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"Is there really a way to prevent cancer?": Exploring cancer prevention information seeking among cancer patients and their caregivers

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"Is there really a way to prevent cancer?": Exploring cancer prevention information

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by

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THESIS

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"Is there really a way to prevent cancer?": Exploring cancer prevention information

seeking among cancer patients and their caregivers

By

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B.A., Communication, University of Delaware, 2016
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ABSTRACT

This thesis investigated cancer prevention information (CPI) seeking among cancer patients and their caregivers. Interviews that were conducted in 2011 were analyzed thematically to deconstruct perceptions and sources of CPI among 47 participants. The thematic narrative analysis of the predominantly Hispanic, low-income and low-education sample revealed differences in CPI seeking related to ways cultural practices and socioeconomic status impact information seeking. The digital divide, Spanish language and perceived high cost presented barriers to information yet created opportunities for patients and family members to emerge as health champions to share information interpersonally and intergenerationally. Understanding CPI processes of racial and ethnic minority, low-income, and Spanish-speaking patients and family members is necessary to better meet the needs of these populations.

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Chapter 1: Introduction

"Why try to look up something that nobody has in your family? Now once it hits your family, that's when it hurts, you know. You start trying to look up things and ask questions and everything. But sometimes it's a little late, you know." - Family Member discussing CPI

Cancer is the second leading cause of death in the United States. Nationally, over 1.6 million new cases of cancer were reported, and more than half a million people died of cancer in 2015 alone, according to the Centers for Disease Control and Prevention (CDC). One of every four deaths in the United States is due to cancer (CDC, 2015). More than 40% of cancer cases and cancer deaths in the United States are considered preventable, as they are linked to modifiable risk factors, and thus might have been prevented (Mendes, 2017). Consequently, understanding these risk factors is an essential step in reducing cancer morbidity and mortality.

Cancer patients and their loved ones represent a specific population that experiences high cancer prevention information (CPI) needs, but these information needs often go unmet (Wigfall & Friedman, 2016). When a patient is diagnosed with cancer, the importance of CPI increases for both the patient and their loved ones. There is a disparity between CPI seekers and non-seekers linked to income, education, race, language, and health consciousness. However, the complex ways in which diverse patients and their families perceive, seek, or avoid CPI has received limited scholarly attention. Specifically, it is "possible that ethnic-based differences in knowledge of prevention strategies is partially attributable to differences in information-seeking behaviors between Hispanics and non-Hispanics," (Waters, Sullivan, & Rutten, 2009, p. 477); however, national surveys about cancer information seeking largely sample "non-Hispanic White, higher SES U.S. adults" (Wigfall & Friedman, 2016, p. 1003).

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Thus the "necessity of identifying, monitoring, and addressing the cancer education and communication needs of Hispanic populations," (Waters, Sullivan, & Rutten, 2009, p. 477) who have lower adherence to cancer screening behaviors, persists.

In an effort to contribute new research on CPI seeking, and the relevance of the digital divide among minority patients, I analyzed interviews of cancer patients and their family members that were conducted in 2011 as part of a larger project that explored their group's CPI seeking (Ginossar, 2014, 2016). My analysis focuses on patients' experiences with information seeking, specifically as concerns the use of digital and non-digital sources of CPI. As society shifts toward reliance on the internet for information, utilization of digital and non-digital health information sources is relevant because there are racial, ethnic, and socioeconomically disadvantaged groups who continue to be underserved and face issues accessing digital materials (Ginossar, 2016). Particularly, there is a need to understand the CPI seeking behaviors of diverse patients and families, including older patients, racial and ethnic minorities, individuals with low income/education, and Spanish-speakers. This study expands on the conclusions drawn by Ginossar (2014, 2016), which indicated a need for deeper understanding of disparities in CPI seeking in order to help healthcare providers and policy makers meet patients and family members' CPI and support needs.

CPI is important for many cancer survivors and their families and caregivers. Patients and families must be educated on risk factors for cancer, and they must also be informed on protective behaviors to decrease their likelihood of a primary or secondary cancer diagnosis. For patients who have already been diagnosed with a first type of cancer, the risk of a reoccurrence is much higher (Demark-Wahnefried, Aziz, Rowland, & Pinto, 2005). Ginossar (2016) maintained that CPI is necessary for people diagnosed with cancer,

and for their families, to "inform lifestyle and screening-related behavior changes"; it may "reduce the likelihood of cancer reoccurrence following remission, reduce second primary cancer diagnosis among cancer survivors, improve overall health outcomes, and reduce anxiety among this population" (p. 2). Some risk factors for cancer include exposure to certain chemicals, tobacco smoke, radiation from the sun's ultraviolet rays, family history, and age (CDC, 2015). Despite high levels of perceived personal importance of CPI and motivational factors such as health consciousness, access to CPI is not universal and is often bypassed by patients and their support networks (Ginossar, 2014). When a patient is diagnosed with cancer, the importance of CPI increases for both the patient and their family, yet when studying CPI seeking among cancer patients and their families, almost half of respondents never sought CPI (Ginossar, 2014).

Health information seeking behaviors (HISBs) are essential for improving cancer patient health outcomes and have recently gained more attention in health communication research. However, growing academic knowledge does not translate to ordinary health consumers' behavioral changes. There are over 100 types of cancer, and the disease's myriad causes, treatments, and prevention measures may make the task of understanding and preventing cancer seem impossible, particularly for socioeconomically disadvantaged patients and individuals with low health literacy. The populations at highest risk for chronic and terminal illness (the elderly, socioeconomically disadvantaged, those with less than high school degree education, or those living in rural areas) are similarly at the highest risk for low health literacy skills. Thus, this study seeks to explore which sources of CPI are reaching, and not reaching, these at-risk groups.

Statement of Problem, Rationale of Study

In this thesis I analyze perceptions of various delivery channels of CPI, including access to and use of the internet by patients, family members, and caretakers. In addition to the demographic antecedents to CPI seeking (Ginossar, 2014, 2016), there are also many other cultural and personal reasons as to why an individual may choose to seek, or to avoid, information about cancer. The interview analysis contributes to understanding how culture, demographic factors, and the digital divide interact and influence the ways patients seek or avoid information to manage uncertainty about cancer prevention.

The development and recent ubiquity of internet-capable devices means there is more information available than ever before; however, this information does not always reach the patients and family members who need it the most. Understanding where racial and ethnic minority, low-income, and Spanish-speaking patients and family members prefer to gather cancer information is necessary to better meet the needs of these populations. Martin et al. (2014) noted:

> Future studies should explore individual patient preferences regarding how they would like to receive the information... the preferred delivery channel may also depend on the type of information that is being imparted. For example, learning about cancer treatment may be a topic best served by an in-person conversation while other cancer related topics, could be easily and effectively delivered through print interventions. For lower income and minority survivors who continue to have worse cancer outcomes than the higher income majority population the need for information remains critically important. (pp. 457-458)

Ginossar (2016) found in a sample of diverse cancer patients and their family members that less than half of respondents said they would seek CPI online, a result significantly associated with education level, ethnicity, age, and prevention orientation. Thus, among this sample, respondents often relied on non-digital channels for meeting their information needs. However, as the above analyses were based on cross-sectional survey data, the ways participants perceive these information sources and information behavior is unknown. A better understanding of decision-making process in CPI seeking will inform how to better reach patients and family members with culturally relevant protective information in the future.

As in the social construction of the meaning of other diseases, there are stereotypes, myths, and misconceptions regarding cancer patients and how cancer is prevented, contracted, spread, and cured. These beliefs are often present despite any contradictions with research findings via the biomedical approach and information sought individually. Cancer is no exception to this phenomenon, as patients rely on cultural notions as well as Western medical knowledge to form opinions and make decisions. For instance, many believe that there is no way to prevent cancer because it is a "genetic" disease, which may be misinterpreted as "inherited."

Barriers to communication about CPI are grounded in larger issues inhibiting open cancer-related communication. The stigma associated with talking about aging, life-threatening illness, death and dying can delay an opportunity for an educational intervention (Goldsmith et al., 2011). Clearly, the norm in the United States, even in the face of negative health diagnoses, is that privacy should be maintained by "pretending life is 'normal'"

(Goldsmith et al., 2011, p. 445), which may decrease interest and motivation in seeking cancer-related information.

Research Questions and Study Objectives

Not all information is created equal, nor is it received and understood in the same ways across diverse audiences. The goal of this project is to center the experiences of the participants to expand what is known about the processes and barriers to receiving CPI. To address this issue, this study explores the following research questions:

RQ1: How do cancer patients and family members from diverse backgrounds describe their CPI behavior before and after the cancer diagnosis?

RQ2: What are the perceptions of CPI sources among cancer patients and family members from diverse backgrounds?

RQ3: How do cancer patients and family members from diverse backgrounds understand CPI seeking processes and barriers?

Addressing these questions through analyzing interviews will advance our knowledge and understanding of the information needs of cancer patients and their families through an emic approach. In this context, cancer patients and family members are the interview participants who are a subsample of the survey respondents of Ginossar (2014, 2016). The participants embody a diversity of backgrounds as patients vary in diagnosis and represent racial/ethnic minorities and socioeconomic groups which are generally under-represented in research. Family members are the individuals who were present at the Cancer Center with the patients, fulfilling a role as caretaker, and represent a variety of relationships to the patients, including their spouses, siblings, children, and others. Among this sample, "diverse backgrounds" from a "largely rural, minority-majority Southwestern state" were oversampled (Ginossar, 2014, p.

94). In particular, recruitment efforts focused on Hispanic and Native American individuals who were oversampled to address their "lower rates of accessing the internet to seek cancer-related information compared to non-Hispanic whites" (Ginossar, 2014, p. 94). Although Native American communities are the most digitally marginalized, the impact of the digital divide on health information seeking among Native Americans was not previously explored (Ginossar, 2016).

In this thesis, I will first (in chapter 2) provide a review of literature on health information seeking behaviors and their connections to the digital divide, social support needs, and contemporary sources of information for cancer patients, such as the internet, social media/social networking sites, interpersonal relations, and traditional mass media including television and print. This review will serve as the foundation for the interview analysis, as the respondents can fill in gaps of what is already known about where cancer patients and their family members prefer to gather information and social support. The literature review is followed (in chapter 3) by an explanation of the qualitative methodology used to analyze the interview data. I will (in chapter 4) analyze cancer patient interviews from 2011 collected by Ginossar (2014) as part of a larger study; these interviews have not previously been analyzed. I will focus on the information needs, sources of information, and internet use of the participants in order to answer the research questions. I will implement qualitative thematic analysis. Finally, in chapter 5, I will discuss the findings from the interview analysis. This chapter will summarize and interpret the key findings and will provide suggestions for future research and for policy and healthcare changes.

Chapter 2: Literature Review

Introduction

This literature review covers research on cancer patients and information seeking. I begin by explaining health information seeking behaviors, and why they are valuable for those cancer patients who seek information. Next, I turn to information needs and social support needs of cancer patients and family members, followed by barriers to information and support. I focus on the limited access to online sources experienced by many cancer patients and family members as a result of the digital divide, and how interpersonal and mass mediated sources work to fulfill information and support needs when the internet does not. Next, I highlight the importance of CPI for cancer patients and family members. I will address how much of the research that covers the topics of cancer information seeking lacks representation of participants from diverse backgrounds.

Health Information Seeking Behaviors

Health information seeking behaviors (HISB) have been defined and studied differently over time, particularly with the complicating factor of the rise of the internet. Following Johnson's (1997) definition, HISB will be operationalized as a "purposive acquisition of information from selected information carriers" (p. 4). HISB is studied within the context of (a) coping with a health-threatening situation, (b) participation and involvement in medical decision making, and (c) behavior change and preventive behavior (Lambert & Loiselle, 2007). Components of HISB include the trigger (such as a diagnosis), channel (such as personal connections like providers, family and friends; impersonal connections such as pamphlets, magazines, books, radio or television; or the internet, which is somewhere in between personal and impersonal), source (chosen depending on perceived

accessibility, familiarity, trustworthiness, attractiveness, and reliability), search strategy, type of information sought (such as medical information or emotional support), and outcomes of seeking information (Galarce et al., 2011).

Whether a person's information needs are going to be followed by an act of HISB, as well as the person's source of information, have been shown to depend on the personal traits and beliefs of the seeker, including their psychological traits, coping styles, self-efficacy, perceived social norms, health beliefs and sociodemographic factors (Galarce et al., 2011; Wigfall & Friedman, 2016). Factors such as self-efficacy and one's capacity to seek health information are influenced by material and social barriers, such as access to an internet connection, or lacking a social support network that can be turned to for information. These barriers are compounded by a patient's sociodemographic factors including age, gender, race, education health literacy, and financial status. Many studies have come to find that being white, young, female, well-educated, and in good financial standing is associated with being an active information seeker (Rains, 2014), and as a result many studies have often sampled this population. This presents an opportunity for research that digs deeper into experiences of marginalized groups, including Spanish-speaking Hispanics, individuals with low incomes, or individuals with low levels of health literacy/education, regarding HISB. Health literacy has been conceptualized as the dynamic state of a patient's ability to seek, understand, and make decisions based on health information (Cameron, Wolf, & Baker, 2011). Literacy and language barriers continue to present issues to accessing CPI and in meeting information needs following a cancer diagnosis. The average reading level of U.S. adults is about 8th grade, but most health/medical websites are written at a college undergraduate level and assume an elevated degree of knowledge on health matters (Goldsmith, Wittenberg-Lyles,

Ragan & Nussbaum, 2011, p. 446). This has the effect of further marginalizing disadvantaged populations' ability to obtain, comprehend, and make treatment decisions based on CPI sought online.

There are several benefits for cancer patients who engage in HISB. Johnson (1997) found that HISBs can provide emotional support to manage levels of uncertainty and anxiety, and contribute to better coping and enacting preventative behaviors. These findings have been confirmed in more recent studies, which have found online cancer information seeking to be associated with colorectal cancer screening adherence and knowledge (Chen et al., 2014; Han et al., 2009), HPV vaccine awareness and knowledge (Kontos et al., 2012), and engaging in skin cancer protective behaviors (Hay et al., 2009). Information seeking has been shown to be associated with health self-efficacy (Bass et al., 2006), preference for active participation in decision making (Lee et al., 2012), and perceived ability to manage one's health (Rice, 2006). Though a degree of uncertainty is sometimes preferred by cancer patients, it is important to offer "information seekers the potential to exert some control over the depth and breadth of the information-acquisition process and access to a range of different types of information sources" (Rains, 2014, pp. 1296-1297).

Uncertainty Management

Information-seeking and communication are important in managing uncertainty among cancer patients. Uncertainty management theory (Brashers, 2001; Brashers et al., 2000) focuses on the role uncertainty plays in motivating information-seeking. Uncertainty "exists when details of situations are ambiguous, complex, unpredictable or probabilistic; when information is unavailable or inconsistent; and when people feel insecure in their own state of knowledge or the

state of knowledge in general" (Brashers, 2001, p. 478). Uncertainty management operates on the principles that there are various forms of uncertainty, and various sources and forms of information exist to acquire information, particularly health information. Shaha, Cox, Talman, and Kelly (2008) identified three major sources that may cause uncertainty in cancer patients, including limited or lack of information, uncertainty about the course and treatment choices, and uncertainty regarding everyday life and coping with cancer. According to Rutten, Arora, Bakos, Aziz, and Rowland (2005), the five major categories of information sources for cancer patients are health care professionals, print materials, media (including the internet), interpersonal sources, and organizational/scientific sources. Rains (2014) argued the internet may provide cancer patients with access to all five of these sources, considering online support groups and social media, scientific sources, media sources like television, and print materials such as newspapers, are all available in digital formats. "Access to such a range of different types of sources may make the Web a particularly useful tool for uncertainty management," (Rains, 2014, p. 1298). Seeking information allows individuals to settle differences between how much uncertainty they feel and the amount of uncertainty they would prefer (Rains, 2014).

Information Needs of Cancer Patients and Family Members

Cancer information seeking is an ongoing and dynamic process. It is complex to tailor the information to each patient's needs, and difficult to ensure the patient and their family/caregiver will receive, understand, and apply information to aid in decision-making about treatment, manage uncertainty, and address emotional needs (Beckjord et al., 2008). It can be deduced that patients continue to want the most information possible, as "eight in ten internet users look online for health information" (Oh, 2013, p. 2073). Though cancer

information seeking has been shown to be positively associated with some cancer-related health outcomes, rates of cancer information seeking among U.S. adults are suboptimal and have not changed much over the past decade (Wigfall & Friedman, 2016). Health information needs and HISB of cancer patients (and patients with other chronic diseases) differ greatly from patients experiencing acute, or short-term, symptoms. Bundorf, Wagner, Singer, and Baker (2006) found among nearly 9,000 survey respondents that patients with chronic diseases were more likely than those with acute symptoms to seek health information on the internet.

Martin et al. (2014) surveyed primarily low-income, Black female cancer survivors in the "I Can Cope" program, which is a "collection of educational modules on coping with cancer that can be delivered individually or combined in a series to meet the needs of participants" (p. 444). Their survey analysis showed that older individuals had higher information needs including learning about cancer, understanding cancer treatment, keeping well in mind and body, relieving cancer pain. In contrast, those with more education or more financial resources had lower information needs. The study concludes with what serves as an important justification for the present research:

> The consistent finding that those with less education and income had greater information needs suggests that our educational interventions should continue to prioritize cancer survivors drawn from this population. Our findings also suggest that delivering quality cancer care involves ensuring that cancer survivors have the skills and confidence needed to obtain desired information. Because information needs vary greatly across patients and the need for information is dynamic, the approach used in this study [ICC] may better meet the needs of cancer survivors compared to programs

delivered with a standard, predetermined educational content that cannot be tailored

to individual patient needs, and=or may not delivered at a time when cancer survivors

have need for or the capacity to process the information (e.g., during times of distress,

during active treatment). (p. 457).

Martin et al. (2014) also found that cancer information needs decrease over time; however,

"need scores at 6 months indicated that not all their information needs were met. Thus,

cancer patients continue to seek information after the time of their initial diagnosis and

completion of treatment" (p. 455).

Other specific information needs of cancer patients include seeking confirmation of

information given to them during a visit to their provider, and information to make decisions

about their treatment and to prepare for procedures (Caita-Zufferey, Abraham,

Sommerhalder, & Schulz, 2010). Patients aim in gathering information is often "preparing

for, complementing, validating, and/or challenging the outcome of consultations" (Oh, 2013,

p. 2073). Patients are complementing the information they receive from healthcare providers

with additional materials sought online, through face-to-face interactions, or from print

materials, depending on the preferences of the patient. The inverse is also true. Cancer

patients who seek information online often discuss the information with a healthcare

provider, which can detract from other pertinent information being shared during a healthcare

setting interaction (Gentile, Markham, & Eaton, 2018).

