

HEALTH INFORMATION SOURCES THAT DEAFENED ADULTS WITH HIGH
PERCEIVED RISK OF CANCER TRUST AND USE: A PILOT STUDY

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DEDICATION

This dissertation is dedicated to several beloved people in my life.

First and foremost, I want to dedicate this dissertation to my parents, Katie R. Hinson and Richard W. Hinson. Mom and Dad, I did it! Thank you for being my greatest supporters and for your unconditional love through my entire higher education journey. Because you raised a confident, stubborn, and persistent daughter, I was able to achieve a life goal.

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ABSTRACT

AMANDA M. HINSON-ENSLIN

HEALTH INFORMATION SOURCES THAT DEAFENED ADULTS WITH HIGH PERCEIVED RISK OF CANCER TRUST AND USE: A PILOT STUDY

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Goals of *Healthy People 2020* aim at increasing information about health information-seeking behaviors (HISB) and decreasing cancer morbidity and mortality rates. Few studies identify which health information (HI) people trust and use. Additionally, studies are being directed toward HISB of individuals with varying perceived cancer risk (PCR) to better tailor HI. However, most HISB pertaining to PCR focuses on mainstream populations and not medically underserved populations such as the deafened. The purpose of this study was to examine: (a) HISB of deafened adults with high PCR, (b) which HI sources deafened adults with high PCR trust, and (c) whether there is a relationship between high PCR and HISB among deafened adults. Data from the English version of the Health Information National Trends Survey (HINTS) 4 Cycle 3 were analyzed. Frequencies were calculated from HINTS 4 Cycle 3 survey questions. Correlation analysis was used to examine relationships between high PCR status and the various trusted HI sources. A significant correlation coefficient (Pearson's r) with p set at .05. Of the 229 self-identifying as being deafened or having

serious difficulty hearing, 46 noted having high PCR. Additionally, over 95% of deafened individuals with high PCR noted they spoke English. In their latest HI search, participants reported that they first accessed HI from the internet (28.3%) followed by healthcare professionals (21.7%). Overall, deafened individuals with high PCR reported their most trusted HI sources were doctors with a cumulative percent of 97.8%.

Pearson's r indicated no significant relationship between PCR status of deafened individuals and degree of trust in HI sources with p set at .05. This study adds to the body of knowledge about the HISB of deafened adults with high PCR and indicates that doctors should be culturally sensitive when communicating with the deafened population. Health educators and health communication specialists should aim to create accessible HI sources for all deafened individuals, including those with high PCR. Additionally, health education and health communication programs should partner with internet cancer HI sources to provide accessible cancer HI for deafened individuals, including those with high PCR. Future research should include a larger sample.

Keywords: deafened, deaf, Deaf, hard-of-hearing, health information-seeking behaviors, health information, cancer health information, cancer, perceived cancer ris

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CHAPTER I

A goal of *Healthy People 2020* is to devise methods to obtain data on health information-seeking behaviors (HISB) in order to improve health outcomes, advance the quality of healthcare, and close the gap of health inequality (U.S. Department of Health and Human Services, Office of Disease Prevention and Health Promotion [USDHHS-ODPHP], 2017). Collecting HISB data allows health educators to develop and deliver health information (HI) that is tailored to underrepresented groups (USDHHS-ODPHP, 2017). According to the National Network of Libraries of Medicine ([NNLM], n.d.), the ability to effectively retrieve and understand credible HI is an important health literacy skill. Health literacy has been defined as “the degree to which individuals have the capacity to obtain, process, and understand basic health information and services needed to make appropriate health decisions” (Ratzan & Parker, 2000, p. v). Health literacy is inextricably linked to health and quality of life. For example, individuals with low health literacy often experience poorer health and are less likely to use preventative healthcare (Institute of Medicine, 2004). Low health literacy is also associated with chronic disease and negatively affects cancer incidence, mortality, and quality of life (NNLM, n.d.). In addition to increasing health literacy, *Healthy People 2020* has another goal to decrease cancer morbidity and mortality rates because cancer is one of the leading causes of death among Americans (Centers for Disease Control and Prevention [CDC], 2016a; USDHHS-ODPHP, 2017). Because of the high rates of cancer and the possibilities of

obtaining HI, research has been aimed at the HISB pertaining to cancer-related HI and cancer HI. Studies of HISB have found that people use HI and cancer-related HI to decrease stress, enhance an individual's ability to cope, increase knowledge about diseases, and raise awareness about the need for social support (Fox, 2011c; Fox, 2014; Fox & Duggan, 2013; Karras, 2010; Robinson & Tian, 2009; Seçkin, 2011; van der Molen, 1999). Further research of HISB has focused on the perceived cancer risk (PCR) of individuals and how it impacts their HISB and their use of HI sources. For example, Amuta, Chen, & Mkuu, (2017) have found that PCR can predict HISB (i.e. individuals with high PCR are more likely to search for HI than those with low PCR). However, most research concerning PCR and HISB focuses on mainstream populations, which leaves a dearth of research about HISB and cancer HISB among the deafened.

