Social Support Networks and Self-Efficacy of Peruvian Women Diagnosed with Cancer:

A Biocultural Analysis of Health Behavior Constructs

Tara Kathleen Hayes Constant

A dissertation
submitted in partial fulfillment of the
requirements for the degree of

Doctor of Philosophy

University of Washington
2016

Reading Committee:
Steven Goodreau, Co-Chair
Bettina Shell-Duncan, Co-Chair
James Pfeiffer

Program Authorized to Offer Degree:
Anthropology

University of Washington

Abstract

Social Support Networks and Self-Efficacy of
Peruvian Women Diagnosed with Cancer:

A Biocultural Analysis of
Health Behavior
Constructs

Tara Kathleen Hayes Constant

Chair of the Supervisory Committee:

Steven Goodreau, PhD
Associate Professor
Anthropology

and

Bettina Shell-Duncan, PhD
Professor
Anthropology

Objectives

The primary goal of this dissertation research study was to contextualize health behavior psychological constructs such as self-efficacy and fatalism among cancer patients in Peru, identifying individual, social, cultural and structural factors that are associated with these constructs. The secondary goal was to identify areas for intervention to support women's self-efficacy when facing a cancer diagnosis. Self-efficacy was considered the primary outcome, a proxy, or at a minimum strong mediator, for treatment continuation and adherence.

Methods

This study employed a mixed methods approach, including an egocentric social support network survey, cognitive interviews and focus groups. Latent analysis methods were used to explore the key domains of interest – self-efficacy, cancer fatalism, deprivation, social networks and social support. Qualitative analysis was employed to aid interpretation and explanation of survey findings.

Results

Women undergoing cancer treatment in Peru who participated in the study reported high self-efficacy, high social support, low fatalism and low SES. These findings were unsurprising given that women with cancer in Peru report facing many challenges regarding their illness, and it is likely that those who remain under treatment have found ways to mount sufficient personal and financial resources to overcome these challenges and to address their illness in a clinical setting. Despite the relative homogeneity of the sample, relationships between the main outcome, self-efficacy, and key domains of interest were largely found to be in agreement with the original study hypotheses. Specifically, social support and latent fatalism factors were associated with self-efficacy.

Conclusion

The findings of this study demonstrated that, in a setting where low-income women have access to cancer treatment, social support interventions may provide useful in supporting their ability to seek and continue with treatment. While family support was identified as critical especially at the

moment of diagnosis, women reported a need for support from other patients who understood their experience and could help them achieve a sense of “new normal.”

A key limitation to the study was that all participants were women under treatment; women diagnosed with cancer who did not seek, receive or continue treatment were not included in the sample, therefore the findings were not generalizable to the whole population of women with cancer in Peru. It may be that such a population-based sample would show even stronger relationships between the key domains. Furthermore, approaches from this survey may be adapted to design a screening tool for Peru’s cancer institute to help identify and intervene with high vulnerability women who may be at risk of loss-to-follow up even once diagnosed.

Preface

This dissertation has been organized around the publication of three manuscripts intended for peer-review publication. There are intended to fill a gap in the literature with respect to low-income women's experiences of cancer in a middle-income country, by using social science theory and analytical approaches to investigate psychosocial and cultural factors related to cancer self-efficacy. Chapter 2, on the framework of vulnerability and hierarchical models, will be submitted to *Social Science & Medicine*. Chapter 3, a deconstruction of cancer fatalism, will be submitted to *Medical Anthropology*. Chapter 4, a mixed methods exploration of the proposed causal model, will be submitted to *Cancer, Epidemiology, Biomarkers and Prevention*.

Acknowledgments

To Nana for the best start possible.
To Lee and Larry for endless bags of books.
To Mom, Dad and Mary for always assuming I could.
To Paul for living it with me (and living *with* me).

The traditional phrase of appreciation, that "this dissertation would not have been possible without the support and collaboration of many people," is certainly true here and perhaps even more important to call out, given the findings of the current study on the role of social support on perceptions of our power to take action in the world.

I would like to thank the women under cancer treatment at INEN, who gave generously of their time and experience by participating in this study. Thank you to my dissertation reading committee: Steve Goodreau, Bettina Shell-Duncan, James Pfeiffer; thanks also to mentors and advocates at Fred Hutchinson Cancer Research Center: Beti Thompson, Linda Ko, Shirley Beresford and Donald Patrick. Thanks to University of Washington faculty and fellow students who helped me get my footing in graduate school, especially Kathleen O'Connor, the team in the Biodemography Lab, and Annette Fitzpatrick.

The momentum for this research was generated and carried forward by parallel work developing breast cancer programs in Peru, in collaboration with my wonderful colleagues (past and present) at PATH: Jenny Winkler, Amie Bishop, Vivien Tsu, José Jeronimo, Ashley Morganstern and Amy Heyden. Thanks for giving me a chance to be a part of this work, to learn and grow through it. Thanks especially to my good friend and colleague Inés Contreras, and her family, for opening their hearts and home to me, and providing considerable time and effort create and implement strong study instruments. Other collaborators include the leadership and staff at INEN, who offered essential institutional support, commentary on the design of the study questions and interpretation of results, and enthusiasm and encouragement throughout: Tatiana Vidaurre, Javier Manrique, Julio Abugattas and Jeannie Navarro. Of course, all errors are mine alone.

Partial support for development of this research came from a Shanahan Endowment Fellowship and a Eunice Kennedy Shriver National Institute of Child Health and Human Development training grant, T32 HD007543, to the Center for Studies in Demography & Ecology at the University of Washington. Implementation of this research was supported by the NCI Biobehavioral Cancer Prevention and Control Training Program (R25CA092408) at the University of Washington (Donald Patrick PI).

TABLE OF CONTENTS

LIST OF TABLES

Table number

LIST OF FIGURES

Figure number

CHAPTER 1: ADAPTATION OF A VULNERABILITY FRAMEWORK FOR CANCER

INTRODUCTION

In 2012 Martha *, a 35-year-old ama de casa (homemaker) with 4 children and a husband working in the rice fields of northern coastal Peru, attended a breast cancer screening program in a semi-rural area where she lives. She received a clinical breast exam from a trained professional midwife at her local health clinic and when a palpable mass was found, she was then referred to her nearby community hospital for fine needle aspiration biopsy. The results of the biopsy were sent to and interpreted by the pathologist at the nearest cancer hospital, in the city of Trujillo, and returned to her with a positive diagnosis for breast cancer. Martha made the two-hour bus trip to the cancer hospital, alone, to meet with an oncologist and establish a treatment plan. As a woman with little income, she qualified for free coverage of care under the national health insurance program.

It is unclear what happened to Martha while at the hospital, who she met there, or what she thought. What is known is that Martha returned home and did not continue with treatment; it took a year of visits from various healthcare providers and others to convince her to return to the hospital and follow the recommended treatment regimen. While there are many factors relevant to Martha's choice to not return to the hospital, she clearly had the motivation and ability to get there under her own power once. What did or did not happen in the interim to support or validate that substantial effort, and help her believe that continuing treatment was a possible option?

The implication here is not that there is any one reason or one individual responsible for delays in cancer-related treatment. Indeed, qualitative research shows that many low-income women in Peru think that medical care should be sought primarily for pain. Likewise, the cancer care system in Peru is a complex, shifting mosaic of institutions and services, a juggernaut that can be daunting to even the most well-informed consumer. However, it is clear that the social networks to which a woman can connect, including clinically-based networks, and their form and the support they provide, very likely play an important role in her understanding of her illness, her expectations of its likely outcomes, and her self-assessed ability to handle both the present and potential future of her disease.

The research project described here seeks to combine quantitative and qualitative social network research methods to describe the structure and function of social support networks for women under treatment cancer at Peru's national cancer institute, and to investigate the potential influence of these networks and supports on her self-efficacy. The overall theoretical framework is one of vulnerability (and its complement, resilience). Within this framework, the key areas of interest (domains) to this study are: deprivation, social networks and social support (i.e. "social support networks"), cancer fatalism, and cancer-related self-efficacy. These concepts are defined below, and located within a conceptual framework based on vulnerability theory.

THEORETICAL FRAMEWORK

Vulnerability

The proposed research agenda utilizes vulnerability theory to build a conceptual framework for understanding women's perceived self-efficacy for dealing with a diagnosis of cancer. Vulnerability theory has been used to situate human responses to, and coping with, natural disasters, famine, and mental health issues (Delor & Hubert, 2000; Watts & Bohle, 1993), and to understand health-seeking behaviors related to infectious diseases like HIV and malaria (DeSantis, Jemal, & Ward, 2010; Ribera & Hausmann-Muela, 2011). Vulnerability is distinct from poverty: "it means not lack or want, but defenselessness, insecurity, and exposure to risks, shocks and stress…[It] has thus two sides: an external side of risks, shocks and stress to which the individual or household is subject; and an internal side which is defenselessness, meaning a lack of means to cope without damaging loss" (Chambers, 2006).

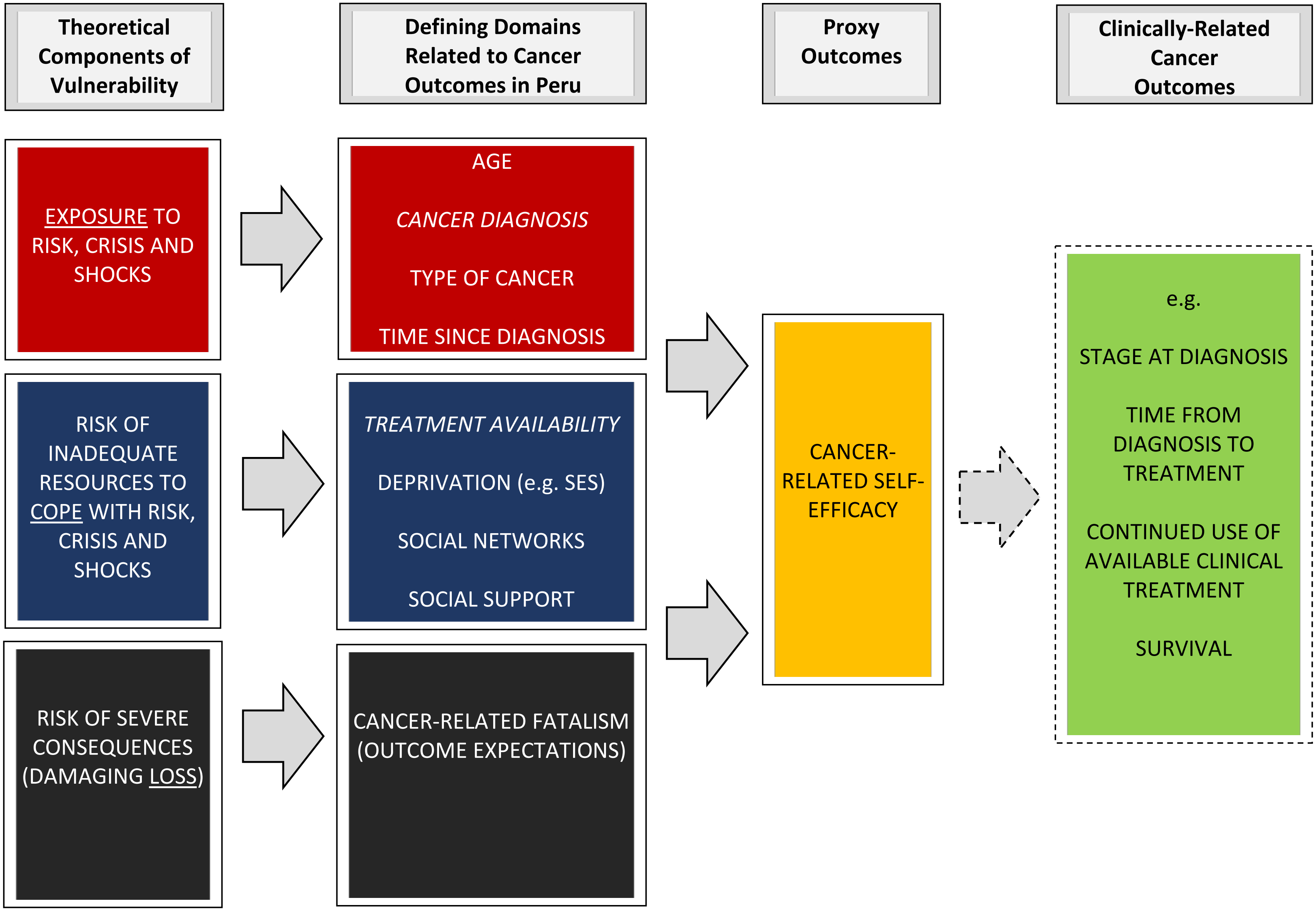
Vulnerability can be understood as three interrelated domains : 1) exposure to risk, crisis and shocks ("exposure"), 2) risk of inadequate resources to cope with risk, crisis and shocks ("coping"), and 3) risk of severe consequences in the face of crisis and shocks ("damaging loss") (Watts & Bohle, 1993). Documenting vulnerability, therefore, requires consideration of these three domains, and the relationships between them, with measures that are reflective of the social context.

In this study a cancer diagnosis is the "exposure;" in other words it is the risk, crisis or shock which a woman has to confront. "Coping" ability here is framed as the resources - material, informational/educational and especially social - available to a woman diagnosed with cancer. It can also be understood more generally as social capital, or a lack of the same (deprivation). Finally, in assessing the domain of "damaging loss" this study prioritizes the experiential knowledge of the participants, meaning that individuals have an understanding of cancer based on their experiences related to the disease within their particular cultural, social, economic and political context; a premise of this work holds that negative cancer expectations ("fatalism") are a personal expression of social disempowerment (Abraido-Lanza et al., 2007; Diaz, 1998), rather than a cultural feature. This premise is also based on previous qualitative work in Peru showing that fatalistic expressions regarding breast cancer were closely tied to assessment of personal resources (Hayes Constant, Winkler, Bishop, & Taboada Palomino, 2014). As such, fatalistic expressions can serve as an individual's estimation of the likelihood incurring "damaging loss" after the shock of a cancer diagnosis.

The model, below, demonstrates the way in which cancer, social support networks, and fatalism fit into a theory of vulnerability, with self-efficacy as the outcome of interest and considering self-efficacy as a potential proxy or mediator for clinically-related outcomes such as treatment continuation (aka "adherence") and time from diagnosis to treatment.

Figure 1

Original conceptual model



In the current study, all women have a diagnosis of cancer and have sought treatment at the national cancer center (INEN). This suggests some level of homogeneity in their vulnerability (the interface between crisis, coping resources and risk of damaging loss), as all have mounted sufficient resources to arrive at the hospital for diagnosis and treatment. To understand the variability within this population, self-efficacy related to cancer is proposed as a potentially sensitive measure of vulnerability, as it is known that women can be lost to follow-up anywhere along the cancer care continuum, and that patients receiving cancer treatment are more and more commonly considered under a model of chronic disease care requiring long-term commitment and perseverance on the part of the patient.

Social Support Networks

While the overarching framework is one of vulnerability, the key independent variables of interest in this study are social support networks. Of interest is how methods of social network analysis can be used to capture some of the social context of women's lives, and the assessment of how these networks interact with key theoretical constructs (self-efficacy, fatalism) derived from the health behavior literature.

Within the field of social network analysis, a substantial body of evidence now indicates that social relationships are important for health; they influence a broad range of disease outcomes as well as all-cause mortality (Berkman, 1999). The pathways through which this takes place require further elucidation but are hypothesized to include any one, or combination of, the following: behavior (health-damaging or health-promoting activity), psychology (cognitive or emotional states), and physiologic mechanisms (i.e. direct health effects) (Berkman & Glass, 2000).

The premise of this study is that women do not make clinical or other health-related assessments in isolation, but rely on others, including clinical staff, for support. The focus of this dissertation research emerged from preliminary qualitative research which indicated that, in this setting of high vulnerability, women's social networks and related supports are a critical resource for coping with health risks, shocks and crises. For instance, low-resource women in Peru indicate a preference for being accompanied by spouse or oldest child when they must interact with the clinical setting; they also express preference for receiving health information and recommendations from family and friends, and for making some clinical care decisions based on the level of personal trust with their providers (Hayes Constant et al., 2014). It is hypothesized that in low-resource settings women may have a particularly high reliance on social relations to meet their health-related needs, from information about health, to practical assistance, to emotional support and encouragement.

In a setting of potentially high vulnerability such as at a public cancer hospital in Peru, where material and financial resources are limited for both the institution and for patients, and where women are often far from home when receiving treatment, emergent and dynamic social networks may serve as a critical coping resource for women diagnosed with cancer, and a potentially important site for intervention.

OBJECTIVES

The long term goal of the research area of this dissertation study is to improve quality of life and access to care for cancer patients seeking treatment at Peru's National Institute for Neoplastic Diseases (INEN) in Lima by identifying vulnerable individuals and applying evidence-based interventions.

Specific Aims

The specific aims of the study presented herein were as follows:

To identify key members of social networks of women under treatment for cancer at INEN, and the types of support the patients receive from these networks.

To measure the self-efficacy of women under treatment for cancer at INEN, where self-efficacy is defined as an individual's confidence in their ability to manage or cope with prospective situations relevant to a cancer diagnosis.

To investigate the construct of cancer fatalism, the expectation of specific negative, fated, outcomes for cancer, among women under treatment for cancer at INEN; to evaluate cancer fatalism as an expression of disempowerment vs a cause of disparities in cancer-related behaviors and outcomes.

Motivating Questions

The primary questions driving the development of the present study were the following:

How can the conceptual domains of self-efficacy and fatalism be understood with respect to a cancer in this setting; how should these domains be interpreted, modified or adapted for this high-vulnerability, low-resource setting?

How do social support networks influence self-efficacy?

Do deprivation and social support networks independently influence a woman's sense of self-efficacy with respect to her cancer diagnosis? Is there a measurable "coping" effect?

Which network ties, and social supports via those ties, are most critical to patient empowerment (where fatalism is seen as a sign of disempowerment)?

Do fatalistic assessments influence self-efficacy? Do fatalistic assessments influence self-efficacy independent of deprivation, and social support networks?

LITERATURE REVIEW

This literature review will cover the major areas of interest in this study: social networks, social support, self-efficacy and cancer fatalism.

Social Networks

Social networks are defined as the structure of individual social ties, whereas social support is defined as the function of those ties. Self-efficacy is the personal assessment of one's ability to take action to manage or cope with a prospective situation; in this study these are situations related to a cancer diagnosis. Finally, fatalism is defined as an expectation of negative outcomes related to cancer, especially the expectation that cancer will result in death.

History of social networks in anthropology

While networks have recently gained growing attention in social analysis, consideration of networks has a long history in anthropology and other social sciences. Theories of kinship, social organization, social roles and reciprocity developed by anthropologists Malinowski, Lévi-Strauss, Radcliffe-Brown, L.H. Morgan and S.F. Nadel, laid a foundation for the exploration of relationships in complex societies.

Anthropologists have a history of investigating the process-based nature of networks, armed with ethnographic research tools that take an iterative rather than an a priori approach to networks, to ask, “How do social networks explain outcomes?” Anthropologists Elizabeth Bott-Spillius and John Barnes are considered founders of the field of network analysis, using the network model to understand the behavior of married couples in England (Bott, 1955) and that of work committees in a Norwegian fishing village (Barnes, 1987). Bott-Spillius and Barnes used inductive methods to discover how people’s interrelationships produce understanding about the world in which they lived; their work is exemplary of anthropology’s interest in networks as a method of analysis rather than a solely as a method of data collection (Knox, Savage, & Harvey, 2006). Bott-Spillius extensively interviewed 20 families to try to understand the variation in how husbands and wives performed their roles, and came up with the Bott-hypothesis, that the connectedness between husbands’ and wives’ social networks is associated with marital role segregation. More recently Robert Trotter and colleagues ("Social Networks, Drug Abuse, and HIV Transmission. Proceedings of a meeting. August 19-20, 1993," 1995) used ethnographic network mapping to study how different patterns of behavior among drug users in specific drug networks are based upon the features of those networks.

Anthropologists have also studied the network itself. “These studies turn their attention to the art of networking, and to the aesthetics and texture of networks in their multiple guises as they appear as variously structural and performative entities” (Knox et al., 2006, p. 128). Anne Mische’s work is a more recent example of this. In the decade she spent studying changes in civic-partisan relations in Brazilian youth politics, Mische asked “How do you study something that is mobile and shifting, composed of sprawling, fluid, and contentious networks…?” (Mische, 2008, p. 9). Mische notes that she sacrificed some depth of research for a breadth of understanding, in order to understand the Brazilian activism as a field (as a network), rather than as isolated groups.

This framing required a form of ethnography that did not conform to traditional methods, wherein a researcher immerses him or herself in what she calls a “culturally cohesive setting.” Her solution was to use a variety of interpretive and network-analytic methods, including in-depth interviews, participant observation, and more formal analysis of member affiliations. Mische was therefore able to not only study the structure of the networks, but also how participants made sense of those networks, and how they dealt with the possibilities and problems that came from being part of them (Mische, 2008, p. 8). This joint study of the structural and “processual” forms of networks holds potential for advancing network studies across disciplines (Knox et al., 2006).

Similarly, anthropologist Annelise Riles studied the participation of Fijian women at a United Nations global forum and self-described networks with social scientists and non-governmental organizations (Riles, 2000). In her study Riles does not seek to define the network, but instead considers it as an ethnographic category, using ethnographic description to document how people explain network relations, and how they depict them in visual form (Knox et al., 2006; Riles, 2000).

Quantitative social network analysis

Recently social network research has largely focused on quantitative methods to measure social relationships (Bishop, Waring, Claudio Bosio, Graffigna, & Scaratti, 2012). Quantitative social network analysis (SNA) emerged from theoretical and conceptual developments in the fields of sociology, psychology and anthropology (Berkman & Glass, 2000; Berkman, Glass, Brissette, & Seeman, 2000; L. C. Freeman, 2011). Twentieth century anthropologists, including W. Lloyd Warner at Harvard, and members of the Manchester School (Bott Spillius, Barnes, and Mitchell), made conceptual and methodological advances furthering quantitative techniques to test hypotheses of social relationships (Berkman & Glass, 2000; Borgatti, Mehra, Brass, & Labianca, 2009; L. C. Freeman, 2011; Wenger, 1991).

The origin of SNA is a story about the development of an increasingly specialized, shared set of methods; SNA itself is not a specific theory but rather a set of tools (Knox et al., 2006; Scott & Carrington, 2011). SNA measures seek to capture the structural features of social relationships such as network size or node connectivity). Traditionally within SNA the structure of networks can be traced using one of two approaches, sociocentric or egocentric. Sociocentric networks define all links within a closed group, while egocentric networks are membership maps centered on individuals (Bernard, 2013). Egocentric social networks can be elicited in several ways, by defining relations based on affective content (subjective orientation or feeling), normative content (specific cultural expectations, obligations and rights between social relations), or exchange content (an interdependence between two actors where the actions of each affect the outcomes of the other) (McCallister, 1978).

Operationalizing networks, especially in the case of egocentric networks, requires the establishment of a boundary, one defined either by the individual (ego) or by the researcher, who determines inclusion and exclusion criteria for the group. The limits of these boundaries are also shaped by pragmatic concerns, like the availability of research resources, and managing respondent burden. These approaches suggest that the network is a stable entity, a “pre-existing ‘whole network’ on which network ties are generated…[yet] the logic may work the other way around, with the definition of the relevant whole population dependent on the cultural framing” (Knox et al., 2006, p. 122). These are two well-recognized problems in quantifying network relationships, the predetermination of the nature of the relationship between the actors, and the difficulties in defining the boundaries of real-world networks (Bishop et al., 2012, p. 310). Mixed methods research can help address these inherent difficulties in SNA.

While theories of relational sociology argue that network research must deal with the interplay between structure and meaning (Fuhse, 2009; White, 2008), much social network research today has advanced the analysis of structure with little exploration at the level of meaning. Meaning, processes and contexts of network formation are not easily accessed through strictly quantitative social network analysis (Bishop et al., 2012, pp. 310-311).

Social Support

Although the conceptual domains of social networks and social support are intrinsically related, it is important to be clear on their differences. Social network measures capture the structural features of social relationships (i.e. network size, connectivity), and social support indicators describe the functional attributes of relationships (e.g., perceived quality of informational, emotional, tangible or appraisal support). Social support is usually divided into four subtypes: informational (advice, suggestions and information), emotional (empathy, trust, caring), instrumental (tangible aid and services), and appraisal (constructive feedback and affirmation) (Heaney & Israel, 2008; House, 1981).

Egocentric networks are widely used in studies of social support (Bernard, 2013). Combining both concepts in a network based inventory of social support, i.e. where ego perceived social support is measured for individual network members, is advantageous in that it allows the researcher to measure the effect of total functional support, as well as by support type and support relationship (Gigliotti & Samuels, 2011). It is acknowledged that social support is one of the key mediating pathways by which social network structure influences health status (Berkman & Glass, 2000). Inclusion of social support measures in social network analysis is one way to approach the meaning of networks (Barrera, 1986; Gigliotti & Samuels, 2011), in addition to their structure, and may prove useful for triangulation for more qualitative-based methods of identifying relationship meaning.

Current evidence from the United States demonstrates a differential effect of social networks, across social groups, whereby groups of women with lower access to, and utilization of, breast care services show a greater social network effect than high access, high utilization groups. This differential effect may be indicative of a moderating role for individual resource availability. Individuals with fewer resources (e.g. undereducated women with limited access to health care and health information) may reap relatively greater gains from social networks, and related supports, precisely because they are more dependent on members of their social network to meet their needs (Messina et al., 2004; Suarez et al., 2000).