Keinki et al. (2016) found that cancer patients most often obtain information from

physicians and nurses (84%), print media (68%), and online sources (59%). Online fora

(7.5%), non-medical practitioners (9.7%), and telephone-based counseling (8.6%) were only

used by a minority of the 185 respondents to the researchers' questionnaire. Thus, the

internet is not the only means for acquiring cancer related health information. Furthermore, the researchers found that nearly half of the patients in the study were not satisfied with the information they received, indicating a need for increased quality and quantity information regarding complementary medicine, nutrition, physical activity, social and legal issues, and psyche, throughout the duration of treatment and aftercare. Considering that the largest proportion of information is provided by physicians, it is paramount that communication between healthcare professionals and patients must be improved. And while other sources of information also are available to patients, Keinki et al. (2016) explained that most mediated sources were produced for people with high health literacy, thus making the information inaccessible to the average CPI seeker.

Information has become increasingly available as a rise of technological and media convergence (Bender et al., 2013; Mosco, 1999) has led to the rapid rise of smartphone use. Due to the increasing accessibility of internet connections, the role of media consumers has changed from that of passive audiences to being active consumers, and often producers, of media content. Many patients now have information, and social support, available at their fingertips any time they may need it. This shift, however, has contributed to a sense of information overload (Gross, 1964; Tefertiller, 2018) for cancer patients, and media consumers at large, who also need to develop a new set of skills, or digital health literacy, to seek, locate, comprehend, and assess health information from electronic sources. Furthermore, the development and ubiquity of internet capable devices means there is more information available to patients than ever before; however, disparities in internet use persist (Wigfall & Friedman, 2016).

To this point, Heynsbergh et al. (2018) reviewed six studies which focused on web-based interventions for "carers" of people with cancer, finding generally positive feedback from study participants about the interventions. Carers' knowledge was improved, "but some carers reported a need for higher level of carer related information," and that they "overall liked web-based interventions, however some carers preferred face-to-face communication" (p. 9). Furthermore, Heynsbergh et al. (2018) reviewed technology-specific barriers, with carers either lacking the skills necessary to use web-based interventions, or preferring interventions in face-to-face settings. They called for more diverse ages, genders and incomes to be represented in future research on the topic.

<center>**Cancer Prevention Information**</center>

In addition to understanding information seeking regarding cancer treatment and support, it is important to gain a deeper understanding patients' and families' engagement with cancer prevention information (CPI) seeking pre and post diagnosis. For colon, lung, breast, and cervical cancers, there are clear primary and secondary prevention measures; however, prevention information is difficult to design and evaluate as the "positive product or outcome [of a successful prevention campaign] is essentially 'nothing'" (Sundar et al., 2011, p. 207). Hispanic men and women have lower adherence to common screening practices, which are considered important cancer prevention strategies (Water, Sullivan & Rutten, 2009). However, the need for prevention information is particularly important for cancer survivors as they are at an increased risk for of cancer following remission and is important for their families and caregivers who may be exposed to genetic and environmental risk factors.

Ginossar (2014, 2016) found that among a diverse sample of patients and family members, a vast majority valued CPI, yet, nearly half of them did not actively engage in CPI seeking. Quantitative analyses of personal relevance, perceived importance of CPI, and health consciousness, in conjunction with sociodemographic, yielded several significant constructs that impact a patient and their family's information seeking behaviors of CPI. Hispanic ethnicity (and particularly limited English proficiency), lower levels of education, and lower incomes were found to be associated with lower rates of seeking cancer information. Non-Hispanic Whites had the highest rate of CPI seeking (67%). Only 34% of Spanish speakers sought CPI. The findings reiterate what is known about "social determinants to health impact communication inequalities" (Ginossar, 2014, p. 100) and add an additional layer of knowledge specifically regarding CPI seeking among marginalized identities. Despite experiencing cancer diagnosis and the high personal relevance of CPI and health consciousness, many respondents have never sought this information. Those who are at risk for health disparities might not have direct experience with successful health information seeking and thus might have been blocked from seeking it.

Social Support Needs of Cancer Patients and Family Members

A cancer diagnosis not only affects a person physically; there is also a psychological or mental toll that comes with the life changing news. Keinki et al. (2016) found that among 185 cancer patients, two thirds rated the impact of the disease on their life to be "medium" or "high" and that three quarters believed the disease would last for a while or for the rest of their lives. Thus, cancer patients do not only have information needs regarding their physical state, but also a need for social and emotional support (Lindop, 2001). Social support can be defined as the belief that one is cared for and loved, esteemed and valued, and belongs to a

network of communication and mutual obligation [regardless of the situation]" (Cobb, 1976, p. 300). "Social support" can be considered an "umbrella term for various theories and concepts that link involvement in social relationships to health and well-being" (Goldsmith & Albrecht, 2011, p. 335). Much like health information seeking, health related social support (HRSS) has been shown to have positive effects on health outcomes as social support includes increased access to resources such as better food, shelter, income, security, and social opportunities (Oh, 2013). Though traditional "face-to-face" social support is still relevant and beneficial to patients, the rise of online social networks, such as Facebook, may improve HRSS through "increased access to one's peers" (Oh, 2013, p. 2072). Support can also go unmet due to stigma surrounding the type of cancer, for example, the assumption that those diagnosed with lung cancer are smokers (Ginossar, 2010). Thus, social support is not exclusively produced or sought face-to-face, but can extend to online interactions where privacy and anonymity are enhanced.

Support needs vary between patients and types of cancers and can come from a variety of sources including face-to-face support groups, online support groups, providers, family, and friends. Often, while social support needs are being met, information needs, and health self-efficacy are also improved, which is important for improving health outcomes (Oh, 2013). The link between social support and information seeking is seen in collaboration with help from others in finding, evaluating, or avoid unwanted information, thus managing uncertainty (Brashers, Goldsmith, & Hsieh, 2002). One study found that 80% of cancer patients rely on family members or friends to assist them with information and decision-making (Galarce et al., 2011). Support networks aid in understanding complex information, and family members are often involved in making treatment decisions.

Scholars now recognize that not all support is beneficial, and may contribute to negative outcomes (Vangelisti, 2009). For instance, Fisher (2010) found that communication between mother-daughter "can be both helpful and unhelpful in women's adjustment to breast cancer" (p. 403). Some support behaviors like listening, showing affection, being humorous, were described as helpful across all ages; however, "use of positive talk" was sometimes labeled "dismissive" or minimizing the problem, even though other scholars have called for more "positive communication skills" in cancer contexts including doctor-patient and family coping (Fisher, 2010, p. 404). Generally, to achieve helpful communication, a shared definition of what constitutes helpful behavior should be establish by both partners in the communication context (Goldsmith, 2004).

It is also important to consider the social and emotional support needs of family members and caretakers of those with cancer. Families are important in health communication as they often provide day-to-day care and shape the beliefs and behaviors regarding health. In the past decade, there has been a shift toward shared decision making in health care settings (away from providers telling patients what to do), in part due to the increased availability of treatment options and of health information (Viswanath, 2005). Pecchioni and Keeley (2011) suggested that health conversations work best as a three-party interaction among patient, health provider, and family member(s). Furthermore, as previously mentioned, family members are important resources for patients, as "just over half of all online inquiries are done for the benefit of someone else," suggesting that patients themselves are often not the always the ones seeking information (Sundar et al., 2011, p. 181). This indicates the importance of studying the experience of cancer patients with health information seeking, and suggests it is just as important to query the caregivers and family

members about their use of the internet for CPI seeking. Nonetheless, there can be tension and stress and trauma felt by those who provide support (Fisher, 2014).

Contemporary Sources of Cancer Information and Social Support

Interpersonal/ Face-to-Face

While social media may be conveniently accessed, and may supplement information seeking and social support, it has not become a direct substitute for face-to-face interactions. The internet can be an important tool for cancer patients, but cancer patients still depend on healthcare professionals, mass media, family and friends, support groups, and other patients, in addition to the internet, to acquire cancer-relevant information (Lee et al., 2012). Shea-Budgell et al. (2014) found that among 411 surveyed cancer patients, 32.6% sought information from doctors and healthcare providers. The providers were overwhelmingly the most trusted source of information, with nearly 95% of respondents reporting "a lot" of trust. The more frequently reported source of information was the internet (57.4%); however, significantly fewer respondents had "a lot" of trust in the internet (~17%-18%). Sixteen percent of respondents gathered information from family and friends, who were more trusted than the internet overall. The least trusted sources were radio, newspaper and television. Furthermore, they found the source of information most commonly preferred was an in-person meeting with a healthcare professional (84.1%). The Shea-Budgell (2014) study is important as it mostly sampled people older than 50 years, and with a mix of education levels, (32.6% with high school or less, 21.2% post-high school, and 32.6% college or university); however, the sample was predominantly White (83.5%), thus creating another opportunity for this thesis to fill in a gap in the research.

Informational social support outside of the medical encounter can also help patients make more informed decisions and can assist patients in navigating the complex healthcare systems. According to Klassen and Washington (2008), among 576 African American women interviewed between 1997 and 1998, support networks (family, neighborhood, church) integrated in community can improve women's knowledge of cancer treatments and increase their likelihood of having a mammogram. This points to the importance of cultural knowledge and interpersonal relationships as necessary to communicate CPI to target populations.

Goldsmith and Moriarty (2008) reported that partners of cancer patients helped initiate treatment, handle information, choose treatments, carry out treatments, interact with health care providers, manage patient outlook and evaluate treatment. Families, particularly, have a major impact on patient treatment decision making. Furthermore, the quality of interaction between providers and family members has been linked to patient outcomes. Rees and Bath (2000) surveyed breast cancer patients' daughters regarding sharing information with their mothers and the results showed that the daughters fulfilled their own needs for information through talking with their mothers and talking with health care providers, as more than half of respondents indicated accompanying their mothers to medical consultations and appointments. The Rees and Bath (2000) study, too, is limited by their sample which was all White women, presenting an opportunity to fill this research gap in the current thesis.

Lee et al. (2012) surveyed 1,641 cancer patients, and found that respondents with less education, and thus less access to medical information, obtain important health information from their primary social network members (p. 816). Head and Bute (2017) call for further research into the influence of everyday conversations with family and friends on health

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decisions and behavior change, noting "social networks disseminate health information, information that undoubtedly spurs us to seek health care, prompts us to ask particular questions of our providers, and informs our decision-making" (p. 787). Applied to the context of CPI, social networks may be important in increasing awareness about prevention and screening.

Traditional Mass Media

Mass media have played a controversial role in disseminating cancer information and narratives to audiences in the United States and have been focus of research for decades. According to Rosenthal, de Castro Buffington and Cole (2018), between 2009 and 2011 "10% of TV health storylines addressed cancer" (p. 141). Previous studies have found that mass media are used for health information, contributes to health knowledge, and that the specific medium used often depends on personal characteristics and individual health needs (Atkin, Smith, McFeters, & Ferguson, 2008). However, there often are shortcomings in the representations of health issues in popular media (Kline, 2011), and thus such media are not the only sources of health information and social support. Kline (2006) compiled a decade of research regarding representations of health in popular media and concluded, "health-related content in popular media is problematic from a health promotion standpoint" in that it is "not likely to facilitate understandings helpful to individuals coping with health challenges; at the same time, popular media is likely to perpetuate social and political power differentials with regard to health-related issues" (p. 44).

Exposure to both fictional/entertainment and nonfictional peer stories has been shown to have both positive and negative effects. Nelissen et al. (2016) surveyed 621 cancer diagnosed individuals in Belgium and found that television was one of the preferred sources

of information for cancer patients; however, respondents reported feeling "fearful and concerned" when following peer stories on entertainment television, more so than when following stories on forums. The researchers suggest that these different emotional responses may be due to the fictional representation of stories on television versus the non-fictional stories online. These distortions on television may influence decision making, thus the study calls for guidelines for cancer information being shared in mass media to be more factual. Nonetheless, entertainment may be a worthwhile mode of sharing persuasive messages, such as about cancer prevention methods, because "narratives are not generally perceived as having an agenda" (Rosenthal, de Castro Buffington, & Cole, 2018, p. 141).

People react to fear of cancer in different ways, depending on personality and context. Nelissen et al. (2015) found that among 621 cancer diagnosed individuals and 1387 non-cancer diagnosed individuals, some will seek more information when experiencing fear of cancer, but some will avoid cancer information seeking and scanning. Apart from active information seeking, audiences may passively be exposed to media messages about cancer or health, often referred to as "information scanning" (Nelissen et al., 2015). Scanning can occur more often than active seeking and this can play an important role in one's "cancer knowledge, lifestyle choices" and prevention behaviors such as screenings (Nelissen et al., 2015, p. 108). Overall, Nelissen et al. (2015) found that scanning behaviors (of either interpersonal or media messages) were more prevalent than seeking among all respondents. However, for cancer diagnosed individuals, active information seeking is more prevalent than scanning behaviors. Furthermore, family members of those with a cancer diagnosis were also more likely engage in more cancer information seeking behaviors. Nonetheless, Dutta (2007) found that respondents who reported learning about disease and its prevention from

television news or television talk shows were more health conscious, health information oriented, and held stronger health beliefs, more so than in viewing soap operas. Thus, scanning behaviors are important among younger respondents, who engage in scanning most frequently. Income was correlated with scanning, in that higher income led to more scanning. Thus, to reach those with lower socioeconomic status (SES) with cancer information, active seeking behaviors may be more efficient.

Mass media messages can impact individual audience members, but can also have larger scale impacts, such as on policy and public levels, especially related to health disparities. The media can set an agenda and can frame health issues according to their ideological positions, which can either strengthen understanding and/or public support for policy change regarding access to health care. McCombs and Shaw's (1972) agenda-setting theory, while originally developed to explain the relationship between news coverage of political issues and audiences' prioritizing of such issues, may suggest that the quantity and prominence of messages about health disparities in the media can influence both issue awareness and issue importance among media audiences. Early surveys of media by Hoffman-Goetz et al. (2003) suggested the scope of illnesses covered by media did not reflect prevalent health threats, for instance, more coverage of diabetes and HIV/AIDS than cancer and cardiovascular disease.

It is important to keep in mind these dynamic perceptions of what effects media have on audiences when considering health representations within these platforms, particularly with health disparities. Health disparities relate to the different outcomes of health across social groups as a result of involuntary social, economic, institutional and political factors. Mass media have been shown to raise awareness of health disparities, highlighting that

societal factors are responsible for disparities, and calling for social change to reduce these inequalities (Niederdeppe, 2013). Furthermore, framing theory posits message quality about health disparities influences beliefs about causes of disparities and whether public policies should play a role in addressing them, thus frames employed in mass media can have material effects on health decisions (Niederdeppe, 2013). For instance, Nicholson et al. (2008) found that cancer screening interest among Black participants was lowered with negative effects generated by disparity frames (which emphasize Blacks have higher cancer death rates than Whites) rather than using progress frames (that cancer fatalities have declined for Blacks).

The Internet

The depth, breadth and reach of cancer information has grown rapidly with the internet, aiding in meeting information and support needs of cancer patients and their families. According to Pew Research Data, 72% of internet users say they have searched for health information (most often, diseases and treatments) online (Fox, 2014). Caregivers and people living with chronic conditions, such as cancer, are more likely than other internet users to share or watch someone else's health experiences online. When CPI and cancer related health information are sought, many individuals turn to the internet for answers. Use of the internet for health information among cancer patients and survivors has the capacity to overcome socioeconomic and geographical barriers associated with care and information need. Still, factors like age, educational attainment, household income and community type remain associated with disparities. Graham and Abrams (2005) suggested that "the internet may be the most important dissemination vehicle to improve individual and overall public

health at a reasonable societal cost," although that by itself will not reduce the burden of cancer.

Despite the shrinking population of people offline, in 2018, 11% of Americans reported they do not use the internet (Anderson, Perrin, & Jiang, 2018). Specifically, about a third of seniors (ages 65 and older) do not use the internet, a third of adults with less than high school education do not use the internet, 19% of households earning less than $30,000 a year do not use the internet, and 22% of rural Americans do not use the internet (Anderson, Perrin, & Jiang, 2018). In 2011, when the interview data to be used in the present study was collected, 79% of Americans used the internet, thus placing the offline population in the minority. A more substantial increase has been seen since that time among Americans 65 and older, only 46% of whom used the internet in 2011, growing to 66% in 2018.

The largest disparities of internet use still relate to age, income, education and community type. In 2011, 46% of those 65-years and older, 64% of those with less than $30,000 income, 43% of those with less than high school education, and 73% of those in rural communities reported going online. This is compared to 94% of those 18 to 29-years-old, 97% of those who make more than $75,000, 94% of college graduates, and 80-81% of urban and suburban residents (Pew, 2018). Though all rates have increased in 2018 surveys, the results show that individuals with higher incomes, more education, and urban/suburban residences are still more strongly associated with internet use. By analyzing interviews from 2011, there is an increased likelihood that patients will identify the relevant non-digital sources in their responses because the dominance of smartphones was still emergent (Smith, 2017). It is important to consider other sources of health information, including medical

providers and social networks; however, these interpersonal relationships often still do not fulfill the information needs of patients and families (Demark-Wahnefried et al., 2005).

Race disparities of internet use have also changed over time. In 2011, 81% of White identifying respondents reported using the internet, where as 72% of both Black and Hispanic respondents reported using the internet. In 2018, those numbers have converged with 89% of Whites, 88% of Hispanics, and 87% of Blacks reporting internet use, in part due to the accessibility of internet through smartphones (Pew, 2018). Data on Native American use of the internet was not available through Pew Research data. Use of the internet for health information among cancer patients and survivors has the capacity to overcome socioeconomic and geographical barriers to care and information need, yet age, educational attainment, household income and community type continue to be correlated with disparities.

The internet is low cost and high reward, allows for anonymity, accessible at any time/place, fulfills emotional or informational support needs, and may benefit at-risk and underserved groups. Despite the advantages of technological innovations expanding the number and diversity of media channels available to access information, the complexity and sheer magnitude of the information options can result in consumers being unable to understand and apply the information to which they are exposed (Huerta, Walker, Johnson, & Ford, 2016). Furthermore, as Kreps and Neuhauser (2010) point out, much online health information does not go through an editorial or gatekeeping process, which is typical for mass-mediated information. Internet users are required to have critical appraisal skills in judging the credibility of online health information for themselves.

 By focusing on the difference between the internet and other traditional health information sources, Lee et al., (2012) confirmed previous associations between education

and information seeking, adding that "education exerted stronger influence on patients' cancer information seeking via the internet than it did on seeking via other channels in both treatment options and quality of life issues" (p. 812). Thus, patients with high levels of education search for and are more capable of making sense of cancer information, and "enjoy the benefits of this information, such as confidence in medical decision-making process and better health outcomes" (Lee, 2012, p. 814). Inversely, patients with less education were found to make decisions based on limited information; even when motivated to seek treatment information, the education barrier could not be surpassed (Lee, 2012). As internet use becomes ubiquitous, cancer patients are taking advantage of the availability of information. Using the internet requires a new set of skills, or digital health literacy, to seek, locate, comprehend and assess health information from electronic sources.

In summary, the cancer information and social support on the internet may be unverified/ inaccurate/unreliable, inaccessible/incomprehensible, commercially driven, irrelevant and overwhelming, and may end up doing more harm than good. However, its vast reach creates an important opportunity for disseminating information quickly.

