressed: How do they cope? What do they do?
   - If a *positive* feeling is expressed: What helps them? Who helps them?
14. Who does most of the cooking while the Latinas diagnosed with breast cancer are in treatment?

Probe: Do they still cook?
Probe: Do others in their family/household cook?
  ▪ How does this make them feel?
  ▪ Does this cause any issues or problems in their house?
Probe: Who does most of the cooking after treatment?

15. Do Latinas diagnosed with breast cancer and their families/household members eat the same foods?

Probe: If no, what are the differences?
  ▪ Do these differences cause any problems or tension?

Thank you. Lastly, I would like to ask you about support that Latinas diagnosed with breast cancer have or do not receive…

16. Since the cancer diagnosis, what type of support do these women receive?

Probe: Who provides them advice and suggestions to help them address problems?
  ▪ How are they provided this informational support?

Probe: What resources and services do they use?
  ▪ Who refers them? What other instrumental support would have been helpful?

Probe: Who provides them empathy, love, and/or trust?
  ▪ How are they provided this emotional support?

Probe: Who provides them constructive feedback and affirmation?
  ▪ How are they provided this appraisal support?

17. We are now done with this interview. Is there anything else you would like to add or anything I may have missed?
September 2, 2015

Pamela C. Birriel, MPH
Doctoral Candidate in Public Health
Department of Community and Family Health
College of Public Health
University of South Florida
13201 Bruce B. Downs Boulevard, MDC 56
Tampa, Florida 33612-3805

Dear Mrs. Birriel,

I write this letter in support of your proposed project entitled “Exploring Nutritional Needs, Roles, and Expectations of Hispanic/Latina Breast Cancer Survivors after Treatment.” I understand that the goal of your study is to gain a better understanding regarding Hispanic/Latina breast cancer survivors’ perceptions of the importance of diet and nutrition in helping them cope with the effect of chemotherapy treatment and survivorship.

I look forward to working closely with you in helping to improve outcomes among Hispanic/Latina breast cancer survivors. I believe that this is an innovative approach to begin to understand what this unique population seeks regarding healthful nutrition and perceives as social support, essentially capturing what may most benefit them as cancer survivors.

[ ] is a non-profit organization that provides support to Hispanic/Latino women and men diagnosed with cancer, their family, and friends. To date we have reached over 400 Hispanic/Latino families with our programs [ ].

Many of the women who have participated in our programs have shared some of the struggles they faced during treatment with regards to nutrition and diet. As a [ ] who has worked closely with Hispanic/Latino cancer survivors, I am knowledgeable of the needs, everyday realities and struggles they face in accessing information, follow-up care, and receiving culturally competent services.

The value of this project extends beyond just the participants that will be involved but to the wider cancer survivor community at large, as it could inform on the ideal teachable moment to provide health information by understanding the connection between diet and cancer survivorship among this population.

I am happy to assist as a key informant, as well as with recruitment and will be able to share project information with cancer survivors that attend our support group meetings.
and activities. As an informant, I understand that I will review the translation of the materials and project interview guides. I will also provide feedback by sharing my ideas and insights as well as help to identify any other relevant information that should be included so that the final product prior to data collection is pertinent for minority cancer survivors, especially Hispanics/Latinas. You are also welcome to come to any of our meetings or outreach events and activities to raise awareness of your study and pass out flyers.

I look forward to helping you in this important study and to working with you on this endeavor.

Sincerely,
10 de septiembre del 2015

Pamela C. Binnie, MPH
Candidata para el Doctorado en Salud Pública
Departamento de la Salud Comunitaria y Familiar
Escuela de Salud Pública
Universidad del Sur de Florida
13201 Bruce B. Downs Boulevard, MDC 56
Tampa, Florida 33612-3805

Estimada Señora Binnie,

Escribo esta carta en apoyo de su proyecto titulado “Exploración de las Necesidades Nutricionales, Roles, y Expectativas de las Hiperanas/Latinas Sobrevivientes de Cáncer de Mama.” Entiendo que el propósito de su proyecto es obtener una mejor comprensión de la perspectiva de las Hiperanas/Latinas sobrevivientes de cáncer de mama sobre la importancia de la dieta y nutrición para hacer frente a los efectos de la quimioterapia y sobrevivencia.