Research on cardiovascular health provides evidence for this “added value” hypothesis. While epidemiological research has shown a consistent relationship between low social support and cardiovascular disease and related outcomes (Lett et al., 2005; Uchino, 2013), Vitaliano et al. (2001) have further demonstrated that the effect of social support on cardiovascular profiles can vary by income level; emotional support showed salutogenic effects on mean arterial pressure and natural killer cell activity for individuals with lower incomes (<=29,000) but not for individuals with higher incomes. Similarly, the beneficial effects of social support in low resource settings, whether through behavioral or physiological mechanisms, has been put forth as a potential explanation for unexpected health advantages observed among Hispanics in the United States (Palloni & Arias, 2004).

Despite growing evidence that social networks and social support influence breast health behaviors, the pathways by which these concepts function are slow to emerge (Pasick & Burke, 2008); social support networks may be related to key cognitive factors, such as self-efficacy, which may subsequently influence cancer related behaviors (Honda & Kagawa-Singer, 2006; von Wagner, Good, Whitaker, & Wardle, 2011). A small but growing literature has begun to look beyond individual cognitive dimensions to explore the role of social relationships in breast health behaviors (Magai, Consedine, Neugut, & Hershman, 2007).

Self-Efficacy

Much of the research on breast health has focused heavily on cognitive variables that are emphasized in individual level health behavior theories, including the Health Belief Model (perceived susceptibility, severity, benefits, barriers), the Theory of Reasoned Action and Theory of Planned Behavior (attitudes, intentions and behaviors) (Magai et al., 2007). Furthermore, these models have frequently been used to frame research with Latinas and other disadvantaged groups in the United States to understand disparities in cancer-related outcomes.

The current study does not seek to ignore the importance of individual-level or cognitive measures to health behavior, but instead seeks to contextualize them and demonstrate the relationship between the availability of coping resources, and women's expectations of breast cancer. These expectations can reflect perception of personal abilities, through the concept of self-efficacy belief, the "perceived ability to overcome each facilitating or constraining condition." (Heaney & Israel, 2008). Bandura (1982) proposed a central role of self-efficacy in human agency. Self-efficacy, however, differs from outcome expectations. While the former is about one's belief in one's ability to take specific action, the latter reflects an assessment of the social environment. In this setting, where fatalistic expressions are shown to be tied to social realities, fatalism can be interpreted as a negative expectation for cancer outcomes.

Cancer Fatalism

While fatalism is the philosophical idea that all events are predetermined, and human beings are powerless to change them, the term "cancer fatalism" in the health literature has been used to describe the belief that all cases of cancer will result in death. A recent review of the literature demonstrates that fatalism and cancer fatalism, have been used to explain health behaviors and even health outcomes; they are also applied predominantly to traditionally underserved populations, suggesting a stigmatization of these populations (Drew & Schoenberg, 2011).Unfortunately, this emphasis on the individual cognition approaches to health behavior, in the absence of an interpretive social analysis, has led some researchers to posit fatalistic attitudes, like self-efficacy, as primary determinants of health behavior, rather than as potential expressions of social disempowerment that have a distal or otherwise complex relationship to social and structural factors (Abraido-Lanza et al., 2007; Diaz, 1998).

Other researcher and policy makers have pointed out the likely relationship between cancer outcomes and the interaction between complex social forces. Dr. Harold Freeman, former associate director of the National Cancer Institute and leader of the national movement to establish navigation services for low-income cancer patients, describes this interaction as the "poverty-cancer spiral' (H. P. Freeman, 1989). Using this concept, he describes the way poverty and medical care intersect, leading to fatalism; i.e. poverty puts individuals at risk of poor cancer outcomes and so leads impoverished people to see cancer as a death sentence thereby making them less likely to seek early detection and treatment, which continues the spiral. The social determinants of health model fits with this approach, whereby the various challenges associated with poverty – such as a lack of education and employment, poor housing and access to medical services – spirals down into a "self-fulfilling prophecy" of poor health outcomes (Drew & Schoenberg, 2011, p. 4; Mayo, Ureda, & Parker, 2001; Shankar, Selvin, & Alberg, 2002). Likewise, the casting of fatalism as a completely irrational viewpoint fails to take into account lived experiences:

> *… the assumption that fatalism is a problematic or irrational response to a health threat privileges certain viewpoints by delineating what constitutes rational behavior. Some of the same questions posed by medical anthropologists in the 1980s about the supposed irrationality of nonadherence can be asked about the reasoned thoughts of fatalism. Experiential knowledge from the traditionally underserved women we interviewed suggests that cancer might very well be a death sentence; they have witnessed their family and friends diagnosed, subjected to painful and sickening treatment, and then hospitalized, only to succumb to cancer shortly thereafter (Shankar et al. 2002). What would any rational person conclude from these experiences?* (Drew & Schoenberg, 2011, p. 11)

While ethnographic and qualitative research has criticized simplistic views of fatalism and worked to contextualize fatalistic expressions, the magnitude of the effect of these factors is unknown. Few quantitative studies have explored this topic in detail. For instance, the literature on cancer fatalism among Latinos often assumes a relationship between fatalistic attitudes and screening, a hypothesis for which findings are inconclusive. In fact, socioeconomic status has been shown to mediate fatalistic beliefs (Espinosa de los Monteros & Gallo, 2011).

The current study provides a unique opportunity to understand cancer related cognitions, both fatalism and self-efficacy, through a lens of vulnerability, via both qualitative and quantitative approaches. It is anticipated here that measures of deprivation will mediate fatalistic expressions in the study populations. In addition, a central premise of this study is one that has not been well-studied, that social resources, measured through social support networks, are a critical coping mechanism influencing both fatalistic beliefs and self-efficacy in low-resource settings.

Deprivation

The concept of deprivation for this current research project was based upon several studies which have attempted to expand the concept or resource availability beyond income measured poverty or SES. The Oxford Poverty & Human Development Initiative developed a Multi-dimensional Poverty Index that contained items to capture deprivation related to education (years of school, child school attendance), health (child mortality, nutrition) and living standard (electricity, improved sanitation, improved drinking water, flooring, cooking fuel, assets ownership) (Alkire, 2012).

Studies in Peru and other Latin American countries have demonstrated the utility of such indices. A study based on the Oxford work found that in El Salvador, Mexico, Brazil and Chile, deprivation in access to proper sanitation and household head level of education were highest contributors to overall multidimensional poverty (Battiston, Cruces, Lopez-Calva, Lugo, & Santos, 2013). Calvo (2008) makes an argument for using a vulnerability to poverty framework, considering that many people may be at risk of poverty if exposed to a given shock (consumption shock, health shock, etc.). The approaches and ideas outlined in this paper fit well with the framework of the current study. Other researchers applied a multidimensional approach to data in Peru to "recount" the poor in Peru (Castro, 2012). The authors provide a good review of the literature on multidimensional indices and selected 6 dimensions to create an index for national data from 2004-2008; deprivation was found to be similar across regions in Peru and to be largely driven by access to clean water and adequate sanitation services.

This approaches described in this literature informed the development of the demographics portion of the survey in the present study, including such items including child school attendance and household health level of education (education), child mortality (health), and housing type and cell phone ownership (living standard).

BACKGROUND

Global and Local Disparities in Cancer Outcomes

The current study is one focused on women's experience of cancer in Peru. Women with a diagnosis of cancer, and receiving treatment at INEN, were eligible for inclusion regardless of cancer type. Overall, cancer is the second leading cause of death in Peru; breast cancer is the second leading cause of cancer death for women in Peru, after cervical cancer. Breast cancer provides a good lens for understanding cancer globally, and in Peru, as it is a cancer that can be detected at early stages through screening, and has effective treatments when detected at early stages. In addition, breast cancer is included as one of Peru's cancer treatment priorities, under the Plan Esperanza. Therefore, an overview of breast cancer is used as an exemplar of cancer more generally.

The global burden of breast cancer is characterized by profound disparities in survival and mortality, disparities that may deepen as rates of cancer rise. Despite the fact that more than half of all new cases of breast cancer occur in high income countries, more than 75% of all deaths from breast cancer occur in low and middle income countries (LMICs) (Hortobagyi et al., 2005). Globally, breast cancer incidence and mortality are predicted to increase by 56% and 62%, respectively, between 2008 and 2030 (Ferlay et al., 2010); this change is expected to occur at a more precipitous pace in LMICs that have historically exhibited low risk profiles and incidence of breast cancer (Bray, McCarron, & Parkin, 2004; Forouzanfar et al., 2011).

Peru is an example of this pattern, where breast cancer incidence is expected to increase 77% between 2008 and 2030, from 4300 to 7617 cases annually; incidence will be outpaced by mortality, which is predicted to increase 86% over the same time interval, from 1365 to 2536 deaths annually (Ferlay et al., 2010). Recognition of this growing disease burden, and evident survival disparity, is prompting the global health community and state-agencies to consider investments in resource-appropriate approaches to breast cancer screening, diagnosis and treatment (Anderson & Cazap, 2009; MINSA, 2013; WHO, 2005). To assure the success of these investments, a better understanding is needed of what motivates women to utilize existing and future services.

Cultural Context

Peru is an incredibly diverse country, ethnically, culturally, linguistically, and geographically. It is comprised of “costa, sierra, selva” or “coast, mountains, jungle.” More than 30 million people live in the country, and 8 million of those live in the coastal capital city of Lima. Lima’s population continues to grow as many people leave more remote and rural regions in search of paid employment and other opportunities more available in the economic center of the country. As more people move to the city they establish “invasiones,” essentially squatter’s rights to land occupied for multiple decades. “Pueblos jovenes” or “young towns” grow at the ever expanding edge of the city, and it is often many years before these towns are incorporated into the infrastructure (water, electricity, etc.).

Peru has a colonial heritage; Spanish conquistador Francisco Pizarro arrived in 1528 and proceeded to founded the first Spanish settlement. Pizarro encountered the Inca culture and the Inca leader at the time, Atahualpa. He eventually captured and murdered Atahualpa after demanding, and receiving, large ransoms of gold and silver. The Inca had a relatively short reign in the area that became Peru; for only about 100 years before the arrival of the Spanish, the Inca were the political group of power, subsuming several other cultural and ethnic groups and bringing them together under a complex and coordinated system of trade and resource distribution.

The multi-cultural heritage and history of Peru is paralleled by its demographic diversity today. Tall, fair descendants of the Spanish conquistadors continue to hold positions of economic, social and political power. Indigenous populations descendent from the Inca live throughout the country, but especially in the mountainous regions where Quechua remains the native language for many. A variety of native tribes continue to live in the Amazon regions of the country, including a handful that do not have contact with the wider Peruvian society. In addition to these groups, influxes of migrants have shaped the population. The culture in the southern part of the country is shaped by Afro-Peruvian descendants of slaves brought during colonial times. In the 1850s Chinese laborers arrived as replacement for slave labor and in the late 1800s immigrant farmers from Japan arrived in search of tillable land; both groups have descendants contribute to the demographic and cultural diversity of the country today.

Peru's diversity is perhaps best exemplified by the regional variety of its foods, and is known both throughout Latin America and globally as a culinary fusion center. Ceviches and other seafood, spit-roasted chicken, Chinese fusion "chifa" restaurants, potato dishes including ocopa and causa, grain based meals of quinoa and rice, are just a few examples of the well-known Peruvian dishes.

The diversity of the country is one of its strengths but also a potential challenge to health systems. Despite attempts to decentralize health systems, the most services are available in the capital city of Lima, where those with income and education largely prefer to live. The health system does not reach all people and all groups equally. All medical providers have an obligatory 2-year residency (a "SERUM"), typically assigned to rural and remote areas of the country. One of the great challenges for Peru is to assure that the health care system is accessible, acceptable and appropriate for, the country's diverse population.

Preliminary Research

Breast cancer care screening program

In advance of implementation of a training program in clinical breast exam (CBE), fine needle aspiration biopsy (FNA) and breast health promotion effort in northern Peru, a preliminary qualitative study was undertaken in 2011 to understand women's perceptions of breast cancer and screening, and those barriers and facilitators likely to influence their use of CBE. This study was informed by the PRECEDE/PROCEED public health model, an ecological framework emphasizing multiple levels of influence (Green, Kreuter, & Green, 2005); it was operationalized through multi-source ethnographic approaches characteristic of anthropology, including semi-structured interviews and focus groups with women in the province and with local clinicians, through unstructured conversations at clinics, participant observation in clinical activities and health campaigns, and qualitative assessment of health systems and resources.

The findings from this formative research (Hayes Constant et al., 2014) informed both the development of a breast health screening program in Pacasmayo, as well as several of the hypotheses presented in this proposal. Social support, in a context of deprivation and uncertainty, emerged as a critical factor in the use of clinical services. Trust and lack of trust among clinical providers was another emergent theme. Furthermore, upon initial discussion of breast cancer, many women expressed negative breast cancer expectations, especially the idea that a diagnosis of breast cancer means death. However, these expectations were revealed, upon further discussion, to be characterized by ambivalence, and closely tied to assessment of personal resources.

During two years of implementation of the screening program, eight women were diagnosed with breast cancer. All of these women underwent treatment for their illness, but several required significant additional support from clinical staff in order to seek care. This pattern is illustrated by the vignette about Martha* at the beginning of this dissertation. After identifying the break in care between diagnosis and treatment, an adjunct to the initial early detection program was developed, one focused on patient navigation, a model of care developed in the United States to address cancer disparities. The concept of patient navigation has been utilized in low-resource populations in many locations to enhance access to care though it has been implemented predominately in North America and Europe (Paskett, Harrop, & Wells, 2011; Wells et al., 2008).

Qualitative research with breast cancer patients

To inform a patient navigation program for women diagnosed with breast cancer in the north of Peru (Pacasmayo and Trujillo), a rapid evaluation (Boyle, Contreras, Taboada, Hayes Constant, unpublished) was carried out through a series of four focus groups and two in-depth interviews with breast cancer patients and their family members, to assess key areas of need that could be addressed through an orientation/navigation program intervention. Lack of informational support regarding the structure and requirements of the healthcare system, as well as poor communication with providers, were both identified as barriers to care. This rapid evaluation was complementary to a qualitative study carried out the previous year to assess the psychosocial support needs of women in Peru with breast cancer.

In that study 31 semi-structured interviews were conducted with patients and providers at the Instituto Nacional de Enfermedades Neoplásicas and La Liga de la Lucha Contra el Cancer in Lima and Trujillo. Results were analyzed using matrices and constant comparative methods to determine major thematic content, and results were presented at the ICCC5 in Lima, Peru. This study demonstrated the importance and fragility of family based social networks during breast cancer diagnosis and treatment. Both healthcare providers and patients identified family as an important source of support, but also pointed out that family ties could prove burdensome to women who worried about the effect of their illness on their relations. Support groups established within the clinical setting were described as a critical outlet for patients who did not want to share with their families all of their thoughts and emotions.

There is no doubt that women with cancer in Peru rely heavily on their families for many forms of support, psychosocial, financial and otherwise. And while familismo is acknowledged as an important value in Latin American culture, the emphasis on the role of family support begs the question: Is the importance placed on families reflective of a social and economic reality where family is the best, only and last line of defense for a person facing a severe health crisis? In other words, how do, or can, other social networks help or hinder women facing life-threatening illness?

Health Care Flows

Breast cancer continues to serve, here, as a useful lens to understand models and of cancer care and relevant health system flows in Peru. In Peru, most women diagnosed with breast cancer are at an advanced stage of disease; in 2010 57.8% of breast cancers were diagnosed at stage 3 or 4 (Department of Epidemiology, Ministry of Health, Peru). Lack of screening is considered to be a major barrier to early stage diagnosis, as is challenges to accessing timely cancer diagnosis and treatment.

The Ministry of Health (MINSA) provides health services to 60% of the population, while the remaining 40% receive services as salaried persons through a state-based system (EsSalud), as members of the military or police, or through the private sector. Cancer care in the public sector is primarily coordinated through INEN and two regional cancer centers. Women who have a diagnosis of cancer, or suspicion for breast cancer, are referred to either their regional center, or to

INEN in Lima. But there are many places where a woman could be lost to follow-up, both before or after referral.

The Peruvian public healthcare system is organized within the country's framework of regions, provinces and districts. Regions encompass provinces which encompass districts. Within each region there are many health networks, defined at the province level and overseen by a regional or departmental public health office, called a Dirección Regional de Salud, or a DIRESA. For instance, the DIRESA La Libertad oversees the all of the provincial health networks within the department of La Libertad. This health network is made up of 10 health facilities.

Health facilities may be either hospitals, health centers or health posts. Hospitals are referral sites for both health centers and health posts; hospitals are characterized by larger staffs including nurses, midwives, general and specialized (often gynecologists) physicians, the capacity to perform some surgeries (including caesarians) and the ability to provide limited emergency care. For instance, in the region of La Libertad, Hospital La Fora is the head of the Pacasmayo Health Network and the referral site for the associated health centers (centros de salud) and health posts (puestos de salud). Health centers are smaller than hospitals and employ one or more physicians. Health posts will have only one physician; the closest district health center oversees the services and health promotion activities at health posts. Hospitals, health centers and health posts pertain to geographic districts within the larger province.

The Ministry of Health (MINSA) oversees the public health system. Approximately 30% of citizens are considered to be in the lowest national income bracket, which qualifies them for free access to health services via a national health insurance program, Seguro Integral de Salud (SIS). Other residents have access to government supported services, but may have to pay some fees.

Under the current model of breast care in Peru breast screening is minimal in much of the country. Women over 40 are recommended to get regular mammography, which is the gold standard for breast cancer screening. This public health message about mammography is incorporated into informational pamphlets and sometimes mentioned to women by an attending physician at the local level. However, in the public health sector, availability of mammography machines and technicians are limited to major urban centers and require many hours of travel for women living outside these centers. Closer, private clinics may offer mammography but are very expensive; private clinic mammograms are more expensive than mammograms offered through MINSA by a factor of 10.

Clinical breast exam has been nominally offered through the public health system in the past, but healthcare providers have little training in this technique, and there has been little policy to support implementation of screening guidelines, recommendations and follow-up, especially among asymptomatic women in the age range of greatest risk (40-59).

For women with potential symptoms of breast cancer few or no diagnostic services are available at the district or province level. Until recently, women with potential symptoms of breast cancer would be referred to the capital, Lima, for evaluation. Continuing with the example of the region of La Libertad, Lima is roughly an eight-hour bus ride from the province of Pacasmayo. All diagnostic, treatment and follow-up services were located in the capital, and coordinated by the national cancer institute, Instituto Nacional de Enfermedades Neoplásicas (INEN).

Transportation, time and economic constraints create significant barriers to care for women with potential symptoms of breast cancer. Furthermore, there is no electronic database to track women who have been referred from their local health network to an urban center for evaluation. Clinical histories are in paper form, stored in boxes or files that are time-intensive to access. Referral and counter-referral forms are entrusted to the patient for delivery and so do little to provide check-points for continuity of care. Provincial health networks are therefore unable to confirm whether a woman attended her referral and what her diagnosis might be. All of these factors are significant barriers to continuity of care, and timely diagnosis and contribute to disproportionately high mortality rates in a context where incidence of breast cancer is already on the rise.

In recognition of these issues, the Peruvian government has recently taken steps to address the breast cancer burden at the national level. The national commission “Peru united against cancer” stated a goal of reducing breast cancer mortality in Peru by 30% within 10 years. In 2010, for the first time in the nation’s history, funds (totaling $10 million) were allocated for the prevention and early detection of cancers. As of 2011 MINSA had a National Cancer Control plan that identifies breast cancer as one of five key targets for reducing neoplastic incidence and mortality, and has involved partnership with both public and private institutions in realizing the vision of this plan. With the launch of Plan Esperanza in 2012, low-income women with breast cancer in Peru who qualified for SIS could access free cancer treatment

The addition of public cancer centers in the north and south of the country over the last 10 years has been an important improvement in the cancer care infrastructure. For instance, the Instituto Regional de Enfermedades Neoplásicas Norte (IREN-Norte) is located in the city of Trujillo, approximately 2.5 hours by bus from the province of Pacasmayo, and offers diagnostic, treatment and follow-up services for the northern region of the country. However, services are not complete at the regional hospitals; at IREN-Norte although a concrete bunker has stood in place for several years, radiotherapy services are still unavailable and therefore referred out to a separate center.

Given that the most comprehensive array of services is available in the capital of Lima, many people from throughout the country receive referrals to Lima when they have a high suspicion or preliminary diagnosis of cancer. Only after an in-house confirmed diagnosis at INEN (which can take 2 months or more to finalize), are patients eligible for treatment. On oncologist at INEN estimates that 40% of the patients he sees are lost to follow-up before initiating treatment.

It has also been suggested by medical providers that women who present and are diagnosed with very severe disease may have had prior clinical contact related to their illness, but did not return for definitive care until symptoms could no longer be ignored. Delays may be related barriers in health systems and clinical care. Research in Mexico showing that on average women had multiple clinical visits before receiving a definitive diagnosis (Bright et al., 2011). Discussions with breast cancer patients in Peru suggest that delays in biopsy results, false-negatives, and delays in results for other services significantly lengthened time from first detection to time of final diagnosis and beginning of treatment. One of the women interviewed as part of the patient navigation rapid evaluation was still awaiting information about her treatment plan, although her surgery had occurred several months prior.

Recently, Peru introduced the Plan Esperanza, a comprehensive cancer care program that is meant to provide complete coverage for now 7 priority cancers, for the poorest in the nation. Officially, women diagnosed with breast cancer, who qualify for the free health insurance, SIS (Seguro Integral de Salud) are entitled to breast cancer care. In reality, as has been observed during the development of a patient navigation program in the north of the country, many patients pay out-of-pocket costs for services, medications and other supplies. In Lima, several women participating in the validation of the survey instrument for this study explained that they quit their jobs when diagnosed with breast cancer, so that they would qualify for SIS.

Since the inception of the Plan Esperanza, Peru’s national strategy to improve access to cancer care, both awareness of cancer services and demand for these services have increased. Patient flow at INEN has increased from 48,480 new patients in 2009, to 64,940 new patients in 2013, highlighting a growing need for services aimed at understanding and ameliorating barriers to care. Although there are two public regional cancer centers in Peru (IREN-Norte and IREN-Sur), many patients are still referred to INEN in Lima; patients come from the capital itself with a metropolitan population approaching 10 million people, from remote provinces and regions of the country lacking oncologic care, and for specialized treatments that are not available outside the capital.

RESEARCH DESIGN

This was a mixed methods study employing ethnographic, focus group and survey methods. Focus groups and surveys were administered, in person, by the lead investigator and research assistants; they were carried out at INEN, the cancer hospital.

Data Collection

Ethnographic observation in semi-public waiting places took the form of note-taking during surveys, and notes were anonymized. The sites of these observations were pre-approved by the hospital, and a waiver of consent was obtained from the relevant IRB bodies. Notes were anonymized, and neither provider nor patient personal identifiers were recorded.

Focus groups were scheduled and held in private, closed meeting rooms available at the hospital reserved for such purposes. During focus groups, participants were advised of the confidential nature of the information shared, asked to keep private what they learn, and also asked to address each other by pseudonyms while participating.

Surveys were conducted while participants waited for services; such waits could often be 2 or more hours long. Participants had the option of pointing to their responses on the visual Likert scale if they preferred that to voicing their agreement or lack of agreement with the proposed questions and affirmations.

Inclusion Criteria

For the current study, women age 18 or older were considered for inclusion if they had been diagnosed with cancer and are seeking or receiving treatment, or were within 6 months of having finished treatment, at INEN. Women who did not have a confirmed cancer diagnosis were excluded from the study. Women whose cancer care was not being overseen by staff at INEN were excluded from the study. Women fitting these inclusion criteria were recruited at the clinical intake areas of INEN, to either participate in a focus group or the quantitative survey, both of which took 1-2 hours.

DATA ANALYSIS

Qualitative Analysis

Qualitative research was comprised of participant responses to the survey, cognitive interviews of a subset of survey-takers, and separate focus groups to probe domains of (i.e. self-efficacy, cancer fatalism, social support, social networks). Extensive observation notes were taken during each of the surveys, documenting participant reactions to, and explanations of, their survey responses. Survey participants were allowed to expound on their thoughts, feelings, and experiences as much as desired, while finally being directed by the researcher to use their understanding to inform their chosen survey responses; survey completion took on average 1.5 hours. Cognitive interviews, focusing on areas disagreement or confusion in the survey, were carried out with 10 individuals (consecutively), after each had completed the survey. Focus groups were carried out separately to elicit in-depth reflection on the key areas of interest (self-efficacy, social support networks, cancer fatalism).

Cognitive interviews and focus groups were transcribed by a contracted professional. All survey notes and transcripts were coded by hand. Data analysis began with the first observation and grounded theory allowed for an ongoing inductive approach. Text was coded to identify emergent concepts within pre-identified domains, using the process of open, categorical, and finally axial coding that grounded theory researchers use to guide their analysis (Bernard & Ryan; Corbin et al., 2008). Survey notes and transcribed cognitive interviews and focus groups were submitted to constant comparative analysis (Corbin et al., 2008) to define thematic content.