Social Media as Health Information Sources

Social media refers to "internet tools that allow individuals and community to gather, communicate and share information, opinions, photos, videos, and other contents within internet applications" (De Martino et al., 2017, p. 141). In 2018, 69% of U.S. adults reported using at least one social media site (Pew, 2018). Adoption of social media has increased in the past 10 years among all demographic categories, including older adults, racial and ethnic minorities, and those with lower incomes and less education. In this new era of

communication, social media has tremendous potential to improve public health, having permeated across all socioeconomic strata and races/ethnicities (Sakar et al., 2018).

According to 2018 Pew Research Center data, the most popular social media platforms among U.S. adults were YouTube (73%), Facebook (68%), Instagram (35%), Pinterest (29%), Snapchat (27%), LinkedIn (25%), Twitter (24%), and WhatsApp (22%). There are, of course, many other platforms to consider, such as Reddit, Tumblr, Yelp, 4chan, etc. More and more, these social media platforms are being embraced for health-related communication. De Martino et al. (2017) describe health-related social media use as usually connected to a need for increasing understanding of one's disease, expressing one's emotions, sharing experiences of the disease and its treatment, being in touch with doctors, finding answers for additional and forgotten questions, getting advice, and checking on one's progress and goals. Social media messages are well integrated into the lives of users and can be easily accessible when users need it the most. The potential for health campaigns to go "viral," increasing audience size and impact, is a theoretical advantage of social media campaigns compared with traditional approaches, but it cannot be predicted or planned. Insomuch as content is easily accessible, it is, however, also easy to turn off. (Sakar et al., 2018). Users can receive content without any transportation time, and at their convenience; however, there is a concern that delivering interventions online may reduce their impact, especially because of the lack of personal connection. Furthermore, one of the major challenges in social media research is the rapid pace at which social media platforms evolve online and gain or lose popularity for certain segments of society (De Martino et al., 2017). The turnover for content is so quick that users may miss a message entirely.

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Despite the beneficial aspects of social media, such as information/social support and active involvement in their care, it is crucial to consider the quality of information. The public availability, possibility to be altered anytime, global audience, spammers, intentional misspelling, information overload, and freshness of the information are threats to the quality of information found on social media (De Martino et al., 2017). It is difficult to regulate social media's sources of information, and "bad or misleading information can be detrimental for patients as well as influence their confidence on physicians and their mutual relationship" (De Martino et al., 2017, p. 144). Web-based social media are also a powerful advertising and marketing tool, as 88% of businesses use social media, and commercial entities have been shown to often use social media to promote unhealthy behaviors. For example, Ricklefs et al. (2016) documented the indoor tanning industry's use of social media as a strategy for maintaining relationships with customers and to offer pricing deals that promote high-frequency tanning. Similarly, e-cigarette advertising is prevalent on Twitter, particularly in states that limit other forms of tobacco advertising (Serrano et al., 2016).

Each social media platform has unique uses and gratifications for users. I will briefly probe the properties most productive and counterproductive of Facebook, as it the only social media network that was mentioned by name in the 2011 interviews.

Facebook

According to a 2018 Pew Research Center report, about 68% of adults in the United States use Facebook. Among these adults, three-quarters (75%) visit the site at least once per day. Though Facebook is popular across demographic categories, more women (74%) use the platform than men (62%), users are more likely to be in urban areas, and users tend to have higher levels of education. It was also reported that 61% of U.S. women get news from

Facebook, but only 39% of men; Whites (62%) are more likely than nonwhites (37%) to use the site for news. Lower-income teens (70%) are more likely than higher-income teens (36%) to use Facebook. These statistics point to the continuing relevance of this platform to reach large audiences with information, daily.

Facebook provides several core functions that allow users to receive information: the news feed, Facebook groups, and Facebook pages (personal profiles of people, business or organizations). Each serves a different function; each has its own benefits and drawbacks to disseminating health information. Research on Facebook groups or disease-related Facebook pages has suggested they offer an opportunity for social support, but that fundraising, and advocacy are the most common uses of the Facebook groups (Gage-Bouchard, LaValley, Mollica, & Beaupin, 2017). Only a small number of Facebook pages were dedicated to disease related support, but were mostly marketing/promotion and information. Gage-Bouchard et al. (2017) found that personal Facebook pages are used differently than disease related groups and pages, as they focus more on sharing the cancer journey and allow cancer caregivers (of pediatric cancer patients) to mobilize financial, informational, emotional and logistical support, which helps in coping processes (p. 337). Facebook has also rolled out a donations function, in which a user can initiate a fundraising effort for a benefactor of their choice and raise money from their friends as a "birthday gift" over a designated period of time. Currently there is a dearth of research focused on the effectiveness of using Facebook to share CPI.

Social support is one of the greatest benefits of using Facebook for health information. According to Oh (2013), 39.18% of 291 surveyed undergraduates had sought health related social support on Facebook. Among these participants, those with health

concerns were more likely to seek health related social support through Facebook, and those who did experienced greater esteem, emotional support, and tangible support from their Facebook friends, and improved health self-efficacy which is a significant influence on health behaviors and health outcomes. Despite the benefits for those who did experience support through Facebook, it is important to note that nearly 60% of participants in this study did not use Facebook to seek health related social support, thus their self-efficacy and feelings of support may be hindered.

Digital Divide

As a result of "efforts to make cancer information available, the depth and breadth of such information has grown rapidly" online (Huerta, Walker, Johnson, & Ford, 2016, p. 1031). Despite the widespread diffusion of the internet, the ever-increasing amounts of health information available online, and heightened interest in seeking health information online, the digital divide (e.g., lack of access to the internet related to economically disadvantages, and sociodemographic, psychological, and health factors) is still a reality (Ginossar, 2016). Notwithstanding the advantages of technological innovations expanding the number and diversity of media channels available to access information, the complexity and magnitude of the information options can make consumers unable to understand and apply the information to which they are exposed (Huerta, Walker, Johnson, & Ford, 2016). Information overload has been associated with "anxiety about being unable to comprehend the amount of information and use it effectively to make decisions" (Gentile, 2018, p. 734). Furthermore, greater information overload is correlated with lower socioeconomic status (Gentile, 2018). However, Chae (2015) found, through two online surveys, that online cancer information seeking from professional health-related websites, social media, and online news had the

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effect of increasing anxiety and worry regarding cancer, which plays a positive role in cancer prevention/screening.

The internet is a valuable source of information for patients and their families, yet many face digital inequalities related to equipment, autonomy, skills, support and purposes (DiMaggio et al., 2004). According to Klawitter and Hargittai (2018), most individuals begin their online search for health information by entering keywords into search engines, such as Google and Yahoo. Hong's (2006) study of 84 university students showed that it "takes high internet self-efficacy to persevere in this task and locate relevant health information," even though most American internet users tend to be highly educated (p. 544). In addition, most information seekers could use more education regarding credibility assessment of online health information (Klawitter & Harittai, 2018). According to 2006 Pew Data, among those who seek health information online, "two-thirds talk about the results with someone else, typically a spouse or friend, and that just over half of all online inquiries are done for the benefit of someone else" (Sundar et al., 2011, p. 181). This finding points to the importance of looking into both the experience of patients themselves with HISB, and of caregivers and family members concerning their use (or lack of use) of the internet for cancer related information seeking. While research has identified many advantages and disadvantages to seeking health information online, there is a dearth of research regarding the use of the internet to seek CPI, especially among minority populations. Taking into account continued disparities regarding access to the internet, it is crucial to identify other sources of CPI for those who do not use the internet.

Research Gaps

Despite efforts to include diverse samples, surveys conducted nationally on this topic have mostly been exclusive to non-Hispanic white, high SES, English speaking, participants (Wigfall & Friedman, 2016). When understudied populations are sampled, such as those with lower SES or Hispanic Spanish speakers, it is mostly quantitatively. Waters, Sullivan, and Rutten (2009) found in the context of studying CPI requests to the Cancer Information Service among Hispanic and Non-Hispanic users, "Neglecting to account for diversity in literacy levels, English proficiency, and cultural norms and practices might inadvertently hinder cancer control efforts on a population level," and thus, "future research should identify information resources and channels that Hispanics use when searching for cancer information." (p. 484). A qualitative approach will help fill gaps in understanding about searching for CPI among understudied populations and add depth and meaning to survey responses.

Chapter 3: Methods

Overview

As the data being used for this thesis was collected for a prior study, I will first explain the work accomplished by Ginossar (2014, 2016). These two publications include results of quantitative survey analysis exploring CPI seeking among a predominantly Hispanic sample. A subpopulation of those surveyed for those two studies were then interviewed, but these interviews were never analyzed. Thus, the interview transcripts from that study have become the data for the present thesis. I will also describe the qualitative methodology that will be used to analyze the interviews for this thesis.

Part I: Data Collection and Past Quantitative Analysis

Following approval by the University Cancer Center Institutional Review Board and the University Institutional Review Board, Ginossar (2014, 2016) began direct recruiting of patients, with oversampling of minority patients in a Southwestern state to better address health disparities among an understudied population. After checking with providers regarding which patients should not be approached (for cognitive or emotional difficulties, which was necessary for the study but may limit the validity of the findings) team members screened patients in, checking for minority status, and offered the option to participate. Acknowledging the "cultural importance of extended family" (Ginossar, 2014, p. 96) if the patients were accompanied by family members, the invitation to participate was extended to them as well.

Screening and Sample Size

Two hundred and forty-nine individuals were approached for recruitment by research team members. From these, 72 refused to participate, or were not able to complete their

participation, for a response rate of 78%. For this part of the study, participants responded to a survey in English (n=213) or in Spanish (n= 36), in accordance with participant's preference. To accommodate differing levels of literacy, participants had the option to fill in the survey themselves or to have the survey read by the interviewer/research team member. For participants who opted to have the survey read to them (n = 54), the interviewer ensured the participants understood the questions, and read loudly and slowly. Demographic information was gathered regarding socio-demographics of gender, education, age, income, marital status, and clinical information of CPI seeking behavior, perceived importance of CPI and health consciousness were measured. Ginnosar's (2014, 2016) study differs from previous work examining cancer information seeking because it uses local participant data rather than national survey data, allowing for an emphasis on understudied populations.

Quantitative Analysis

CPI seeking behaviors and perceptions were measured using selected items from the National Cancer Institute Health Information National Trends Survey (HINTS) in addition to gathering sociodemographic information of participants. Specifically, the participants were asked "Have you ever looked for information about cancer prevention?" and "When was the last time you searched for information about how to prevent cancer?" In contrast to previous studies that examined either survivors' cancer information seeking in general, or CPI seeking among the general population, "the goal of this study was to conduct a formative research on CPI seeking among a diverse sample of cancer patients and their families that can inform a future intervention," (Ginossar, 2014, p. 97); hence, other forms of cancer information seeking examined in previous studies were not included in the questionnaire

The Comprehensive Model of Information Seeking (CMIS) was incorporated in the study. This model functionalizes cancer information seeking as a "quasi-causal process that begins with antecedent factors that motivate a person to seek information" (Ginossar, 2016, p. 94). The model considers antecedents such as age, gender, race, ethnicity, education, and income, as well as illness experience, salience needs, and beliefs as relevant to one's information sources and information seeking behaviors. These considerations are akin to the social determinants of health perspective, which also considers structural level factors and resources to be integral to information seeking processes.

To assess whether participants were CPI seekers or not, a binary logistic regression was implemented to determine multivariate predictors of CPI seeking. In the study, 54% (n=130) of participants had sought CPI. The results of the analysis showed that ethnicity was a significant variable in CPI seeking, as non-Latino Whites had the highest rate of CPI seeking (60%). 52% of English-speaking Hispanics and 53% of Native Americans sought CPI, compared to only 34% of Spanish speakers who sought CPI. Education was also a significant ($p < 0.01$) predictor of CPI seeking, with 70% of those with post-high school training, some college, or advanced degrees reported seeking CPI. In contrast, only 28% of those who did not complete high school indicated seeking CPI. Lastly, income was significant ($p < 0.01$) in predicting CPI seeking. Half of respondents (50%) with less than $50,000 annual household income reported seeking CPI, compared to 69% of respondents with household annual income above $50,000 seeking CPI.

Part II: Methods for this Thesis

Interviews

   In this thesis, I focused on analysis of the interviews that were previously collected. The purpose of the interviews was to gain a deeper understanding of the experiences of the participants' information seeking strategies and preferences, from their perspectives, adding nuance and depth which cannot always be gathered from survey data. Interviews were conducted until theoretical saturation was achieved, or until no new data appeared (Guest, Bunce, & Johnson, 2006). The interviews were semi-structured and guided by open-ended questions (see Appendix A). Participants were asked to share the story of their diagnosis, what things they wanted to know following the diagnosis, what things they wished they had known before they were diagnosed and were asked to talk about their family's communication about cancer prevention. My position as a researcher was aimed at preserving in their own words the experiences of the patients and their loved ones. Aligning with Fisher (2010), "my voice and subjectivities are not relevant as I was attempting to capture their stories" (p. 394). Nonetheless, my personal experiences are the lens through which I read and coded the interviews.

Qualitative Analysis

   Following the completion of the surveys, a sub-sample of the participants (n = 50, patients = 32, caregivers = 18) participated in in-depth interviews. These interviews were collected in 2011 at the same time as the survey, however, the interviews were never fully analyzed prior to the present study. I engaged in a thematic analysis of these interviews of both cancer patients and their family members regarding their conceptualization of cancer prevention before and after a cancer diagnosis, their sources of CPI, and CPI seeking

processes and perceived barriers to information. The total number of interviews I analyzed was 47 (n = 29 patients; n=18 family members). The final product of this analysis sought to "provide voices of participants, a reflexivity of the researchers, a complex description and interpretation of the problem, and a study that adds to the literature" (Creswell, 2013, p. 65).

The purpose of the thematic narrative analysis in this study was to connect the lives depicted in the interviews to the macro-contexts in which they occur. This form of analysis also has the benefit of attending to political, social, and historical contexts that shape the individual accounts being shared, noting that social inequalities weigh heavily on their lives (Riessman, 2008, p.58). A narrative in this case refers to "an extended story about a significant aspect of one's life" (Chase, 2005, p. 652), particularly their cancer journey. Following the thematic narrative analysis, as explained by Riessman (2008), this study will work "with a single interview at a time, isolating and ordering relevant episodes into a chronological biographical account," which, when completed, the researcher "zooms in" to identify the "underlying assumptions in each account and naming (coding) [the interviews]." (p. 57). Zooming into the interviews exposed details of the lived experiences on a micro scale, and the analysis therein could also zoom out to connect with macro contexts. By identifying recurring themes within the interviews, recommendations can be made for directions of future research, and for changes in healthcare settings.

Thematic and Narrative Analyses

The analysis included elements of narrative analysis with a focus on thematic analysis as the primary methods to analyze the interviews. "Interviewees as narrators" does not automatically assume that an authentic self will be revealed, as their voices are mediated by the social contexts in which they speak; nonetheless, the narrator shares their "particular

biographical experiences as he or she understands them" (Chase, 2005, p. 661). Thus, through this inductive and emic process of narrative thematic analysis, I identified patterns that pointed to the nature of CPI seeking within the social structures and contexts of 2011.

I applied Braun and Clarke's (2006) thematic analysis definition as "a method for identifying, analyzing and reporting patterns (themes) within data" (p. 79). I also followed Riessman (2007, 2008) who has stated that many studies concerning health topics have "adapted the approach to uncover and categorize thematically patients' experiences of illness" (p. 53). Riessman (2008) suggests the application of "thematic analysis" when a researcher analyzes "what" is spoken during data collection, which will be prioritized over "how" a story is told, as thematic analysts "generally do not attend to language, form, or interactions" (Riessman, 2008, p. 59).

Thematic analysis was preferred over similar approaches because it offers the flexibility to develop research guided by prior theory, preserves the story, considers historical context of the account, and is case-centered (Riessman, 2008, p. 74). The results of the thematic analysis are grounded in the data; however, several predetermined categories were used in the analysis based on salient themes from the literature review, including: information seeking, uncertainty management, the digital divide, and informational and emotional support.

Below I outline the stages which this thematic analysis process followed. I used a "data analysis spiral" which involves moving in "analytic circles rather than using a fixed linear approach" (Creswell, 2013). The notion of a spiral suggests that while these phases must all be completed, the order outlined here may not perfectly captured what occurred naturally in the analysis process.

Phase 1: This initial step involved organizing the data within NVivo, the computer software used for the analysis. This step ensured that all interview files were in working order, and that patient interviews were separated from family member interviews.

Phase 2: The next step was to read and reread the transcripts. Following Agar's (1980) advice, I "read the transcripts in their entirety several times" and "immersed [myself] in the details, trying to get a sense of the interview as a whole before breaking it into parts" (p. 103). I also took notes of key ideas and phrases. This helped me to form initial categories, identifying and selecting relevant quotations which supported and contributed to the overall theme.

Phase 3: This step consisted of coding, or "aggregating the text into small categories of information…then assigning a level to the code" (Creswell, 2013, p. 184). I used both "prefigured," or a priori (as listed above), categories, as well as "emergent" categories (Creswell, 2013, p. 185). Chase argues that it is important to first locate "the voices *within* each narrative" before locating themes *across* interviews (2005, p.663). This approach draws attention to the complexities within each participant's story—each "narrative strategy" (Chase, 2005, p. 665) is unique—before connecting to broader and shared constructs.

Phase 4: After gathering the codes, I synthesized them down into themes, "broad units of information that consist of several codes aggregated to form a common idea" (p. 186). These themes guided the final narrative of the analysis.

Phase 5: The next step was to interpret the data by "abstracting out beyond the codes and themes to the larger meaning of the data" (Creswell, 2013, p. 187). This stage was key for making specific suggestions to better address the participants' information needs in the context of their socioeconomic status.

Phase 6: The final phase included representing the "essence" of the experiences described by the participants in the discussion of the paper.

Methodological Justification

Qualitative researchers interview people to understand their perspectives, to retrieve their experiences from the past, to gain expert insight or information, to obtain descriptions of events that are normally unavailable for observation, to foster trust, to understand sensitive relationships, and to verify information obtained from other sources (such as the survey) (Lindlof & Taylor, 2002, p. 173). Semistructured interviews have been widely adopted in health-related research. According to Graham, this approach "counteracts the tendency of surveys to fracture women's experiences" (as cited by Lindop, 2001, p. 763), enabling the richness of those experiences to be communicated. On the other hand, it allows women to fragment their experiences themselves if they wish in order to evade difficult and painful topics (Lindop, 2001). This is also true for male participants. When fragmented speech occurs, for the purposes of clear and concise transcription, the analysis includes "'the told'- the content of speech, the events and cognitions to which the language occurs" (Riessman, 2008, p. 58). This allows for the researcher to transform messy spoken language into easily readable passages. Interviews were conducted until theoretical saturation was achieved, or until no new data appeared (Ginossar, 2014).

A qualitative approach is useful for various types of studies, including instances when "a complex, detailed understanding is needed…and when the researcher seeks to understand the context or settings of participants" (Creswell, 2013, p. 65). Qualitative research in health communication has been used to "restore the integrity of patient experience," while focusing on the "importance of gender, class and racial identities in the

co-construction of often-competing meanings for pain, discomfort, health and illness, the body, mind, and spirit, and mortality" (Lindlof & Taylor, 2002, p. 27).