Several factors influence HISB, and some of those same factors can also present barriers for the deafened population. For example, language proficiency, English literacy, and regular exposure to HI all impact individuals' HISB. However, deafened individuals who do not have access to English earlier in life often have limited English proficiency and low English reading levels, which puts them at risk for health disparities associated with low health literacy (Pollard, Dean, O'Hearn, & Hayes, 2009; Zazove, Meador, Reed, & Gorenflo, 2013). This is further compounded by the fact that most HI in written format (including captioned TV and the internet) is targeted toward those with a reading level of seventh grade or higher (Freda, 2005), whereas the average reading

level for deaf adults is approximately the 4th grade (Cawthon, 2004). Even HI that is not in written format can present difficulties. Smith, Kushalnagar, and Hauser (2015) found that some deaf adolescents face significant challenges in accessing cardiovascular HI through five main sources—family, health education teachers, healthcare providers, printed materials, and informal sources. In addition, Smith and Chin (2012) pointed out that not only are some deaf individuals underexposed to HI, they are also underexposed to environmental stimuli that might serve as cues to seek more HI and enhance their health knowledge. For example, Simons, Moreland, and Kushalnagar (2018) suggested that low health literacy and poor communication between the patient and physician might prevent Deaf individuals from adequately understanding their diagnosis of hypertension. Issues such as this raise concerns as access to HI contributes to deaf individuals' health and quality of life (Kushalnagar et al., 2014).

According to Volkman et al. (2014), over 50% of U.S. adults accessed the internet as their first source of HI, followed by 12% who first sought HI from their healthcare providers. On the other hand, studies of d/Deaf adults' HISB pertaining to sexual behaviors, sexually transmitted diseases, flu shots, and doctor visit satisfaction revealed that these individuals consulted their parents and Deaf friends for HI (Bukowski, 2015; Karras, 2010; Karras & Rintamaki, 2012). A number of Deaf adults also expressed skepticism of the quality of HI on the internet and were dissuaded from searching for HI on the internet due to language barriers (Karras, 2010; Karras & Rintamaki, 2012). Even

with high self-reported literacy levels, some deaf individuals are more likely to find HI online but have limited understanding of medical vocabulary and can become overwhelmed by medical jargon (Smith et al., 2015). This difficulty hinders their understanding of health issues such as cancer, impetigo, colitis, and cardiovascular disease, which can negatively impact their understanding of the progression and prevention of such health issues (Berman et al., 2013; Folkins et al., 2005; Pollard & Barnett, 2009; Smith et al., 2015). Moreover, difficulty in understanding medical vocabulary has the potential to negatively affect cancer incidence and mortality among those with low health literacy (NNLM, n.d.), which includes many within the deafened population.

Another barrier is that most HI is not available in American Sign Language (ASL), which is the primary language for many deaf individuals (National Institute on Deafness and Other Communication Disorders [NIDCD], 2017), particularly those with early hearing loss. While many late-deafened (LD) individuals have English proficiency and may not know or use ASL (Jones, Renger, & Kang, 2007; P. Kushalnagar, personal communication, June 3, 2017), they too can experience challenges of obtaining appropriate HI (Berman et al., 2017; Jones et al., 2007; McKee, 2013; Smith & Kampfe, 1997; Witte & Kuzel, 2000). Therefore, although deaf individuals possess a range of language and communication preferences (Kushalnagar & Kushalnagar, 2018), there is still a need to provide deafened individuals access to reliable, accurate HI that is

captioned and presented visually through ASL (Smith, Massey-Stokes, & Lieberth, 2012). Furthermore, even when health websites present videos in ASL, deaf individuals with low health literacy rates can still experience challenges in locating the information (Kushalnagar et al., 2015).

An additional concern involves the lack of understanding regarding which specific HI sources deafened individuals trust and use. Folkins et al. (2005) discovered that Deaf males were more likely to trust HI from doctors than family and friends. The most trusted sources of HI among Deaf males after doctors were Deaf community services, the internet, and health education programs (Folkins et al., 2005). In another study, d/Deaf women reported that most of their HI came from physicians or family and friends; but there was no indication which HI sources were most trusted (Berman et al., 2013). Additionally, there are no known studies to the researcher regarding PCR status among deafened individuals and their subsequent HISB. Therefore, there is limited knowledge regarding the HISB of deafened individuals with high PCR and the HI sources they use and trust.