Quantitative Analysis

The survey had distinct sections that coincided with the domains of interest: demographics and clinical data, self-efficacy questions (24), cancer fatalism questions (16), and social support networks. The social support network section of the survey was set up for egocentric data collection; first participants were given a name generating prompt ("Please list all of the people who, since you have known about your illness, have been a help to you as you have gone through the process treatment), and were encouraged to list as many members as they considered to fit the prompt. Member name (first name only) and type (family, friend, healthcare provider, religious person, other) were recorded for the total network membership.

Then participants were asked, of this total network, to identify their core social network, meaning those network members they considered the most important in helping them during their illness; participants could select up to 5 members from the total network list to be in their core network. Finally, the participants were asked a series of social support questions for each of their core network members: 3 informational support questions (two on availability of informational support and one on trust of information), 2 emotional support questions, 2 tangible support questions, 2 appraisal support questions, and a frequency of member contact question.

The survey as a whole was tested for validity via cognitive testing, as described above. It was tested for reliability using psychometric tools including exploratory factor analysis, principal components analysis and Cronbach's alpha.

To test the internal reliability of ethnographically and literature-based items of cancer-related self-efficacy Cronbach's alpha was computed to assess the average correlation of items. The results determined retention of items for summated ratings as predictor components in the objective models. Fatalism variables were submitted to exploratory factor analysis to elicit latent factors. A deprivation index was constructed using principal components analysis. Multi-item scales and indices such as those described above were preferable to single-item questions which can be unreliable. Support scores (informational, tangible, emotional, appraisal) were calculated for each of the participants' 5, self-identified core network members. A ranked global support score was calculated based on all 5 support scores.

For data collected from the fully validated survey, descriptive statistics were calculated for the demographic variables, self-efficacy variables, cancer fatalism variables, and social network and social support variables, inclusive of summation ratings and indices. For continuous variables standard deviations and ranges were calculated. For categorical variables counts and percentages were calculated.

With self-efficacy as the dependent variable, linear regressions were run on four models, both adjusted and unadjusted: deprivation, social support networks, cancer fatalism and a complete model including all domains. Akaike’s Information Criterion (AIC), a measure of goodness-of-fit, was calculated for each candidate model. AIC is not restricted to nested models and includes a penalty for each additional parameter to avoid overfitting; the better fit model is that with the lowest AIC value.

CHAPTER 2: BUILDING A GROUNDED MODEL OF CANCER-RELATED SELF-EFFICACY

ABSTRACT

Objective

The objective of this study was to create and implement a social support survey, grounded in both ethnographic research and health behavior theory, with sufficient sensitivity to measure key theoretical concepts, considered “domains” (self-efficacy, social support, fatalism, deprivation) evaluate their associations, and test the relative magnitude of their effects within a sample of low-income women under treatment for cancer at Peru’s central public cancer hospital. It was hypothesized that the domains of social support, fatalism and deprivation would each be associated with the domain of interest, cancer-related self-efficacy, specifically that: an increase in SES would be associated with an increase in self-efficacy; an increase in fatalism would be associated with a decrease in self-efficacy; and an increase in social support would be associated with an increase in self-efficacy.

Methods

In recognition of the complexity of the key theoretical constructs (“domains”) the survey was designed using a series of thematic questions measured with a Likert scale, to be submitted to latent construct analysis for the creation of composite scores, indices and factors, as necessary: 24 self-efficacy questions resulted in a normally distributed, internally reliable score, normalized to 0-1; demographic variables submitted to principal components analysis resulted in a socioeconomic index, normalized to 0-1; social support available from up to 5 key network members was summarized as a rank score; and 16 fatalism items were submitted to exploratory factor analysis, resulting in two factors, “Death from cancer” and “Life with Cancer,” both normalized to 0-1.

Descriptive statistics were carried out comparing women from the region of Lima to women from all other regions of the country. Bivariate analysis was carried out comparing independent variables in each domain to the outcome of interest, cancer related self-efficacy, categorized as “low,” “medium,” or “high.” Hierarchical adjustments were carried out within each domain, and then combined into a complete regression model. Akaike’s Information Criterion was used to determine the relative strength of the hierarchical and complete models.

Results

The women in the sample overall reported high levels of cancer-related self-efficacy: 40 women (30.77%) had a self-efficacy score greater than 76% of the total possible; 78 women (60.00%) had a self-efficacy score between and 51% and 75% of the total possible; only 12 women (9.23%) had self-efficacy scores of 50% or less of the total possible. Several central hypotheses were proven correct in the unadjusted models, although the effects were not necessarily large.

Women with very high social support (n=86), had 0.83% higher self-efficacy scores, compared to those with low, medium and high social support combined (n=44); this relationship was statistically significant (p=0.032). While women in the sample overall reported low fatalism scores, women with higher fatalism scores on both the “Death from Cancer” and “Life with Cancer” factors had lower self-efficacy scores. Women reporting the highest *relative* values on “Death from Cancer” fatalism (i.e. within the sample) had a 27.7% lower self-efficacy score compared to women reporting the lowest *relative* values. Likewise, women reporting the highest relative values on “Life with Cancer” fatalism had a 23.5% lower self-efficacy score. Both of these relationships were statistically significant at p = 0.006 and p=0.013. Socioeconomic score was not statistically significantly associated with self-efficacy, but bivariate analysis demonstrated a trend in the expected direction, with women with higher ranked self-efficacy having a higher mean SES score relative to the sample overall.

In the complete model only the fatalism factors remained statistically significant. Application of Akaike’s criterion indicated the best relative fit by the hierarchically adjusted model for the fatalism domain (AIC = - 44.771), although this was closely followed by a model that included both the hierarchically adjusted fatalism and social support domains (AIC = - 43.916); the latter model explains 8.1% of the variability in cancer-related self-efficacy while the former model explained 7.3% of this variability.

Conclusions

Cancer-related self-efficacy has multiple contextual contributors, including available social support and outcome expectations (expressed as two different fatalism factors.) While SES was not shown to be statistically related to self-efficacy in this population, a trend was observed in the expected direction, with women of with higher ranked self-efficacy having higher mean SES. Given that primarily low-income women are treated at the public cancer hospital, it is quite possible that the range of SES in the sample was not large enough for statistical sensitivity to this relationship. These findings demonstrate that social support related interventions, as well as exposure to information and experience to alter outcome expectations, may support Peruvian women's cancer-related self-efficacy, despite limited financial resources.

INTRODUCTION

Self-efficacy is a central concept in the health sciences literature, and considered to be strongly tied to health-related behaviors. However, overemphasis on self-efficacy in the absence of contextual and environmental factors, fails to recognize the constraints these factors place on individual action, and the role they play in individual cognitions. The current study seeks to contextualize cancer-related self-efficacy among female cancer patients in Peru, utilizing a framework of vulnerability theory.

MATERIALS AND METHODS

Instrument Design

Female cancer patients were recruited from Peru's national cancer hospital in Peru, to participate in an interviewer-lead survey. Inclusion criteria included the following: a confirmed diagnosis of cancer, were 18 years of age or older, principle medical management at INEN, under treatment or with fewer than 6 months of post-treatment control. Women who had been under control for 6 months or more, or without a confirmed diagnosis at INEN were excluded from the study.

The survey was composed of 6 domains: clinically related variables, patient and household demographics, cancer-related self-efficacy, cancer "fatalism"/cancer outcome expectations, egocentric social network lists, and network member provided social support (informational, emotional, tangible and appraisal). (See Appendix A: Final Survey). These 6 domains were organized conceptually within 3 theoretical categories: exposure, coping and damaging loss.

Demographic and clinical items were both categorical and continuous. Patients rated twenty-four cancer-related self-efficacy items and sixteen cancers "fatalism" items on a Likert scale (1-4, no middle option); a validated visual support to the Likert scale was provided (See Appendices B and C: Visual Likert scale 1 and 2, respectively).

For the egocentric social network domain participants were prompted to list all people who had helped them since they had received their cancer diagnosis; they were given no limit to this list. Participants were then asked to identify those network members who had been most helpful to them (core network members), up to a maximum of 5. For each core network member, the participant was asked to respond to a series of social support questions (3 informational, 2 emotional, 2 tangible, 2 appraisal) ranking support received on a Likert scale (1-4, no neutral option); a visual support to the Likert scale was provided and an additional categorical item on frequency of contact with was collected for each member. At the end of the survey, interviewers documented the completeness of the survey, and their subjective measure of how easy or difficult, cognitively, it was for the participant to answer the survey questions.

Power Calculation

The sample size required for the study was powered on the outcome of interest, cancer-related self-efficacy for the primary hypotheses, that social support would be positively associated with cancer-related self-efficacy. Pilot testing of the survey suggests that this outcome would have sufficient variability in the population of interest. A priori power analysis, with standard assumptions of two-sided significance of $\alpha=.05$ and power = .80, indicated that 128 women would need complete the survey to detect a change in mean cancer-related self-efficacy, assuming 1:1 allocation ratio and a moderate effect size (Cohen's d=0.5) for a difference between independent means (Faul, Erdfelder, Buchner, & Lang, 2009).

Post-hoc power analysis for the complete model, a linear regression of cancer-related self-efficacy on 9 independent variables, with 128 cases and standard assumptions of two-sided significance of $\alpha=.05$, indicated insufficient power (0.35) to detect a small effect size (Cohen's $f^2=0.02$), but sufficient power (0.99) to detect a moderate effect size (Cohen's $f^2=0.15$) (Faul et al., 2009).

DATA MANAGEMENT

Data Cleaning

Data missingness for the survey overall was very low, due to tight interviewer control of survey administration. For instance, questions would often prompt women to give a narrative description of their response, even for those participants who found the Likert scale quite understandable (as measured by subjective interviewer scoring). In these instances, the interviewer would allow the participant to respond in the narrative style, while taking notes. When the participant finished with the narrative, the interviewer would respond: "Thank you for explaining that to me. Given what you have just told me, which of the following responses best matches your experience?" Then the interviewer would repeat the items for the relevant Likert scale. Women who wanted a neutral response would be asked whether their experience reflected more one side of the Likert scale or other; women were counseled that the option of "undecided/don't know" was to be used only in situations where the participant did not understand the question or felt that the question did not apply to her.

The main outcome variable, self-efficacy, was measured on 24 items. With 130 participants the total number of potential responses was 130x24=3120. Of these total potential responses, only 28 (0.8%) were missing or undecided/don't know. Internal reliability analysis carried out on a complete-case of these self-efficacy items resulted in a high Cronbach's alpha: 0.86 with interitem correlation of 0.18. For those 28 missing responses, the average within-item value (integer) was imputed; this method assumes <10% missingness, which is appropriate for this dataset. After imputation Cronbach's alpha for the 24 self-efficacy items increased to 0.91; this was considered reasonable given the high internal reliability of the complete case analysis.

Some missingness was also found in the 16 cancer "fatalism" items, 48 out of 2080 (16x130) possible responses were either missing or undecided/don't know, for 2.3% missingness. A complete case analysis compared to a conservative (low fatalism) imputed case analysis demonstrated no significant change in effect on the outcome of interest; therefore, the conservative case dataset was used in all further analysis.

All relevant demographic variables were complete; there was some missingness in clinical variables, particularly time related variables, leading to a complete case analysis of 128, rather than 130. Data was complete on all core network members. Only 6 social support responses were missing of a possible 5850 (130x9x5) responses, and these were imputed as the average of the individual's social support score.

Data Transformation

Domains of interest were transformed into scales and indices, as required by the goals of the study and based on descriptive analysis of the data. The outcome of interest, cancer-related self-efficacy, when summed across all 24 items, was normally distributed. Exploratory factor analysis further demonstrated that all 24 items loaded onto one factor. Given these findings, it was determined that linear regression would be an appropriate approach for this dependent variable, the summed self-efficacy score. This score was father normalized to a range of 0-1, *based on the total possible range of self-efficacy score*, for ease of interpretation. It should be noted that using this approach means that 0 is the lowest possible (not reported) score and, likewise, 1 is the highest possible (not reported) score.

Demographic variables were submitted to principle components analysis to create a deprivation index (Vyas & Kumaranayake, 2006). Four variables (education of participant, education of head of household, income and cell phone access) loaded onto the first component, with an eigenvalue of 2.31; together this component explained 58% of the variability in the items. Other demographic variables were dropped from analysis. The deprivation index was then normalized to a range of 0-1 for eases of interpretation. It is important to note that using this approach of PCA, which is data-driven, the deprivation index only represents the actual range among the participants. In other words, 0 is the lowest deprivation index reported by participants and 1 is the highest deprivation index reported (where low means fewer resources and high means more resources). This means that the range of deprivation index is representative of the sample, not of the wider population in Peru.

Cancer "fatalism" items were submitted to an in-depth and theoretically driven exploratory factor analysis, further described in chapter 3. Of the initial 16 items, 11 were retained in two factors labeled "Death from Cancer" and "Life with Cancer." Both of these factors were normalized to a range of 0-1 for ease of interpretation. Similar to the deprivation index, use of EFA to uncover latent factors in the "fatalism" items, and regression analysis implied in this process to create factor scores, means that both factor scores are based on the sample, rather than a total possible score; women reporting the lowest fatalism in the sample therefore have a score of 0 and those reporting the highest fatalism have a score of 1.

Social network members were maintained as total counts. Summated social support scores (both thematic and global), were not normally distributed, with the exception of informational social support. Given this lack of normality, global social support was transformed into rank scores.

Statistical Analysis

Descriptive statistics were calculated based on the mean (standard deviation) or count/n (percent) for key variables of interest, stratified by region (participant was from Lima, or participant was from another region of Peru) and tested for significance with Pearson's chi-squared or Fisher's exact tests for categorical variables and independent t-tests for continuous variables. For each level of the specified outcome (low, medium and high self-efficacy) bivariate associations were evaluated within each of the conceptual domains (clinical variables, demographics, social networks, social support, and cancer-related fatalism) and were tested for significance with

Fisher's exact test for categorical variables and Kruskal-Wallis mean rank test for continuous and ordinal variables; small cells size in the low self-efficacy group (n=12) necessitated the use of Fisher's exact tests, while violation of assumptions for use of ANOVA, across the three groupings of self-efficacy, required the use of the non-parametric Kruskal-Wallis mean rank test.

Given the normal distribution of the continuous self-efficacy outcome, linear regression was used to investigate associations between individual self-efficacy score and each of the independent variables using a hierarchical approach for covariate adjustment. Unadjusted logistic models were first developed for all covariates. Outcomes were then adjusted hierarchically by the domains of interest (clinical variables, demographics, social networks, social support, and cancer-related fatalism), while controlling for age, location, and time since diagnosis as determined *a priori*.

A complete model was created with all variables, removing those with excess collinearity and adjusting for relevant confounders. For all models coefficients, 95% confidence intervals (CI) and p-values are shown. Finally, the quality of all the statistical models (the hierarchically adjusted domain models and the complete model) were evaluated utilizing Akaike's Information Criterion (AIC). AIC is a means of model selection, estimating the quality of each model relative to each of the other models by taking into account the trade-off between model goodness of fit and model complexity (i.e. number of independent variables). Models with lower AIC indicate a relatively better fit among the compared models, but do not indicate the quality of the models in any absolute sense.

RESULTS

Descriptive Statistics by Region

Descriptive statistics are presented comparing women in the sample who live permanently in the region of Lima, compared to women from all other regions of the country. The capital city and main commercial center is the city of Lima, in the region of Lima. The national public cancer hospital, INEN, is located in the city of Lima. This distinction is important geographically, socioeconomically and culturally. In addition, the burden of travel and the cost of extended stays for those traveling from outside Lima is another reason to consider the characteristics of the sample by this binary variable.

Clinical variables domain

In considering their clinical characteristics, the patients participating in the study were quite similar regardless of whether they were from Lima region, the major metropolitan center where the cancer hospital is located, or from another part of the country. The greater part of patients in the sample (>40%) had a diagnosis of breast cancer, while the rates of cervical cancer (>16%) were relatively lower. The rate of cervical cancer diagnosis compared to that of breast cancer indicates successful public health outreach for screening, diagnosis and treatment of pre-cancerous cervical lesions, and an opportunity to achieve something similar in the country with respect to screening for breast cancer. The great majority of the participants (>80%) were under active treatment at the time of their participation in the study.

A clinically important difference is observed with regards to time from diagnosis to time of initial treatment when comparing women from Lima to women from outside of Lima. All participants were asked to recall the month and year they first received their cancer diagnosis, whether at the cancer hospital in Lima or elsewhere, and the month and year that their treatment was initiated at the cancer hospital. Almost without exception, the participants readily recalled these dates to the month and year, especially as their diagnosis date was a day most stated they would never forget. Dates were estimated from the middle (15th day) of the month(s) indicated.

On average, women from outside of Lima experienced a delay of almost 100 additional days (3+ months) from diagnosis to treatment when compared to women from Lima. It is recognized that a delay of 3 months has clinical significance with respect to cancer staging, treatment and outcomes. The average time from diagnosis and treatment for both groups is relatively high, though this is influenced by large standard deviations; time from diagnosis to treatment has a bimodal sample distribution, with more than 40% of women initiating treatment within 60 days/two months, and another 25% delayed for more than 120 days/ 4 months.

Interestingly, women from any region other than Lima received their initial diagnosis further in the past, compared to women from Lima; the reason for this unclear. While differences noted in the sample were not statistically significant, they are clinically relevant and important when considering nation-wide access to timely cancer care.

Table 1

Cross-tabulation of Participant Home Region and Clinical Domain Variables

		Participant Home Region		
		Lima n=65	Other Region n=65	*p*
Cancer Diagnosis				
	Breast Cancer	27 (41.54%)	29 (44.62%)	*0.670*
	Cervical Cancer	9 (13.85%)	12 (18.46%)	
	Other Cancer	28 (43.08%)	24 (36.92%)	
	Missing	1 (1.53%)	0 (0.00%)	
Time to Survey Date, from Diagnosis				
	Days	493.1 (667.0)	670.7 (860.7)	*0.192*
		n=65	n=64	
Time from Diagnosis to Treatment*				
	Days	159.2 (479.7)	252.4 (611.4)	*0.359*
		n=60	n=57	
Current Treatment Status				
	Recent Diagnosis	5 (7.69%)	6 (9.23%)	*0.117*
	In Treatment	54 (83.08%)	52 (80.00%)	
	Observation (<6m)	6 (9.23%)	2 (3.08%)	
	Palliative Care Only	0 (0.00%)	4 (6.15%)	
	Missing	0 (0.00%)	1 (1.54%)	

Notes: For continuous variables standard deviations appear in parentheses to the right of means

**Not all patients had initiated treatment by the date of their interview, and so are excluded from this analysis*

Demographics domain

Geographic differences were notable in the demographic data. Women from Lima tended to have more education, higher household incomes, and fewer children and have experienced less child mortality when compared to women from other regions. This difference was also captured in a Deprivation Index, the calculation of which is described under the "Data transformation" subheading; women from Lima had a relatively higher Deprivation/SES Index score, a geographical difference which approached statistical significance: p = 0.071. Given the greater availability of paid employment and social infrastructure (e.g. schools, electricity and water) in Lima, the findings of a differential in SES between Lima and other regions is not surprising. National assessments of regional poverty are in agreement with these findings.

There were fewer geographical differences in religious affiliation and attendance, with approximately 60% of women in the sample identifying as Catholic, another 23% identifying as Evangelical Christian, and the remainder identifying with other religions or with none in particular. Likewise, most women (~60%) stated that they had attended a religious event within the week prior to their interview. Patient age also differed little by geography, which is unsurprising given the pathophysiology and age-associated natural history of cancer. The cancer hospital in Lima is a public, rather than private, hospital, and as such covers treatment for low-income citizens under the national insurance program, Seguro Integral por Salud (SIS). More than 85% of the patients interviewed at the hospital were covered by SIS, with another 11% covered by an insurance for government employees and their families (ESSALUD).

Table 2

Cross-tabulation of Participant Home Region and Demographic Domain Variables

		Participant Home Region		
		Lima n=65	Other Region n=65	*p*
Age				
	Years	46.7 (10.8)	49.2 (12.6)	*0.209*
Education				
	No education	0 (0.00%)	3 (4.62%)	*0.268*
	Primary incomplete	4 (6.15%)	8 (12.31%)	
	Primary complete	5 (7.69%)	7 (10.77%)	
	Secondary incomplete	12 (18.46%)	9 (13.85%)	
	Secondary complete	21 (32.31%)	17 (26.15%)	
	Secondary +	13 (20.00%)	7 (10.77%)	
	Superior complete	10 (15.38%)	14 (21.54%)	
Civil Status				
	Single	19 (29.23%)	21 (32.31%)	*0.057*
	Cohabitating	16 (24.62%)	10 (15.38%)	
	Married	17 (26.15%)	19 (29.23%)	
	Separated/Divorced	11 (16.92%)	5 (7.69%)	
	Widowed	2 (3.08%)	10 (15.38%)	
Head of Household				
	Self	25 (38.21%)	21 (32.31%)	*0.463*
	Other	50 (61.54%)	44 (67.69%)	
Head of Household Education				*0.054*
	No education	0 (0.00%)	3 (4.62%)	
	Primary incomplete	1 (1.54%)	9 (13.85%)	
	Primary complete	6 (9.23%)	5 (7.69%)	
	Secondary incomplete	10 (15.38%)	11 (16.92%)	
	Secondary complete	27 (41.54%)	17 (26.15%)	
	Secondary +	8 (12.31%)	6 (9.23%)	
	Superior complete	13 (20.00%)	14 (21.54%)	
Monthly household income				
	<499/S (<$199)	14 (21.54%)	34 (52.31%)	*0.001*
	500-999/S ($200-$399)	35 (53.85%)	18 (27.69%)	
	1000-1499/S (400-599)	7 (10.77%)	5 (7.69%)	
	1500-1999/S	3 (4.62%)	6 (9.23%)	
	2000+/S	6 (9.23%)	2 (3.08%)	
Insurance				
	SIS	57 (87.69%)	54 (83.08%)	*0.463*
	ESSALUD	7 (10.77%)	7 (10.77%)	
	Private/Other	1 (1.54%)	4 (6.15%)	
Children				
	Integer	2.2 (1.7)	2.8 (2.2)	*0.117*
Child Mortality				

	Has no children	12 (18.46%)	18 (27.69%)	*0.001*
	No child has died	50 (76.92%)	32 (49.23%)	
	One child death	3 (4.62%)	8 (12.31%)	
	Two or more deaths	0 (0.00%	7 (10.77%)	
Home type				
	Guest	4 (6.15%)	5 (7.69%)	*0.636*
	Rent	12 (18.46%)	11 (16.92%)	
	Family	24 (36.92%)	18 (27.69%)	
	Own	25 (38.46%)	31 (47.69%)	
Religion				
	None	3 (4.62%)	3 (4.62%)	*0.897*
	Catholic	42 (64.62%)	39 (60.00%)	
	Evangelical Christian	15 (23.08%)	15 (23.08%)	
	Other (e.g. Mormon)	5 (7.69%)	8 (12.31%)	
Recent religious attendance				
	No	27 (41.54%)	26 (40.00%)	*0.858*
	Yes	38 (58.46%)	39 (60.00%)	
Deprivation Index*				
	Score (0-1)	0.53 (0.20)	0.46 (0.25)	*0.071*

Notes: For continuous variables standard deviations appear in parentheses to the right of means
**Deprivation index includes 4 variables selected based on Principal Components Analysis (See Data Transformation for details); a higher score indicates relatively higher Deprivation Index within the sample.*

Fatalism domain

Geographic differences were also seen in both cancer "fatalism" factors: "Death from cancer" and "Life with cancer." For both factors, women from other regions had higher scores (i.e. higher "fatalism") compared to women from Lima; these relationships were statistically significant at the 0.05 cut-off.

Table 3

Cross-tabulation of Participant Home Region and Fatalism Variables

	Participant Home Region		
	Lima n=65	Other Region n=65	*p*
Factor 1: Ultimate Causation, Control over **death from cancer**			
Score (0-1)	0.28 (0.18)	0.36 (0.18)	*0.017*
Factor 2: Proximate Causation, Control over **life with cancer**			
Score (0-1)	0.30 (0.20)	0.40 (0.18)	*0.003*

Notes: For continuous variables standard deviations appear in parentheses to the right of means. Fatalism factors includes 12 variables selected and scored based on Exploratory Factor Analysis (see Chapter 3 for details), and then normalized to 0-1. A higher score indicates a relatively more "fatalistic" view, within the sample.

Social networks domain

Most social network variables did not vary significantly across region. There were two exceptions to this. One exception was whether a participant had any core network member who was not a family member, religious member, or healthcare member; in the data these “other” members were primarily friends, co-workers and neighbors. Women from Lima reported these “other” members more frequently than women from outside of Lima, and this association approached significance (p=0.067). Similarly, women from Lima more frequently reported having a core network member who was not a family member, and this association also approached significance (p=0.079).