The software used for this analysis was NVivo, a program specifically used for qualitative research. Creating "nodes" within the program is used to organize the codes and themes that are present in interviewee's answers. NVivo is useful for qualitative research as it helps "analyze, manage, shape and analyze qualitative data," (p. 204). The program allows for line by line reading of the text and permits side-by-side note taking with the transcripts. Furthermore, the program will allow for a more dynamic coding process by easily being able to add, delete, or change codes.

Chapter 4: Results

Overview of Findings

This chapter is broken down into three main themes: uncertainty management before and after diagnosis, need for more information versus information overload/avoidance, and family processes of information seeking and processes of behavior change. Each of these overarching themes is guided by the research questions and are supported by subthemes which include quotes and examples. I first share how respondents conceptualized CPI, and how interviewees managed uncertainty about prevention before diagnosis and after diagnosis, with some overlap. Next, I will cover the need for more information compared to the sense of information overload and information avoidance. Finally, I will explain the role of family processes in gathering information and in making changes to enact prevention behaviors.

Though individuals in the sample all had unique experiences throughout diagnosis, treatment and information seeking processes, there were overlapping sentiments about uncertainty about cancer prevention before and after diagnosis, as well as differing sentiments about amount and quality of information. Patients and their loved ones also identified ways in which sources of information work together to meet information needs and decrease uncertainty, though some felt they were overloaded with information. Many barriers to accessing, understanding and applying CPI, in the lives of patients and family members, were identified. Different participants emerged as health champions, those who encourage and inform others about enacting preventative behaviors, to help overcome some of the barriers to CPI. Some patients and family members focused on remaining positive about the

benefits of prevention behaviors after a diagnosis, while others took a more fatalistic stance.

Table 1 below contains relevant demographics of participants, including age, education, income, race/ethnicity and language, as well as reported health insurance status, and internet access.

Table 1: Demographics

		Breast cancer patient (N=11)	Other cancer patient (N=18)	Family member (N=18)	All Ages (N=47)
Age					
Age Mean		55.27	54.06	49.78	52.70
Age Min		36.00	30.00	27.00	27.00
Age Max		72	75	77	77
Education					
Less than 8 years	N	0	3	1	4
	%	0.0%	6.5%	2.2%	8.7%
8 to 11 years	N	1	3	3	7
	%	2.2%	6.5%	6.5%	15.2%
12 years or completed high school	N	4	4	6	14
	%	8.7%	8.7%	13.0%	30.4%
Post high school training	N	1	2	3	6
	%	2.2%	4.3%	6.5%	13.0%
Some College	N	3	5	3	11
	%	6.5%	10.9%	6.5%	23.9%
College graduate	N	1	0	0	1
	%	2.2%	0.0%	0.0%	2.2%
Postgraduate	N	1	0	2	3
	%	2.2%	0.0%	4.3%	6.5%
Total	N	11	17	18	46
	%	23.9%	37.0%	39.1%	100.0%
Income					
Lower than 20k	N	7	13	11	31
	%	14.9%	27.7%	23.4%	66.0%
20-35k	N	1	2	2	5
	%	2.1%	4.3%	4.3%	10.6%
35-50k	N	2	1	1	4
	%	4.3%	2.1%	2.1%	8.5%
50-70k	N	1	1	2	4

	%	2.1%	2.1%	4.3%	8.5%
70k+	N	0	1	2	3
	%	0.0%	2.1%	4.3%	6.4%
Total	N	11	18	18	47
	%	23.4%	38.3%	38.3%	100.0%

Race/Ethnicity

American Indian/Alaska Native	N	1	2	0	3
	%	2.1%	4.3%	0.0%	6.4%
Asian & African American	N	0	0	1	1
	%	0.0%	0.0%	2.1%	2.1%
Non-Hispanic White	N	1	1	3	5
	%	2.1%	2.1%	6.4%	10.6%
Hispanic (English Speaker)	N	7	10	9	26
	%	14.9%	21.3%	19.1%	55.3%
Hispanic (Spanish Speaker)	N	2	5	5	12
	%	4.3%	10.6%	10.6%	25.5%
Total	N	11	18	18	47

internet Access

No internet	N	7	14	12	33
	%	14.9%	29.8%	25.5%	70.2%
internet	N	4	4	6	14
	%	8.5%	8.5%	12.8%	29.8%
Total	N	11	18	18	47
	%	23.4%	38.3%	38.3%	100.0%

Health Insurance

No Health Insurance	N	2	4	8	14
	%	4.3%	8.5%	17.0%	29.8%
Yes Health Insurance	N	9	14	10	33
	%	19.1%	29.8%	21.3%	70.2%
Total	N	11	18	18	47
	%	23.4%	38.3%	38.3%	100.0%

Uncertainty Management before Diagnosis

This section will mainly address the first research questions about describing prevention before and after a cancer diagnosis, as well as touching on perceptions of CPI sources shared by the interviewees. While some participants were taking prevention measures, many patients and family members described feeling uncertain about CPI and found the information irrelevant before a cancer diagnosis. Uncertainty about relevance of CPI led to feelings of invincibility, such as thinking that cancer could never happen to them, were prevalent among patients and family members who did not take health precautions, particularly for those who did not have a family history of cancer. Participants who expressed uncertainty about CPI often did not enact prevention behaviors. Those who did not enact prevention behaviors also identified ways in which they were blocked from performing prevention behaviors.

Participants who did enact protective behaviors before a diagnosis shared concrete descriptions and conceptualizations of CPI, and that they felt these behaviors were a promise or guarantee that they would not face a cancer diagnosis in the future. This created a source of uncertainty for whether these behaviors were worthwhile.

Participants' Conceptualization of CPI

The first research question focused on how cancer patients and family members from diverse backgrounds conceptualize cancer prevention. Interviewees explained in both concrete and abstract terms what cancer prevention means to them. For some, CPI was not clear and contributed to uncertainty, while others felt CPI available was clear and concrete, and they adhered to it, which led to feeling of "broken promises" upon a cancer diagnosis. In a concrete sense, most identified a healthy diet, exercise, getting screenings and checkups,

not smoking, and being protected from the sun as important steps to decrease their risk of a cancer diagnosis. More abstractly, some included prayer, spirituality and stress management as important factors to avoid cancer.

What participants considered "healthy" eating varied, but their knowledge aligned with recommendations for a healthy diet according to American Cancer Society Guidelines (Kushi et al., 2012). Interviewees acknowledged that consuming organic foods, leafy greens, more fiber, low fat, low sugar, drinking water, and avoiding red meats, alcohol, and foods with "toxins" and hormones, were all important steps they could take to decrease their odds of a cancer diagnosis or of a recurrence of cancer. Diet was often contextualized within cultures and framed as a shared process within the family as the surrounding environment and those in the support network who may or may not want to make dietary changes. There was tension between what foods they know to be "healthy" with foods they "grew up with" that they "absolutely love to have." Though diet and exercise are two different things, they were often mentioned together under the umbrella of self-care. Exercise was loosely defined by participants but included weight management, an overall healthy "lifestyle," removing junk foods from the house, and discussing nutrition with family members, to decrease the likelihood of a cancer diagnosis.

Breaking a cigarette habit, avoiding secondhand smoke, and never having smoked at all, were all identified as relevant steps to preventing cancer. Many participants framed not smoking as the obvious and informed approach to decreasing one's odds of a cancer diagnosis. Some participants recognized that smoking causes cancer yet continued to be smokers themselves. Family members and patients who continued to smoke after a cancer diagnosis tried to negotiate the dissonance between their knowledge and their actions by

explaining that they don't do it around other family members, or that they are trying to cut back or quit. Some barriers to quitting were the cost of quitting aids, such as nicotine patches or gum, and feeling like they already have cancer, so it would be pointless to quit now. Nonetheless, the American Cancer Society attributes one-third of cancer deaths to exposure to tobacco products (Kushi et al., 2012, p. 30). Both diet and tobacco exposure can be considered choices made by the individual, yet, as posited by Kushi et al. (2012), healthy choices "may be facilitated or impeded by the social, physical, economic, and regulatory environment in which people live. Community efforts are therefore essential to create an environment that facilitates healthy food choices and physical activity" (p. 31).

Routine doctor visits, annual screenings, and performing self-checks were emphasized in the interviews. Furthermore, specific types of checks such as pap-smears and mammograms were mentioned as crucial prevention steps. These decisions were framed as the responsible choice for one's own body, often just considered part of a general health routine and not always specific to cancer prevention. Another breast cancer patient suggested: "get checkups regularly. General checkups, not only breast, because [cancer] can come out somewhere else..." Despite awareness of getting checked as a prevention measure, participants identified barriers to accessing exams, including costs and insurance.

To avoid redundancy, examples of each of these conceptualizations of cancer prevention will be shared within the other analysis sections. Explanations of prevention behaviors overlapped with perceptions and uncertainty about CPI as well as processes and barriers of seeking and enacting protective behaviors.

Protective Behaviors as a Broken Promise

A strong sense of uncertainty about the idea and value of prevention emerged among participants before a cancer diagnosis in the family. Those who perceived a risk of cancer before a diagnosis often managed uncertainty by enacting protective behaviors such as a healthy diet, exercise, and regular checkups. Performing these behaviors was framed as a contract or guarantee to avoid a cancer diagnosis, and thus created a lot of uncertainty about what causes cancer and uncertainty about the value of protective behaviors. One 49-year-old female Hispanic Spanish-speaking patient explained, "I was always very healthy, I didn't even get headaches, if I got a cold, it would go away right away, but it was rare that I got one." Because of her history of being generally healthy, she did not expect cancer. Similarly, one 53-year-old Hispanic Spanish-speaking breast cancer patient responded "I thought I was a healthy person because I didn't smoke or anything and I never thought about cancer prevention, at all. As a matter of fact, my pap-smear exams…it was like my prevention," as the patient went in for a pap-smear exam and was recommended a mammogram as well which identified her cancer very early on. "Feeling healthy" has been found to be both positively related to screening and a barrier to screening behavior (Ginossar, 2010). These participants highlight a recurrent philosophical question asked by patients: "why me?" Aligning with Lindop and Cannon (2001), denial of cancer often is followed by anger, rage, envy and resentment, and asking "why me?" (p. 767), considering they had been enacting protective behaviors.

Learning how to prevent cancer was about the right (and wrong) timing of when to receive that information. The 55-year-old Hispanic melanoma patient explained that after her diagnosis she wanted to learn more prevention information, and took to the internet and print

materials, but, following her diagnosis: "your mind is so overwhelmed, you don't want to take it in anymore. It's like what do I do, it's too late now." She continued: "you don't know what to believe at that point because here you are, you're dealing with it, and you're thinking to yourself, I was eating good, I was exercising well, I was doing everything I could do. And I didn't think I would ever come down with cancer 'cause it certainly didn't run in my family. So, you don't know what to believe anymore."

Several participants indicated feeling that cancer is inevitable in many cases, no matter what steps one takes to decrease their odds of having the disease. This was explained as "cancer is in everybody, just whether or not it comes out," "we're all born with cancer" or "is there really a way to prevent cancer?" A feeling of pessimism was shared by those who subscribed to this idea that prevention doesn't *really* prevent cancer. One 62-year-old Hispanic breast cancer patient explained:

> Some people can live by the Bible and they still get it. So who's to say how do you prevent it? Nobody knows. Or if they do, they're really not giving us the right answer because it's a money maker, you know. I mean they want money to do research and research, and then you read somewhere they have but, you know, drugs is what makes the world go round. If they give it a cure, then how are they gonna, do you know what I mean? You could not smoke. You could eat really good the way you're supposed to and you still get every disease. I don't know. We just learn to deal with what's dealt to us.

She raises several concerns here that were shared by others interviewed – that no matter how "good" a person you are, you can get cancer; that more prevention is not available because that would lose money for those with stakes in the treatment of cancer; and that those who do

have the disease were "dealt" that hand. The point is reiterated by a 50-year-old Native

American lower stomach and spleen cancer patient who shared:

> You could do everything that they say for you to do for prevention, you know, but I
>
> mean, if it's in your genes, it's in your genes, you're gonna get it, you know. That's
>
> the way I feel. You can do whatever you want to do, but you're still going to catch
>
> that ball. And ever since I was young, I knew I was gonna catch this ball.

His stance was more oppositional in that he suggested that many people assume protective

behaviors function as a promise or contract to avoid cancer, but he felt that genetics and

family history are stronger predictors of having cancer or not.

Invincibility

Many participants explained how, before a cancer diagnosis, they never "worried

about it" and did not seek prevention information, especially those participants who did not

have a family history of cancer, which emerged as a form of uncertainty management. For

instance, when one 49-year-old Hispanic Spanish-speaking patient was asked about her CPI

seeking before her diagnosis, she shared: "I never thought I would have cancer because no

one in my family has been diagnosed with cancer or diabetes or any disease," and added, "I

never thought that I would get cancer, much less such a malignant type." She highlights the

feeling of irrelevancy of CPI, and lack of cancer worry, and feeling of invincibility for those

who have never experienced cancer in their family. This feeling was shared by a 47-year-old

Hispanic spouse of a cancer patient, who "never went out of my way to find literature about

how to prevent cancer" and explained it was "because it really never hit close to home or I

never really had to worry about it." Personal relevance of CPI and "perceptions of high

personal levels of risk information" are important motivating factors in seeking CPI (Ginossar, 2014, p. 95). Thus, with low perceived personal relevance, CPI was not sought.

Feelings of invincibility also related to avoidance of protective behaviors, such as annual checkup and screenings. For example, the sister of two patients at the Cancer Center explained, "I don't care if you're low-income and close to poverty or you're a CEO of a company. Everybody thinks they're invincible, you know, until something like that hits you like oh my god. You have to change your lifestyle." She reiterated the point that many people do not feel like cancer prevention is relevant to them until someone close to them gets a diagnosis. In another instance, despite thinking that cancer prevention is important to "everyone," one patient doubted anyone is thinking about prevention:

> Everyone's too caught up in their day-to-day lives to think about things like that.
> Plus, no one ever thinks it's gonna happen to them. So if they don't think it's gonna
> happen to them, why should they try and prevent it?

Feelings of invincibility and denial of risk were also strong among smokers. A 63-year-old male Hispanic lung cancer patient shared that he "talked to people that smoke and most of them, they really don't care, you know. They just, they don't think it can happen to them." As mentioned, breaking a cigarette habit, avoiding secondhand smoke, and never having smoked at all were all identified as relevant steps to preventing cancer. Many participants framed not smoking as the obvious and informed approach to decreasing one's odds of a cancer diagnosis. For instance, the 46-year-old caretaker for her husband's uncle urged, "obviously, don't ever smoke. Both my brother and my sister died of lung cancer and they were both heavy smokers. It's like, you know, get a clue. Who doesn't know not to smoke anymore?" She also mentioned general healthy eating and exercising, but because of

the personal connection to lung cancer, the emphasis on not smoking was stronger. The tension between smokers and nonsmokers resonates with findings from Ginossar (2010), which found conflict among online lung cancer support group members, some of whom blamed smokers for having cancer, while others discussed the addictive nature of smoking and shared frustration and difficulties of quitting.

Concerns about secondhand smoke emerged for some who felt protected because they were not smokers themselves. As one 56-year-old African American family member put it,

I didn't smoke, and I had thyroid cancer. But now we're hearing all this stuff about secondhand smoke, you know. Our family smoked. I didn't smoke, couldn't stand it. Then all of a sudden I got this thyroid cancer and all of a sudden this cancer is showing up in our family.

He shares his suspicion about the source of his own cancer to be second-hand smoke. Concerns about secondhand smoke were shared among other family member participants: "How many parents are there that smoke in the presence of their children today? Why? Because people are ignorant," stemming from a daughter of a lung cancer patient's experiences growing up in a small home in Mexico where her father smoked around the family. Though they felt protected by not smoking personally, they were put at risk due to others' smoking.

Often associated with this feeling of invincibility was a greater sense of shock upon receiving a cancer diagnosis. This occurred among participants who knew about a history of cancer in the family as well as among those who did not. A 54-year-old Hispanic breast cancer patient said: "they were shocked, too, because no one in the family has had, you know, like breast cancer or anything like that that we could figure out, you know." One 59-

year-old Hispanic breast cancer patient shared a very similar story: "I did know my father had stomach cancer. And, you know, I knew there was cancer, but I mean as far as breast cancer it was just a shock to my family, my siblings, everybody in my family." She indicated a potential risk for cancer in her family, but because it was a different type of cancer, it did not feel relevant and created uncertainty and shock.

Prevention Behaviors and Information Were Unattainable

Some participants shared difficulties in enacting protective behaviors before diagnosis, such as lack of information, and cost and access barriers to healthy food and to screenings. These behaviors were framed as an unattainable privilege and emerged as a tactic to manage uncertainty. One 72-year-old Native American breast cancer patient wished she had received CPI before her diagnosis: "I wanted to know what to do before, you know, how to prevent it and all. I never knew about it until after my surgery. I think they have pamphlets you can read and what to do and what not to do and what to eat and what not to eat." She indicated desiring more information before her diagnosis, and uncertainty about whether or not these sources, such as pamphlets, were available. In addition to cost barriers, cultural dietary habits and resistance to change were mentioned as obstacles to trying to prevent cancer. Several of these barriers to having a healthy diet overlapped for one 62-year-old Hispanic breast cancer patient:

> We can't afford to eat healthy. We don't have the money to eat healthy, you know. You have to have a moderate income. I would love to live on vegetables and fruits. I can't afford it. I get it once a month. Everything is boxed now. I hate it. Everything comes in boxes, you know. But I think what your intake is real important, what you put into your body, you know. And some of us just can't afford to eat the way we

would like to. So you either poorly or you eat junk food, you know. And us

Hispanics, we live on tortillas, beans, fried potatoes, and I still make that, you know,

and look at all that grease, but hey.

This woman's experiences illuminate a common thread shared among other participants who

have low-incomes and eat foods in their cultures. Though they know that a change to a

"healthy" diet may be ideal for prevention of an initial or secondary diagnosis of cancer, the

changes may be difficult to implement.

Lastly, cost barriers to screening behaviors were mentioned by some participants. The

daughter of one of the patients explained how she navigated the health care system in the

United States:

I always found a way to get my exams; even living here in the US when I didn't have

insurance I would go to Mexico to have my exams because I couldn't let a year go by

without getting them. For example, my mammogram, like I say it's tough to get

insurance here, so I start a savings for my mammograms and all of that.

This participant highlighted the high level of self-efficacy required to acquire a mammogram

when you lack insurance in the United States. This finding aligns with barriers faced by

Hispanic women seeking breast cancer screenings including lack of insurance, financial

resources, lack of time and locations of clinics (Ginossar et al., 2010). This participant

displayed high levels of motivation in seeking CPI and was able to act on it, though such

self-efficacy is not always present. A 62-year-old Hispanic breast cancer patient explained a

situation in which she was informed about what screening she needed, but couldn't afford the

procedure:

I found another lump on the same, where they did the reconstructive, and there was a big bruise on it so they wanted to do another biopsy. And they were gonna do a CAT scan, but I couldn't afford the fifty dollars, so I don't know what I'm gonna do.