Espero trabajar con usted para ayudar a ampliar el conocimiento al respecto de este grupo de Hiperanas/Latinas sobrevivientes de cáncer de mama. Creo que su proyecto tiene un enfoque innovador para empezar a entender lo que esta población busca en relación con la nutrición saludable y percibe como apoyo, esencialmente capturando lo que más les beneficia como sobrevivientes de cáncer.

La misión de [insertar información relevante] es aumentar el conocimiento sobre el cáncer de mama a través de talleres y charlas. Como sobreviviente de cáncer he trabajado en colaboración con otras Hiperanas/Latinas sobrevivientes de cáncer y reconozco las necesidades, realidades cotidianas, y luchas que esta población enfrenta para obtener acceso a la información relacionada y recibir servicios culturalmente competentes.

Estoy encantada en poder ayudarle como informante, repartir folletos de reclutamiento, y compartir la información de su proyecto con nuestros miembros en reuniones, eventos, y actividades de divulgación. Como informante, entiendo que compartiré mis ideas y puntos de vista como sobreviviente de cáncer. También, ayudaré a identificar cualquier otra información pertinente que debe ser incluida en sus documentos antes de coleccionar información y escuchar las perspectivas de las sobrevivientes. Por último, les invitamos a ustedes a brindar a nuestra próxima charla y a otros eventos, reuniones, y actividades para compartir información sobre su proyecto y repartir folletos.

Espero poder ayudarle con su proyecto tan importante y trabajar con ustedes en este esfuerzo.

Atentamente,
September 10, 2015

Pamela C. Birriel, MPH
Doctoral Candidate in Public Health
Department of Community and Family Health
College of Public Health
University of South Florida
13201 Bruce B. Downs Boulevard, MDC 56
Tampa, Florida 33612-3805

Dear Mrs. Birriel,

I write this letter in support of your proposed project entitled “Exploring Nutritional Needs, Roles, and Expectations of Hispanic/Latina Breast Cancer Survivors after Treatment.” I understand that the purpose of your study is to gain a better understanding regarding Hispanic/Latina breast cancer survivors’ perceptions of the importance of diet and nutrition in helping them cope with the effect of chemotherapy treatment and survivorship.

I look forward to working closely with you in helping to improve outcomes among Hispanic/Latina breast cancer survivors. I believe this is an innovative approach to begin to understand what this unique population seeks regarding healthful nutrition and perceives as social support, essentially capturing what may most benefit them as cancer survivors.

The mission of [redacted] is to increase knowledge about breast cancer through workshops and teach self-breast examination. As a cancer survivor, who has worked closely with Hispanic/Latino cancer survivors, I am knowledgeable of the needs, everyday realities and struggles they face in accessing information, follow-up care, and receiving culturally competent services. Because of this, I also share my own personal experience with cancer to raise awareness of this disease.

I am happy to assist as an informant, pass out recruitment flyers, and share project information with our members at any of our meetings and at outreach event and activities. As an informant, I understand that I will provide feedback by sharing my ideas and insights as a cancer survivor, as well as helping to identify any other relevant information that should be included so that the final product prior to data collection is pertinent for minority cancer survivors, especially Hispanics/Latinas. You are also welcome to come to any of our meetings and to any of our outreach events and activities to raise awareness of your study and pass out flyers.

I look forward to helping you in this important study and to working with you on this endeavor.

Sincerely,

[Signature on Support Letter Written in Spanish]
September 22, 2015

Pamela C. Birriel, MPH  
Doctoral Candidate in Public Health  
Department of Community and Family Health  
College of Public Health  
University of South Florida  
13201 Bruce B. Downs Boulevard, MDC 56  
Tampa, Florida 33612-3805

Dear Mrs. Birriel,

I write this letter in support of your proposed project entitled “Exploring nutritional needs, roles, and expectations of Hispanic/Latina breast cancer survivors after treatment.” I understand that the purpose of your study is to gain a better understanding regarding Hispanic/Latina breast cancer survivors’ perceptions of the importance of diet and nutrition in helping them cope with the effect of chemotherapy treatment and survivorship.