Table 4

Cross-tabulation of Participant Home Region and Social Network Domain Variables

		Participant Home Region		
		Lima n=65	Other Region n=65	*p*
Total social network size (no maximum)				
	Integer	15.9 (11.1)	13.9 (8.1)	*0.228*
Core social network size (maximum of 5)				
	Integer	4.1 (1.2)	3.9 (1.5)	*0.358*
Family member in core network				
	No	3 (4.62%)	5 (7.69%)	*0.718*
	Yes	62 (95.38%)	60 (92.31%)	
Religious member in core network				
	No	55 (84.62%)	56 (86.15%)	*0.804*
	Yes	10 (15.38%)	9 (13.85%)	
Healthcare professional in core network				
	No	58 (89.23%)	62 (95.38%)	*0.324*
	Yes	7 (10.77%)	3 (4.62%)	
“Other” member in core network (e.g. friend)				
	No	37 (56.92%)	47 (72.31%)	*0.067*
	Yes	28 (43.08%)	18 (27.69%)	
Any core network member that is not family				
	No	29 (44.62%)	39 (60.00%)	*0.079*
	Yes	36 (55.38%)	26 (40.00%)	

Notes: For continuous variables standard deviations appear in parentheses to the right of means

Social support domain

Reported social support scores did not vary significantly by region, though it is interesting to note that women from Lima more frequently reported very high emotional support (50.77%) compared to women from anywhere except Lima (35.38%).

Table 5

Cross-tabulation of Participant Home Region and Social Support Variables

	Participant Home Region		
	Lima n=65	Other Region n=65	*p*
All Social Support (% of total possible)			
Very Low: (0%-25%)	4 (6.15%)	6 (9.23%)	*0.943*
Low: (26%-50%)	15 (23.08%)	15 (23.08%)	
High: (51%-75%)	23 (35.38%)	23 (35.38%)	
Very High: (76%-100%)	23 (35.38%)	21 (32.31%)	
Informational Support			
Very Low: (0%-25%)	4 (6.15%)	7 (10.77%)	*0.834*
Low: (26%-50%)	17 (26.15%)	15 (23.08%)	
High: (51%-75%)	29 (44.62%)	28 (43.08%)	
Very High: (76%-100%)	15 (23.08%)	15 (23.08%)	
Emotional Support			
Very Low: (0%-25%)	3 (4.62%)	6 (9.23%)	*0.206*
Low: (26%-50%)	15 (23.08%)	14 (21.54%)	
High: (51%-75%)	14 (21.54%)	22 (33.85%)	
Very High: (76%-100%)	33 (50.77%)	23 (35.38%)	
Tangible Support			
Very Low: (0%-25%)	3 (4.62%)	6 (9.23%)	*0.722*
Low: (26%-50%)	13 (20.00%)	15 (23.08%)	
High: (51%-75%)	27 (41.54%)	24 (36.92%)	
Very High: (76%-100%)	22 (33.85%)	20 (30.77%)	
Appraisal Support			
Very Low: (0%-25%)	4 (6.15%)	6 (9.23%)	*0.734*
Low: (26%-50%)	17 (26.15%)	17 (26.15%)	
High: (51%-75%)	22 (33.85%)	25 (38.46%)	
Very High: (76%-100%)	22 (33.85%)	17 (26.15%)	

Notes: Social support is not distributed normally, with the exception of informational support, and therefore should be represented as an ordinal variable, rather than as a continuous one.

Bivariate Associations with Ranked Self-Efficacy

Clinical variables domain

None of the reported clinical variables were associated with ranked self-efficacy. These were cancer diagnosis, time since diagnosis (to survey date), time from diagnosis to treatment initiation, and current treatment status. However, while not a statistically significant association, women with the highest reported self-efficacy also had the shortest average time from diagnosis to treatment initiation, 143.5 days.

Table 6

Bivariate Associations between Cancer Related Self-Efficacy and Clinical Variables

	Cancer-Related Self-efficacy			
	Low *(0-50%)* n=12	Medium *(51%-75%)* n=78	High *(76%-100%)* n=40	*p*
Cancer Diagnosis				
Breast Cancer	5 (41.67%)	33 (42.31%)	18 (45.00%)	*0.691*
Cervical Cancer	1 (8.33%)	16 (20.51%)	4 (10.00%)	
Other Cancer	6 (50.00%)	28 (35.90%)	18 (45.00%)	
Missing	0 (0.00%)	1 (1.28%)	0 (0.00%)	
Time to Survey Date, from Diagnosis				
Days	517.3 (455.6)	636.3 (843.4)	490.6 (697.6)	*0.550*
Time from Diagnosis to Treatment*				
Days	177.4 (206.6)	241.2 (581.5)	143.5 (562.4)	*0.122*
	n=12	n=69	n=36	
Current Treatment Status				
Recent Diagnosis	0 (0.00%)	8 (10.26%)	3 (7.50%)	*0.637*
In Treatment	10 (83.33%)	64 (82.05%)	32 (80.00%)	
Observation (<6m)	1 (8.33%)	3 (3.85%)	4 (10.00%)	
Palliative Care Only	1 (8.33%)	2 (2.56%)	1 (2.50%)	
Missing	0 (0.00%)	1 (1.28%)	0 (0.00%)	

Notes: For continuous variables standard deviations appear in parentheses to the right of means

**Not all patients had started treatment by the date of their interview, and so are excluded from this analysis*

Demographic domain

None of the demographic variables had a statistically significant association with ranked self-efficacy. This was also true of the Deprivation Index. However, the trend in the Deprivation Index was as one might expect, with women reporting higher self-efficacy also having, on average, a higher Deprivation Index score (where higher values means greater resource availability).

Table 7

*Bivariate Associations between Cancer Related Self-Efficacy and Demographic Domain Variables**

		Cancer-Related Self-efficacy			
		Low *(0-50%)* n=12	Medium *(51%-75%)* n=78	High *(76%-100%)* n=40	*p*
Age					
	Years	50.2 (10.9)	48.0 (12.3)	47.5 (11.0)	*0.668*
Education					
	No education	0 (0.00%)	3 (3.85%)	0 (0.00%)	*0.395*
	Primary incomplete	1 (8.33%)	10 (12.82%)	1 (2.50%)	
	Primary complete	0 (0.00%)	5 (6.41%)	7 (17.50%)	
	Secondary incomplete	2 (16.67%)	14 (17.95%)	5 (12.50%)	
	Secondary complete	4 (33.33%)	25 (32.05%)	9 (22.50%)	
	Secondary+	4 (33.33%)	4 (5.13%)	12 (30.00%)	
	Superior complete	1 (8.33%)	17 (21.79%)	6 (15.00%)	
Civil Status					
	Single	4 (33.33%)	23 (29.49%)	13 (32.50%)	*0.999*
	Cohabitating	2 (16.67%)	17 (21.79%)	7 (17.50%)	
	Married	4 (33.33%)	20 (25.64%)	12 (30.00%)	
	Separated/Divorced	1 (8.33%)	10 (12.82%)	5 (12.50%)	
	Widowed	1 (8.33%)	8 (8.26%)	3 (7.50%)	
Head of Household					
	Self	3 (25.00%)	27 (34.62%)	16 (40.00%)	*0.644*
	Other	9 (75.00%)	51 (65.38%)	24 (60.00%)	
Head of Household Education					*0.347*
	No education	1 (8.33%)	2 (2.56%)	3 (7.50%)	
	Primary incomplete	1 (8.33%)	6 (7.69%)	5 (12.50%)	
	Primary complete	0 (0.00%)	6 (7.69%)	0 (0.00%)	
	Secondary incomplete	3 (25.00%)	13 (16.67%)	5 (12.50%)	
	Secondary complete	6 (50.00%)	28 (35.90%)	10 (25.00%)	
	Secondary+	0 (0.00%)	6 (7.69%)	8 (20.00%)	
	Superior complete	1 (8.33%)	17 (21.79%)	9 (22.50%)	
Monthly Household Income					
	<499/S	5 (41.67%)	28 (35.90%)	15 (37.50%)	*0.631*
	500-999/S	6 (50.00%)	34 (43.59%)	13 (32.50%)	
	1000-1499/S	1 (8.33%)	5 (6.41%)	6 (15.00%)	
	1500-1999/S	0 (0.00%)	5 (6.41%)	4 (10.00%)	
	2000/S+	0 (0.00%)	6 (7.69%)	2 (5.00%)	
Insurance					
	SIS	11 (91.67%)	66 (84.62%)	34 (85.00%)	*0.676*
	ESSALUD	0 (0.00%)	9 (11.54%)	5 (12.50%)	
	Private/Other	1 (8.33%)	3 (3.85%)	1 (2.50%)	
Children					
	Integer	1.7 (1.7)	2.6 (2.1)	2.5 (1.9)	*0.313*

Child Mortality					
	Has no child	4 (33.33%)	18 (23.08%)	8 (20.00%)	*0.568*
	No child death	8 (66.67%)	45 (57.69%)	29 (72.50%)	
	One child death	0 (0.00%)	9 (11.54%)	2 (5.00%)	
	Two or more deaths	0 (0.00%)	6 (7.69%)	1 (2.50%)	
Home Type					
	Guest	0 (0.00%)	4 (5.13%)	5 (12.50%)	*0.655*
	Rent	2 (16.67%)	15 (19.23%)	6 (15.00%)	
	Family	4 (33.33%)	28 (35.90%)	10 (25.00%)	
	Own	6 (50.00%)	31 (39.74%)	19 (47.505)	
Religion					
	None	1 (8.33%)	4 (5.13%)	1 (2.50%)	*0.628*
	Catholic	6 (50.00%)	52 (66.67%)	23 (57.50%)	
	Evangelical Christian	3 (25.00%)	16 (20.51%)	11 (27.50%)	
	Other (e.g. Mormon)	2 (16.67%)	6 (7.69%)	5 (12.50%)	
Recent Religious Attendance					
	No	5 (41.67%)	33 (42.31%)	15 (37.50%)	*0.927*
	Yes	7 (58.33%)	45 (57.69%)	25 (62.50%)	
Home Region					
	Lima	7 (58.33%)	38 (48.72%)	20 (50%)	*0.896*
	Other Region	5 (41.67%)	40 (51.28%)	20 (50%)	
Deprivation Index*					
	Score (0-1)	0.43 (0.14)	0.48 (0.24)	0.53 (0.23)	*0.474*

Notes

**Deprivation Index variables selected based on Principal Components Analysis (See Data Transformation for details); a higher score indicates relatively greater availability of resources (income, personal education, head of household education, cell phone access) within the sample.*

Cancer fatalism domain

Both cancer "fatalism" factors are significantly associated with cancer-related self-efficacy, with women reporting higher self-efficacy also reporting lower fatalism.

Table 8

Bivariate Associations between Cancer Related Self-Efficacy and Fatalism Variables

	Cancer-Related Self-efficacy			
	Low *(0-50%)* n=12	Medium *(51%-75%)* n=78	High *(76%-100%)* n=40	*p*
Factor 1: Ultimate Causation, Control of **death from cancer**				
Score (0-1)	0.43 (0.25)	0.33 (0.17)	0.27 (0.17)	*0.028*
Factor 2: Proximate Causation, Control of **life with cancer**				
Score (0-1)	0.34 (0.14)	0.40 (0.19)	0.26 (0.18)	*0.001*

Notes: See chapter 3 for more detail about fatalism factors

Social network domain

Social network variables were not significantly associated with ranked self-efficacy.

Table 9

Bivariate Associations between Cancer Related Self-Efficacy and Social Network Variables

	Cancer-Related Self-efficacy			
	Low *(0-50%)* n=12	Medium *(51%-75%)* n=78	High *(76%-100%)* n=40	*p*
Total social network size (no maximum)				
Integer	10.9 (7.7)	15.6 (10.6)	14.8 (8.1)	*0.273*
Core social network size (maximum of 5)				
Integer	3.8 (1.2)	3.9 (1.3)	4.2 (1.4)	*0.222*
Family member in core network				
No	0 (0.00%)	6 (7.69%)	2 (5.00%)	*0.872*
Yes	12 (100%)	72 (92.31%)	38 (95.00%)	
Religious member in core network				
No	11 (91.67%)	69 (88.46%)	31 (77.50%)	*0.263*
Yes	1 (8.33%)	9 (11.54%)	9 (22.50%)	
Healthcare professional is core network				
No	11 (91.67%)	71 (91.03%)	38 (95.00%)	*0.788*
Yes	1 (8.33%)	7 (8.97%)	2 (5.00%)	
“Other” member in core network (e.g. friend)				
No	6 (50.00%)	50 (64.10%)	28 (70.00%)	*0.450*
Yes	6 (50.00%)	28 (35.90%)	12 (30.00%)	
Any core network member not family				
No	5 (41.67%)	43 (55.13%)	20 (50.00%)	*0.667*
Yes	7 (58.33%)	35 (33.87%)	20 (50.00%)	

Notes

Social support domain

Of all of the types of social support, informational support and emotional support had the strongest, statistically significant, associations with reported self-efficacy. Women who reported higher self-efficacy also reported higher levels of informational and emotional support, a difference especially seen in the percentage of women reporting very high support for these items. Tangible and appraisal support, as well as global social support did not meet the 0.05 cut-off criteria for significance. However, it should be noted that in this bivariate analysis where the outcome of interest is ranked rather than continuous, these three associations approached significance if applying a cut-off of $p<0.20$.

Table 10

Bivariate Associations between Cancer Related Self-Efficacy and Social Support Domain Variables

	Cancer-Related Self-efficacy			
	Low *(0-50%)* n=12	Medium *(51%-75%)* n=78	High *(76%-100%)* n=40	*p*
All social support (% of total possible)				
Very Low: (0%-25%)	1 (8.33%)	6 (7.69%)	3 (7.50%)	*0.175*
Low: (26%-50%)	2 (16.67%)	21 (26.92%)	7 (17.50%)	
High: (51%-75%)	5 (41.67%)	30 (38.46%)	11 (27.50%)	
Very High: (76%-100%)	4 (33.33%)	21 (26.92%)	19 (47.50%)	
Informational Support				
Very Low: (0%-25%)	1 (8.33%)	7 (8.97%)	3 (7.50%)	*0.009*
Low: (26%-50%)	2 (16.67%)	23 (29.49%)	7 (17.50%)	
High: (51%-75%)	6 (50.00%)	39 (50.00%)	12 (30.00%)	
Very High: (76%-100%)	3 (25.00%)	9 (11.54%)	18 (45.00%)	
Emotional Support				
Very Low: (0%-25%)	1 (8.33%)	5 (6.41%)	3 (7.50%)	*0.028*
Low: (26%-50%)	3 (25.00%)	19 (24.36%)	7 (17.50%)	
High: (51%-75%)	4 (33.33%)	29 (37.18%)	3 (7.50%)	
Very High: (76%-100%)	4 (33.33%)	25 (32.05%)	27 (67.50%)	
Tangible Support				
Very Low: (0%-25%)	1 (8.33%)	5 (6.41%)	3 (7.50%)	*0.082*
Low: (26%-50%)	2 (16.67%)	20 (25.64%)	6 (15.00%)	
High: (51%-75%)	7 (58.33%)	33 (42.31%)	11 (27.50%)	
Very High: (76%-100%)	2 (16.67%)	20 (25.64%)	20 (50.00%)	
Appraisal Support				*0.140*
Very Low: (0%-25%)	1 (8.33%)	6 (7.69%)	3 (7.50%)	
Low: (26%-50%)	2 (16.67%)	25 (32.05%)	7 (17.50%)	
High: (51%-75%)	6 (50.00%)	28 (35.90%)	13 (32.50%)	
Very High: (76%-100%)	3 (25.00%)	19 (24.36%)	17 (42.50%)	

Notes

Hierarchically Adjusted Models

Approach

Model testing took place via a hierarchical approach to linear regression. Domains of interest fall within theoretical categories, as described in Table 11: the *exposure* category contained potential confounders; the *coping* category contained the deprivation, social network and social support domains; the *damaging loss* category contained the cancer "fatalism" domain. Cancer-related self-efficacy score (0-1) was regressed on each of the variables within the domains of interest for the unadjusted models. These single variable models were then adjusted for confounders, considered *a priori* to be exposure-related variables (age, cancer type and time since diagnosis), to produce the adjusted models. Finally, the self-efficacy was regressed on all variables within a domain, controlling for *a priori* confounders, to produce the domain models. A complete model (Table 12), was created including all domain variables and all a priori confounders.

Findings

The *a priori* confounders were not associated with self-efficacy and had little effect on variable associations with self-efficacy. Variables within the deprivation domain (deprivation index and region) were not significantly associated with cancer-related self-efficacy.

Core network size was not significantly associated with self-efficacy, while social support was; the association between social support and self-efficacy became borderline significant when controlling for core network size. When controlling for core network size, women reporting very high global social support reported 8.7% higher cancer-related self-efficacy compared to women reporting any other level of global social support (p=0.058)

Both fatalism factors were significantly associated with cancer-related self-efficacy; higher factor score equates with higher fatalism. Women reporting the highest "Death from Cancer" factor scores (score of 1) had 20% lower self-efficacy compared to women reporting the lowest "Death from Cancer" factor scores (score of 0). Likewise, women reporting the highest "Life with Cancer" factor scores (score of 1) had 21% lower self-efficacy compared to women reporting the lowest "Life with Cancer" factor scores (score of 0). In other words, women who more strongly associated cancer with death, and who saw fewer opportunities to live with cancer, reported lower self-efficacy. It should again be noted that, overall, women participating in this study reported low fatalism overall; "fatalism" factor comparisons are made within the sample range of scores. These are relative, not absolute, comparisons.

In the complete model, described in Table 12, only the “Death from cancer” factor remained statistically significant. Social support was no longer significant and the “Life with cancer” factor was marginally significant.

Table 11

Linear Regressions: Hierarchically Adjusted Models of Cancer-Related Self-efficacy among Peruvian Women with a Cancer Diagnosis

Theoretical Model	Defining Domains	Unadjusted		Adjusted*		Domain **	
		coefficient [95% CI]	*p*	coefficient [95% CI]	*p*	coefficient [95% CI]	*p*
Risk of Inadequate Coping Resources	Deprivation						
	Deprivation Index						
	Score (0-1)	0.087 [-0.074-0.248]	*0.286*	0.083 [-0.083-0.248]	*0.324*	0.091 [-0.076-0.258]	*0.284*
	Region						
	Lima	REF	*REF*	REF	*REF*	REF	*REF*
	Other Region	0.021 [-0.052-0.094]	*0.564*	0.022 [-0.053-0.097]	*0.557*	0.028 [-0.048-0.103]	*0.470*
	Social Coping						
	Social Networks						
	Integer	0.013 [-0.015-0.040]	*0.368*	0.021 [-0.008-0.049]	*0.147*	0.005 [-0.028-0.037]	*0.783*
	Social Support						
	All other support	REF	*REF*	REF	*REF*	REF	*REF*
	Very high support	0.083 [0.007-0.159]	*0.032*	0.094 [0.017-0.171]	*0.018*	0.087 [-0.003-0.078]	*0.058*

Risk of Damaging Loss	Cancer-Related Fatalism						
	Death from Cancer						
	Score (0-1)	-0.277	*0.006*	-0.243	*0.021*	-0.219	*0.034*
		[-0.472- -0.082]		[-0.448- -0.038]		[-0.422- -0.016]	
	Life with Cancer						
	Score (0-1)	-0.235	*0.013*	-0.232	*0.017*	-0.211	*0.028*
		[-0.420- -0.050]		[-0.422- -0.043]		[-0.400- -0.023]	
Risk Exposure	Confounders						
	Age						
	Years	-0.001	*0.618*				
		[-0.004-0.002]					
	Cancer Type						
	Breast cancer	REF	*REF*				
	Cervical cancer	-0.052	*0.343*				
		[-0.159-0.056]					
	Other cancer	0.001	*0.981*				
		[-0.080-0.082]					
	Time since diagnosis						
	Days	-0.00	*0.906*				
		[-0.000-0.000					

*Notes *Adjusted for age, cancer type, and time since diagnosis. **Within-domain model adjusted for age, cancer type and time since diagnosis*

Table 12

Complete Model, including all Domains and Adjusting for a priori Confounders

Theoretical Model	Defining Domains	Fully adjusted model	
		coefficient [95% CI]	*p*
Risk of Inadequate Coping Resources	Deprivation		
	Deprivation Index		
	Score (0-1)	0.007 [-0.167-0.182]	*0.934*
	Region		
	Lima	REF	*REF*
	Other Region	0.058 [-0.017-0.133]	*0.127*
	Social Coping		
	Social Networks		
	Integer (0-5)	0.002 [-0.031-0.034]	*0.927*
	Social Support		
	All other support (<75%)	REF	*REF*
	Very high support (75%+)	0.063 [0.027-0.155]	*0.153*
Risk of Damaging Loss	Cancer-Related “Fatalism”		
	Death from Cancer		
	Score (0-1)	-0.226 [-0.448- -0.004]	*0.046*
	Life with Cancer		
	Score (0-1)	-0.204 [-0.403-0.006]	*0.043*
Risk Exposure	Confounders		
	Age		
	Years	-0.001 [-0.004-0.002]	*0.570*
	Cancer Type		
	Breast Cancer	REF	*REF*
	Cervical Cancer	-0.037 [-0.143-0.069]	*0.487*
	Other Cancer	0.002 [-0.081-0.077]	*0.958*
	Time since Diagnosis		
	Days	0.000 [-0.000-0.000]	*0.889*

Akaike's Information Criterion for Model Selection

After hierarchical analysis, Akaike's Information Criterion (AIC) was applied to all models, adjusted and unadjusted, including the complete model (Table 13). AIC value indicates relative model fit, controlling for the number of variables in the model; a lower AIC value indicates a better fit. By this criteria, the best model was Model 5 (AIC = -44.920), the model with all cancer "fatalism" domain variables, unadjusted for the *a priori* confounders. This model was statistically significant at the 0.05 cut-off and explained 7.4% of the variability in cancer-related self-efficacy.

Model 10 was a close second for fit (AIC -43.899); model 10 included both social coping domain variables and cancer "fatalism" domain variables, unadjusted for *a priori* confounders. This model was also statistically significant and explained 8.0% of the variability in self-efficacy.

Table 13

Model Evaluation with Akaike's Information Criterion

Model	df	*p*	Model Log Likelihood	AIC	adj. R^2
Model 1: Deprivation Domain, Unadjusted	3	*0.375*	20.512	-35.024	0.000
Model 2: Deprivation Domain, Adjusted	7	*0.772*	21.219	-28.438	0.000
Model 3: Social Coping Domain, Unadjusted	3	*0.069*	22.253	-38.506	0.042
Model 4: Social Coping Domain, Adjusted	7	*0.273*	23.440	-32.881	0.013
Model 5: Cancer-Related Fatalism Domain, Unadjusted	3	*0.003*	25.460	**-44.920**	0.074
Model 6: Cancer-Related Fatalism Domain, Adjusted	7	*0.059*	25.818	-37.636	0.049
Model 7: Confounders Domain Model	5	*0.776*	20.429	-30.857	0.000
Model 8: Complete, Unadjusted	7	*0.011*	28.183	-42.366	0.084
Model 9: Complete, Adjusted	11	*0.069*	28.648	-35.297	0.059
Model 10: Social Coping and Cancer-Related Fatalism, Unadjusted	5	*0.006*	26.949	-43.899	0.080
Model 11: Social Coping and Fatalism, Adjusted	9	*0.060*	27.369	-36.738	0.056

Notes: For all AIC models n=128 due to small missingness in cancer type and time since diagnosis.

DISCUSSION

Cancer-related self-efficacy was shown to be associated with several of the key domains of interest, although the total variability explained by the models was relatively low (<10%). This is an important finding, given the import some researchers have placed on individual-level psychosocial factors for uptake and adherence to clinical services.

The cross-sectional nature of the study precluded any determination of causality, but the associations and their magnitudes are of interest. The fact that these relationships were found even within a relatively homogeneous sample of women (high self-efficacy, high social support, low fatalism and low SES), is noteworthy; it may be that the effects and explanatory power of the models would improve with a more heterogeneous, or population-based sample.

Greater social support was associated with higher self-efficacy, while core network size was not. Total network size was not associated with self-efficacy. This suggests that the function of networks, rather than their structure (or quality rather than quantity) may be the most critical element in this setting. Future study will investigate questions of structure (e.g. member type and position) to assess whether this remains true. Likewise, fatalistic constructs were strongly associated with cancer-related self-efficacy, but again did not have full explanatory power; women who had agreed with more fatalistic concepts were less self-efficacious. However, while health behavior constructs such as fatalism were relevant to women’s sense of self-efficacy, they do not explain it completely.

CHAPTER 3: UNPACKING THE CANCER FATALISM CONSTRUCT

ABSTRACT

Objectives

The objective of this study was to make explicit the often implicit assumptions about cancer fatalism in the health sciences literature, especially the common framing of fatalism as an individual or cultural failing, and to critique and test these assumptions. This was to be achieved by unpacking the construct of cancer fatalism - clearly describing its broader theoretical elements and delineating relationships with empirical, quantitative, findings.

Methods

A total of 16 cancer “fatalism” questions were administered to a sample of 130 women under treatment for cancer at Peru’s national cancer institute (INEN). These 16 questions were designed to reflect the existing health sciences literature on cancer fatalism as well as fatalistic-type concepts and language elicited in prior qualitative research on cancer in Peru; each question was considered *a priori* to fall into one of four theoretical fatalism domains: typical cancer fatalism, God/fate/luck fatalism, social risks/stigma fatalism, or outcome expectations fatalism. Exploratory factor analysis (EFA) was conducted to find latent factors relating to the fatalism items.

Results

EFA resulted in two factors, retaining 12 of the original 16 fatalism items. Of these 13 items, 8 loaded onto factor 1 and 4 loaded onto factor 2. The two factors were labeled “Death from cancer” and “Life with cancer” as they represented two different, but not mutually exclusive, conceptualizations of cancer. “Death from cancer” as a latent factor contained items that touched on ultimate outcomes that could be considered outside of human or individual control. “Life with cancer” as a latent factor contained items that touched on proximate outcomes, possibilities regarding the process of having cancer, regardless of the ultimate outcome of the illness.