Patients and family members recognized how important these checks are to have done regularly for early detection if something potentially cancerous were found, but pointed out that many people still do not do it. The reasons for avoiding checkups included feelings of machismo, feelings of invincibility, neglect for information that is available to them, and cost barriers. A gendered difference regarding screening emerged: as noted above, women were informed about specific exams for cancers that primarily occur in women, whereas many men often avoid seeing a doctor. The daughter of a breast cancer patient shared: "I knew that we could get cancer anywhere, but I thought women were more susceptible to cancer because of childbearing." This patient was "always concerned with getting my pap-smears," as well as mammograms.

Uncertainty Management after Diagnosis

Following a cancer diagnosis in the family, feelings about CPI, and strategies to manage uncertainty changed. Both patients and family members explained the ways in which their information needs changed after a cancer diagnosis in the family, which functioned to manage their uncertainty. Among family members, the diagnosis led to increased cancer worry, which either led to higher information needs or decreased interest in CPI/information avoidance. When the diagnosis "hit close to home," their interest in actively seeking CPI increased for some. Feelings of invincibility and irrelevancy turned into cancer worry, thus sparking behavior changes (such as learning about healthy diet, decreasing smoking, and seeking checkups and screenings). Paradoxically, a cancer diagnosis in the family,

particularly for those who had been enacting preventative behaviors before the diagnosis, created more uncertainty about the effectiveness of these behaviors. Only a few participants indicated that a cancer diagnosis decreased their interest in CPI. Generally, the interviews aligned with findings from Rutten and colleagues (2016) who found that "respondents with personal history of cancer reported having sought cancer information (69.8%) compared to those with a family history (51.2%) or no history (29.6%) of cancer" (p. 350).

A diagnosis also resulted in split reactions of either seeking positivity and hope or feeling fatalistic. A diagnosis also fostered a sense of health championship, to share CPI with others, particularly children in the family. For some, a diagnosis did not change attitudes towards CPI, because other health issues took precedence.

Cancer Worry

Fears or uncertainty of a reoccurrence of cancer, or a first diagnosis of cancer for another family member, were prevalent after a cancer diagnosis. These worries often led to greater likelihood of seeking CPI and performing protective behaviors such as screenings, thus, "worry plays a positive rather than a negative role in the cancer context" (Chae, 2015, p. 144). Similarly, a 54-year-old Hispanic Spanish-speaking husband of a cancer patient confirmed the points:

> Why try to look up something that nobody has in your family? Now once it hits your
> family, that's when it hurts, you know. You start trying to look up things, you know,
> and ask questions and everything. But sometimes it's a little late, you know."

Participants felt as though cancer prevention was irrelevant for relatives until there was a diagnosis in the family. Similarly, participants talked about how, despite people have been exposed to CPI, they chose not to act on it. This aligns with "nearly half of U.S. adults" who

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agree that it seems everything can cause cancer, there aren't many ways to lower chances of getting cancer and that there are so many recommendations it is "hard to know which ones to follow" (Niederdeppe, 2010, p. 230).

One 50-year-old Hispanic breast cancer patient wondered: "since I had it there, is it gonna come back in a different place?" and her doctor explained, "there was a possibility, so that if I kept getting check-ups like I'm supposed to and everything then I would be okay. But that was my biggest fear was to ask is it gonna come back." This patient was encouraged to continue to enact protective behaviors in order to decrease her chance of a secondary diagnosis. Targeted checks, such as mammograms, were considered important enough that patients often encouraged their family members to have them done yearly. This was especially true after a cancer diagnosis in the family, which patients said increased cancer worry among relatives and led to more screening behaviors. For example, the 68-year-old aunt of a breast cancer patient explained how after her niece was diagnosed, the patient's sister became more concerned with getting checked; the sister called the doctor and said: "I want a mammogram because my sister got diagnosed for cancer. We don't have any cancer in the family, you know. And I want to make sure that I'm okay." This same aunt also talked to her own daughters about getting checked, telling them: "you guys got to go for a mammogram…'cause my girls are already in their 40s. And, 'oh, Mom, we already had one last year,' 'oh, you got to,' I said, 'because you know what? We are from a cancer family.'"

The importance of getting checked was shared by a 54-year-old Hispanic breast cancer patient. She explained:

I think it would be good to have some information, like, how can I prevent it, what to eat, cause they're thinking about it and they're all getting checked, so I mean I think

at first it scares them so they're looking, and I think after a while then they just sort of

go back to normal and I think they need to not go back to normal. I think they need to

really just take care of themselves and spread the word, you know, to get checked.

This patient described the value of cancer worry in increasing screening behaviors, as

supported by the comprehensive model of information seeking (CMIS) ability to predict

information seeking based on salience, or personal relevance, risk perception and fear (Chae,

2015).

Worry about preventing a reoccurrence was shared by a 53-year-old Hispanic woman

with melanoma: "finding out the best foods that you can eat, like how can you use your diet

to help you prevent a relapse [of cancer] and what vitamins they say are good too," adding: "I

think I eat healthier now. I try to buy organic as much as I can, you know, find places that

have the cheapest organic." This last point hints at one of the many barriers to achieving a

"healthy" diet for cancer prevention. Though they know that a change to a "healthy" diet may

be ideal for prevention of an initial or secondary diagnosis of cancer, the changes may be

difficult to implement. For instance, the 47-year-old Hispanic wife of a Native American

male cancer patient noted she tries to "eat cleanly" such as eating more "fresh fruits, fresh

vegetables, things that aren't quite so processed." However, when asked if there were any

difficulties in making these changes, she added: "Fresh fruits and vegetables are very

expensive, you know. And then they have meatless meat, they're made out of tofu, they're

actually pretty good, and they're kind of expensive. So you have to really kind of plan your

meals well, and make large amounts at a time and then freeze them and it's kind of a lot of

work and kind of expensive," adding "maybe if I had a better job, a better education," it

would be easier to implement these changes. Her position as a spouse of a cancer patient has

led to dietary changes, resulting from a "scared into action" effect (Ginossar, 2010, p. 79), but she shared her perceptions about limited access to healthy foods due to her socioeconomic status.

Fatalism

Upon being diagnosed with cancer, participants were split in their emotional responses. While some remained hopeful and focused on staying positive to manage uncertainty for themselves and their families, others leaned toward fatalistic and pessimistic views. Those who stayed positive often sought support and prevention information, while those who were pessimistic had a decreased interest in CPI. Fatalistic beliefs are "characterized by pessimism, helplessness, and confusion and ambiguity about ways to avoid getting cancer," (Niederdeppe, 2010, p. 230), and cancer fatalism has not been shown to be associated with race and ethnicity (Lee, Niederdeppe, & Freres, 2012). According to Go and Han You (2018),

> individuals with a high level of fatalism are likely to behave passively, as they believe that whatever happens to them is the result of uncontrollable powers, whereas those with a low level of fatalism tend to exhibit motivation to change their current situation" (p. 872).

There was much higher uncertainty regarding how worthwhile cancer prevention is, and uncertainty of how it was applicable to them as they already had the disease. For instance, a 73-year-old male lung cancer patient did not see a need for doctors or nurses to share CPI with him: "There's no need anymore because I already have it. I don't know what they could say. Stop smoking. I don't smoke, you know. Quit eating something. I don't know what causes cancer." Though this patient identified potential routes to aid in cancer

prevention, he questioned his own knowledge and understanding of the concept and relevance to him as a cancer survivor. Similarly, a 55-year-old melanoma patient explained how she desired information about how to cure her cancer and prevent it from coming back, but remained largely doubtful. She asked:

> What caused it and what's the outlook, what are my chances, what do I do to stop it, to keep it from growing back, but those aren't answers they can give you. They don't know. They don't know what's gonna change it or if they can stop it. Cause I mean that's all a patient wants to hear. Get it out of me. Don't let it come back. What do I need to do to keep it from coming back? But you can't get those answers.

Despite her interest in CPI, she was unable to get the information she needed to feel hopeful, especially considering her diagnosis. A 73-year-old Hispanic lung cancer patient described his avoidance of prevention information: "I'm 73, I don't want to go though, you know. My life is ending, I know. All I need is rest, freedom, enjoy whatever I can when I can…too much information is not good. You get tired."

The wife of a cancer patient shared that she was not interested in CPI after her husband's diagnosis, saying "I don't dwell on it and I try not to think about it every day of my life," explaining that her energy should be focused on helping her husband, and not spent worrying about cancer in the future. Lack of impetus for CPI seeking among patients themselves was sometimes shared with family members who were "not concerned" about learning how to prevent cancer. For instance, "There's some that know what can cause cancer but that doesn't change their lifestyles. They're not concerned." In another instance, a patient's wife said: "a lot of them just want to sweep it under the rug and not think about it," regarding getting information about preventing cancer.

Some patients were of the mindset that "there's no need anymore because I already have it…I don't know what they could say," regarding receiving CPI after a cancer diagnosis. One 30-year-old bone cancer patient explained how she processed her diagnosis and her thoughts on cancer prevention:

I thought I was gonna beat it, you know, but I guess, and it looked that way, but now I just, I fell into a rut of when I first found out, and now I've learned that I had to deal with it, you know, and I did. But now, it's just, I don't know what to do anymore, you know. It's just at the point to where, like I told my mom, I just want to be with my family and that's it, you know… I was thinking about preventing it when I was doing everything I needed to do. I was taking, doing everything. But now it's like, okay, I'm dying, so why should I do it? I'm just gonna let it go and do whatever. Like I told the doctor, I said, "When God wants me, he's gonna take me," you know, and I told them, "I don't need you to tell me that I'm dying." I said, you know, "I got cancer, you know, cancer's getting the best of everybody now."

This patient later shared that she now knows that prevention is important, but at the time she was resigned to her fate. Her religious tone was relevant for those who remained hopeful.

Hope

Fatalistic thought patterns were noticed by a family member who understood that a cancer patient might think "why are you telling me now about preventing? I already have it," but, she argued:

They need to get out of that mindset and say, 'yes, I want to know,' because you have people that are gonna follow you, which are gonna be other brothers and sisters or

your children or their children, and everybody is at risk of cancer…you want to know

what can prevent it because knowledge is power."

Her statement aligns with what is known about patients who have a high perception of

control of the disease who "significantly more often used any source of information available

to them and were more often interested in additional information on all topics" (Keinki et al.,

2016, p. 612). This marks the shift from fatalism and lack of information seeking, towards

hope and the importance of CPI, especially for future generations. Hope functioned as a form

of emotional support and strategy to manage uncertainty following a cancer diagnosis. One

75-year-old colon cancer patient explained how he manages the uncertainty of his diagnosis

by listening to the advice of his sister:

> She says, "Don't give up. Don't defeat yourself." I says, "I don't. I'm always, you
>
> know, I always stay positive about it whatever the outcome is. I mean, you know,
>
> there's only one doctor that can cure me," I says, "and that's the man upstairs." I
>
> mean here I got medical help here. I says, "They're not doing too bad. They're doing
>
> good." I says, "I don't have any qualms about what they're doing. I trust their, you
>
> know, whatever they do."

He explained that he trusted the doctors and God to help cure him and that he stayed positive

in the face of uncertain outcomes of his illness.

In contrast, some participants had experiences with doctors who did not meet their

emotional support needs during the time of diagnosis. Cultural differences between patients

and doctors emerged as a source of uncertainty and may have decreased the participant's

interest in seeking CPI directly from the provider. The 40-year-old aunt of a patient

explained:

Our belief is, if you have cancer, if you go to a doctor in Mexico and he knows you

have terminal cancer, he's going to meet the family first and tell the family, you

know, 'this member of the family has cancer and we have to talk about it all

together." Then they call the member. And here it's different. Here they just, you just

sit and they say, "You have cancer and this is terminal,'"

She indicated a desire for more compassion and empathy from the doctor during the time of

diagnosis. A 53-year-old Native American male patient shared a similar experience with his

diagnosis:

I wasn't impressed really with [the doctor] per se. He just came out, "You've got

cancer," like it was, like, "you want a stick of gum," you know, kind of like that, but,

it's just, I believe he's Israeli, so, you know, it's just people from different cultures

are different. They're brought up differently and that's all they know, you know. It's

just hard to gauge people just by their etiquette because you don't know what they're

like.

One 62-year-old Hispanic breast cancer survivor suggested navigating and

supplementing doctors through support groups.

There's support groups. I feel the doctors, they're too busy, you know. So get

somebody from your support group, get somebody that's where you're at, that has

breast cancer too or been through what you're going through, you know, that's

willing to buddy up with you. I think it's real important to have a buddy system. Find

somebody…and then it helps you 'cause depression sets in and you don't want to

show the family because they're depressed.

Maintaining hope was also found among online lung cancer support groups, as members of

the group shared needs for hope that "physicians failed to give them hope" and that "losing hope is the worst thing that can happen to a patient" (Ginossar, 2010, p. 5). Other patients sought comfort in talking to others who have gone through similar experiences with cancer. For instance, another colon cancer patient, a 56-year-old man, explained:

> Some of them that's already gone through it has helped me a little bit and just understanding what to expect and not to expect or what they went through and if it's a helpful thing to try something that will cure it that's what I'm all about it. I don't want to hear the negatives though, just the positives.

Staying positive was also found to be an important communication strategy between breast cancer patients and their daughters, according to Fisher (2010), who found that "Across ages, women engaged in positive talk in a variety of ways including reassurance, encouragement, being optimistic, maintaining a positive attitude, sharing survivors' stories, and complimenting one's strength" (p. 398). Lindop and Cannon (2001) found that 97.5 of respondents in their study felt it was at least "important" to have a positive outlook and attitude to their illness.

One family member mentioned that prayer came to mind when asked about cancer prevention. She stated, "Pray. Pray it doesn't happen to you…pray that we don't have it or pray that they don't have it." Prayer became more integral after a cancer diagnosis. Patients and family members considered prayer to be a positive social support. Religion was important to many participants, as they sought comfort in religious support groups, church, and knowing that others cared about their health.

Lastly, two patients mentioned yoga as both prevention and treatment options. One participant, a 53-year-old non-Hispanic White woman with melanoma, explained how

"meditation, stress reduction, exercise, you know, walking to get like your circulatory going, and like yoga and things like that, to like stretch to get that positive energy flowing through your body" were important alternative options for prevention. She even suggested "the Cancer Center to hold [yoga classes] there and that way it's like a central place that people can go and have it be geared for cancer patients so it's not so strenuous." This connection between body and mind resonated with other participants who took a more all-encompassing "self-care" approach to cancer prevention, including stress management, getting enough sleep, and having a positive outlook. One patient explained: "I think that if one can live relatively decent diet and harmonize your emotions and your spirituality to a somewhat passive place to be, I think all those are important factors in preventing it."

Hope also came from mediated sources such as television. Television personality Dr. Oz was mentioned specifically by five participants as a source of CPI, before and after diagnosis. Participants explained that Dr. Oz "says it's never too late to start working on changing diet, exercise, all that, and just the attitude, you know. I pray a lot no matter what's going on, you know. It's to stay positive." Another patient explained how watching Dr. Oz is just part of a larger information environment in which "everybody should be able to look and see and prevent [cancer]" and adds that on Dr. Oz,

> He has a lot of like, preventions on breast cancer and how not to get it or what to do, the foods to eat, what you should and shouldn't be doing… like you have to eat right, exercise, not stress, you know, the normal everyday stuff.

Other advice gathered from Dr. Oz included "I think he said one was to cut down on red meat, I think, so I don't. Once in a while I'll have red meat but not all the time," highlighting the importance of diet and exercise for prevention.

One family member compared the information she received by watching Dr. Oz and Dr. Ramos on television to the information from the clinic. She explained "Stuff about cancer is always all over the news, all over TV… and I don't know how much, how good the information is. I've never really had to worry about it until now." This juxtaposition was highlighted by a 65-year-old Hispanic liver cancer patient, who shared:

I did start watching Dr. Oz and he says something about antioxidants, you know, berries and all this kind of stuff, you could try and this and it would help, you know, something about it would help prevent it before you had it, but I thought, well, if it helps prevent it, maybe it'll help get rid of it or shrink it or something. So I started doing a lot of the things that have antioxidants in it. And he said something about milk thistle and I asked Dr. Lee's assistant about it Monday and he said, "Oh, the boss don't believe in stuff like that," so it wasn't brought up anymore so I don't know.

This quote highlights the tension between hope and uncertainty following a cancer diagnosis. While this patient found temporary comfort and interest in the information she received passively though watching television, she was later faced with more uncertainty about the validity of this information.

Her experience of bringing unreliable information learned from another source to the doctor's appointment is not uncommon. Lewis, Gray, Freres, and Hornik (2009) explained that outside information can complicate or complement physician information, and "both bringing information to physicians and being referred to other sources reflects patients' engagement with health information, preference for control in medical decision making, and seeking and scanning for cancer-related information" (p. 723). Despite perceived interest and

access to television, one participant pointed out that, while she would suggest television as a means to share CPI, noted, "I would say the TV but a lot of those people on the reservation don't have TV so…there's some stuff on TV that they can use but they don't have TV on the reservation like, you know, like I have here."

Participants identified the television as a worthwhile tool to get CPI to people, including even TV commercials, which could be "talking about a way of life and things about these bottled waters and, the sun, they just need to give more information about how not to, or the right way we should prepare and food and water," according to one patient. Furthermore, television content was indicated as a source of information which would then be shared interpersonally. For example, one patient explained that she would have a conversation about "new breakthroughs where it's a positive thing" and that the information is "broad and general information. Whether you're thinking about it or not, it exposes itself." This comment supported the finding that even information gathered passively can still have an impact. Previous research has explored the role of television in learning behaviors and building knowledge, but that "learning occurs only when the message has been processed centrally and, therefore, only in those circumstances when the individual is motivated to process the message" (Dutta, 2007, p.3). Thus, it can be inferred that cancer worry may increase message recall from television.

Need for More Information

This theme addresses the second research question about perception of CPI sources by first focusing on some participants felt their sources of CPI left them needing more information. In addition to various emotional responses, participants identified how their information needs changed following a cancer diagnosis. Most patients shared that they

"wanted to know everything" following a cancer diagnosis. The sources identified by participants often worked together, rather than separately, for meeting their information needs. Those interviewed often shared what they learned with others, relating to the idea of becoming health champions, which is covered in the next section. Reported sources of information shared by interview contributors aligned with what is known from previous research: "Healthcare providers are an important source for information about diagnosis, treatment, and prognosis. However, patients seek cancer information from a variety of sources including friends and family, printed materials, television, radio, and the internet" (Rutten et al., 2016, p. 349).

A cancer diagnosis "triggered a ripple effect" of information seeking and made others "take it serious." Interest in more information often increased among patients and their family members. One 54-year-old Hispanic breast cancer patient explained: "my daughters have, my aunts have now, and probably my cousins have [sought information], too. I think I triggered a ripple effect of them really looking into this, for them to get checked." Furthermore, a cancer diagnosis can spark interest in CPI because "when it happens to one person and they're close to somebody then they're wondering how can they prevent it, or whatever from it happening to them," as shared by one 36-year-old breast cancer patient. This extended to a medullary cancer patient, a 42-year-old Hispanic Spanish speaker, who "wanted to know everything I could find out about my cancer. Of course, I worry a lot about my daughters because they told me that this cancer is hereditary." This patient connects increased cancer worry with increased need of information, leading to active information seeking. This type of informational support can also function as emotional support: "Narratives are effective in communicating cancer-related information and teaching people

healthy behavior…stories can inspire individuals to enact certain behaviors." (Fisher, 2010, p. 406).