I look forward to working closely with you in helping to improve outcomes among Hispanic/Latina breast cancer survivors. I believe this is an innovative approach to begin to understand what this unique population seeks regarding healthful nutrition and perceives as social support, essentially capturing what may most benefit them as cancer survivors.

As a [redacted] who has worked closely with Hispanic/Latina cancer survivors, I am knowledgeable of the needs, everyday realities and struggles they face in accessing information, follow-up care, and receiving culturally competent services.

I am happy to assist as a key informant. As an informant, I understand that I will provide initial feedback regarding the translation of materials and project interview guides, as well as help to identify any other relevant information that should be included so that the final product prior to data collection is pertinent for minority cancer survivors, especially Hispanics/Latinas.

I look forward to helping you in this important study and working with you on this endeavor.

Sincerely,
September 28, 2015

Pamela C. Birriel, MPH
Doctoral Candidate in Public Health
Department of Community and Family Health
College of Public Health
University of South Florida
13201 Bruce B. Downs Boulevard, MDC 56
Tampa, Florida 33612-3805

Dear Mrs. Birriel,

I write this letter in support of your proposed project entitled “Exploring Nutritional Needs, Roles, and Expectations of Hispanic/ Latina Breast Cancer Survivors after Treatment.” I understand that the purpose of your study is to gain a better understanding regarding Hispanic/ Latina breast cancer survivors’ perceptions of the importance of diet and nutrition in helping them cope with the effect of chemotherapy treatment and survivorship.

I look forward to working with you in helping to improve outcomes among Hispanic/ Latina breast cancer survivors. I believe that this is an innovative approach to begin to understand what this unique population seeks regarding healthful nutrition and perceives as social support, essentially capturing what may most benefit them as cancer survivors.

It will be a pleasure to assist as a key informant, as well as with recruitment and will be able to share project information with potential participants. As an informant, I understand that I will provide feedback by sharing my ideas and insights. You are also welcome to attend our meeting in October, as well as any of the [redacted] events to raise awareness of your study and pass out fliers.

I look forward to helping you in this important study and to working with you on this endeavor, together with the members of the support group here in Orlando, FL.

Sincerely,
May 17, 2016

Pamela C. Birriel, MPH  
Doctoral Candidate in Public Health  
Department of Community and Family Health  
College of Public Health  
University of South Florida  
13201 Bruce B. Downs Boulevard, MDC 56  
Tampa, Florida 33612-3805  

Dear Mrs. Birriel,  

I write this letter in support of your research study entitled: *Exploring Nutritional Needs, Roles, and Expectations of Hispanic/Latina Breast Cancer Survivors*. I understand that the purpose of your study is to gain a better understanding regarding Hispanic/Latina breast cancer survivors' perceptions of the importance of diet and nutrition in helping them cope with the effect of chemotherapy treatment and survivorship.  

I look forward to working closely with you in helping to improve outcomes among Hispanic/Latina breast cancer survivors. I believe this is an innovative approach to begin to understand what this unique population seeks regarding healthful nutrition and perceives as social support, essentially capturing what may most benefit them as cancer survivors. I hope that what you find will add to the understanding of unmet needs that could contribute to the development of future nutrition education programs, interventions, and/or services that could provide support for Hispanic/Latina breast cancer survivors.  

I am happy to distribute your flyers to our current Hispanic cosmetic and reconstructive patients. I look forward to helping you in this important study and working with you on this endeavor.  

Sincerely,
Appendix H. IRB Letters of Approval

3/7/2016

Pamela Guzara
Community and Family Health
13201 Bruce B. Downs Boulevard
MDC 56
Tampa, FL 33612

RE: Expedited Approval for Initial Review
IRB#: Pro00022937
Title: Exploring Nutritional Needs, Roles, and Expectations of Hispanic/Latina Breast Cancer Survivors

Study Approval Period: 3/6/2016 to 3/6/2017

Dear Mrs. Guzara:

On 3/6/2016, the Institutional Review Board (IRB) reviewed and APPROVED the above application and all documents contained within, including those outlined below.