Conclusions

Cancer fatalism among cancer patients in Peru was not a unidimensional concept. Typical conceptions of cancer fatalism have failed to acknowledge the complexity of fatalistic expressions, and that such expressions are not necessarily nor logically at odds with the pursuit of cancer

services and cancer care. Among Peruvian women diagnosed with cancer, fatalistic expressions were low overall, while responses indicated that fatalism constructs were a nuanced blend of interpretations about cancer, taking into consideration personal background, knowledge and experience, as well as wider social norms.

INTRODUCTION

The concept of cancer fatalism, and its hypothesized role in health behaviors, has been broadly applied to low-resource and vulnerable populations in an attempt to explain health disparities and to identify potential areas for intervention. Treatment of cancer fatalism as an individual or cultural construct, in the absence of broader context runs the risk of stigmatizing vulnerable populations and blaming individuals for structural deficiencies.

LITERATURE REVIEW

The question on whether fatalism represents a cultural belief, and how it relates to other constructs, has been raised by authors outside of the cancer research literature. This critique includes anthropologists in particular who have questioned the use and interpretation of the cancer fatalism construct. This literature on fatalism theories, and its critiques, was used to inform the development of the fatalism items included in the present survey with the goal of allowing for empirical and quantitative study of these issues as they relate to cancer.

The economist Gabriele Ruiu (2012) suggested that the concept of fatalism is similar to that of locus of control, in other words whether outcomes in one’s life are determined by their actions (internal locus of control) or external factors (external locus of control). Ruiu points out the difficulty in separating psychological traits and cultural beliefs; he argues that cultural beliefs are a social construct while psychological traits are individual, with the former being influenced by the latter. Ruiu provides a comprehensive overview of the fatalism construct, contextualizing its recent use in different areas of academic research, from uptake of income redistribution systems to household savings behavior, to use of health screening services and response to natural disasters. Ruiu and others (Acevedo, 2005), propose models of fatalism that are informed by two sociologists and philosophers, Max Weber and Emile Durkheim, where Weberian fatalism is a cultural view of fatalism and Durkheimian fatalism is a structural view.

Ruiu, desiring to investigate the sources of fatalism, set up an analysis based on two different approaches to the construct, cosmological/Weberian versus structural/Durkheimian fatalism:

> *the aim of the analysis is to test if once controlled for individual characteristics that may influence fatalistic tendencies (age, gender, education, health status, etc.), the income inequality and the strictness of the regulation (the Durkheimian vision of fatalism), cultural factors as religion (the Weberian vision of fatalism) and the interaction between these two*

> *factors (my vision of fatalism) are still significant determinants of fatalism* (Ruiu, 2012, p. 7)

Ruiu used data from the World Values Survey (WVS) data. The WVS investigates basic values and beliefs held by individuals in more than 80 countries, and includes detailed demographic data.

Ruiu used two WVS data points to stand in for cosmological and structural fatalism. The structural fatalism question was:

> *Some people feel they have completely free choice and control over their lives, while other people feel that what they do has no real effect on what happens to them. Please use this scale (1 means ―none at all‖ and 10 means ―a great deal‖) to indicate how much freedom of choice and control you feel you have over the way your life turns out.* (Ruiu, 2012, p. 6)

The cosmological fatalism question was:

> *Some people believe that individuals can decide their own destiny, while others think that it is impossible to escape a predetermined fate. Please tell me which comes closest to your view on this scale on which 1 means ―everything in life is determined by fate‖ and 10 means that ―people shape their fate themselves.―.* (Ruiu, 2012, p. 6)

Ruiu's models supported the Durkheimian hypothesis that more regulated societies were more fatalistic. Ruiu also found a direct association between religion and fatalistic beliefs.

Other authors have studied fatalism more explicitly with respect to cancer and screening, and have applied latent analysis methods to understand it. Vanderpool and colleagues (2015) studied fatalism and its role on HPV screening in Appalachia. The authors used principle components analysis to identify fatalism subscales. The analysis started with 8 fatalism questions on a 5-point Likert scale (Strongly agree - Strongly disagree), which included a neutral option. Demographic and clinical variables were also collected, as were variables regarding HPV self-efficacy and intention. The analysis resulted in two components: "Inevitability over cancer" and "Lack of control over cancer," accounting for 52% of the item variance. In a model including the total fatalism score on the 8 items, and controlling for other key collected variables, the fatalism score was not significantly associated with completion of the HPV vaccination series. In a logistic model that included the two subscales and the control variables the "Inevitability of cancer" scale was not significant but the "Lack of control over cancer" scale was significantly associated with not completing the HPV series.

Questions of cancer fatalism tend to be applied to low-income populations or populations that are otherwise considered vulnerable and who likewise may have relatively poor cancer screening use or poor cancer-related outcomes. Espinosa de los Monteros et al. (2011) reviewed the literature on the relationship between cancer screening and fatalism among Latinas in the United States. The conclusion of this review was that there is evidence of a relationship between cancer fatalism and cancer fatalism, even when controlling for structural factors, although the effect sizes were small. The authors further argued that these findings are inconclusive due to methodological challenges. Of 11 studies, 7 showed a relationship between fatalism and screening after controlling for structural factors like age, SES and access to health care. Four of the studies did not find an association between screening and fatalism. Only one study had a prospective experimental design. The authors of the review noted that there was little agreement on the operationalization of the fatalism construct, for example whether questions reflected a global fatalism, or disease-specific fatalism; they argued that this warrants efforts to understand the factors underlying fatalism.

Much of the anthropological work on fatalism to date has been qualitative in nature. Drew and colleagues (2011) are an example of this, in their presentation of two ethnographic case studies on fatalism among low-income Appalachian women, relating to hysterectomy and Pap smear. This paper provided a well-considered overview of how the fatalism construct has been used in the health sciences, namely the commonly reported finding that perceptions are associated with health behavior and that they offer a potentially more modifiable variable for intervention rather than more difficult-to-change structural variables. The authors cite Harold Freeman’s poverty spiral as a more nuanced view of fatalism, as it described how constrained resources shape people’s abilities to manage a cancer diagnosis or potential diagnosis.

The researchers had 3 main streams of evidence from their case studies: evidence of women’s attempts to retain agency despite constrained resources; evidence against the assumption that religiosity led to adverse health behaviors (or that religiosity was adversarial to optimal health behavior); and evidence against the idea that fatalism is an irrational response to thinking about cancer. Drew and colleagues used their qualitative findings to demonstrate the importance of considering context rather than just fatalism as a deterministic psychological factor in health behaviors, calling out the role of “complex negotiation of cognitive, socioeconomic and environmental realities” (Drew & Schoenberg, 2011, p. 175). The authors argued that researchers and health scientists should neither throw out fatalism construct nor rely on it as explanatory factor for "irrational" health behavior, but recognize the complexity of the construct.

THEORETICALLY INFORMED EFA

The goal of this part of the study was to have a series of questions that represented a broader, and more explicit, interpretation of the concept of fatalism than is typically employed in cancer studies, and to assess the latent structure of these variables. By doing so the aim was to identify contextually appropriate ways to operationalize the fatalism construct. All of the questions specifically addressed cancer, and so are different from studies that attempt to measure an individual's global fatalism.

Of course, it was recognized that there could be overlap in these questions or differences in how participants interpreted them compared to the intention of the researcher. That was the reason for conducting the present exploratory analysis, as well as cognitive interviews (see Chapter 4). There were four core categories considered for question development: typical cancer fatalism, God/fate/luck fatalism, Social risks/stigma fatalism, and Outcome expectations fatalism.

Typical Cancer Fatalism (survey items 3.11, 3.12, 3.17, 3.19, 3.23 3.25)

The concept of "cancer fatalism" was frequently used in the literature and tied to associations between death and cancer and presumably related perceptions about the utility of early detection. The survey included two fatalism questions specifically about cancer and death (3.11, 3.25), 3 questions about the utility of early detection (3.12, 3.17, 3.23) and one question that combined these two concepts (3.19)

God/Fate/Luck Fatalism (survey items 3.10, 3.13, 3.16, 3.18)

Another common concept of fatalism is that it is the outcome of a belief system that a higher power, fate, luck or chance determines one's life. This is a cosmological or Weberian view of fatalism which is often cast as being at odds with values of individualism and personal responsibility promoted in western medicine and public health. One question was included about the role of god in cancer (3.16), two about luck or chance (3.10 and 3.18) and one about the role of personal actions (3.13).

Social risks/Stigma Fatalism (survey items 3.14, 3.20, 3.22, 3.24)

The third category, that of Social Risks/Stigma was shaped from a model of structural fatalism based in the theories of Emile Durkheim, where fatalistic ideas are sourced to externally imposed constraints within a society. They could further be viewed as expressions of disempowerment or what Mark Nichter calls "cultural idioms of distress" (Nichter, 2010). These questions were formed with a strong reference to language emerging from qualitative work with women, and what they identified as the anticipated social costs of a cancer diagnosis. These included questions around the ideas that worry can make cancer worse, that cancer treatment can make cancer worse, that cancer can cause damage to close social relationships, and that cancer will be very physically painful.

Outcome Expectations Fatalism (survey items 3.15, 3.21)

Finally, the category of outcome expectations was conceptualized in part based on Alfred Bandura's theories, and that outcome expectations are separate from self-efficacy expectations (another key component of the survey and the assessment of one's ability to carry out certain actions). This is a nuanced but important distinction, and attempts to tease apart beliefs around cancer *meaning* death as in cancer fatalism (i.e. being associated with death in the mind of the participant) versus beliefs about the *possibility* that cancer can be treated or cured. Therefore, these questions touch on whether the participant believes that one can get better or be cured if she receives treatment.

MATERIALS AND METHODS

Survey Question Design

The survey included 16 fatalism questions that were developed from the literature on the theoretical construct of fatalism (Acevedo, 2005; Carr & Steel, 2013; Ruiu, 2012) as well as previously developed cancer fatalism scales (Lopez-McKee, McNeill, Eriksen, & Ortiz, 2007; Powe & Finnie, 2003); items were also developed based on prior qualitative and ethnographic work on cancer in Peru(Hayes Constant et al., 2014).The questions were formulated and validated in Spanish, and were back translated here into English in the right-hand column of Table 14.

The Likert scale response options were as follows:

Very much agree (4) **Agree** (3) **Disagree** (2) **Very Much Disagree** (1) **Unsure** (.)

The option of “unsure” (i.e. undecided or don’t know) was not considered a middle or neutral option but instead a missing value; participants were instructed to use that option only if they did not understand the question or if they felt the question did not apply to them. All “unsure” responses were recoded to “missing” and imputed as previously described.

Those items marked by an asterisk in Table 14 were reverse coded to keep consistency within the items (where a higher score indicates agreement with more fatalistic expressions). Although many studies using Likert items treat them as interval variables, it was determined more appropriate to treat these items as ordinal variables; the relative distance is between any two responses may not be considered equal. This assumption was supported by the fact the responses of these items were strongly skewed in favor of the less fatalistic responses and were not normally distributed.

Table 14

Sixteen fatalism items and distribution of participant responses, n=130

Factor item Survey ID	Spanish language question	English language question	Original Responses	n (%)	Responses with imputation	n (%)
f_tocaba 3.10	Yo pienso que si a una persona le da cáncer, es así, porque eso le tocaba en su vida.	I think that if a person gets cancer, that is how it is, because this fell to them in their life.	Very much disagree	18 (13.85%)	Very much disagree	18 (13.85%)
			Disagree	54 (41.54%)	Disagree	60 (46.15%)
			Agree	41 (31.54%)	Agree	41 (31.54%)
			Very much agree	11 (8.46%)	Very much agree	11 (8.46%)
			Unsure	6 (4.62%)		
			Missing	0 (0.00%)		
f_muerte 3.11	Yo pienso que cáncer significa muerte.	I think that cancer means death.	Very much disagree	39 (30.00%)	Very much disagree	40 (30.77%)
			Disagree	57 (43.85%)	Disagree	57 (43.85%)
			Agree	20 (15.38%)	Agree	20 (15.38%)
			Very much agree	13 (10.00%)	Very much agree	13 (10.00%)
			Unsure	0 (0.00%)		
			Missing	1 (0.77%)		
f_atiempo 3.12*	Yo pienso que es posible detectar el cáncer a tiempo para encontrar una solución.	I think that it is possible to detect cancer in time to find a solution	Very much agree	76 (58.46%)	Very much agree	76 (68.46%)
			Agree	51 (39.23%)	Agree	52 (39.23%)
			Disagree	1 (0.77%)	Disagree	1 (0.77%)
			Very much disagree	2 (1.54%)	Very much disagree	2 (1.54%)
			Unsure	0 (0,00%)		
			Missing	0 (0.00%)		
f_noimporta 3.13	Yo pienso que si una persona va a sufrir de cáncer, no importa cómo se comporte esta persona en su vida, igual va a sufrir de cáncer.	I think that if a person is going to suffer from cancer, it doesn't matter how this person behaves in their life, they will still suffer from cancer.	Very much disagree	17 (13.08%)	Very much disagree	17 (13.08%)
			Disagree	53 (40.77%)	Disagree	60 (46.15%)
			Agree	41 (31.54%)	Agree	41 (31.54%)
			Very much agree	12 (9.23%)	Very much agree	12 (9.23%)
			Unsure	7 (5.38%)		
			Missing	0 (0.00%)		
f_preocupacion 3.14	Yo pienso que la preocupación de saber que uno tiene cáncer puede	I think that the worry from knowing that one has cancer can make the illness worse.	Very much disagree	4 (3.08%)	Very much disagree	4 (3.08%)
			Disagree	17 (13.08%)	Disagree	17 (13.08%)
			Agree	61 (46,92%)	Agree	61 (46.92%)
			Very much agree	48 (36.92%)	Very much agree	48 (36.92%)
			Unsure	0 (0.00%)		

	empeorar la enfermedad.		Missing	0 (0.00%)		
f_mejorar 3.15*	Yo pienso que si alguien tiene cáncer y recibe tratamiento, puede mejorar.	I think that if someone has cancer and receives treatment, they can get better.	Very much agree	61 (46.92%)	Very much agree	62 (47.69%)
			Agree	64 (49.23%)	Agree	64 (49.23%)
			Disagree	2 (1.54%)	Disagree	2 (1.54%)
			Very much disagree	2 (1.54%)	Very much disagree	2 (1.54%)
			Unsure	1 (0.77%)		
			Missing	0 (0.00%)		
f_dios 3.16	Yo pienso que el tener cáncer o no, está en las manos de Dios.	I think that having cancer or not is in the hands of God.	Very much disagree	6 (4.62%)	Very much disagree	6 (4.62%)
			Disagree	17 (13.08%)	Disagree	17 (13.08%)
			Agree	51 (39.23%)	Agree	51 (39.23%)
			Very much agree	56 (43.08%)	Very much agree	56 (43.08%)
			Unsure	(0.00%)		
			Missing	(0.00%)		
f_avanzada 3.17*	Yo pienso que es posible detectar el cáncer antes de que esté en etapa avanzada.	I think that it is possible to detect cancer before it is in an advanced stage.	Very much agree	70 (53.85%)	Very much agree	70 (53.85%)
			Agree	58 (44.62%)	Agree	58 (44.62%)
			Disagree	2 (1.54%)	Disagree	2 (1.54%)
			Very much disagree	0 (0.00%)	Very much disagree	0 (0.00%)
			Unsure	0 (0.00%)		
			Missing	0 (0.00%)		
f_suerte 3.18	Yo pienso que el tener cáncer o no, es un asunto de mala suerte en la vida.	I think that having cancer or not is an issue of bad luck in life.	Very much disagree	33 (25.38%)	Very much disagree	33 (25.38%)
			Disagree	74 (56.92%)	Disagree	76 (58.46%)
			Agree	14 (10.77%)	Agree	14 (10.77%)
			Very much agree	7 (5.38%)	Very much agree	7 (5.38%)
			Unsure	2 (1.54%)		
			Missing	0 (0.00%)		
f_temprano 3.19	Yo pienso que si alguien tiene cáncer, no importa si lo detectan temprano o tarde, porque de todas maneras esa persona va a morir de cáncer.	I think that if someone has cancer, it does not matter if they detect it early or late, because in any case this person will die from cancer.	Very much disagree	34 (26.15%)	Very much disagree	36 (27.69%)
			Disagree	61 (46.92%)	Disagree	61 (46.92%)
			Agree	23 (17.69%)	Agree	23 (17.69%)
			Very much agree	10 (7.69%)	Very much agree	10 (7.69%)
			Unsure	2 (1.54%)		
			Missing	0 (0.00%)		

f_avance 3.20	Yo pienso que algunos tratamientos contra el cáncer pueden hacer que éste avance más rápido.	I think that some treatments against cancer can make this [disease] advance more rapidly.	Very much disagree Disagree Agree Very much agree Unsure Missing	13 (10.00%) 67 (51.54%) 30 (23.08%) 6 (4.62%) 13 (10.00%) 1 (0.77%)	Very much disagree Disagree Agree Very much agree	13 (10.00%) 81 (62.31%) 30 (23.08%) 6 (4.62%)
f_curar 3.21*	Yo pienso que si alguien tiene cáncer y recibe tratamiento, se puede curar.	I think that if someone has cancer and receives treatment, they can be cured.	Very much agree Agree Disagree Very much disagree Unsure Missing	52 (40.00%) 67 (51.54%) 7 (5.38%) 2 (1.54%) 1 (0.77%) 1 (0.77%)	Very much agree Agree Disagree Very much disagree	54 (41.54%) 67 (51.54%) 7 (5.38%) 2 (1.54%)
f_querido 3.22	Yo pienso que si alguien tiene cáncer, sus seres queridos se van a alejar.	I think that if someone has cancer, their loved ones will leave them.	Very much disagree Disagree Agree Very much agree Unsure Missing	31 (23.85%) 74 (56.92%) 22 (16.92%) 2 (1.54%) 1 (0.77%) 0 (0.00%)	Very much disagree Disagree Agree Very much agree	32 (24.62%) 74 (56.92%) 22 (16.92%) 2 (1.54%)
f_demasiado 3.23	Yo pienso que si alguien tiene cáncer, ya es demasiado tarde para buscar tratamiento.	I think that if someone has cancer, it is already too late to look for treatment.	Very much disagree Disagree Agree Very much agree Unsure Missing	32 (24.62%) 84 (64.62%) 10 (7.69%) 3 (2.31%) 1 (0.77%) 0 (0.00%)	Very much disagree Disagree Agree Very much agree	33 (25.38%) 84 (64.62%) 10 (7.69%) 3 (2.31%)
f_dolores 3.24	Yo pienso que si alguien tiene cáncer, va a sufrir de fuertes dolores físicos.	I think that if someone has cancer they will suffer from strong physical pain.	Very much disagree Disagree Agree Very much agree Unsure Missing	7 (5.38%) 31 (23.85%) 66 (50.77%) 17 (13.08%) 9 (6.92%) 0 (0.00%)	Very much disagree Disagree Agree Very much agree	7 (5.38%) 40 (30.77%) 66 (50.77%) 17 (13.08%)
f_morir 3.25	Yo pienso que si a una persona le da cáncer, esa persona va a morir de cáncer.	I think that if someone has cancer they will die from cancer.	Very much disagree Disagree Agree Very much agree Unsure Missing	25 (19.23%) 71 (54.62%) 21 (16.15%) 11 (8.46%) 2 (1.54%) 0 (0.00%)	Very much disagree Disagree Agree Very much agree	27 (20.77%) 71 (54.62%) 21 (16.15%) 11 (8.46%)

Exploratory Factor Analysis Strategy

EFA is an iterative analysis process, best used when the analyst has a theoretical framework to inform decision-making. In this study, a theoretical framework was in place, as outlined previously in this article. Furthermore, decision-making was informed by the approach outlined by Mastunaga (2015). Specifically, the following criteria were used:

1. Retain factors with eigenvalues greater than 1 and which are comprised of more than one item
2. Confirm retention of factors visually with a scree plot
3. Retain items with factor loadings greater or equal to 0.5 (absolute value)
4. Rerun correlation and factor matrices on retained factors and items
5. Apply oblique rather than orthogonal rotation to the factors, allowing for inter-factor correlation.

RESULTS

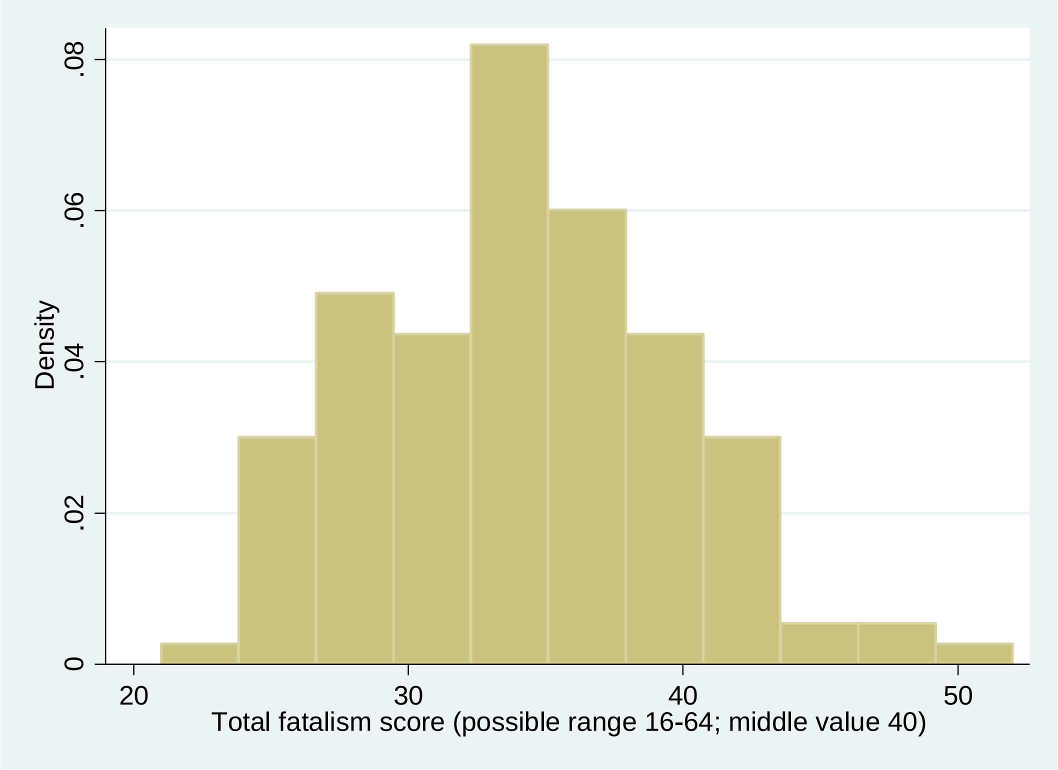
Descriptive Analysis

Prior to transformation of the fatalism items via Exploratory Factor Analysis and normalization, the variables were looked at descriptively, both pre and post imputation (see Table 14). As described in chapter 2, the small level of missingness in the 16 fatalism items was dealt with by a conservative imputation approach. After imputation Cronbach's alpha was calculated for all 16 items, giving an alpha of 0.76. This score indicates acceptable level of internal reliability; it does not indicate whether the items measure a unidimensional construct.

Given that there were 16 items, and a possible response of 1-4 for each item, the lowest possible "fatalism" score was 16 and the highest possible score was 64. The middle possible score was 40. Overall, women reported very low fatalism on the 16 items as can be seen in Figure 2; only 16 women had total fatalism scores greater than 40.

Figure 2

Histogram of total fatalism score on 16 items



Preliminary EFA

Exploratory Factor Analysis (EFA) was the approach used to determine scale dimensionality for the 16 fatalism items. All EFA analysis was carried out using STATA version 13.1 (StataCorp, 2015) Given that respondents provided answers to the 16 items on a Likert scale (See Appendix B), the items were considered to be ordinal variables and so a Pearson's correlation matrix was not applicable. A polychoric correlation matrix was applied instead, which is a technique for estimating the correlation between two theorized normally distributed continuous latent variables, from two observed ordinal variables (Holgado-Tello, Chacon-Moscoso, Barbero-Garcia, & Vila-Abad, 2010).

In the preliminary factor matrix there were three factors with eigenvalues greater than one; these three factors had eigenvalues of 4.34, 1.94, and 1.05, respectively, and together accounted for 84% of the variability within the items. In the scree plot produced from these factors, seen in Figure 3, it is difficult to discern a break or "elbow" after the third factor. Next factors loadings were studied for each factor, displayed in Table 15. Using the 0.50 factor loading (absolute value) as retention criteria, the following items were dropped from analysis: f_noimporta, f_dios, and f_dolores. These three items did not load well on any of the 3 factors retained at this preliminary stage of analysis.