Seeking Information Interpersonally

Respondents strongly indicated preferences for face-to-face information gathering. The sources ranged from health care professionals, to family and friends, to support groups. These interpersonal relations often complemented information gathered from other interpersonal, print, or online sources of information. People trust doctors, but there are a lot of barriers to getting CPI directly from them, such as time constraints and understanding unclear explanations or jargon. Because of this, many patients and family members rely on various combinations of CPI sources, particularly interpersonal information sharing and internet information seeking. As a result, doctors *increased* uncertainty by overloading patients with other details, and increased uncertainty by omission of CPI. Information received from doctors needed to be supplemented through other sources.

Disparities regarding the digital divide made this uncertainty about information from doctors worse because patients who did not use the internet had fewer options of where to seek supplemental information, a finding which is consistent with research that has showed "internet-based cancer information seeking is lower among Hispanics than among non-Hispanic Whites…differences attributed to socioeconomic differences such as lower educational attainment, income and English proficiency among Hispanics" (Waters, Sullivan, & Rutten, 2009, p. 483).

Seeking information from doctors, nurses, or community health representatives was strongly preferred by participants. Huerta et al. (2016) found that cancer information seekers sought information more often from a health care professional in 2014 (11.4%) than in 2003

(10.9%), noting an increase in seeking information on the internet between those years. Among interviewed patients and loved ones, information seeking from health care professionals sometimes included CPI, and extended to asking questions about causes of cancer, treatment options, "how long do I have?" or "why me?"

Availability of face-to-face information gathering from a trusted health care provider cut across barriers which may limit someone's ability to seek information elsewhere, such as lack of internet access or literacy skills. This also provided the opportunity to get information specific to the needs of that individual patient. Patients and family members indicated talking to someone was often their first choice for gathering cancer information because they trusted the information. As one 54-year-old Hispanic Spanish-speaking husband of a patient put it, "we have a lot of faith in doctors because they are professionals in their field, and we have a lot of faith in them." Furthermore, when asked where one male cancer would like to get CPI, he stated, "I'd rather hear it from the doctor straight up." For one 36-year-old White breast cancer patient, she would ask her doctor when she needed information:

> I don't have internet or anything else like that, so I mean like that's the only way I would find out anything is through my doctors and if they didn't , and I will have to say about my doctors, if they didn't know the answer, they would find out for me, you know, so I was very appreciative of that.

Noting her limited access to online information, she relied heavily on providers with whom she communicated. A similar feeling was shared by a 50-year-old male Native American cancer patient who didn't seek his own information. For him,

> it was the doctors over there at the clinic where I go, they pretty much set everything in motion for me, you know, what I needed to do, where I needed to go, you know.

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And with the CHR, I guess, over there they have the CHR, Community Health

Representative, they helped me quite a bit and so they referred me to this lady, [gives

name of CHR], Native American whatever for the hospital, so she proved to be a very

helpful person.

Generally, participants indicated they would like to receive CPI information from providers,

but that they have not received CPI from doctors in the past other than encouraging family

members to get checked.

Though face-to-face communication with a professional is preferred, and there is high

trust with doctors specifically, this is not always available as an option. Many times, nurses

were deemed to be more available for providing clear, helpful information. One 51-year-old

male patient explained, "The nurses, like I said, I had no complaints with the nurses. But the

doctors, I guess, need to be more open-minded as far as what the patient has to ask" as means

to get information he wanted to know. An appreciation for nurses was shared by patients and

family members alike, as this patient stated: "I think the nurse actually was on some levels

probably had more time and answered more questions than the doctor really had time to

answer. I mean he did the best he could. He has a really heavy accent so it took me a while to

understand what he was saying." This 46-year-old White family member pointed out several

limitations to gathering information directly from the doctor – including lack of time, and a

heavy accent making his speech unclear for the caregiver. Noticing a lack of time was also

apparent for one 54-year-old Spanish-speaking family member, as he said:

If I asked somebody who is a doctor, not my doctor but I knew that he was a doctor,

and I asked him he would say, "I don't have time to explain this to you." It is

something we can't ask a doctor because sometimes the doctor may even get upset,

especially if he isn't my doctor. I can ask the doctor that I see these questions, I can

ask him, "and how can I take information from this." then he will probably tell me.

But sometimes when we know doctors, we must be comfortable with them before

asking them questions, because an unfamiliar doctor might tell me, "well come to my

office if you want to know about illnesses, pay for a visit and go see me." Something

like that.

This patient's experience highlighted a perceived lack of availability among doctors to

provide information, especially if they were not being paid for the exchange. Her experience

resonated with the findings by Ginossar, De Vargas, Sanchez, and Oetzel (2010), in which

Hispanic women lamented "impersonal, noninformative visits with providers, which they

perceived as disrespectful towards them due to their poverty" (p. 75).

Print Materials

Pamphlets. A very popular print material for information seeking about cancer

generally, and for CPI specifically, was pamphlets. Pamphlets were considered convenient

(as available and accessible) and capable of overcoming language barriers. However, a few

participants felt the information provided in pamphlets was too "introductory" and not

specific enough to their information needs. One participant felt that "pamphlets are a little bit

better than the internet" and that print materials are valuable because "if you have a question,

and you think, wait, I know I saw that somewhere…you can go always go back" to the

materials and find it again easily, compared to trying to find the same online sources again.

Three patients mentioned that pamphlets in the waiting rooms were often "discarded

everywhere" and were "scattered all over," and suggested the doctor hand them out to the

patient while they are in the examination room. One patient explained the convenience of pamphlets as

> good because when you get there (to the clinic), they take a while to attend to you and you can just grab a pamphlet and people will pay attention to that. And if you didn't get to finish reading it you can just put it in your purse and bring it home.

One participant also suggested having pamphlets available in the examination rooms, as wait times can be long.

Pamphlets present an opportunity to overcome language barriers. The Spanish-speaking daughter of the patient who explained bringing pamphlets home with her added: "they should also have them in Spanish, because there are a lot of Hispanics" who could benefit from Spanish-language pamphlets. Language barrier was a major difficulty in participants getting the information they needed, as noted by this patient:

> As an older person, I don't speak English, and that happens with other people as well. We arrive at chemotherapy and there's nothing but English-speaking nurses, up front it's the same thing; how are we supposed to ask them if they have pamphlets or anything? No, we can't. That's the reason we can't find any information.

Her suggestion aligned with language preferences among Hispanics who sought CPI: "Nearly half of Hispanics who sought cancer prevention information did so in Spanish, and the percentage of Hispanics who sought cancer prevention information in Spanish increased over time" (Waters, Sullivan, & Finney Rutten, 2009, p. 482). This patient's difficulty in information seeking was two-fold: she could not ask the English-speaking nurse for materials, and even if she had been able to request a pamphlet, the document would likely have been in English.

Magazines. Like pamphlets, magazines were valued for their convenience in waiting rooms. This location in the waiting room was explained by 54-year-old Hispanic breast cancer patient:

There's the family members that come, and they sit around reading magazines and stuff. I think it would be good to have some information like how can I prevent it, you know, what to eat, cause they're thinking about it and they're all getting checked...

This patient described the value of cancer worry to increase screening behaviors, and highlighted magazines in the waiting room as potential sources of information about getting checked, and to share information about what to eat.

Books. Participants who identified books as a valuable source of CPI explained they could find materials specific to their interests (such as natural medicine), that they were often available at the Cancer Center, and that one could revisit the information. For instance, the 40-year-old Spanish-speaking niece of one patient explained, "I'm always looking on, like, natural books, reading about plants and seeing what plants are good to treat all kinds of cancers. I like natural medicine," regarding her use of print materials for CPI. Another participant shared the value of print materials for a non-internet user such as herself:

The internet can tell you a lot, but to me, I'm not an internet, computer fan, you know. I don't like to deal with that kind of stuff. I mean you can get a lot of information, but I think that if they give you books and stuff to read, you can always go back, cause you question yourself. If you have a question within you and you think, wait, I know I saw that somewhere, you can grab a book and look at it and find it.

The wife of one patient explained that she received some books in Las Vegas, Nevada, upon her husband's initial diagnosis, and that she found some more books at her local cancer center. She found the books helpful because "the information, it was pretty clear. It wasn't like all medical terms. It made it very easy to read and to distinguish." Lastly, the Hispanic husband of one patient suggests for someone to "write a book and tell what things not to do" to prevent cancer.

Materials in the mail. Having CPI materials sent in the mail was considered a convenient option, but many thought others in their families would disregard the documents as "junk mail" and that sending print materials in the mail was not worth the cost. One patient explained email would be the best way to reach the younger people in her family, but that to reach "the rest of them, you'd probably have to have something mailed to them, and I'm not even sure they'd open it and look at it…"

Information Overload and Avoidance

Despite high information needs among family members and patients, and a desire for "knowing everything" at the time of diagnosis, a sense of information overload and uncertainty about information emerged in some interviews as a result of interpersonal information seeking from healthcare providers. One important reason for using the internet was to check or clarify information received from doctors. This approach was useful for both patients and family members.

One 56-year-old American Indian cancer patient said: "They flood you with so much things and appointments and medicines so it's like whoa, whoa, whoa, stop," agreeing with the idea that providers can give so much information that it becomes hard to comprehend it all. This overload effect can be compounded by a doctor's use of medical jargon. One family

member recalled feeling overwhelmed by medical terms and needing to supplement the doctor's input with online sources for a clearer understanding of the information:

> Even if the doctors explain it to you, they explain it to you in medical terms, and you're like, uh, okay, whatever. Then you go home, and you look it up and you're like, 'Okay, now I get it. I understand.' I think on the internet they gave you a little more English terms that you can understand," adding: "I've been in doctor's offices when they're telling me things and I'm just like, I have no idea what you're talking about.

A similar experience was shared by the 27-year-old boyfriend of a patient, who explained that, to seek information, he

> asked doctors, nurses. Like I said, I have some family in the medical field as well. I asked them. If there's any other questions I have that I can't think of when they're around, I can always get on the internet and do a couple searches.

This indicates a preference for talking with someone about questions, and an advantage for those with a healthcare professional in the family. One 53-year-old White cancer patient explained "I always follow up online" when the doctors provide information.

Participants identified benefits and drawbacks to seeking CPI online, including being able to confirm or clarify information received interpersonally; however, low internet literacy could lead to feelings of information overload, and uncertainty about source credibility. Though the interviews were conducted in 2011, most participants were familiar with the capabilities of the internet and knew someone who could access the internet on their behalf. Nonetheless, opinions were mixed regarding the relevance and reliability of information sought online. Overall, fewer than half of all interview participants used the internet to seek

CPI (n=14). More family members than patients used the internet, and many interview participants relied on someone else to access the internet for them when they had a question to look up. There are many barriers to obtaining, understanding and applying the information sought online, and seeking information online also contributed to feelings of information overload.

Digital Divide

Barriers such as a lack of understanding or interest in how to use the internet, a dearth of resources/the cost to get online, an uncertainty about which sources to trust, uncertainty about which information is relevant, and feeling of information overload all emerged from the data. One 50-year-old Hispanic breast cancer patient shared her thought that "I just don't know how to get on the internet…I feel like I don't have the brains for it." A 49-year-old Spanish-speaking cancer patient simply was "satisfied with the doctors' diagnosis," stating that "I don't have access, my son has internet, but I've never tried to go online…I don't want to." One patient's husband explained he doesn't have a computer "because I can't afford one."

Even when one can get online, there are more hurdles to gathering information. Participants struggled with "finding trustworthy sources" and reported being "always doubtful," asking questions like "is it really true?" when finding information online. Other participants less critically reported: "I just assume it's true," without justification. More critical online information seekers, such as the 32-year-old Spanish-speaking family member of a patient, "would verify where that information was coming from, if the information was accurate, when it had been written, all that." Another family member shared that she "didn't want websites that were run by drug companies"; rather, she "wanted websites run by

treatment providers, and top-notch research type outfits as opposed to someone trying to push the next drug that not gonna cure you that's gonna cost a million dollars."

In addition to uncertainty about trustworthiness of information, there was also a reported sense of information overload when seeking information online. Participants felt they struggled to find sources that were specific to their needs, and that were explained in clear language. Between the use of jargon online, and a proliferation of resources, one 27-year-old family member described it as "looking for a needle in a haystack." One patient complained about "so much work and frustration" trying to find information, and suggested having "all the links on one site" instead of resorting to Google.

Some internet-using patients asked doctors questions they were unable to find answers to online. Other internet-using patients used online sources to confirm information they received from doctors. One patient described her post-appointment process: "When you go to the doctor's [office], they do a good job of providing you with information, I always follow up online." In a more extreme example, one 36-year-old Hispanic breast cancer patient switched oncologists after not getting enough information from her previous provider:

> I would ask questions and I wouldn't get straight answers. I would get CT scans and I would Google my information because I wasn't explained what was going on. She would just tell me, well, you're fine, you're stable, we can stay on this treatment. That's fine. But I want to know when I go, what does this mean, you know.

Though a low percentage of total participants used the internet themselves, many of them recognized the internet as a powerful tool to seek information. One 61-year-old White breast cancer patient described feeling empowered by her use of the internet: "It feels good to read, and find out more, and get educated, and it feels good to learn, and even read things that

people have gone through themselves, and you just learn from it." Participants pointed out that internet access was widespread, suggesting that "now everybody has access to the internet," and that "now, I don't think there's an excuse [to not find CPI], because two out of every three homes have computers," according to one 77-year-old Hispanic Spanish speaking husband of a breast cancer patient. For him, going online was even considered "the best source to obtain information," because "they have everything there, for everyone, in every language, so right now I don't see any excuses for a person to say, 'okay, it's because I didn't know, it's because they didn't tell me," and added that "there's so many sources [on the internet] out there when I could find out in a matter of minutes." These participants identified the option to seek information, answer one's own questions, and seek prevention information. Among those using the internet, it was popular to "go to Google and type in 'cancer' and 'food' it's that simple" for one 46-year-old White female family member, and similarly, "I don't remember if it was WebMD, and if not, I think I just Googled 'preventing cancer' and it had stuff like, changing of lifestyles is eating different, sleeping, getting enough sleep, getting the right kinds of foods…" for a 55-year-old female Hispanic family member.

Family Processes of Information Seeking

This final section will address the third research question, which asked about how cancer patients and how family members from diverse backgrounds understand processes of seeking, and barriers to gathering and performing, CPI. Family members played an essential role in helping patients search for information following a diagnosis, provided emotional support, and made changes to implement protective behaviors. Getting information online was often done through a family member proxy, as many patients were unfamiliar with

navigating the internet at the time of the interviews. This shared information seeking responsibility alleviated some of the strains of uncertainty about quality of cancer information and to overcome the digital divide. Additionally, family members shared CPI interpersonally, which often led to considering making behavioral changes. Some participants, however, identified resistance from family members who were not interested in CPI or in making changes to their behaviors. Many of these themes emerged simultaneously when participants talked about family members.

Digital Proxy

Though some participants were able to use the internet themselves, many relied on others in their families, generally children or grandchildren, to get online. There is relatively little research on the importance of accessing the internet for cancer information via a second party. While those who personally sought information online felt empowered and informed about cancer prevention, and about their ability to answer other cancer-related questions, many participants who relied on access to the internet via caregivers or family members felt similarly informed, and went through similar search processes, but felt generally less empowered. One 65-year-old Hispanic patient relied on her husband to navigate the computer: "He is a very thorough person, so he asked [questions] and then he even got on the computer to just confirm what he was told." Similarly, a 67-year-old Hispanic breast cancer patient explained: "I don't touch a computer," noting that her "kids are the ones that, since I don't know about computers, they would go on there and they would come with me to every [appointment]." She would tell her kids what the doctors told her and "they'd look it up real quick."

More specifically about navigating the internet, the 47-year-old White wife of a patient describes how "we just went to Google.com" with her kids to look up information. Though she accessed the internet with the aid of her children, she found the information they found to be "good" and "self-explanatory." A similar experience was shared by other patients and family members, for instance: "I don't touch a computer, but my children look for me," "my daughter will get on it though and my neighbor, oh, he loves to get on his internet. I've got stacks of stuff that he's brought me," and "my wife would look it up on the internet and she would kind of tell me what she had read up on it and stuff." Accessing the internet with the help of another person was also important to overcome language barriers. For example, the daughter of a patient explained

> Since I don't speak English, I ask my son to search for me. The internet has very good information, but we Latinos don't have that much access to the internet because we're a little behind. For the youth all of that is fabulous but it's harder for the older generation. But, I ask my son to look things up for me and then I read it.

By accessing the internet with the help of another person, these participants were still able to reap the benefits of managing uncertainty found among internet users (Rains, 2014).

When some participants spoke about their children helping them get information online, a gendered difference between sons and daughters emerged. It was often the case that daughters were more interested in actively seeking information while the sons were more avoidant of information. This aligns with findings from Lee et al. (2014), who found female gender and being younger were significantly associated with more online health information seeking among a largely Hispanic sample. For instance, a 55-year-old Hispanic melanoma

patient in the present study explained that her two daughters were involved in doing research, while her son was more resistant to seeking information. She explained,

> All three kids are very intellectual, but my two daughters are like me. They like to be informed and they like to have access to information, so they did a lot of internet research. My son is more like in the denial stage. 'You're gonna be fine. There's nothing wrong,'

her son would tell her. This patient explained the help she received from her daughters in finding information, but noted that her son provided more emotional support and positivity, though he was also avoiding information. A 65-year-old Hispanic liver cancer patient shared her experience with her daughter and son:

> My daughter's the one that does. She'll hear something and right away she'll look it up, send it to me or, you know, print it out and bring it to me... She's the one that's more involved with it with me. But like I said, my older son's in denial. He just doesn't really, I guess, doesn't want to deal with it. And my younger one just waits till, you know, after the doctor's visit. 'What did they say? What are they gonna do? What will happen?' And that's about it. But he doesn't really do any research. He'll just wait for us to tell him.

A similar experience was shared by a 62-year-old Hispanic English-speaking breast cancer survivor:

> My oldest daughter is real good about it. She knows how to ask questions and she'll go on and on with the doctors. She likes to go to my doctor visits with me… The boys are, they'll talk to my older daughter because they don't want to talk to me about it.

You know how boys are. They got to put up that front, I think. They feel real macho,

I guess, or whatever.

H ere she explained how her daughter provided emotional and information support by asking

questions with the doctors. Lastly, a 50-year-old breast cancer patient talked about her son,

who was diabetic, and his avoidance of information, both about cancer and about diabetes.

She explained,

You can tell he doesn't really want to know about it. I think he's just scared…Well,

his diabetes, when they diagnosed him with diabetes, he didn't want to know about it

either. He didn't want me to talk to him about it. He would get really, really upset

with me. When I would try to talk to him about it he would throw a fit, you know.

And it had to be my sisters to talk to him about it, not me. He didn't want me to talk

to him about it.