Approved Item(s):
Protocol Document(s):
Study Protocol Version 1, Initial 3-2-2016.pdf

Consent/Assent Document(s):
Informed Consent, Latina Breast Cancer Survivor, ENGLISH 3-1-2016.pdf
Informed Consent, Latina Breast Cancer Survivor, SPANISH 3-1-2016.pdf
Informed Consent, Supportive Individual, ENGLISH 3-1-2016.pdf
Informed Consent, Supportive Individual, SPANISH 3-1-2016.pdf
Pre-Screening Introduction Script, ENGLISH 3-1-2016.pdf
Pre-Screening Introduction Script, SPANISH 3-1-2016.pdf

It was determined by the IRB that your study qualified for expedited review which includes activities that (1) present no more than minimal risk to human subjects; and (2) involve only procedures listed in one or more of the categories outlined below. The IRB may review research through the expedited review procedure authorized by 45 CFR 46.110 and 21 CFR 50.110. The research proposed in this study is categorized under the following expedited review...
category.

(6) Collection of data from voice, video, digital, or image recordings made for research purposes.

(7) Research on individual or group characteristics or behavior (including, but not limited to, research on perception, cognition, motivation, identity, language, communication, cultural beliefs or practices, and social behavior) or research employing survey, interview, oral history, focus group, program evaluation, human factors evaluation, or quality assurance methodologies.

For pre-screening and for obtaining verbal consent from participants your study qualifies for a waiver of the requirements for the documentation of informed consent as outlined in the federal regulations at 45 CFR 46.117(c) which states that an IRB may waive the requirement for the investigator to obtain a signed consent form for some or all subjects if it finds either: (1) That the only record linking the subject and the research would be the consent document and the principal risk would be potential harm resulting from a breach of confidentiality. Each subject will be asked whether the subject wants documentation linking the subject with the research, and the subject’s wishes will govern, or (2) That the research presents no more than minimal risk of harm to subjects and involves no procedures for which written consent is normally required outside of the research context.

As the principal investigator of this study, it is your responsibility to conduct this study in accordance with IRB policies and procedures and as approved by the IRB. Any changes to the approved research must be submitted to the IRB for review and approval via an amendment. Additionally, all unanticipated problems must be reported to the USF IRB within five (5) calendar days.

We appreciate your dedication to the ethical conduct of human subject research at the University of South Florida and your continued commitment to human research protections. If you have any questions regarding this matter, please call 813-974-5638.

Sincerely,

[Signature]

Kristen Salamon, Ph.D., Vice Chairperson
USF Institutional Review Board
5/26/2016

Pamela Guevara
Community and Family Health
13201 Bruce B. Downs Boulevard
MDC 56
Tampa, FL 33612

RE: Expedited Approval of Amendment
IRB#: Amc1_Pro00022937
Title: Exploring Nutritional Needs, Roles, and Expectations of Hispanic/Latina Breast Cancer Survivors

Dear Ms. Guevara

On 5/26/2016, the Institutional Review Board (IRB) reviewed and APPROVED your Amendment. The submitted request and all documents contained within have been approved, including those outlined below.

This amendment request is to be able to expand that eligibility criteria to "undergoing or having received chemotherapy within the last three years."

Revised Protocol, version 2, 05/18/2016
Revised Consent Latina Breast Cancer Survivor Spanish, version 3, dated 05.25.2016
Revised Consent Supportive Individual English, version 3, dated 05.25.2016
Revised Consent Supportive Individual Spanish, version 3, dated 05.25.2016
Revised Introduction English, version 2, 05.18.2016
Revised Introduction Spanish, version 2, 05.18.2016
Revised Flyer English, version 2, 05.18.2016
Revised Flyer Spanish, version 2, 05.18.2016
Revised Interview Guides, version 2, 05.18.2016
Revised Questionnaires, version 2, 05.18.2016

Approved Item(s):
Protocol Document(s):
Consent Document(s):
CLEAN Informed Consent LEC5-ENGLISH V3 5.25.2016.pdf
CLEAN Informed Consent LEC5-Spanish V3 5.25.2016.pdf
CLEAN Informed Consent Support-Spanish V3 5.25.2016.pdf

The IRB does not require that subjects be reconsented.