Figure 3

Scree plot of preliminary EFA factors, 16 items

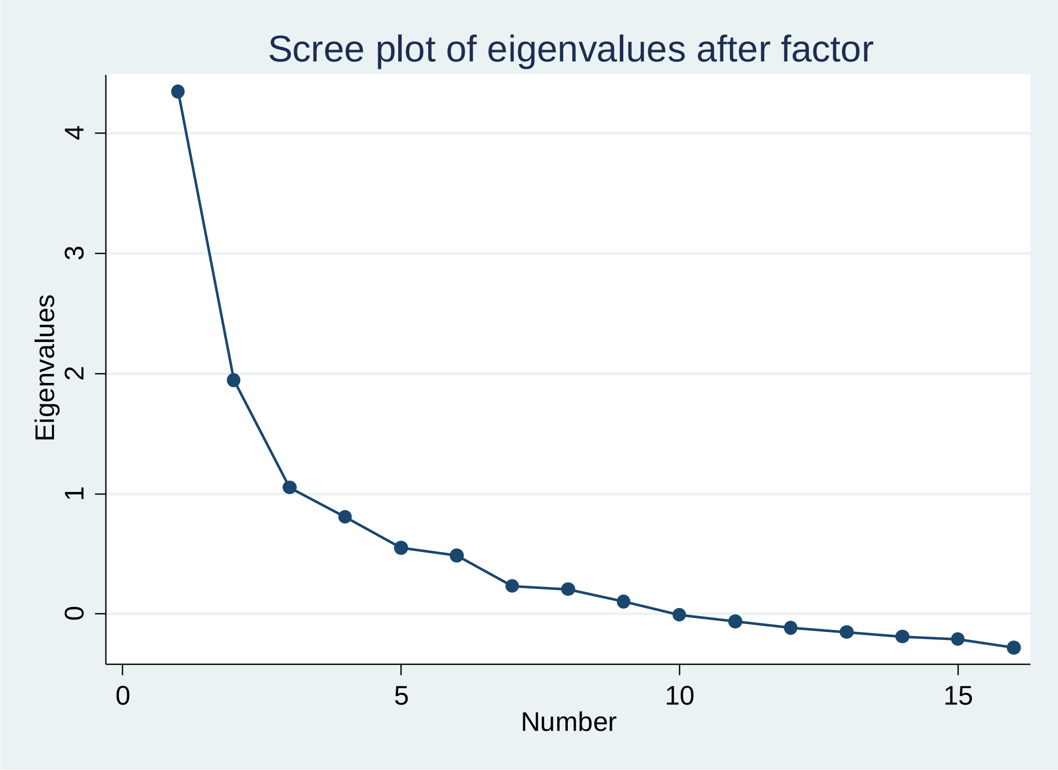


Table 15

Preliminary EFA factor loadings

Item	**Factor 1**	**Factor 2**	**Factor 3**
1. f_tocaba	**0.6330**	0.1560	-0.0924
2. f_muerte	**0.6772**	0.0905	0.0597
3. f_atiempo	0.3465	**-0.5359**	0.2519
4. f_noimporta	0.3881	0.3069	0.1704
5. f_preocupacion	-0.0130	**0.6526**	-0.1163
6. f_mejorar	0.4477	**-0.5450**	0.1266
7. f_dios	0.0992	0.2350	0.0241
8. f_avanzada	0.2612	**-0.5910**	0.1756
9. f_suerte	0.4748	0.1231	**0.5426**
10. f_temprano	**0.7838**	0.1044	0.1994
11. f_avance	**0.5551**	0.1105	-0.1381
12. f_curar	**0.5560**	-0.3812	-0.3564
13. f_querido	**0.5910**	0.0096	-0.2684
14. f_demasiado	**0.6480**	-0.0511	**-0.5275**
15. f_dolores	0.3295	0.3842	0.2267
16. f_morir	**0.7743**	0.2600	0.0579

Another polychoric correlation matrix was run on the remaining 13 items. Factors 1 and 2 had eigenvalues of 4.07 and 1.62, respectively, and accounted for 83% of the variability in the remaining items. Factor 3, had 2 items (f_suerte and f_demasiado) with factor loadings greater than 0.5, and had an eigenvalue of below 1 (0.88). Therefore, factor 3 was dropped from further analysis; f_suerte was no longer retained because it did not load on either factor 1 or 2; f_demasiado loaded onto factor 1 and so was retained.

Final EFA

Finally, a polychoric correlation was run on the remaining 12 items, retaining just 2 factors. For this analysis, factor 1 had an eigenvalue of 3.87 and factor 2 had an eigenvalue of 1.60; together they accounted for 89% of the variability in the remaining items. The scree plot based for the remaining 2 factors comprised 12 items, seen in Figure 4, and shows a more distinct elbow after the 2nd factor. Again applying the 0.50 cutoff for factor loadings, Table 16 shows that 8 items load on factor 1, and 4 items load on factor 2.

Figure 4

Scree plot of preliminary EFA factors, 12 items

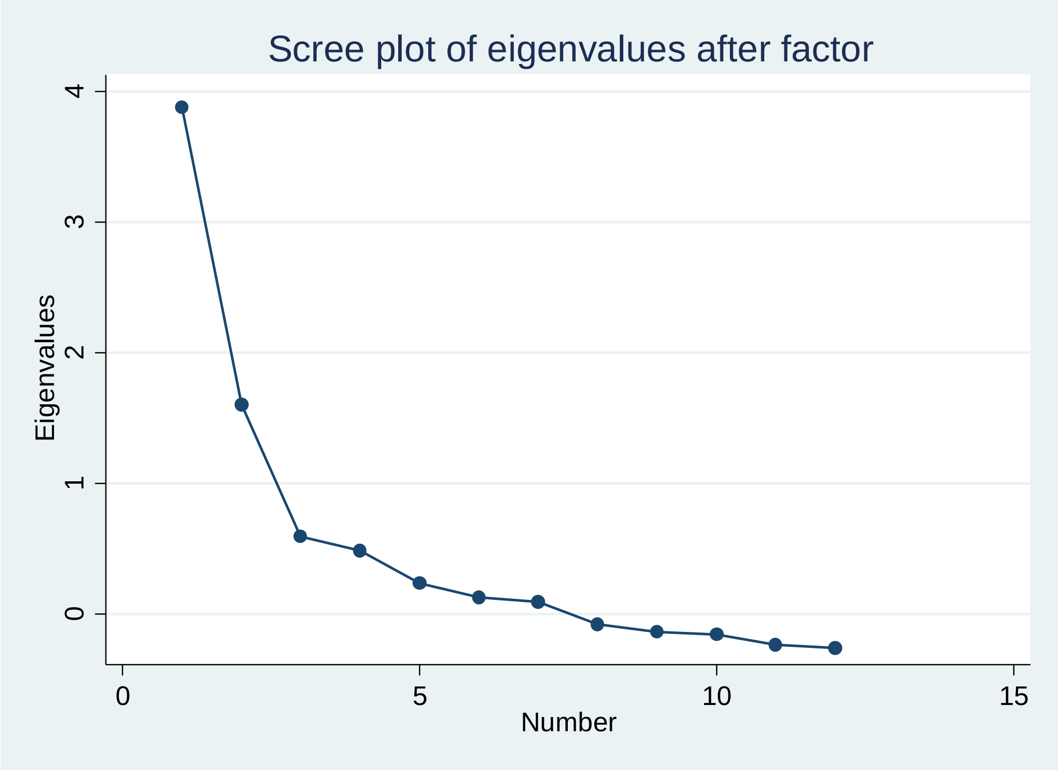


Table 16

Final EFA factor loadings

Item	Factor 1	Factor 2
f_tocaba	**0.6083**	0.2217
f_muerte	**0.6571**	0.1225
f_temprano	**0.7417**	0.1306
f_avance	**0.5529**	0.2125
f_curar	**0.6195**	-0.2622
f_querido	**0.5936**	0.1268
f_demasiado	**0.6816**	0.1608
f_morir	**0.7260**	0.3208
f_atiempo	0.3810	**-0.5521**
f_preocupacion	-0.0792	**0.6099**
f_mejorar	0.4960	**-0.5095**
f_avanzada	0.3041	**-0.5710**

Finally, the remaining factors and items were obliquely rotated for ease of interpretation. The rotated factor loadings, including the uniqueness of each item, can be seen in Table 17. A positive factor loading indicates that the item has a positive relationship with the underlying (latent) factor; a negative factor loading indicates that the item has a negative relationship with the underlying (latent) factor.

. Uniqueness is a measure of how much unique variance was accounted for by an individual variable and not by its associated factor. Low item uniqueness is preferred in EFA as it indicates a strong latent factor, one that is captured by multiple items rather than driven by just one or a few items. The least unique items were f_temprano, f_morir, f_mejorar, indicating that these items, in particular, are well explained by their respective factors.

Table 17

Rotated factor loadings and item uniqueness

Item	Factor 1	Factor 2	Uniqueness
f_tocaba	**0.6521**	-0.0254	0.5809
f_muerte	**0.6455**	0.0863	0.5532
f_temprano	**0.7248**	0.1049	0.4328
f_avance	**0.5982**	-0.0338	0.6492
f_curar	**0.4183**	0.4487	0.5474
f_querido	**0.5912**	0.0623	0.6316
f_demasiado	**0.6865**	0.0568	0.5096
f_morir	**0.8066**	-0.0849	0.3700
f_atiempo	0.0603	**0.6560**	0.5500
f_preocupacion	0.2370	**-0.6177**	0.6218
f_mejorar	0.1840	**0.6504**	0.4944
f_avanzada	-0.0175	**0.6503**	0.5815

After rotation, factor scores were generated to be used in later multivariate analysis, using predictive regression analysis methods. Table 18 shows the scoring coefficients from this regression.

Table 18

Scoring coefficients for factor item regressions

Item	Factor 1	Factor 2
f_tocaba	0.16	-0.05
f_muerte	0.13	0.02
f_temprano	0.20	0.09
f_avance	0.12	-0.01
f_curar	0.11	0.19
f_querido	0.11	0.03
f_demasiado	0.20	0.01
f_morir	0.27	-0.12
f_atiempo	-0.01	0.24
f_preocupacion	0.05	-0.23
f_mejorar	0.01	0.33
f_avanzada	-0.01	0.22

The distributions of the factor scores were tested for normality; factor 1 was not normally distributed, while factor 2 was normally distributed. Descriptive statistics (mean, median, range) can be found for the original factors, in Table 19. Finally, for ease of interpretation, both factors were normalized to 0-1. Histograms of factor 1 and factor 2 scores were produced for Figures 5 and 6. It was important to note that the final, normalized, factor scores only represent the range of scores reported by women in the study, not the total possible range of response.

Table 19

Descriptive statistics of non-normalized factor scores

	Mean (SD)	**Median**	**Range**
Factor 1	2.83 (0.69)	2.76	(1.61-5.40)
Factor 2	0.66 (0.51)	0.67	(-0.25-2.35)

Figure 5

Histogram of factor 1 normalized scores

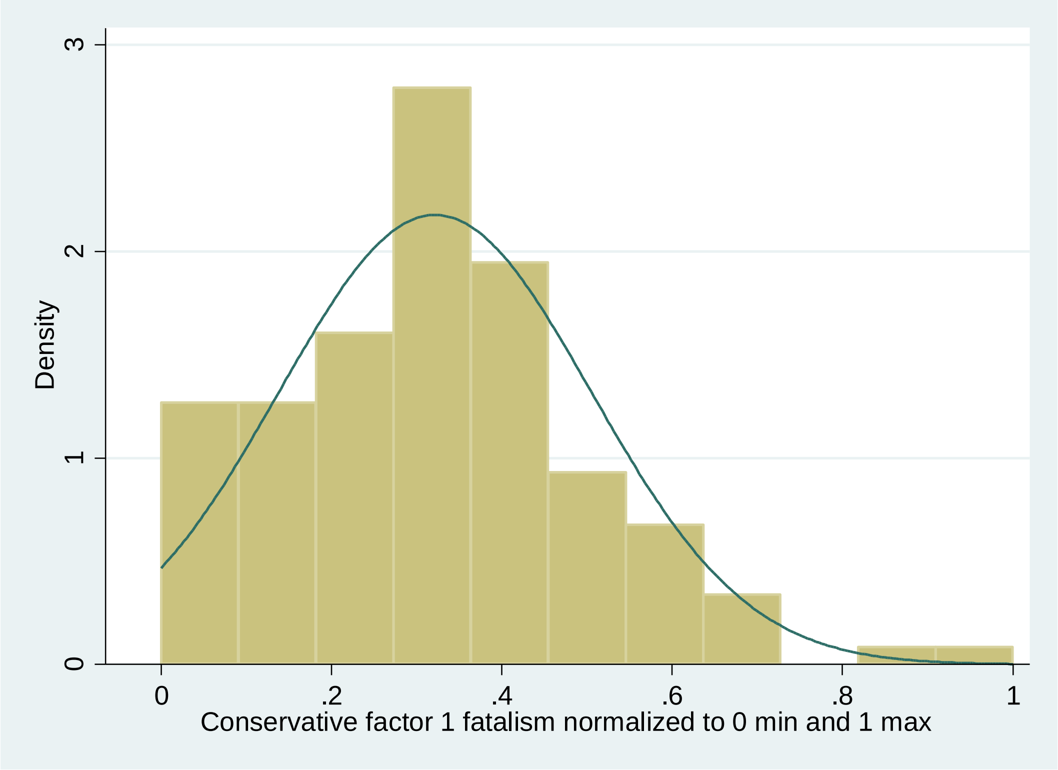
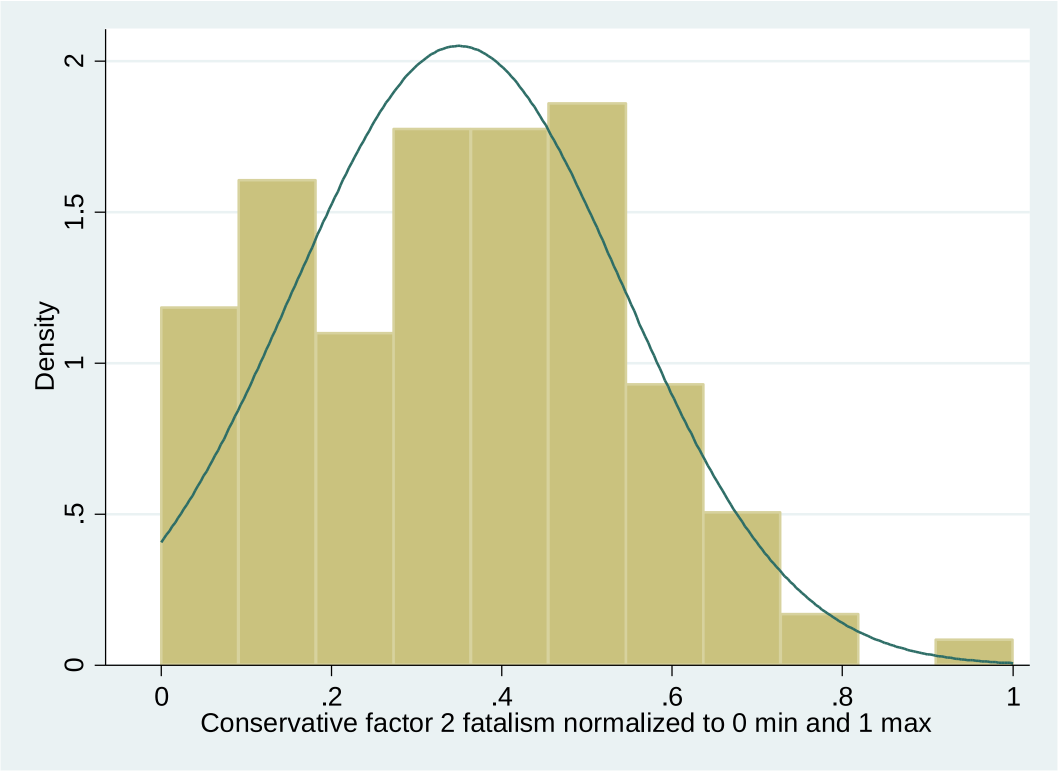


Figure 6

Histogram of factor 2 normalized scores



Interpretation

An important but sometimes neglected element of EFA is the need to interpret the results and explain how they do or do not make sense based on a prior theory. As previously described, each of the fatalism items was placed in a theoretical category, prior to analysis. There were 6 items in the “Typical cancer fatalism” category, which circumscribed the idea of cancer inevitably leading to death and, as a logical corollary, screening as a futile activity. There were 4 items in the God/fate/luck category, which circumscribed the cosmological idea that events in life, including cancer, were determined by chance or supernatural forces. There were 4 items in the Social risks/stigma category, which circumscribed notions of structural fatalism, that societal structures constrain human action. There were two items in the final category of “Outcome expectations” was based largely on Alfred Bandura’s theories, and sought to capture the idea of whether it was possible to cure cancer in general.

There were 4 items that were dropped from the EFA. The item f_noimporta, as part of the "God/fate/luck" category, was poorly worded and confusing to participants so it is unsurprising that it did not load well on either factor. The item f_dios was also part of the "God/fate/luck" category and specifically touched on whether a higher power was responsible for cancer and its outcomes; it was likewise not surprising that this item did not load well given the variety of narrative interpretations participants provided for this question (for example, the idea that a loving God does not cause illness or the idea that through God all can be resolved or the idea that God works through healthcare providers). A third God/fate/luck item (f_suerte) was dropped as it only loaded on the 3rd factor. It appeared that ideas of chance and luck did not play significantly into women's expectations of cancer outcomes. Finally, f_dolores was dropped from analysis as it did not load well on either factor; this item focused very specifically on whether or not cancer is painful, a concept that emerged in previous qualitative work and was considered part of the "Stigma/social risks" category.

Of the "Typical cancer fatalism" variables four loaded well onto factor 1. These were f_muerte, f_temprano, f_demasiado and f_morir. However, the other two "Typical cancer fatalism" items (f_atiempo and f_avanzada) loaded onto factor 2. The only remaining item in the "God/fate/luck" category (f_tocaba) loaded onto factor 1. Of the remaining 3 "Stigma/social risks" items (f_preocupacion, f_avance, and f_querido), f_preocupacion loaded on factor 2 while the other items loaded on factor 1. Of the 2 "Outcome expectation" items, f_curar loaded onto factor 1 and f_mejorar loaded onto factor 2. Overall, we can see that "Typical cancer fatalism" items tend to hand together while "God/fate/luck" items as part of factor 1, but that "Stigma/social risk" and "Outcome expectation" items are more split between the two factors.

A closer study of the wording of the questions in each factor, however, revealed an important pattern. Factor 1 items are more absolute, more about ultimate outcomes that are not within the power of participants. Factor 2 items are more about proximate outcomes, the possibility of playing some role in the process of living with cancer, separate from whether the ultimate outcomes are under one's control.

More of the "Typical cancer fatalism" and "God/fate/luck" aligned with lack of control over ultimate outcomes, and therefore hung with factor 1; the 2 remaining "Typical cancer fatalism" items that hung with factor 2 (f_atiempo and f_avanzada) were phrased in terms of "possibilities" and not ultimate outcomes. Absolutist ideas about "cure" (f_curar) hung with factor

1, while more subjective ideas about getting “better” (f_mejorar) hang with factor 2. Two of the “Stigma/social risk” items were about externally driven events, like how loved ones would react (f_querido) and the effects of treatment (f_avance); these two items hang with factor 1. The third “Stigma/social risk” item was about an internal process of worry (f_preocupacion) and this hangs better with factor 2. Factors 1 and 2 were given the names “Death from cancer” and “Life with cancer,” respectively.

While the participants in this study overall expressed low levels of fatalism, their responses also show that expressions that may be considered “fatalistic” are not unidimensional, and that ideas about cancer meaning death, and being able to live with cancer, can and do exist side by side. This analysis indicates that female cancer patients in Peru hold ideas about certain cancer-related outcomes that are beyond their control, and other processes which they can influence.

Table 20

Retained items in fatalism factors

Factor 1 with rotated factor loadings: Ultimate outcome: Will one die *from* cancer? **“Death from cancer”**	Factor 2 with rotated factor loadings Proximate outcome: Can one live *with* cancer? **“Life with cancer”**
f_tocaba (+0.65) I think that if a person gets cancer, that is how it is, because this fell to them in their life.	**f_atiempo* (+0.66)** I think that it is possible to detect cancer in time to find a solution.
f_muerte (+0.65) I think that cancer means death.	**f_preocupacion (-0.62)** I think that the worry from knowing that one has cancer can make the illness worse.
f_temprano (+0.72) I think that if someone has cancer, it does not matter if they detect it early or late, because in any case this person will die from cancer.	**f_mejorar (+0.65)** I think that if someone has cancer and receives treatment, they can get better.
f_avance (+0.60) I think that some treatments against cancer can make this [disease] advance more rapidly.	**f_avanzada* (+0.65)** I think that it is possible to detect cancer before it is in an advanced stage.
f_curar* (+0.42) I think that if someone has cancer and receives treatment, they can be cured.	
f_querido (+0.59) I think that if someone has cancer, their loved ones will leave them.	
f_demasiado (+0.69) I think that if someone has cancer, it is already too late to look for treatment.	
f_morir (+0.81)	

I think that if someone has cancer they will die from cancer.

Notes:

** Item was reverse coded*

(+/-) Direction of item relationship with factor

DISCUSSION

The women participating in this study reported low levels of fatalism, but acknowledged that ideas of cancer and death are common in Peru, and in fact were ideas they held prior to their diagnosis and treatment. Fatalistic expressions may be an expression of disempowerment, as suggested by Mark Nichter's "idioms of distress." Access to treatment is an important step in altering the contexts that lead to a sense of disempowerment, but will not change perceptions overnight.

> *In Western mainstream culture, where the expectation is to be autonomous, independent, self-directed and a manager over one's future, expressions of fatalism strike many as benighted, irrational, and counterproductive. Yet as our case studies reveal, "fatalism is an entirely rational way of coping with a world in which one feels powerless and has potential benefits, such as enhanced enjoyment of the present that Western, achievement oriented cultures tend to discount" (Heyman et al. 1997:51)." Simply offering free or reduced cost services is not equated with unfettered access…Such a conclusion fails to account for the many years of frustrations and inadequate access that, in part, create reasoned patterns of avoidance of care* (Drew & Schoenberg, 2011, pp. 176-177).

The findings from the current study are supported by a recent analysis carried out by an INEN epidemiologist which found that more impoverished regions of the country have higher rates of late-stage diagnosis for cancer (pers. comm.). SES may contribute to fatalistic expressions and social support may provide a means to ameliorate these concerns.

CHAPTER 4: TESTING RELATIONSHIPS OF CANCER VULNERABILITY

ABSTRACT

Objectives

The goal of this analysis was to understand how different elements of a vulnerability conceptual model interact, recognizing that elements of cancer-related exposure, coping and damaging loss are not independent of each other.

Methods

To investigate these relationships path analysis was applied to the survey results based on an *a priori* conceptual model, and qualitative analysis of focus groups and cognitive interviews was employed to aid in an explanation of path analysis findings.

Results

An inverse association between deprivation (SES Index) and self-efficacy was not found in the sample. Social support did have a positive relationship with self-efficacy. Social support was associated with a lower level one type of fatalism - “Life with cancer” fatalism; deprivation (higher SES index) was associated with a lower level of a second type of fatalism – “Death from cancer” fatalism. Women identified these relationships in focus groups and cognitive interviews.

Conclusions

Self-efficacy and fatalism are psychosocial constructs that are influenced by many factors that interact in complex ways. Addressing both structural determinants of cancer (social justice, access to treatment) as well as social support interventions are necessary to support women in confronting a potentially catastrophic diagnosis of cancer.

INTRODUCTION

At the outset of this study, several hypotheses were developed about the relationships between key domains contained framed by vulnerability theory. These hypotheses included the following:

H^1: There will be an inverse association between measures of deprivation and self-efficacy.

H^2: There will be a positive association between measures of social support networks and self-efficacy.

H^3: There will be an inverse association between measures of social support networks and fatalistic expressions.

H^4: Social support networks will moderate the effect between deprivation and self-efficacy. (More deprived women will experience a greater benefit of social support networks than less deprived women, with respect to their self-efficacy.)

MATERIALS AND METHODS

A mixed methods approach was used to inform the testing and interpretation of the current model of cancer-related vulnerability. After survey data collection, cleaning and transformation, as described in previous chapters, all variables in the domains of interest were incorporated into a single model, via path analysis. Several hypotheses were laid out prior to implementation of the study, about the relative roles and relationships of key variables; these are described visually in Figure 7. These relationships were set up for testing in path analysis, a series of regressions.

Path analysis was developed by geneticist Sewall Wright, as method to determine whether or not a multivariate set of nonexperimental data fits well with a particular *a priori* causal model.

> *Path analysis is the application of multiple regression for testing conceptual models of multivariate relations—that is, for testing specific theories about how the independent variables in a multiple regression equation may be influencing each other—and how this ultimately leads to the dependent variable outcome…it depends crucially on the researcher's best guess about how a system of variables really works. It is, in other words, a nice combination of quantitative and qualitative methods…Path analysis lets you test a particular theory about the relations among a system of variables, but it doesn't produce the theory; that's* your *job.(Bernard, 2013, pp. 671-672)*

Path models have both endogenous (measured) and exogenous (unmeasured) variables.

To provide additional interpretative power, qualitative data were collected around the domains of interest. Two focus groups were carried out with female cancer patients at INEN, to ask open-ended questions around the concepts of self-efficacy, social networks, social support and cancer fatalism (See **Appendix D: Focus Group Questions**). Ten cognitive interviews were carried out on 11 questions from the survey (3 from the self-efficacy domain, 5 from the fatalism domain, and 3 from the social support domain), as these were identified as rich areas of the survey where women differed widely in their responses or where they struggled to choose or explain their response (See **Appendix E: Cognitive Interview Questions**). Finally, extensive notes were taken by the interviewer on the narrative explanations that survey participants offered, in addition to their quantitative responses; this narrative description proved invaluable in making analysis decisions.