In this case it was his mom as the source of information which resulted in avoidance of

information. The son preferred receiving information from one of his aunts, though the

participant made it sound like even that was still difficult to get through to him. One 52-year-

old Hispanic male cancer patient urged: "don't be so macho. Just go get a check-up every

once in a while."

Becoming Health Champions

Health champions, in this context, are those patients and family members who seek

information and then share that information with others and encourage others to enact

protective behaviors. Related are "community health champions," which are defined as:

... individuals who possess the experience, enthusiasm and skills to encourage and

support other individuals and communities to engage in health promotion activities.

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They also ensure that the health issues facing communities remain high on the agenda

of organizations that can effect change. Health champions offer local authorities and

community partnerships short-term support as consultants, encourage them to share

good practice and help them develop activities to improve the health of local people.

(NICE, 2008, p. 40)

Health champions challenge the traditional top-down approach of information dissemination of health campaigns and can form a lateral network of information sharing among community members.

Some of these health champions function similarly as a digital proxy, but often seek information through a variety of sources, not just the internet. For instance, as participants identified the need to "spread the word" about getting checked, other participants shared experiences of informing and encouraging others to enact preventative behaviors following a cancer diagnosis in the family. This theme aligns with Ginossar, De Vargas, Sanchez and Oetzel's (2010) findings among Hispanic breast cancer patients who became "advocates for the community" to "disseminate breast health information and helping others to seek care, and as motivating others by talking about breast cancer with family and friends, thus overcoming the traditional taboo concerning talking about cancer, and physically assisting women to receive screening" (p. 80). Patients and family members began talking and sharing information with others about what they could do to protect themselves. Some patients even went as far as paying for others to get checked. The duty to share CPI was of particular concern for participants who had children. One 61-year-old breast cancer patient said, "I even told my son, you got to check yourself…I do tell them to continue checking themselves."

Information sharing among family members and friend groups was identified as an important strategy to learn about cancer prevention. This strategy stems from a "learn from experience" way to gathering information, and then sharing that information with others they know. A breast cancer patient said that "asking different people who have had it, or knew somebody that has it or somebody in their family" helped get her the information she needed. Specifically, she asked neighbors, and sometimes went to the veterans' hospital or to a PTSD support group. As a result of her learning from others, she explained the best way to reach her family with CPI was "word of mouth" because "you talk to them and they talk to other people," to create a snowball effect of information sharing. The "snowball" metaphor was also described as a "wildfire" by a 55-year-old Hispanic sister of a patient. As she put it, "the prevention, if you can get that knowledge out to people, that information, maybe they'll change their lifestyles, of how they live and, maybe it'll spread like wildfire." She went on to describe the importance of CPI for the patients, family members and to help others:

> If you don't know the information you're like a person that cannot see. But when you get the information, your knowledge broadens and not only can you help the patient, yourself as a caregiver and a family member, but even other people and other people. And I can tell you right now I have helped a lot of people, even if it's the little bit that I know but it's a lot more than other people know. They know nothing. Because you know why? It's not because people are stupid. It's because you've never gone through it. And until you go through it is when you're forced to get the information and you're either gonna absorb it like a sponge or you're gonna run and hide from it. And that's why I'm saying if this information can, the prevention and the effects of cancer, can be put out starting at earlier ages when you have no, you're not forced

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into learning, then maybe you can actually help yourself and other people be preventive.

She touched on many key points about word-of-mouth information sharing, and the value of learning though experience, and nudged for an earlier start to CPI education for children. A 54-year-old Spanish-speaking husband of a patient shared these values of learning though experience, and explained his ideas about learning and sharing CPI to the youth:

Find people related to this program that are more experienced, talk to them. For example, so I can tell my daughters, my sons, my grandchildren, explain to them a little, because none of our youth is particularly interested in any of this…They don't want to know about their grandparents or parents, if they're sick or not, the kids only worry about video games and the internet. There is a lot of useful information on the internet about illnesses, but the kids don't care about that. We only talk to our kids about venereal diseases, but we never talk about cancer until it happens. I think that the parents need the information first, so that we can pass it on to our children. That's just what I believe.

In another example, a 50-year-old Hispanic breast cancer patient shared her interest in wanting to know how to prevent cancer:

My daughters are young, and my son. They're young enough for us to be able to make a change in their lives right now where they can watch themselves and eat healthier and exercise and, you know, stuff like that, that our parents, like me with my parents, they never really taught us anything like that. It was just there, you know. We never thought about cancer.

She explained the shift from not thinking about cancer to increased cancer worry following the diagnosis, and her hope to help her children make changes early on to protect themselves. This same participant continued:

> I wanted to know exactly what was going on because my girls and my son, you know, my family, they kind of got scared. I did, too. But they kind of got scared and I wanted to be able to answer their questions, you know, questions that they had. But, you know, the doctor and the nurses were real helpful with that.

A 62-year-old breast cancer survivor talked about her family sharing information with her, and with others in their social network:

> My husband is a hundred percent involved. If he hears something he'll share it with me. As a matter of fact, he was telling me last night, he goes, "It is just amazing," he says, "since we found out that you had cancer, how many people at work, you know, have loved ones or know someone who has some form of cancer." And he'll talk to them and compare notes and he'll say, "Yeah, well, my wife is going through this," etc., you know, like that. And then anything my daughter brings us he'll read. And then he doesn't really do much research, except when we're at the doctor's office, you know, he'll read all these pamphlets and stuff, but he doesn't really get on the computer and find out. Or if he hears that something is going to be on TV about cancer he'll watch it.

Her interview highlighted the importance of face-to-face information sharing, which for her also functioned as an emotional support. This finding echoed that of Fisher (2010, p. 402) who found that, among breast cancer patients and their daughters, "although suggestions were often informational in nature, mothers described them as emotional support because it

made them feel better." She also explained how her husband and daughter adopted a multimodal approach to information seeking, rather than relying on a single source of information.

While many female participants identified mammograms and self-checks as an integral part of cancer prevention, only one man mentioned getting a colonoscopy. The 53-year-old brother of a pancreatic cancer patient, who is a prostate cancer survivor himself, explained differences between himself and his brother:

He doesn't do regular check-up and that kind of thing. So his health has always just been a back burner like typical male, his physical. The last thing he wants to do is go to a doctor. But for me, I go to a doctor once every three months, and I see a dentist every six months so, you know, it's just. When you're married your wife makes you do that kind of thing.

This participant suggested a strong gendered difference regarding cancer prevention, and by implication, regarding general health. His statement aligned with the finding from Ginossar (2014) that marital status was a significant predictor of CPI seeking. The patient went on to explain how he worked to challenge these embodied gender differences regarding prevention by taking, and paying for, six of his friends to get checked following his prostate cancer diagnosis:

It's something you need to check and once they get to my age, it's even more important. And there are, there's a lot of guys out there that won't do it. But, I took six guys to UNM to get checked and paid for them to do it because it's important to, you know, it's important to me.

Other health champions took it upon themselves to find information to help manage their own uncertainty in addition to helping others. For instance, a 55-year-old sister of a colon cancer patient explained her process of managing her fears following a cancer diagnosis through information seeking:

> Because of the knowledge that I have found out whether it had been through my own diligence in researching through the internet or magazines or pamphlets here at the clinic, the hospital, in the lobby areas, or just looking around or asking, saying, "Hey, do you have anything on this," and me absorbing that information, I had more knowledge and I feel like I, you know, I'm not as scared and I could help my brother, I could help other people.

She identified three categories of recipients of benefits for her information seeking: herself, her brothers and others. Similarly, a 61-year-old breast cancer patient talked about helping others who were scared and who did not have the resources to find information on their own, particularly among those who were older and those who were Spanish-speaking:

> [It] just depends on the age of the person and the technology that they can have cause some people can't go in the internet. There's some people that you need to talk to, which I've talked to that are Spanish-speaking, for instance, that don't have no way to find out, you know, that I've talked to and they're scared and so it's good to learn how to talk to these people, how to find out things and research…I worked with the YWCA that one time and we were making phone calls. We made phone calls to Spanish-speaking women and reminding them about their appointments or if they needed help financially to be able to get an exam and that. So I think that helps if the

different community has someone that does that, that can do volunteer work or can go

out and talk to these people and help them out.

This patient embodied health championship by volunteering her time to get information to

those who needed it most. She also used a combination of sources of information and worked

to promote Spanish-speaking women in getting breast exams and helping make sure they

were financially able to get the exam.

Reaching Families with CPI

There is a split among family members who want more information and those who

don't want CPI following a cancer diagnosis. The participants were asked to consider

specific strategies to get CPI to their family members. A popular suggestion for reaching

family members with CPI was to do so via online means. Particularly, many participants felt

sending emails with CPI would be effective because it is fast, low-cost, convenient (no travel

or scheduling issues), and has the possibility of including visual aids. Email was seen as

particularly practical for younger family members, but for "an older generation" print

materials would still be preferable. Nonetheless, participants urged the need to educate

younger generations on CPI and indicated email would be more effective than holding a class

at the Cancer Center, sending materials in the mail, or discussing CPI over the phone.

There were also two suggestions for using Facebook, which "can become an effective

space for supportive interaction" and can "benefit users by enhancing their confidence in

managing their own health" (Oh, 2012, p. 2078), to share CPI. One patient, not herself a

Facebook user, described the platform as a potentially useful site for others to find CPI.

Another respondent, a 55-year-old Hispanic family member, suggested that Facebook could

create "a domino effect" of information sharing and could "reach millions of people"; this

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individual also stated that there are comments that "could get the feedback" about the intervention and would entice users who want to know "what was so interesting" about a post. Her vision of information-sharing on Facebook would cover "different kinds of cancer, and the devastation of cancer not only for the patient but for the family members." She also suggested that tweets and YouTube links embedded in Facebook posts would garner interest in CPI among users.

One 55-year-old Hispanic family member suggested teaching prevention in schools: "incorporate this in fun, in schools for these little children. I'm not talking about kindergarten, but I'm talking like mid school." Another family member, a 46-year-old White woman, explained that even though they should bring CPI to schools, she doubted if "anyone's listening to them. It's very hard to get through to younger people who feel good all the time, you know. They're full of energy. They feel great. It's like nothing's gonna happen to me." One participant pointed out that "in Mexico in our town, they offered that at schools," referring to prevention information. Two participants were interested in hearing about CPI in church settings, or mentioned that church settings were important interpersonal settings to share information with others. One individual touched on many key points about word-of-mouth information sharing, and the value of learning though experience, advocating for an earlier start to CPI education for children.

A 54-year-old Spanish-speaking husband of a patient discussed these values of learning through experience, and explained his ideas about learning and sharing CPI to the youth:

> Find people related to this program that are more experienced, talk to them. For example, so I can tell my daughters, my sons, my grandchildren, explain to them a

little, because none of our youth is particularly interested in any of this…They don't want to know about their grandparents or parents, if they're sick or not, the kids only worry about video games and the internet. There is a lot of useful information on the internet about illnesses, but the kids don't care about that. We only talk to our kids about venereal diseases, but we never talk about cancer until it happens. I think that the parents need the information first, so that we can pass it on to our children. That's just what I believe.

He raised many concerns about a barrier to sharing CPI with younger folks due to lack of interest and hoped that his knowledge and experience would be enough to get them engaged and informed about precautions one can take. The above sentiments were shared by a 59-year-old Hispanic male family member who urged, "Get informed and share it with others" as "the only way" to learn about cancer prevention. He also indicated a Spanish language and regional barrier to CPI gathering:

I've been living here in the US for 25 years and the English I know is minimal because here on the border no one speaks English, everyone speaks Spanish, everyone, so we get used to that. But since the information comes from other places, it's in English. I have to search and search through pamphlets before I find one in Spanish, that's hard. And for us, over here in Southern New Mexico, life is so hard because the state has forgotten about us over here.

This difficulty in getting print information in Spanish may be why he put a lot of value on word-of-mouth information sharing to overcome the language barrier. Another family member stated that the idea that word-of-mouth was often better than something in print

because "if I'm sitting there having a conversation with them, they're going to listen to me and talk with me and give me their opinions instead of like throwing a piece of paper away."

Participants also identified innovative interventions to share CPI with family members that weren't suggested by the researcher during the interviews. Specifically, hiring an educator to teach CPI would be effective, and starting to teach CPI in schools and sharing CPI in church would also reach family members who need the information. Hiring an educator was explained as a win-win by one 55-year-old Hispanic female family member:

> I can see a creation of jobs here for people that, you could have people that are trained and educated to maybe schedule an appointment every so often with each patient and sit down and discuss their nutrition and discuss their exercise and discuss their family issues with them, you know. Here we are in this economy slump and, you know, money's tight with everybody for everything, but, boy, wouldn't that create some nice jobs as well as be helpful for the patients and the family.

The benefits would be for both the family members who need prevention information, and for people who need to make a living. This idea was suggested slightly differently by another participant who describes in their rural location in New Mexico:

> Get as much information as possible over to us on this side (of NM), don't forget about us over here because a lot of people die here waiting/hoping to get help but there isn't as much help here as there is over there. At least send us a lot of information and show us the possibilities of going to get medical attention over there because there are a lot of poor people and there isn't any help here but there is over there. In my area, like I said, I think it would be very important to get information to us, be it through clinics, get-togethers, whatever, just something to inform the people.

Tell them to pay you [the interviewers] all a little bit more and send you over her to

give us some classes. Too bad I couldn't talk to your boss. You can take a vacation

and come over here and give us some classes. Tell them there's a big need for

information and everything out here because we're very disconnected.

This 59-year-old Hispanic male family member recognized a wide variety of information and

support needs that were not being met.

Sources That Will Not Work

Though most suggested sources faced some resistance and some acceptance, there

were some options that were widely rejected. Calling people on their cell phones was not a

popular idea because people mostly ignore calls (they think those calls are spam or

telemarketing), people do not have the time to sit and talk about all-important information

(too busy), and people would not take notes. Classes at the Cancer Center were perceived to

be a good option for patients (who are already physically there, but they doubted family

members would take the time and travel to get there for a class or support group). Support

groups faced similar doubts about time and travel commitments, as well as being framed as

"too negative" to be productive in the cancer journey.

Other Health Issues Prevent CPI Seeking

There were many participants with family members who had illnesses other than

cancer. In some cases, these other diagnoses helped a family make changes and enact cancer

prevention behaviors. In other cases, however, the non-cancer diagnosis would take

precedence over the cancer diagnosis and was used as a reason that a family member would

not be interested in CPI. For instance, the 56-year-old Native American colon cancer patient

identified his brother as a family member who was not interested in learning how to prevent

cancer because he was "in depression. He's shut down for right now…he has his own issues." This framing shifted the focus away from CPI toward other pressing concerns about his brother's mental health.   Similarly, the 72-year-old Native American breast cancer patient identified her sister, who was diabetic and on dialysis, as not interested in CPI:

> She's not really interested in anything at all. I hate to say this but, you know, since she's been on dialysis she doesn't do very much. And then when she had that heart attack in July, it's even worse because sometimes she's not with it or she's, and right now she's waiting to see the eye doctor because I think she has cataracts and she can't really see that well, so she doesn't really talk to me about it or she's not really interested in [CPI].

Her sister's amalgamation of health issues resulted in the sister avoiding information about making changes.

Family Processes and Barriers to Behavior Changes

Though there were many instances of a cancer diagnosis sparking information seeking and interest in adopting protective behaviors changes in a family, there were also many instances of resistance to change within a family. Shared decision making regarding adopting protective behaviors (such as screening) might be seen as "community-level issues…involving the larger Hispanic community" (Ginossar, De Vargas, Sanchez, & Oetzel, 2010, p. 81). Participants were informed about what changes they should make, but identified barriers to making these changes, such as cultural dietary habits, costs, and lack of interest, and other health issues which took precedence among those in their direct support networks. It emerged that after a cancer diagnosis in a family, the surrounding environment and those in the support network may or may not want to make changes.

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In addition to changes in her own cooking, a 47-year-old Hispanic wife of a Native American male cancer patient noted she that she tried to "eat cleanly," but she identified struggles to sustain dietary changes with those in their extended family:

> My husband's Native American and of course they like to eat mutton and soak the bones and they eat a lot of fat. And sometimes when they come over here and they want to visit and they think they're being all nice and they make these things that my husband shouldn't be eating and, yeah, there should be changes.

This example speaks to the importance of social support networks throughout the cancer journey, as well as in the cancer prevention processes. Though there may be information available to a patient and their caregiver, this information may not be enacted upon due to lack of desire to change, as well as cultural and economic systems that restrict access.

In order to overcome some of these difficulties, patients and caregivers often negotiated a balance between what foods they knew to be "healthy" with foods they "grew up with" that they "absolutely love[d] to have." For instance, a 55-year-old Hispanic sister of a cancer patient explained "we allow ourselves every so often" to eat the foods, such as tamales, that they had been informed by a handout to avoid. This stance was shared by a non-Hispanic White woman who was the primary caregiver for her husband's uncle with pancreatic cancer, who felt it was important to be realistic to "maintain a healthy lifestyle, but not denying yourself all fun all the time. There has to be some chocolate cake in there and a beer once in a while."

For one 56-year-old Native American colon cancer patient, it was easy for everyone in his family to change their diet because "my mom sets the table" and that his mother was "a

kitchen manager…usually you have respect for her kitchen." As a result, the whole family began eating:

> more salads, less red meats, meats and no sugars and just more of a health, more healthier foods of a diet that prevents it, you know what I mean, and just like you try to, you try to cure yourself the best cause it's a terrible feeling to be sick.

It was particularly important for this family to make dietary changes because the patient's father had diabetes as well.

Though diet and exercise are two different things, they were often mentioned together under the umbrella of self-care. Exercise was loosely defined by participants but included facets of health such as weight management and an overall healthy "lifestyle" which tied in with removing junk foods from the house, and discussing nutrition with family members to decrease the likelihood of a cancer diagnosis. Exercise was more feasible for the children of patients and caregivers who were more physically able than for those with a cancer diagnosis, as their physical capabilities may have been hindered by treatments. For instance, one 63-year-old White male lung cancer survivor noted his children would be very interested in CPI because they were "very healthy and they go to the gym a lot and they're always looking into diet and what's the best thing to controlling, maintaining good health."

For current or former patients, it was necessary that exercise be lower impact. For example, a 72-year-old Native American breast cancer patient began walking more after her diagnosis. She described how she "just had to look at myself and had to think, you know, what can I do to start getting myself motivated to start losing some weight and change my diet and cut down on certain food," after her diagnosis.

Resistance

Though many participants explained ways in which their families changed for the better, several participants faced resistance from family members who did not want to make changes. This resistance formed a barrier for the participant themselves to make desired changes. Past research has shared reasons a person may resist cancer-related prevention behaviors such as "lack of perceived self-efficacy," and "because they are unconvinced that screening can actually save their life" (Kreuter et al., 2007, pp. 223, 224). Among those interviewed, one 72-year-old Native American breast cancer survivor explained that:

> I try to make changes for myself and I also try to make changes for my sister, but my sister's kind of really stubborn. She didn't like the stuff that I would prepare for supper or something like that. She would rather stick to her ole, you know, red meat and all that stuff and she's not supposed to, well, she's diabetic, she's on dialysis and she's not supposed to eat certain foods and she craves for that food. And I'll try to switch it over to something else and she doesn't really care for it. She'd rather have her daughter-in-law bring food from her house, which, her cooking is, different, from mine.