As the principal investigator of this study, it is your responsibility to conduct this study in accordance with USF HRPP policies and procedures and as approved by the USF IRB. Any changes to the approved research must be submitted to the IRB for review and approval via an amendment. Additionally, all unanticipated problems must be reported to the USF IRB within five (5) calendar days.

We appreciate your dedication to the ethical conduct of human subject research at the University of South Florida and your continued commitment to human research protections. If you have any questions regarding this matter, please call 813-974-5638.

Sincerely,

John Schinka, Ph.D.
Chairperson
USF Institutional Review Board
10/4/2016

Pamela Guevara
Community and Family Health
13201 Bruce B. Downs Boulevard
MDC 56
Tampa, FL 33612

RE: Expedited Approval of Amendment
IRB#: Ame2_Pro00022937
Title: Exploring Nutritional Needs, Roles, and Expectations of Hispanic/Latina Breast Cancer Survivors

Dear Mrs. Guevara:

On 10/3/2016, the Institutional Review Board (IRB) reviewed and APPROVED your Amendment. The submitted request and all documents contained within have been approved, including those outlined below:

My original study included informal discussions with five key informants which I have maintained throughout conducting my research. Moving forward, after receiving advice from my doctoral committee members, future discussions with key informants will be formal interviews.

Additionally, up to this point I have been able to interview 23 survivors and five supportive individuals. I am finding that it is really difficult to recruit participants within my (small time-frame) eligibility criteria of: "undergoing or having received chemotherapy within the last three years." From all of the recruiting that I have been doing, I know that there are potential participants outside of undergoing or having received chemotherapy "within the last three years." This amendment request is to be able to expand that eligibility criteria to "undergoing or having received chemotherapy within the last five years" to then be able to reach more supportive individuals to interview. I have already received approval from my doctoral committee about making the change to my eligibility criteria. The literature and my current experience with participants already interviewed is that there will be little to no recall bias, since survivors are really able to talk about their experience with this traumatic event of diagnosis and treatment.

Approved Item(s):
Protocol Document(s):
Study Protocol_Version 3_Birriel_9.27.2016.pdf
Consent Document(s)*:
CLEAN_Informed Consent_Key Informant_ENGLISH_V3_10.3.2016.pdf
CLEAN_Informed Consent_Key Informant_SPANISH_V3_10.3.2016.pdf
CLEAN_Informed Consent_LBCS_ENGLISH_V5_10.3.2016.pdf
CLEAN_Informed Consent_LBCS_SPANISH_V5_10.3.2016.pdf
CLEAN_Informed Consent_Support_ENGLISH_V5_10.3.2016.pdf
CLEAN_Informed Consent_Support_SPANISH_V5_10.3.2016.pdf

*Please use only the official IRB stamped informed consent/assent document(s) found under the "Attachments" tab on the main study's workspace. Please note, these consent/assent document(s) are only valid during the approval period indicated at the top of the form(s) and replace previously approved versions. **Verbal Consents are not stamped.

The IRB does not require that subjects be reconsented.

As the principal investigator of this study, it is your responsibility to conduct this study in accordance with USF HRPP policies and procedures and as approved by the USF IRB. Any changes to the approved research must be submitted to the IRB for review and approval via an amendment. Additionally, all unanticipated problems must be reported to the USF IRB within five (5) calendar days.

We appreciate your dedication to the ethical conduct of human subject research at the University of South Florida and your continued commitment to human research protections. If you have any questions regarding this matter, please call 813-974-5638.