RESULTS

The findings of this study were based upon path analysis of survey results, and qualitative analysis of focus groups and cognitive interviews. The reason for this mixed methods approach was to understand the direction and magnitude of relationships between key domains, and to also allow for women to describe these domains in their own words, to understand women's definitions of such concepts as self-efficacy, social support, and fatalism.

Qualitative Results

Self-efficacy domain

In order to assess self-efficacy, focus group participants were asked about what goals they currently had related to their illness. In other words, what they were hoping to achieve, rather than what the researcher might consider their objectives should be. This approach let women define the goals toward which cancer-related self-efficacy would be oriented and further explored. In addition, 3 self-efficacy questions were pulled from the survey and included in the cognitive interviews. These items were selected because of the way initial participants responded, indicating a need to further explore women's interpretation of these questions. These three questions were: How certain are you that you can participate in decision-making about your treatment?; How certain are you that you can follow the procedures in this hospital?; How certain are you that you can "keep going"?. Together, the focus group responses and cognitive interview questions were interpreted to understand how participants defined self-efficacy.

Participants initially stated goals largely focused on continuing with treatments and being with their families. Further conversation revealed additional goals that women described having throughout the course of their illness. The most common themes for goals that were mentioned were:

1. To keep going forward.

This goal was one that was commonly stated in response to the original focus group prompt question. The phrase "seguir adelante" means to keep going forward and was also a phrase included in the survey questions based on previous qualitative work. Women clearly identified continuing to show up for treatment as a way they could keep going forward. The cognitive interviews revealed an important clarification of what steps women felt they needed to take in order to reach this goal.

Two of the self-efficacy cognitive interview questions were designed to understand how women saw their ability to take an active role in their treatment process. Taking an active role was found to be largely defined by women as "showing up," and doing what their doctors indicated, but not actions beyond this. For instance, when asked about what it meant to participate in "decision-making about treatment" and to "follow the procedures in the hospital," one participant responded: "I feel very good and I am not thinking about stopping coming here, because I can still walk and I feel very strong, a fighter still…Yes, I'll keep going with what the doctors says." (CI #1, p1). Another said "Making decisions is for me to have come here to confront my illness and to receive the treatments that the doctors indicates for me, and accept it, to heal myself." (CI #3, p1).

Women described an internal goal to keep going, and defined their success with this as continuing to show up at the hospital. This idea was extended in women's narratives about their first experiences at the hospital, and that showing up and going through with their first treatments was a major hurdle, but that things got better after that first experience.

2. To hide fear and sadness from family.

This goal was one that was revealed from women's narratives of their experiences. Women described their families as sources of support, but also didn't want to burden them with their own fear and sadness. Women described a need to present a strong face to their families, both to protect their family members, but also for fear that seeing their family members struggle would add to their own psychosocial burden.

> *What option did I have? Just to be strong, to overcome the chemotherapy, all the nausea and all to be strong for my family. Because I knew that my family would feel bad if they saw that I felt bad. So I made myself strong, I tried to eat, tried to do the things I didn't*

> *want to do, just so that they would see that I was okay. But nobody knew that inside I wanted to die; I never let them see that.* (FG 2, “Sol,” p7)

This finding was important because it demonstrated that while family members were key sources of support for patients, they were also in some ways a burden. This finding was expanded further by the fact that many women explained that they didn’t want to be treated as different, or with pity, by their family members in others in society and that they highlighted the importance of developing a sense of community and communality with other patients.

3. To confront public perceptions of cancer patients.

Throughout the focus groups and narrative descriptions offered during surveys, many women described a process through which they changed from hiding their diagnosis, to sharing it, to even being bold and flaunting it in some ways. They did this both within their families and in public. For instance, one patient described the reaction of her uncle of learning of her diagnosis:

> *I had an uncle who didn’t want to see me because he that he would find me totally destroyed. He said ‘No, I want to remember you the way you were.’ [laughs] I told him ‘Uncle, I’m not bad, I’m fine, I’m fine.’ I don’t know what he thought he would see! [laughs]* (FG 2, “Sol,” p11)

Participants laughed as they described their sassy responses to people’s questions about their illness, or how they went out in public bald. And they stated explicitly a desire to inform the public about the reality of cancer, that it is difficult but not something to be scared of or pitied. On focus group participant said:

> *Yes, they looked at me. It didn’t affect me at all because it’s more, I have said that I have cancer and I want other people to know that I have cancer and that they shouldn’t be afraid if it happens to them, they have to confront it with the courage that I am confronting it (FG #1, Amor, p9).*

Another focus group participant said:

> *I went out everywhere, bald…I put on my sunscreen and went out to the street. And the people were looking at me. [I said] “So what? Have you never seen a bald woman in the street?” or like “Why are you looking at me?” That’s how I answered them. And sometimes they came up to me and said “Friend, I have cancer,” and I said “So do I and I’m still alive so you can keep going too” [laughs]…I know you can live with cancer, and I have survived, I have come out ahead and it has gone well for me. So why can’t it for everyone else? Yes, it is just the strength of will and a desire to come out ahead and the desire to get healthy. (FG #2, Mar, p5)*

The goals that women describe demonstrate a changing experience of cancer over time, the challenge to confront the illness at the start, to adjust to physical and emotional changes and incorporate these into a new identity and understanding of self, and to share their experiences and teach others. With these changing goals, it can be expected that the orientation of self-efficacy, and the actions women have to take to achieve their goals, changes over time.

Demographics domain (deprivation)

Questions about demographics or resource availability were not brought up explicitly by the interviewer in the focus group questions or cognitive interviews. Instead women were asked what they needed to achieve the goals they described. Participants then brought up economic concerns and how important it was to have access to free treatment through Peru's public insurance programs for cancer, SIS and Plan Esperanza. Two themes arose around this topic: the importance of access to treatment, and contention over the role of personal responsibility.

1. The critical importance of free cancer treatment.

Several participants indicated that the other focus group questions about social support, and related topics were important, but were built on the premise of having access to treatment**:**

> *Look, you ask us what gives you this strength…what has to go first is the medicine. If there is no medicine, there is no going forward. The medicine is, the worst thing is that our medicine is the most expensive [Laughs]. Am I right? What they should do, now that cancer has proliferated in all parts is, apart from prevention, not charge.* (FG 1, "Esperanza," p 19)

Not all women surveyed were in fact covered by the public programs, and some only qualified once they had already spent significant funds or when they stopped working.

> *I think that once with the diagnosis and all, what also worries you and generates a lot of worry is the economic part. Because you are aware that it is a costly illness, the treatment is expensive. So at the start my family said, 'Don't worry, we will, I don't know what we will do but we will pay this.' But paying this is expensive. At the beginning they paid the laboratory, some exams, but now there is no money. What to do now? One of my nieces right then began to find out about SIS and the Plan Esperanza … they activated my SIS. I don't pay anything.* (FG 1, "Sol," pp 21-22).

2. Disagreement on the role of personal responsibility.

The focus groups proved useful for understanding women's perceptions of the role structural factors play in the behavior of cancer patients, as the participants shared ideas and debated each other. Some participants felt that individual will was the ultimate determinant of health behavior, while others argued that one's background or financial situation might limit their ability to take action. However, most participants seemed to agree that free cancer treatment should be available to all, not just low income patients. This came up in both the focus groups as well as in women's narratives during surveys. While most women surveyed or interviewed were covered by SIS and Plan Esperanza, some were paying out of pocket, especially some women covered by another government insurance (ESSALUD), who felt they could get better and more timely treatment at the public cancer hospital.

Among women who are cancer patients under treatment at a public cancer hospital, there was not absolute agreement about how personal responsibility plays into cancer outcomes, yet there was broad agreement on the need for free treatment for all. This finding may indicate broader social attitudes about the role of personal responsibility in health and merits further investigation; future studies might be recommended to include explicit questions about this topic.

Fatalism domain

Cancer fatalism was explored explicitly in both the focus groups and cognitive interviews. In the focus groups participants were asked directly if cancer was a terminal illness. In the cognitive interviews, women were asked to explain their interpretations of key phrases in the context of several of the fatalism questions, including: "it fell to them in life"; "how one behaves in life"; "worry"; "bad luck"; and "will die." The key themes found regarding fatalism were that cancer treatment, if available, can lengthen and improve one's life, death itself is beyond one's control; and cancer is not an insurmountable challenge

1. Cancer treatment, if available, can lengthen and improve one's life.

During the cognitive interviews, when asked about cancer, several participants drew a line connecting the idea death from cancer with availability of financial resources:

> *Well, I think that you will die always when they don't do the treatments. Many times for the economic situation that sometimes they can't manage the costs, because this illness is, how can I say…hearing the name is terrifying because one thinks "Now where am I going to get enough to cure me, the medications, the travel, how much are they going to charge?" In my case if I didn't have SIS, how would I cure myself, so I would be thinking that my path was certain and that is to die from cancer, so many times the economic factor is the most important (CI #3 p3)*

This finding was in agreement with findings from previous qualitative work among women who did not have cancer (Hayes Constant et al., 2014). Women consistently identified clinical treatment as a viable option for dealing with cancer for both survivorship and quality of life

2. Death is ultimately beyond our control.

During the original survey, many women responded to questions about cancer being fatal responses along the lines of "Well, we are all going to die." Those participants taking part in the cognitive interviews provided more detail about the meaning of this response, that the fact that they were going to die someday was out of their hands, but that it would not necessarily be from cancer; something else could be the cause of their death:

> *The word "going to die" is because maybe we don't do our controls, instead of coming to our treatment we are negative, so maybe we will die faster. But we are going to die, well God gives us a certain time and says "to here and no more" or our date comes, right? But not just illnesses, I say it could also be an accident or you fall or I don't know any other thing could happen to die. (CI#5, p3)*

In other words, death is coming for all of us, and we don't ultimately have control of how we will die, but we can do something about cancer to have a longer life than if we left it untreated.

3. Cancer is not an insurmountable challenge.

The previous theme was further illuminated by women's descriptions of their reactions upon first learning they had cancer; most described thinking that they were going to die soon but that with time they came to feel they could confront the disease; they explained that it wasn't easy, but neither was it as terrible as they had anticipated. Participants explain that their reactions would be typical for other people in Peru, based on common perceptions of cancer:

> *There is always in common, in the population, the fear, or a fear has been created of the treatment, that really when one is inside the treatment, it is difficult but it is not so terrible as one thought when you didn't know…when one is aware of the disease it is like a monster with seven heads, but in reality it only has one head.* (FG 1, "Sol," p. 27)

When pushed to state whether they think cancer will ultimately result in death, not all, but majority of women said that, yes, cancer is fatal if something else doesn't bring our death first. Several described it as a chronic disease that has to be controlled and managed, and that may lie latent and return:

> *I think it is more that you can control it, you can come to control it and come to live with the issue. Because even the doctors, when a person already starts a treatment for cancer unfortunately the body of this person can more easily generate it again. So practically*

> *you have it, you have it constantly with you, just that you have to learn to control it and care for yourself so that it doesn't start to grow again, right?* (FG 2, "Mar," p16)
>
> *Of course it is true. I believe yes the disease is that you know that it will be long, doing, living, how to say this? To not have pains, nothing of this. Quality of life. So you know or you don't know, but they are giving you treatment, and the moment comes that it ends* (FG 1 "Esperanza," p33).

These qualitative findings coincide very well with the survey findings and exploratory factor analysis finding that two parallel latent fatalism factors expressed in this study sample: "Death from cancer" and "Life with cancer." In both dataset women described the ability to hold both ideas simultaneously, that cancer can ultimately mean cancer, but that one can live with it, deal with it and have a good quality of life.

Social support networks domain

When participants responded to specific prompts about who were the important people for a cancer patient, family members were always mentioned first. However, further discussion revealed that while family member networks were important, there was a thematic chronology regarding when different types of network members were needed.

1. Emotional benefits and burden of family members.

Participants identified the family members as important throughout their illness, but especially at the moment of diagnosis as a source of emotional support:

> *The family tries to hold you up because you know in this moment they told you had cancer and you had the idea of death, how many days do you have left, and what's going to happen to you now? And there are your sisters, your brothers who are going to tell you, 'Look, relax, don't worry. Look, we are going to come out of this and with treatment you are going to be able to do it.' They try to lift you up and give you hope and there comes in hope, faith that yes we are going to overcome this and they are the ones you take you there.* (FG 1, "Amistad," p 14)

Women identified family members as motivations to keep going, and for emotional support, including addressing the financial fears that such a diagnosis provoked.

2. Community of survivors for re-establishing a sense of normality.

However, patients also identified some limitations for family members of their network, especially that family members did not understand what they were going through, or that they would treat them differently – with pity or with "exaggerated concern." Many participants in both the focus groups and surveys talked about their contacts with friends, including new friends made among other patients, as critical to getting over their fear of treatment and for feeling normal. The chemotherapy ward was one place where many women reported making friends:

> *Despite the fact that you are with family you feel alone because, in my case I felt alone because, ok, they are with me, helping me, but nobody really knew what I was going through, the fears I felt, the first chemo I was terrified…So when I first started chemo…this first day I spoke with a lot of people, I also spoke with a woman my age and we became friends…so in my case it wasn't easy, I had a rough time, but I felt accompanied, I felt identified with other people and felt I could talk with them.* (FG 2, "Sol," p5)

Participants identified that they needed people around them to treat them as normal, and not different:

> *[To be strong] I think basically trying to treat the person with cancer as if they didn't have it, because the fact is that they treat you like a sick person and you start to feel bad. If they treat you like a person, as if you were well, obviously with care...I think that would be a better way …because that way the person can also forget a little bit about what is happening* (FG 2, "Mar," p12)

3. Hospital staff as an untapped source of information.

Hospital staff were identified as important primarily for information. Many women reported that physicians would answer questions, but only if asked, not unprompted. They identified an explanation of side effects and treatment methods, as well as non-pharmacological health supports as information needs. However, while some participants said they wished physicians would provide this information outright, some women questioned the need to have a physician explain him or herself or the course of treatment. Many participants reported going to the internet for information about their treatments and side effects, as well as hearing ideas and comments from family members and other patients.

4. The kindness of strangers.

Finally, many women reported receiving unanticipated help, particularly spiritual support, from people they had not known previously. Similarly, several study participants reported that they were more open to interacting with a wider variety of people through the process of their illness, than had been their tendency previously.

The lack of importance of medical providers generally was an unanticipated finding, and one that administrative staff at the hospital saw in a positive light; the administrators interpreted the lack of need of a "special relationship" or access to a "gatekeeper" at the hospital was a sign that care was equally available to all. It was also surprising that tangible support from family members and other intimates did not emerge as a major social support need for women. Certainly participants described receiving financial help from family members but, due to the overwhelming cost of cancer care for both individuals and families, identified state-sponsored treatment as more critical.

Path Analysis Results

Path analysis beta coefficients were displayed in **Figure 7**; coefficients in red and orange indicate a statistically significant relationship (at $p < 0.05$ and < 0.10, respectively) between the two variables connected by a given arrow; the head of each arrow indicates a dependent variable in one regression. The sample size for this analysis was n=116, due to some missingness in time-related variables. The results from this analysis provided information that built upon the data transformation described in Chapter 2.

Beta coefficients

As expected based on the egocentric study design, core social network size was positively associated with social support (β=0.53). Also, as previously observed, social support had a borderline significant positive relationship to self-efficacy (β= 0.15). Likewise, SES index (deprivation) was associated with region (β= -0.15), with women from anywhere other than Lima having lower SES than women from Lima; this is also unsurprising given descriptive statistics from Chapter 2.

What was new and exciting in this analysis were some of the relationships demonstrated for the fatalism factors elicited through exploratory factor analysis in Chapter 3. It could be seen that the two fatalism factors had borderline statistically significant relationships with self-efficacy in the path analysis, with greater "Death from cancer" and "Life with cancer" fatalism being associated with lower self-efficacy (β= -0.19 and β= -0.16, respectively). Both fatalism factors were regressed on the SES/deprivation index and social support variables. The results demonstrated that "Death from cancer" fatalism" had a negative association with SES index (β= -0.42) but not social support while "Life with cancer" had a negative association with social support (β= -0.22) but not SES index.

In other words, women with higher SES held less fatalistic ideas about "Death from cancer" than women with lower SES. And women with higher social support held less fatalistic ideas about "Life with cancer." These findings suggest two things that were already identified in the qualitative work and that were proposed as key hypotheses in this study: structural factors like SES influence fatalism, specifically the belief that a cancer diagnosis means death; social support helps women face cancer and feel they can live with cancer, even if they can't control death as an ultimate potential outcome.

To document the magnitude of these relationships, two independent linear regressions were run, with "Death from cancer" and "Life with cancer" as the respective outcomes, and with SES index and social support as the independent variables. Women on the sample with the highest SES (1) had 33% lower "Death from cancer" fatalism scores than women with the lowest SES (0), controlling for social support; $p<0.001$. Even within a relatively homogenous sample, with women being of low SES, belief in cancer as a death sentence was very strongly influenced by variability in SES. Women in the sample reporting very high social support had 9% lower "Life with cancer" fatalism scores compared to women reporting any other level of social support, controlling for SES Index; $p= 0.016$. Even among women reporting overall high social support, an increase in social support positively influences a woman's sense of self-efficacy.

Mediation and moderation

Finally, although there was insufficient evidence to support the hypothesis (H^4) that social support moderates the effect of deprivation on self-efficacy, the results from the path analysis suggested it would be worthwhile to assess whether social support and SES index/deprivation mediated the effect of fatalism on self-efficacy.

These mediation pathways were assessed through Baron and Kenny's (1986) procedure for establishing mediation. To assess social support and SES index/deprivation as mediators in the pathway between cancer fatalism and self-efficacy, several relationships must hold true.

For "Death from cancer" fatalism the following must be true to show evidence that self-efficacy is mediated by SES index/deprivation:

1. Fatalism (predictor) is significantly associated with self-efficacy (outcome);
2. Fatalism (predictor) is significantly associated with SES index/deprivation;
3. SES index/deprivation score (predictor) is associated with self-efficacy, when fatalism is included in the model.

For “Life with cancer” fatalism the following must be true to show evidence that self-efficacy is mediated by social support:

1. Fatalism (predictor) is significantly associated with self-efficacy (outcome);

2. Fatalism (predictor) is significantly associated with social support;

3. Social support (predictor) is associated with self-efficacy, when fatalism is included in the model.

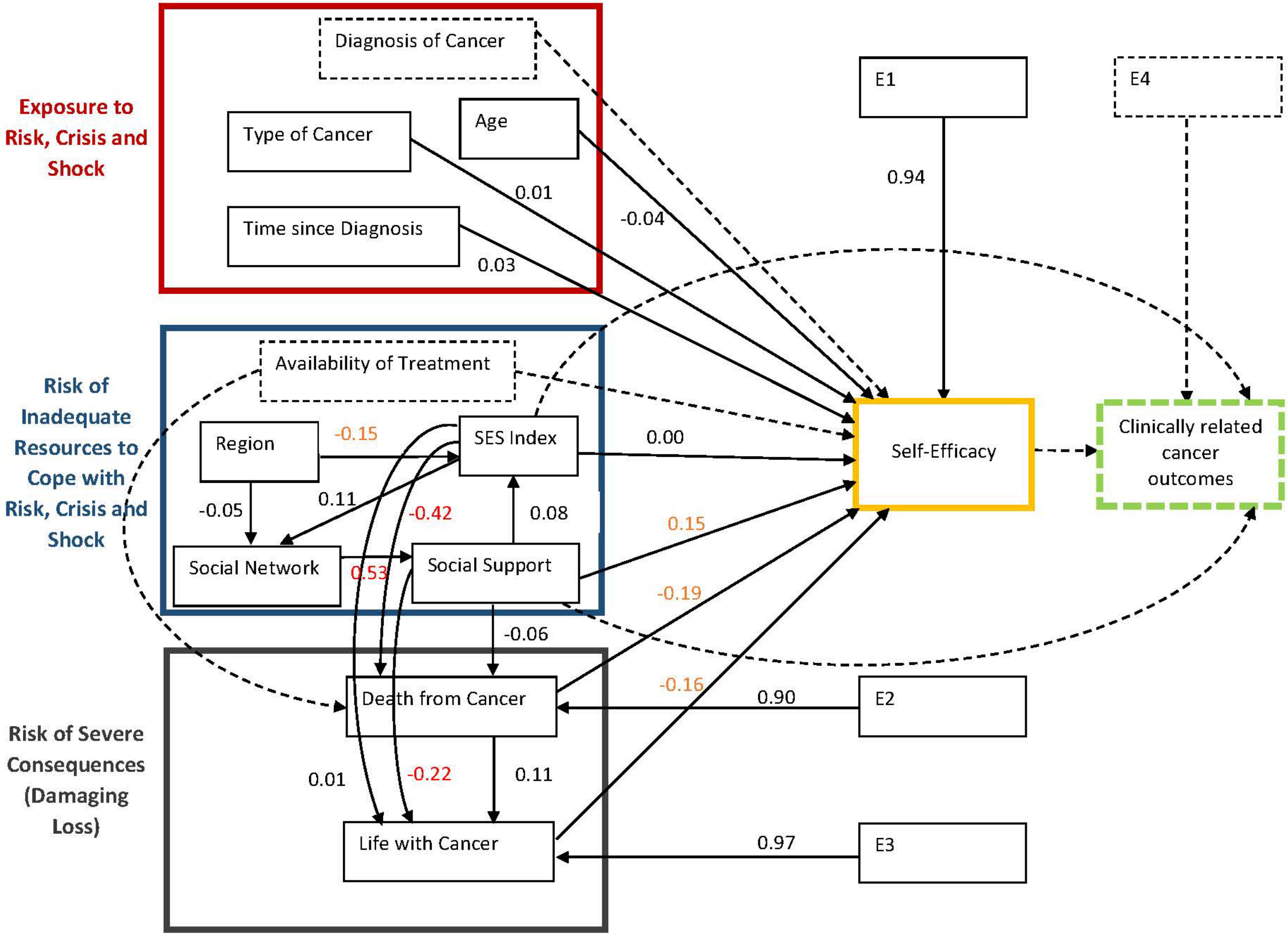
With respect to the “Death from cancer” model, requirements 1 and 2 were met, as demonstrated in the path analysis. However, in a model regressing self-efficacy on both “Death from cancer” fatalism and SES index/deprivation, SES index/deprivation was not associated with self-efficacy (p=0.942).

With respect to the “Life with cancer” model, requirements 1 and 2 were met, as demonstrated in the path analysis. In a model regressing self-efficacy on both “Life with cancer” fatalism and social support, social support remains borderline significantly associated with self-efficacy (p=0.095).

In this study sample, SES does not appear to mediate the effect of “Death from cancer” fatalism on self-efficacy, while social support may mediate the effect of “Life with cancer” fatalism on self-efficacy. These findings deserve to be explored more broadly, for instance among the wider Peruvian public.

Figure 7

Path analysis model



DISCUSSION

Alfred Bandura identified four factors as sources of self-efficacy: experience or mastery, modeling or vicarious experience, social persuasion or encouragement, and physiological responses (Bandura, 1977). These four factors were interpreted in light of the findings from this study, and used to consider questions for future research.

The first theoretical source of self-efficacy, that of experience or mastery, was reflected in participant's illness narratives. Women described a process of gaining experience as they went through the process of cancer treatment, and feeling less overwhelmed by the task of being a patient. While the survey was cross-sectional and so could not capture changes in self-efficacy over time, in the qualitative components of the study women reported that taking part in treatment was most difficult at the beginning, for example the first time they went into the chemotherapy ward. In the quantitative analysis of survey results, time since diagnosis was not associated with self-efficacy, but it may be that there are more sensitive markers (e.g. treatment initiation) that could capture this experience effect.

The second theoretical source of self-efficacy, that of modeling or vicarious experience, was in evidence in women's reports that making friends with other patients was helpful to them. Several women made comments along the lines of "if she could do it, why can't I?"; many more explicitly stated said they themselves wanted to be models for the wider population, in other words "If I can do it, why can't you?" By anticipating the utility of survivorship modeling women demonstrated their expectation that modeling could increase the self-efficacy of others confronting cancer. The results of the social network survey were also relevant to this second theoretical source of self-efficacy. Women who reported having friends as part of their cancer support social network were more likely to be from a region other than Lima. The category of "friends" was not sufficiently disaggregated to capture patient or survivor versus non-patient or non-survivor friends; this will be investigated in future studies of the qualitative survey notes, and is also recommended as a network question for inclusion in future research.

The third theoretical source of self-efficacy, that of social persuasion or encouragement, was most evident in women's narratives of how family members gave this kind of support in the earliest hours and days after diagnosis. Certainly, of the four kinds of support reported, emotional support was found to have the strongest relationship with self-efficacy. Women described the emotional support from their families as of critical importance, and when recounting what their family members said at the critical time of recent diagnosis, many reported family members saying they would help them through this period, help them to find the financial and other resources they would need. In future work it would be important to have seek out a larger number of respondents who were recently diagnosed, in order to see if these women are in any way different from other respondents with respect to both socioeconomic status and self-efficacy.

The fourth theoretical source of self-efficacy, that of physiological response, was unmeasured in this population. However, biocultural hypotheses about nature and role of the stress response points the way for future studies with this population to include stress-related or inflammatory biomarkers such as cortisol, C-reactive protein and Epstein Barr Virus.