This participant identified her sister, who has diabetes, as resistant to change, despite it being in her best interest. The patient added, "I think I changed a lot…I would like my sister to make some changes, but she won't, she will not, not, not change." Her sister's resistance to change also presented a barrier to getting CPI to the sister.

Aside from dietary changes in a family, addressing smoking habits was faced with strong resistance. A couple of participants recognized that smoking caused cancer yet continued to smoke. Family members and patients who continued to smoke after a cancer

diagnosis tried to negotiate the dissonance of their knowledge and their actions by explaining that they didn't do it around other family members, or that they were trying to cut back or quit. For example, a 50-year-old Native American sarcoma patient shared that his son would address him and his mom, urging, "hey, mom, you need to stop smoking," and "oh, dad, you better not do that. It might cause cancer," and adding: "I don't like talking about it because my wife, she's kind of, she gets upset when we talk about it. I'd rather not talk about it though." In this case the participant expressed avoidance of information that caused him and his wife discomfort about their smoking habits.

Table 2: Overview of Findings

RQ1: Describe CPI behavior before and after diagnosis	Uncertainty Management before Diagnosis	Conceptualization of CPI → Concrete / Abstract Protective Behavior as Broken Promise Invincibility Prevention Behavior and Information were Unattainable
	Uncertainty Management after Diagnosis	Cancer worry Fatalism Hope → sources of hope, positivity
RQ2: Perceptions of sources	Need for More Information	Seeking Info Interpersonally → supplement info from doctors Print materials
	Information Overload/ Avoidance	Digital Divide → uncertainty about information
RQ3: Understand CPI processes and barriers	Family Information Seeking Processes	Digital Proxy Health Champions Reaching Family with CPI → Sources that will/will not work; other health issues blocking CPI seeking
	Family Processes and Barriers of Behavior Changes	Accepting behavior changes Resistance to behavior changes

The next chapter will review principal findings of the interview analysis, address practical and theoretical implications, review study limitations and suggest directions for future research and interventions.

Chapter 5: Discussion & Conclusion

This thesis sought to examine CPI perceptions, needs and behaviors among a predominantly Hispanic, low-income and low-education, through a thematic analysis of narratives of cancer patients and their family members. The study was motivated by the importance of understanding this phenomenon, in view of its importance to the health of this population. The interview analysis resulted in several important findings that can advance understanding of information behavior in this population and may have practical implications for future interventions in distributing CPI, particularly among Hispanic cancer patients and family members, and among those who do not seek information online. The analysis provided insight to uncertainty management of participants, from conceptualizations of cancer prevention before and after a cancer diagnosis, perceptions about sources of CPI, and processes and barriers to CPI among cancer patients and caregivers/family members from diverse backgrounds. Though most people in the United States have access to the internet, there remains a non-digital population whose members face disparities in cancer treatment and prevention information, and many who struggle with the literacy demands of online health information environment. This thesis contributed to a better understanding of how cancer patients and family members from diverse backgrounds use digital and non-digital sources to learn about, and share, CPI.

In this final chapter, the findings of the analysis will be synthesized, implications of the findings will be discussed, and the limitations of the study will be addressed.

Principal Findings

The overarching finding from the interviews was that participants felt cancer prevention was important for everyone, especially for family members of those with a cancer

diagnosis. Though there was a shared understanding of what includes cancer prevention behaviors, self-efficacy, Hispanic and Native American cultures, and socioeconomic status influenced perceived ability to adopt and sustain a healthy lifestyle (diet and exercise), to quit/avoid smoking, and to get annual checkups. Participants shared feeling uncertain about CPI before and after a cancer diagnosis. Many had not actively sought CPI before there was a cancer diagnosis in the family, and only began to do so when cancer worry was increased after the diagnosis occurred. While there were some proactive participants who actively sought CPI before a cancer diagnosis, this was not the norm, as not all individuals were "able to seek information or to act on their preferred information sources" (Ginossar, 2016, p. 8). Disparities among this ethnically and socioeconomically diverse sample demonstrated a "double divide" of "blocking those who need this information the most from accessing it" (Ginossar, 2016, p.8). Furthermore, these active information seekers were also members of families with other chronic health conditions, including prior cancer diagnoses, making them aware of their own risk and increasing cancer worry. Other participants passively learned CPI through television, or though conversations with family members, but very few had talked about cancer prevention with a doctor or had actively sought CPI online before it "hit close to home." Furthermore, cultural beliefs such as the idea that "we are all born with cancer" and that prevention does not really work were related to information avoidance and risk denial, despite research showing that 4 in 10 cancer cases and deaths are linked to modifiable behaviors (Mendes, 2017). Those who resorted to faith and prayer for prevention would not receive the benefits of enacting other protective behaviors.

The analysis showed that having *knowledge* of prevention behaviors does not always indicate the *performance* of said behaviors. Despite a shared understanding across

demographic groups of self-care, screening and checkups, not smoking, and uncertainty about prevention, there were many specific barriers related to culture and socioeconomic status that blocked enacting prevention measures. This finding connects to the barriers to making changes that were reported by these interviewees, particularly cost and economic strain. For instance, several participants identified not smoking as a practice to prevent cancer, yet were smokers themselves. In some of these cases, the barrier to quitting was the cost of cessation aids like nicotine gum or patches. Cost barriers also manifested in accessing the internet. Though some participants who were offline indicated they had no interest in getting online, others felt that if they had the resources (such as a computer and an internet connection), they would be inclined to learn how to seek information though these means. Perceptions of costs as being too high were associated with screening behaviors, and with changes in diet and exercise, as shown by some participants believing they could not afford fresh fruits, vegetables, or organic produce.

Some other important findings concerned the framing of prevention behaviors. Many behaviors were described as avoiding something, such as in one's own diet, exercise, smoking, and sun protection. Participants explained they "should not" eat certain cultural foods that were too fatty or greasy, they should not smoke, they should not be out in the sun for too long, etc. These behaviors were framed as individual responsibilities. This attitude was also applied to getting annual checkups or screenings, and while one person in the family might urge someone else to get checked, it was seen as being up to the individual to actually follow through. However, the ramifications of extended family not partaking in prevention behaviors became apparent, for example, when one family member made dietary changes after her husband was diagnosed while other family members continued to cook unhealthy

food, which didn't align with the changes the wife was trying to make. This highlights the importance of environment and understanding cultural practices in making and sustaining behavior changes.

Regarding the second research question, which asked about perceptions of CPI sources, the analysis revealed that people used a combination of sources to fulfill their information and support needs. It was more commonly reported that more than one source and different channels of information were used than it was reported that a single source could answer all the questions an individual had. These source combinations served to check information gathered interpersonally (such as from a doctor) on the internet, or vice versa; asking a relative to help answer a question by using the internet; a patient asking a doctor about information she heard on television; learning about something in a support group and using that information to ask better questions to the doctor. Few participants had complete faith in the information provided by their doctors and didn't seek additional information. Though healthcare professionals and providers emerged as a central source of information, they were not sufficient to meet all information and CPI needs, and often contributed to feelings of uncertainty. Participants recognized the limitations of individual channels of information, and thus utilized multiple sources of CPI. As a result of learning though various sources, participants' understanding of what CPI entails often included a combination of behaviors. In this vein, health champions emerged as leaders in information seeking and interpersonal information sharing. Health champions may be important to cut across language and access barriers related to the digital divide as they can provide information in an understandable language (in the sense that there is no medical jargon, and in the preferred language such as English or Spanish). Furthermore, health champions sharing personal

narratives and "learning from experience" with cancer was highlighted as an important quality for an information source to have.

Theoretical Implications

This research sampled diverse populations to address gaps in studies on the topic. By hearing experiences of predominantly Hispanic and/or lower SES patients, the context of cultural norms and practices impacting CPI seeking and behaviors were highlighted. Specifically, this thesis accounted for diversity in English language proficiency, filling an important gap in the literature. Finally, a qualitative approach was used to add depth to the many quantitative studies on the topic.

Learning and enacting cancer prevention is a complex and interconnected process between mediated sources and interpersonal information sharing. The definitions of "cancer prevention" provided by the participants varied, yet shared understanding of healthy lifestyles, getting checked, and a sense of uncertainty to their effectiveness cut across demographic lines. The ways in which participants learned these meanings, however, varied greatly between those who were active information seekers before or after a cancer diagnosis, and those who were passive information seekers. Inequalities in seeking health information and CPI based on socioeconomic and ethnic/racial-based characteristics have been linked to disparities in health outcomes (Ginossar, 2014), and this research has helped fill in some gaps in the literature about information seeking of patient and caregivers from diverse backgrounds.

An important theoretical implication from the analysis is the emergence of health champions and digital proxies to accessing information. Health champions appeal to the preferences of face-to-face information seeking shared by many participants and can

overcome language barriers and literacy issues. Furthermore, health champions encourage protective behaviors and increase self-efficacy, which may trigger a ripple effect among others to seek more information and to encourage others to enact prevention measures. Similarly, those who identified a digital proxy, or a person who accessed the internet on their behalf, experienced similar benefits of knowledge building and managing uncertainty. This approach to information seeking, too, overcame barriers related to the digital divide, such as the cost of a computer and internet connection, managing information overload and uncertainty about information quality, and navigating translation and low literacy. Previous literature has focused on individual attitudes and behaviors of information seeking, thus this presents an important step forward.

It is important for information sources to work together to create a support network for those patients who have lower literacy skills, who do not have access to a computer or an understanding of how to seek information online, or who face language barriers when having to deal with print materials not in their preferred language. Behavior changes were framed as a shared responsibility in the interviews and were related to environmental and cultural factors. Resistance to change was also connected to cultural, environmental and socioeconomic barriers.

Other barriers, such as an unhealthy environment (cultural diets, second-hand smoke), cost barriers and resistance to change also need to be addressed. Taking a holistic approach to cancer prevention goes beyond targeting the individual level behaviors and works to change the context in which patients live. Interventions and information must seek to go beyond sharing knowledge to sharing strategies to enact that knowledge. Support can be informational, emotional, and enacted, each of which are important in cancer prevention.

This may reflect a cultural value among the predominantly Hispanic sample of the interview participants. There was a sense of shared responsibility for caring about the patients, and about getting information to younger members in the family to educate them about preventing cancer for themselves. Nonetheless, results of this analysis revealed that information-seeking and CPI in particular is a shared task and is often not solely in the hands of one individual. This supports what is known from previous research and extends it to the current sample.

Practical Implications

In order to best reach people with CPI, a multi-pronged approach, including interpersonal and mediated sources, would be ideal. Many participants preferred receiving information from a face-to-face source, and specifically from a trusted health care professional. However, when questioned about which strategies would be most effective to reach family members with CPI, interpersonal sources were rated as below mediated sources such as going online, checking emails, watching television or reading print materials. Each of these channels came with the understanding that there will always be barriers to receiving, understanding, and applying the information being disseminated. For instance, a doctor might not have the time to explain prevention strategies to a patient or family member, or they may not have the language to explain information in words a patient can understand and remember. For some, this barrier could mark the end of the information-seeking road. Without the necessary understanding, or self-efficacy, to access other sources, some questions may go unanswered. It would be practical to target interventions towards those who presented themselves as health champions. By ensuring that information reaches an individual who is known to share what they learn with others, a snowball effect will occur.

This, too, will help overcome barriers to information for those who do not seek information themselves. Some participants identified themselves as the best channel for sharing CPI to others in the family, and that hearing prevention information from someone with experience with cancer was valuable. Thus, strategies for those who learn and make changes to share that information with others they know can allow for a discussion of family history and genetic implications of cancer.

These findings point to a potential need to re-frame "cancer prevention." This must occur in two parts. First, "prevention" needs to be framed in less certain terms; among this sample, "prevention" implied that enacting certain behaviors can guarantee a cancer-free life. This idea, that successful prevention will yield a null result, caused uncertainty about prevention among study participants. Cancer patients who felt they had done "all the right things" but still ended up with a cancer diagnosis would probably be less likely to enact preventative behaviors again the in the future because they didn't work the first time. By re-framing cancer prevention in ways that are more neutral and more honest – for example, by using the term "cancer risk reduction" -- allows for room for instances in which someone can eat healthfully, perform annual screenings, and not smoke to continue these practices to decrease the chances of a reoccurrence of cancer. "Nearly half of U.S. adults" agree that it seems everything can cause cancer, that there aren't many ways to lower chances of getting cancer and that there are so many recommendations it is "hard to know which ones to follow" (Niederdeppe, 2010, p. 230) thus this step is crucial to increase efficacy and understanding of performing protective behaviors.

Second, based on the interviews, it could be important to frame preventative behaviors in a positive, rather than negative, light, particularly in reaching those with a

cancer diagnosis in the family. Shifting language about prevention behaviors away from negative or punitive verbiage, to a more positive and encouraging approach, could be more effective in encouraging long-term adoption of protective behaviors. One way to do this, for instance, would be rather than saying "you should NOT smoke cigarettes," the targeted behavior should show the benefit of making that behavioral change, such as keeping one's children safe from the effects of secondhand smoke. Many participants shared the importance of "staying positive" throughout the cancer journey, and this should be reflected in cancer prevention information as well. Furthermore, because of the "invincibility" factor among those resistant to change and performing preventative behaviors, a focus on helping others, rather than themselves, may foster a new way of thinking about a habit. This idea is supported by other research (Niederdeppe, 2013) which shows the power of positive frames on prevention behaviors. Furthermore, the shared roles of information seeking among family members and patients may inform future campaigns which can encourage interpersonal and intergenerational CPI seeking and sharing. Utilizing a positive frame will encourage change and can still preserve the serious nature of cancer prevention communication. This may enhance interest among those who avoided cancer information.

Participants shared a desire for a single source to help identify trustworthy, plain-language, multi-translated, materials online. It may be worthwhile to develop a pamphlet with tips on what to look for in a digital CPI source. To take it a step further, it may be important to inform and encourage health championship among internet-using family members and caregivers of cancer patients. Interviewees' experiences supported findings from Rain (2014) that showed internet users were better able than non-users "to achieve the level of uncertainty that they desired."

Limitations

While this thesis has covered important ground, there is still room for improvement. A major limitation of this study is that the data was collected in 2011, eight years before the analysis was conducted. Because of the timing of the data collection, the interviews did not cover the emerging importance of mobile phones, allowing for internet access from the palm of one's hand. This also limits the potential to discuss the use of apps in disseminating CPI. The year of the data collection may also be reflected in the relatively few participants who reported using and having access to the internet (n=14). In the years since the interviews took place, seeking information about health online has expanded to include most internet users. Further, the rise of smartphones is related to this effect. The other limitation connected to the timing of the interviews is that member checks could not be performed. Though they are often ideal, it was not feasible in this case.

As an individual researcher working on this thesis, there is no inter-coder reliability for the categorization and organization of the interview data. I recognize my biases in deciding what information to deem pertinent or not. Had there been a second, or even third, member of the team, the resultant categories, themes and selected examples to defend these points would likely have been different.

Future Directions

This thesis has replied to calls for more understanding of cancer information seeking among diverse populations, but the conversation does not stop here. This thesis only captured a single moment in time, thus a longitudinal approach should be considered in future study designs to best capture the ever-changing needs and information seeking practices of those with lower SES and individuals who are not English speakers. Furthermore, conscious efforts

should continue to be made to represent Native American populations in study samples, as the needs, prevention practices, and preferences of CPI seeking among this group remain largely unknown.

Future interventions to deliver CPI should adopt a multi-pronged approach, utilizing interpersonal and mediated sources. It would be practical to target interventions towards those who presented themselves as health champions and to use a positive message frame. Encouraging health championship among internet-using family members and caregivers of cancer patients will increase reach of CPI. It may be worthwhile to develop a pamphlet with tips on what to look for in a digital CPI source. Future research should examine the balance between digital and human elements of information seeking and sharing among the populations who experience a high need for CPI.

Appendix A: Interview Questions

Introduction: name, role in the team.
In this research, we want to understand what type of information patients and families need about cancer. We also try to understand if patients and their families would like to know more about how to prevent cancer.

1. Demographic questions from survey- go to Q#9: marital status and confirm, talk about who is in the family (children, their ages, do they live at home? Nearby?)
2. Where do you live? (name of place, not full address)
3. Please tell me about your (or your family member's) diagnosis- how were you diagnosed with cancer?
4. When you were diagnosed, what type of things did you want to know?
5. At the time of diagnosis, were there things you did not want to know?
   > if it has been awhile after diagnosis:
   > What are the questions that you have now (probe- what type of things you would like to know) (probe: is it different than what you wanted to know when you were diagnosed?)

In this study, we are particularly interested in how the family and different family members use information. Can you tell me a little bit about your family? (probe-marital status, children, ages of children) anyone else is involved, like sisters and brothers?

6. How did different people in your family feel about information- did they want to know different things?
7. What type of information do you think people like you should know about cancer?
8. How did you find information when you needed it? (Probe: can you give me an example of a question you had, and how you found information?)
9. What can be done to help people like you receive the information they want to know?
10. When a person is diagnosed with cancer, some people want information about how to prevent cancer, and others do not want such information. We want to learn more about what type of information you want, and if you wanted information about preventing cancer.

11. When you think about cancer prevention, what is the first thing that comes to mind?
12. How important is cancer prevention? (Probe- who is it important for?, should people like be thinking about how to prevent cancer?)
13. After the diagnosis (of your family member), did you feel that you wanted to know about how to prevent cancer? (Probe- what did you do to know more? How did you feel?)
    –if it has been over 6 months: ask if they are interested now.

14. Did you, or someone in your family make changes after diagnosis, trying to prevent having cancer?
    If yes- what were the changes, how did they make the decision, what made it possible?
    If no- probe- do you feel that there are things you can do to prevent cancer? is it hard to make these changes? What are the difficulties? What can help you?

Are there other people in the family that should make changes?
Probe- are there family members who smoke? Are they interested in quitting? Have they tried?

15. Do you think that doctors or nurses in the cancer center should talk to patients and family members about preventing cancer? Would it help you if they did?
16. Is there information about preventing cancer that you think you should know, but were not able to get this information? (probe: Can you think of a time when you wanted to learn about how to prevent cancer, and were not able to do so?- what did you want to know)
17. Can you think about times when you were successful in finding information about how to prevent cancer?
18. As I mentioned, we are interested in how family members need information. Do you feel that your family members are interested in getting information about preventing cancer (what makes you think that- do you talk about it in your family?)
19. If the staff at the cancer center were to provide information to you and your family about preventing cancer, what type of things you would like to know?
20. What would be the best way to reach all your family with information about how to prevent cancer? (if do not mention- how about: information over cell phone, meeting/classes at the cancer center, support groups, mail, pamphlets in waiting room- for each source ask why or why not would work for the family
21. When you think about your family, are there people that would be more interested in learning how to prevent cancer? (probe-can you tell me who they are and why they are interested)
22. In many families there are people who are not interested to learn about how to prevent cancer. is there someone like that in your family? Can you tell me about them?
23. Is there anything else that you would like to share?

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