Sincerely,

John Schinka, Ph.D.
Chairperson
USF Institutional Review Board
Appendix I. Approval for Use of Transactional Model of Stress and Coping Figure

Subject: RE: NON RIGHTSUNI: Permission Request for Dissertation Document
Date: Wednesday, November 2, 2016 at 7:02:25 AM Eastern Daylight Time
From: Wiley Global Permissions permissions@wiley.com > (sent by Masheter, Aimee - Chichester <amasheter@wiley.com>)
To: Birriel, Pamela <pguevara@health.usf.edu>

Dear Pam Birriel,

Thank you for your request.

Permission is granted for you to use the material requested for your thesis/dissertation subject to the usual acknowledgements (author, title of material, title of book/journal, ourselves as publisher) and on the understanding that you will reapply for permission if you wish to distribute or publish your thesis/dissertation commercially. You must also duplicate the copyright notice that appears in the Wiley publication in your use of the Material; this can be found on the copyright page if the material is a book or within the article if it is a journal.

Permission is granted solely for use in conjunction with the thesis, and the material may not be posted online separately.

Any third party material is expressly excluded from this permission. If any of the material you wish to use appears within our work with credit to another source, authorisation from that source must be obtained.

Best wishes,

Aimee Masheter
Permissions Coordinator
John Wiley & Sons Ltd
The Atrium
Southern Gate, Chichester
West Sussex, PO19 8SQ
UK

From: Birriel, Pamela [mailto:pguevara@health.usf.edu]
Sent: 14 October 2016 21:20
To: Wiley Global Permissions
Subject: NON RIGHTSUNI: Permission Request for Dissertation Document

To whom it may concern,

I hope you are doing well. My name is Pamela Birriel, and I am a doctoral student at the University of South Florida’s College of Public Health. I am currently working on my dissertation research towards earning a PhD degree in Public Health. I am contacting you today to request permission to re-use a figure in my dissertation document from a book that John Wiley & Sons, Inc. copyrighted published by Jossey-Bass.

I would like to use and refer to the figure within my dissertation document. More specifically, please find
below the information regarding my source of the figure:

**Book Title**: Health Behavior and Health Education: Theory, Research, and Practice

**Authors**: Karen Glanz, Barbara K. Rimer, and K. Viswanath (Editors)

**Edition**: Fourth Edition

**Copyright Year**: 2008

**Publication Year**: 2008

**Chapter Title**: Chapter 10: Stress, Coping, and Health Behavior

**Chapter Authors**: Karen Glanz and Marc. D. Schwartz

**Figure Title**: Figure 10.1: Transactional Model of Stress and Coping

**Page Number**: 216

I will be writing my dissertation document, and my final document will be made available online via my institutional repository. Please let me know if you need further information regarding moving forward with obtaining permission to use the figure. Thank you for your time.

Best regards,

Pam Birriel

---

**Pamela C. Birriel, MPH, CHES**

Doctoral Candidate in Public Health

Department of Community & Family Health

College of Public Health, University of South Florida

13201 Bruce B. Downs Blvd., MDC 56

Tampa, Florida 33612-3805

Email: guevara@health.usf.edu

Phone: (813) 541-5504
ABOUT THE AUTHOR

Pamela C. Birriel received a Bachelor of Science degree in Exercise Science in 2008 from Florida State University, College of Human Sciences, Department of Nutrition, Food, and Exercise Sciences in Tallahassee, Florida. She received a Master of Public Health degree in Global Health Practice, with a Graduate Certificate in Disaster Management, in 2010 from the University of South Florida, College of Public Health, Department of Global Health in Tampa, Florida. Mrs. Birriel became a Certified Health Education Specialist in 2015.

While in the doctoral program at the University of South Florida, College of Public Health, Department of Community and Family Health, Mrs. Birriel has been employed as Project Coordinator of the Florida Maternal, Infant, and Early Childhood Home Visiting program evaluation. She possesses strong theoretical and practical experience, as well as skills in research design, mixed-methods analysis, cross-cultural research, and community-based research and evaluation.

Mrs. Birriel’s passion in the field of public health stems from her drive to help underserved and vulnerable populations through culturally and linguistically tailored health education programs. She is eager to continue to contribute to public health and apply her skills along with her passion to better serve communities and families in need, improve the quality of life of populations, and ultimately improve the health of generations.