CHAPTER 5: CONCLUSION

This study was a biocultural analysis of health behavior concepts because it considered the role of resource availability on cultural norms and psychology when considering individual conceptualizations of, and reactions to, illness. Furthermore, it sought to elucidate some of the pathways by which unequal distributions of resources can lead to health disparities.

Biocultural anthropology as a discipline considers both biology and culture to respond to forces of natural selection, though in ways that are notoriously difficult to disentangle, so much so that some reject the possibility of their synthesis in academic study. This dissertation argues that such a synthesis is both challenging and fruitful. The fact that we are a social species capable of collaboration as well as cultural diversity and change has been, perhaps one of our greatest evolutionary advantages to date.

As a species, we confront an incredibly broad range of environments, all with their macro and micro contextual constraints. Certainly the social and economic milieu are important components of the environment and should be considered when trying to understand both human behavior and biology. Considering the forces of natural selection, adaptation and evolution in human behavior and health does not negate but rather complements phenomenological approaches to the study of culture, and the social justice goals of critical medical anthropology and political economy. Constrained resources and negotiating tradeoffs offer a commonality among these lenses. A fellow anthropologist summarizes this orientation well:

> *…[W]e should continue to appreciate the core concepts of biological anthropology, including the focus on human adaptability. In the same way that evolution, a term synonymous with teleological and progressive change in everyday usage, is often conceived of quite differently by biologists, the concept of adaptation is more complex than sometimes acknowledged…[A] number of authors have suggested that the term adaptation implies that a trait or behavior is both positive and sufficient for mitigating environmental stress (Goodman and Leatherman 1998, Leatherman and Goodman 1997; Singer 1996). The danger in this term then would be naturalizing embodied inequalities, and the forces that create them…the solution to this problem is to focus on social and economic inequality as important aspects of our environment, not to ignore potential evolutionary explanations for human biology. Most evolutionary biologists conceive of adaptation as compromise solutions to competing environmental constraints rather than some optimal solutions without costs or tradeoffs (Mayr 1983)* (Hicks, 2008)

Cancer is a resource intensive illness, with respect to the time, psychological, and social resources of individuals; it is also resource intensive with respect to the economic, political and societal supports required to address it. In many ways it is an exemplar illness to study from a biocultural perspective. It is itself a biological tradeoff, a product of the same forces of mutation, diversification and natural selection that led to the development of our, and all, multicellular organisms. And through most of human history cancer has been a harbinger of death, as Siddhartha Mukherjee documented so eloquently in his book "The Emperor of All Maladies."

Yet, humans have found tools to combat cancer, certainly imperfect tools that are not cost-free in terms of financial, personal, psychological or physical costs. Women facing cancer and choosing treatment have to negotiate these costs. Self-efficacy may be a prerequisite for dealing with cancer in what is considered a "rational" way, through treatment adherence; fatalistic expressions may be an indication of the costs that may be incurred by both the disease and its treatment; social support may be an adaptive strategy for managing costs and risks associated with cancer. Consideration of these constructs may help identify patients at high risk of discontinuing treatment to provide the support necessary to mitigate the expected costs of cancer.

Applications

The results of this research have practical applications. Rather than prioritizing interventions at the individual level to provide, for instance, patient education in the hopes of changing "modifiable" self-efficacy or fatalistic perceptions, interventions may be more effective if targeted at broader social networks, especially patient social support networks. Several possibilities include the following: family based interventions at diagnosis, peer teaching or support groups prior initiation of treatment, informational outreach from providers to groups of patients, survivor groups for community outreach. Furthermore, by improving the experience of today's patients, thereby creating a pool of survivors and advocates, broader societal expectations may of cancer may change over time, leading to increased uptake of screening services with concomittent early detection, treatment and improved rates of survival nation-wide.

Limitations

While the current study does not claim to resolve the tensions inherent in the biocultural synthesis, and captures neither biological nor direct health behavior data, the findings offer some support for the ways in which resource constraints affect health through behaviorally mediated tradeoffs. The findings from the health sciences literature were not ignored, but instead reinterpreted within a more complex framework. Highly individual-focused constructs such as self-efficacy and fatalism have sometimes been considered “malleable” or more likely sources for intervention compared to more intractable structural factors. The current study investigates how such malleable constructs are likely, at least in part, already responses to a host of external forces. “Most existing health behavior models and empirically based studies demonstrate an association between beliefs and behaviors; however, the relationship is not necessarily linear or causal” (Drew & Schoenberg, 2011, p. 176)

As with most research, the current study may have raised more questions than it answered. However, it has provided important baseline information for evaluating the experience of cancer patients in low and middle-income countries, and for understanding these patient’s responses to their illness.

APPENDICES

Appendix A: Final Survey

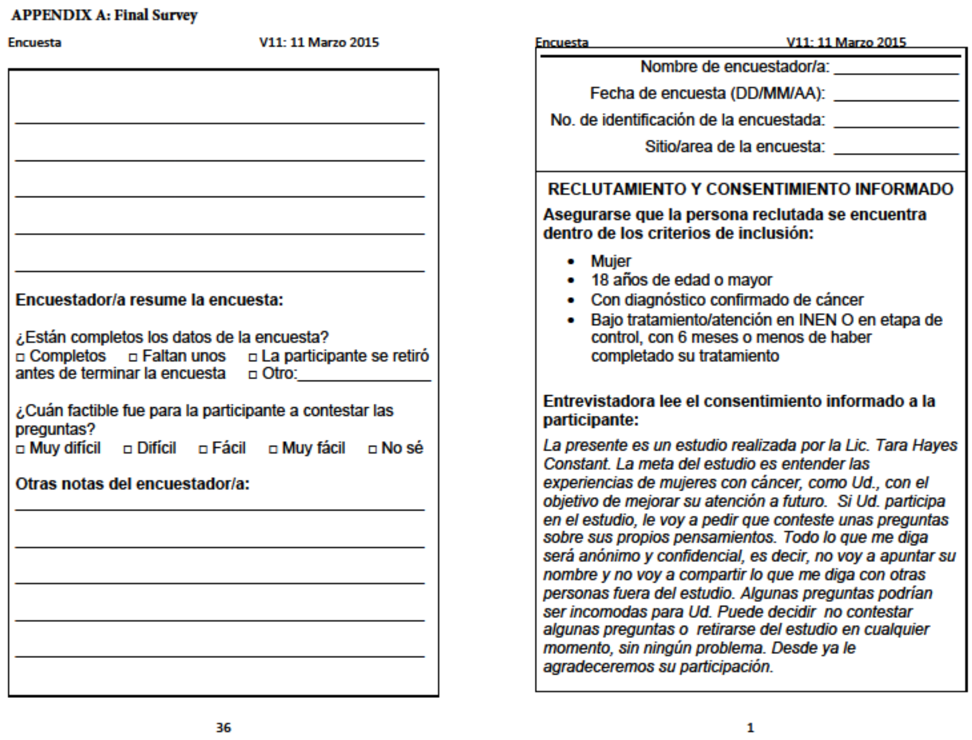
Appendix B: Likert scale 1

Appendix C: Likert scale 2

Appendix D: Focus Group Questions

Appendix E: Cognitive Interview Questions

[double click object insert below to see all appendices in pdf format]



APPENDIX A: Final Survey

Encuesta V11: 11 Marzo 2015

Encuestador/a resume la encuesta:

¿Están completos los datos de la encuesta?
☐ Completos ☐ Faltan unos ☐ La participante se retiró antes de terminar la encuesta ☐ Otro:______________

¿Cuán factible fue para la participante a contestar las preguntas?
☐ Muy difícil ☐ Difícil ☐ Fácil ☐ Muy fácil ☐ No sé

Otras notas del encuestador/a:

36

Encuesta V11: 11 Marzo 2015

Nombre de encuestador/a: ______________
Fecha de encuesta (DD/MM/AA): ______________
No. de identificación de la encuestada: ______________
Sitio/area de la encuesta: ______________

RECLUTAMIENTO Y CONSENTIMIENTO INFORMADO

Asegurarse que la persona reclutada se encuentra dentro de los criterios de inclusión:

- Mujer
- 18 años de edad o mayor
- Con diagnóstico confirmado de cáncer
- Bajo tratamiento/atención en INEN O en etapa de control, con 6 meses o menos de haber completado su tratamiento

Entrevistadora lee el consentimiento informado a la participante:

La presente es un estudio realizada por la Lic. Tara Hayes Constant. La meta del estudio es entender las experiencias de mujeres con cáncer, como Ud., con el objetivo de mejorar su atención a futuro. Si Ud. participa en el estudio, le voy a pedir que conteste unas preguntas sobre sus propios pensamientos. Todo lo que me diga será anónimo y confidencial, es decir, no voy a apuntar su nombre y no voy a compartir lo que me diga con otras personas fuera del estudio. Algunas preguntas podrían ser incomodas para Ud. Puede decidir no contestar algunas preguntas o retirarse del estudio en cualquier momento, sin ningún problema. Desde ya le agradeceremos su participación.

1

REFERENCES

Abraido-Lanza, A. F., Viladrich, A., Florez, K. R., Cespedes, A., Aguirre, A. N., & De la Cruz, A. A. (2007). Commentary: Fatalismo reconsidered: A cautionary note for health-related research and practice with Latino populations. *Ethnicity & Disease, 17*(1), 153-158. Retrieved from http://www.ncbi.nlm.nih.gov/pmc/articles/PMC3617551/

Acevedo, G. A. (2005). Turning anomie on its head: Fatalism as Durkheim's concealed and multidimensional alienation theory. *Sociological Theory, 23*(1), 75-85. doi:DOI 10.1111/j.0735-2751.2005.00243.x

Alkire, S., Adriana Conconi, and José Manuel Roche. (2012). Multidimensional Poverty Index 2012: Brief Methodological Note and Results. *University of oxford, Department of International Development, oxford Poverty and Human Development Initiative, oxford, UK.*

Anderson, B. O., & Cazap, E. (2009). Breast health global initiative (BHGI) outline for program development in Latin America. *Salud Pública de México, 51*, s309-s315.

Bandura, A. (1977). Self-efficacy: Toward a unifying theory of behavioral change. *Psychological Review, 84*(2), 191-215. doi:10.1037/0033-295X.84.2.191

Bandura, A. (1982). Self-efficacy mechanism in human agency. *American Psychologist, 37*(2), 122-147. doi:10.1037/0003-066X.37.2.122

Barnes, J. A. (1987). Citation-Classic - Class and Committees in a Norwegian Island Parish. *Current Contents/Social & Behavioral Sciences*(23), 18-18.

Baron, R. M., & Kenny, D. A. (1986). The Moderator Mediator Variable Distinction in Social Psychological-Research - Conceptual, Strategic, and Statistical Considerations. *J Pers Soc Psychol, 51*(6), 1173-1182. doi:Doi 10.1037/0022-3514.51.6.1173

Barrera, M. (1986). Distinctions between Social Support Concepts, Measures, and Models. *Am J Community Psychol, 14*(4), 413-445. doi:Doi 10.1007/Bf00922627

Battiston, D., Cruces, G., Lopez-Calva, L., Lugo, M., & Santos, M. (2013). Income and Beyond: Multidimensional Poverty in Six Latin American Countries. *Social Indicators Research, 112*(2), 291-314. doi:10.1007/s11205-013-0249-3

Berkman, L. F. (1999). The Role of Social Relations in Health Promotion. In I. Kawachi, B. P. Kennedy, & R. G. Wilkinson (Eds.), *The Society and Population Health Reader: Income Inequality and Health* (Vol. 1, pp. 171-183). New York: New Press.

Berkman, L. F., & Glass, T. (2000). Social integration, social networks, social support, and health. In L. F. Berkman & I. Kawachi (Eds.), *Social Epidemiology* (pp. 137-173). New York: Oxford University Press.

Berkman, L. F., Glass, T., Brissette, I., & Seeman, T. E. (2000). From social integration to health: Durkheim in the new millennium. *Social Science & Medicine, 51*(6), 843-857. doi:http://dx.doi.org/10.1016/S0277-9536(00)00065-4

Bernard, H. R. (2013). *Social research methods : qualitative and quantitative approaches* (2nd ed.). Los Angeles: SAGE Publications.

Bishop, S., Waring, J., Claudio Bosio, A., Graffigna, G., & Scaratti, G. (2012). Discovering healthcare professional-practice networks: The added value of qualitative SNA. *Qualitative Research in Organizations and Management: An International Journal, 7*(3), 308-322. doi:doi:10.1108/17465641211279770

Borgatti, S. P., Mehra, A., Brass, D. J., & Labianca, G. (2009). Network Analysis in the Social Sciences. *Science, 323*(5916), 892-895. doi:DOI 10.1126/science.1165821

Bott, E. (1955). Urban Families: Conjugal Roles and Social Networks. *Human Relations, 8*(4), 345-384. doi:10.1177/001872675500800401

Bray, F., McCarron, P., & Parkin, D. (2004). The changing global patterns of female breast cancer incidence and mortality. *Breast Cancer Research, 6*(6), 1-11. doi:10.1186/bcr932

Bright, K., Barghash, M., Donach, M., de la Barrera, M. G., Schneider, R. J., & Formenti, S. C. (2011). The role of health system factors in delaying final diagnosis and treatment of breast cancer in Mexico City, Mexico. *Breast, 20*, S54-S59. doi:DOI 10.1016/j.breast.2011.02.012

Calvo, C. (2008). Vulnerability to Multidimensional Poverty: Peru, 1998–2002. *World Development, 36*(6), 1011-1020. doi:http://dx.doi.org/10.1016/j.worlddev.2007.10.001

Carr, B. I., & Steel, J. (2013). *Psychological aspects of Cancer : a guide to emotional and psychological consequences of Cancer, their causes and their management*. New York: Springer.

Castro, J. F., Jessica Baca, and Juan P. Ocampo. . (2012). Counting the Poor in Peru: A Multidimensional Approach. *Latin american journal of economics, 49.1*, 37-65.

Chambers, R. (2006). Vulnerability, Coping and Policy (Editorial Introduction). *IDS Bulletin, 37*(4), 33-40. doi:10.1111/j.1759-5436.2006.tb00284.x

Delor, F., & Hubert, M. (2000). Revisiting the concept of 'vulnerability'. *Social Science & Medicine, 50*(11), 1557-1570. doi:10.1016/s0277-9536(99)00465-7

DeSantis, C., Jemal, A., & Ward, E. (2010). Disparities in breast cancer prognostic factors by race, insurance status, and education. *Cancer Causes Control, 21*(9), 1445-1450. doi:10.1007/s10552-010-9572-z

Diaz, R. M. (1998). *Latino gay men and HIV: Culture, sexuality, and risk behavior.* . New York: Routledge.

Drew, E. M., & Schoenberg, N. E. (2011). Deconstructing Fatalism: Ethnographic Perspectives on Women's Decision Making about Cancer Prevention and Treatment. *Medical Anthropology Quarterly, 25*(2), 164-182. doi:DOI 10.1111/j.1548-1387.2010.01136.x

Espinosa de los Monteros, K., & Gallo, L. (2011). The Relevance of Fatalism in the Study of Latinas' Cancer Screening Behavior: A Systematic Review of the Literature. *International Journal of Behavioral Medicine, 18*(4), 310-318. doi:10.1007/s12529-010-9119-4

Faul, F., Erdfelder, E., Buchner, A., & Lang, A. G. (2009). Statistical power analyses using G*Power 3.1: tests for correlation and regression analyses. *Behav Res Methods, 41*(4), 1149-1160. doi:10.3758/BRM.41.4.1149

Ferlay, J., Shin, H.-R., Bray, F., Forman, D., Mathers, C., & Parkin, D. M. (2010). Estimates of worldwide burden of cancer in 2008: GLOBOCAN 2008. *International Journal of Cancer, 127*(12), 2893-2917. doi:10.1002/ijc.25516

Forouzanfar, M. H., Foreman, K. J., Delossantos, A. M., Lozano, R., Lopez, A. D., Murray, C. J. L., & Naghavi, M. (2011). Breast and cervical cancer in 187 countries between 1980 and 2010: a systematic analysis. *The Lancet, 378*(9801), 1461-1484.

Freeman, H. P. (1989). Cancer in the socioeconomically disadvantaged. *CA Cancer J Clin, 39*(5), 266-288.

Freeman, L. C. (2011). The Development of Social Network Analysis - with and Emphasis on Recent Events. In J. G. Scott & P. J. Carrington (Eds.), The SAGE Handbook of Social Network Analysis (pp. 26-39). London ; Thousand Oaks, Calif.: SAGE.

Fuhse, J. A. (2009). The Meaning Structure of Social Networks. *Sociological Theory, 27*(1), 51-73. doi:DOI 10.1111/j.1467-9558.2009.00338.x

Gigliotti, E., & Samuels, W. E. (2011). Use of Averaged Norbeck Social Support Questionnaire Scores. *ISRN Nursing, 2011*, 6. doi:10.5402/2011/567280

Green, L. W., Kreuter, M. W., & Green, L. W. (2005). *Health program planning : an educational and ecological approach* (4th ed.). New York: McGraw-Hill.

Hayes Constant, T. K., Winkler, J. L., Bishop, A., & Taboada Palomino, L. G. (2014). Perilous Uncertainty: Situating Women's Breast-Health Seeking in Northern Peru. *Qualitative Health Research, 24*(6), 811-823. doi:10.1177/1049732314529476

Heaney, C. A., & Israel, B. A. (2008). Social Networks and Social Support. In K. Glanz & B. K. Rimer (Eds.), *Health Behavior and Health Education: Theory, Research and Practice* (pp. 189-210). California: John Wiley & Sons, Inc.

Hicks, K. A. (2008). *Social support and women's health in El Alto, Bolivia.* (PhD), Northwestern University. (3331102)

Holgado-Tello, F. P., Chacon-Moscoso, S., Barbero-Garcia, I., & Vila-Abad, E. (2010). Polychoric versus Pearson correlations in exploratory and confirmatory factor analysis of ordinal variables. *Quality & Quantity, 44*(1), 153-166. doi:10.1007/s11135-008-9190-y

Honda, K., & Kagawa-Singer, M. (2006). Cognitive mediators linking social support networks to colorectal cancer screening adherence. *Journal of Behavioral Medicine, 29*(5), 449-460. doi:DOI 10.1007/s10865-006-9068-1

Hortobagyi, G. N., de la Garza Salazar, J., Pritchard, K., Amadori, D., Haidinger, R., Hudis, C. A., . . . Albain, K. S. (2005). The global breast cancer burden: variations in epidemiology and survival. *Clin Breast Cancer, 6*(5), 391-401. doi:10.3816/CBC.2005.n.043

House, J. S. (1981). *Work stress and social support*. Reading, Mass.: Addison-Wesley Pub. Co.

Knox, H., Savage, M., & Harvey, P. (2006). Social networks and the study of relations: networks as method, metaphor and form. *Economy and Society, 35*(1), 113-140. doi:10.1080/03085140500465899

Lett, H. S., Blumenthal, J. A., Babyak, M. A., Strauman, T. J., Robins, C., & Sherwood, A. (2005). Social support and coronary heart disease: Epidemiologic evidence and implications for treatment. *Psychosomatic Medicine, 67*(6), 869-878. doi:DOI 10.1097/01.psy.0000188393.73571.0a

Lopez-McKee, G., McNeill, J. A., Eriksen, L. R., & Ortiz, M. (2007). Spanish Translation and Cultural Adaptation of the Powe Fatalism Inventory. *Journal of Nursing Scholarship, 39*(1), 68-70. doi:10.1111/j.1547-5069.2007.00145.x

Magai, C., Consedine, N., Neugut, A. I., & Hershman, D. L. (2007). Common psychosocial factors underlying breast cancer screening and breast cancer treatment adherence: a conceptual review and synthesis. *J Womens Health (Larchmt), 16*(1), 11-23. doi:10.1089/jwh.2006.0024

Matsunaga, M. (2015). How to Factor-Analyze Your Data Right: Do’s, Don’ts, and How-To’s. *International Journal of Psychological Research, 3*(1), 97-110.

Mayo, R. M., Ureda, J. R., & Parker, V. G. (2001). Importance of fatalism in understanding mammography screening in rural elderly women. *J Women Aging, 13*(1), 57-72. doi:10.1300/J074v13n01_05

McCallister, L., and Claude S. Fischer. . (1978). A procedure for surveying personal networks. . *Sociological Methods & Research, 7.2* 131-148.

Messina, C. R., Lane, D. S., Glanz, K., West, D. S., Taylor, V., Frishman, W., & Powell, L. (2004). Relationship of social support and social burden to repeated breast cancer screening in the women's health initiative. *Health Psychology, 23*(6), 582-594. doi:Doi 10.1037/0278-6133.23.6.5852

MINSA. (2013). Plan Esperanza: Para la atención integral de cáncer. Retrieved from http://www.minsa.gob.pe/portada/Especiales/2012/esperanza/index.asp

Mische, A. (2008). *Partisan publics : communication and contention across Brazilian youth activist networks*. Princeton: Princeton University Press.

Nichter, M. (2010). Idioms of distress revisited. *Cult Med Psychiatry, 34*(2), 401-416. doi:10.1007/s11013-010-9179-6

Palloni, A., & Arias, E. (2004). Paradox lost: Explaining the hispanic adult mortality advantage. *Demography, 41*(3), 385-415. doi:10.1353/dem.2004.0024

Pasick, R. J., & Burke, N. J. (2008). A critical review of theory in breast cancer screening promotion across cultures. *Annual Review of Public Health, 29*, 351-368. doi:DOI 10.1146/annurev.publhealth.29.020907.143420

Paskett, E. D., Harrop, J. P., & Wells, K. J. (2011). Patient navigation: an update on the state of the science. *CA Cancer J Clin, 61*(4), 237-249. doi:10.3322/caac.20111

Powe, B. D., & Finnie, R. (2003). Cancer fatalism: the state of the science. *Cancer Nurs, 26*(6), 454-465; quiz 466-457.

Ribera, J. M., & Hausmann-Muela, S. (2011). The Straw That Breaks the Camel's Back Redirecting Health-Seeking Behavior Studies on Malaria and Vulnerability. *Medical Anthropology Quarterly, 25*(1), 103-121. doi:10.1111/j.1548-1387.2010.01139.x

Riles, A. (2000). *The network inside out*. Ann Arbor: University of Michigan Press.

Ruiu, G. (2012). Is fatalism a cultural belief? An empirical analysis on the origin of fatalistic tendencies. *Munich Personal Archive Paper, 41705*.

Scott, J., & Carrington, P. J. (2011). *The SAGE handbook of social network analysis*. London ; Thousand Oaks, Calif.: SAGE.

Shankar, S., Selvin, E., & Alberg, A. J. (2002). Perceptions of cancer in an African-American community: a focus group report. *Ethn Dis, 12*(2), 276-283.

Social Networks, Drug Abuse, and HIV Transmission. Proceedings of a meeting. August 19-20, 1993. (1995). *NIDA Res Monogr, 151*, 1-215.

StataCorp. (2015). Stata Statistical Software: Release 14. College Station, TX: StataCorp LP.

Suarez, L., Ramirez, A. G., Villarreal, R., Marti, J., McAlister, A., Talavera, G. A., . . . Perez-Stable, E. J. (2000). Social networks and cancer screening in four U.S. Hispanic groups. *Am J Prev Med, 19*(1), 47-52.

Uchino, B. N. (2013). Understanding the links between social ties and health: On building stronger bridges with relationship science. *Journal of Social and Personal Relationships, 30*(2), 155-162. doi:Doi 10.1177/0265407512458659

Vanderpool, R. C., Dressler, E. V. M., Stradtman, L. R., & Crosby, R. A. (2015). Fatalistic Beliefs and Completion of the HPV Vaccination Series Among a Sample of Young Appalachian Kentucky Women. *The Journal of Rural Health, 31*(2), 199-205.

Vitaliano, P. P., Scanlan, J. M., Zhang, J., Savage, M. V., Brummett, B., Barefoot, J., & Siegler, I. C. (2001). Are the salutogenic effects of social supports modified by income? A test of an "added value hypothesis". *Health Psychol, 20*(3), 155-165.

von Wagner, C., Good, A., Whitaker, K. L., & Wardle, J. (2011). Psychosocial Determinants of Socioeconomic Inequalities in Cancer Screening Participation: A Conceptual Framework. *Epidemiologic Reviews, 33*(1), 135-147. doi:10.1093/epirev/mxq018

Vyas, S., & Kumaranayake, L. (2006). Constructing socio-economic status indices: how to use principal components analysis. *Health policy and planning, 21*(6), 459-468.

Watts, M. J., & Bohle, H. G. (1993). The space of vulnerability: the causal structure of hunger and famine. *Progress in Human Geography, 17*(1), 43-67. doi:10.1177/030913259301700103

Wells, K. J., Battaglia, T. A., Dudley, D. J., Garcia, R., Greene, A., Calhoun, E., . . . Patient Navigation Research, P. (2008). Patient navigation: state of the art or is it science? *Cancer, 113*(8), 1999-2010. doi:10.1002/cncr.23815

Wenger, G. C. (1991). A Network Typology - from Theory to Practice. *Journal of Aging Studies, 5*(2), 147-162. doi:Doi 10.1016/0890-4065(91)90003-B

White, H. C. (2008). *Identity and control : how social formations emerge* (2nd ed.). Princeton: Princeton University Press.

WHO. (2005). *Cancer prevention and control resolution.* Paper presented at the 58th World Health Assembly, Geneva, Switzerland.