Statement of Purpose

This study examined: (a) HISB of deafened adults with high PCR, (b) which HI sources deafened adults with high PCR trust, and (c) whether there is a relationship between high PCR and HISB among deafened adults.

Research Questions

The current study had the following research questions:

1. Which HI sources did deafened adults with high PCR access first on their most recent search?
2. What are the top three HI sources that deafened adults with high PCR trust the most?
3. What are the top three HI sources that deafened females with high PCR trust the most?
4. What are the top three HI sources that deafened males with high PCR risk trust the most?

Hypothesis

The following null hypothesis was tested at the 0.05% level of significance:

There will be no relationship between deafened adults with high PCR and their degree of trust regarding HI sources.

Delimitations

The current study possessed the following delimitations:

1. Participants were deafened individuals aged 18 years and older and living within the United States.
2. Participants completed the Health Information National Trends Survey (HINTS) 4 Cycle 3 in English.

Limitations

The current study possessed the following limitations:

1. HINTS 4 Cycle 3 was a mailed survey and not translated into ASL, which may have been a limitation for participants whose primary language is ASL.
2. The HINTS 4 Cycle 3 study instrument was developed to fit the priority population and was not tested for validity or reliability.
3. HINTS 4 Cycle 3 utilized stratification based on race rather than hearing status; therefore, external validity is limited, and study results cannot be generalized.
4. Survey data were self-reported and therefore subject to error and reporting bias, which also limits external validity.
5. HINTS 4 Cycle 3 does not have a question asking about the onset of deafness.

Assumptions

The current study possessed the following assumptions:

1. Participants voluntarily completed the HINTS 4 Cycle 3 in English.
2. Participants correctly self-identified as deaf or having trouble with hearing.
3. Participants could read and comprehend the survey questions in English.
4. Participants were honest and accurate in responding to the survey questions.

Definition of Terms

deaf— those who self-identify their condition of deafness as a medical condition, which is denoted by a lower-case “d” (Cawthon & Garberoglio, 2017; Shearer, Hildebrand, & Smith, 1993, 2017)

Deaf— those who identify their condition of deafness as way of life and a contributor to their self-identity within the Deaf culture, which is denoted by an upper-case “D” (Cawthon & Garberoglio, 2017; Shearer et al., 1993, 2017)

Deafened— those who identify as having difficult hearing (Aguayo & Coady, 2001)

d/Deaf— those who self-identify as deaf or Deaf (Cawthon & Garberoglio, 2017; Shearer et al., 1993, 2017)

DHH— an abbreviation that includes those who self-identify as deaf, Deaf, and hard- of- hearing

Hard-of-hearing— those who self-identify as having a range of mild to severe hearing loss but have some usable hearing, they can self-identify as being part of the Deaf community (Cawthon & Garberoglio, 2017; Shearer et al., 1993, 2017)

Health information (HI)— also known as consumer health information, is intended for individuals who will potentially use a wide range of medical and healthcare services.

The main focus is on self-care, preventive actions, and information that is appropriate for community-wide distribution and use (National Center for Biotechnology Information, n.d.).

Health information-seeking behaviors— actions of obtaining HI either passively or actively through various forms of media (Longo, 2005)

HINTS 4 Cycle 3— The Health Information National Trends Survey (HINTS) is disseminated by the National Cancer Institute, U.S. Department of Health and Human Services, and National Institutes of Health to monitor HI and other national data. HINTS data are publicly available (National Institutes of Health [NIH] & National Cancer Institute [NCI], n.d.)

Perceived cancer risk (PCR)— the likelihood that a person believes she/he is susceptible to developing cancer

Significance of Study

Deafened individuals need access to reliable HI they understand and trust; however, there is a clear gap in the literature regarding the HISB of deafened individuals and what HI sources they trust. Moreover, to address the HI needs of deafened adults with high PCR, it is important to investigate the HISB of these individuals, particularly regarding the HI sources they trust and use. The findings of the current study can help health educators, deaf educators, and health communications specialists, tailor appropriate forms of media and programs to deliver credible, accessible, and culturally sensitive HI for deafened individuals with high PCR. Furthermore, the current study reveals important insights about the HISB of deafened individuals, particularly those with high PCR, and contributes to the body of knowledge across the disciplines of health

education and health promotion, deaf education, health communications (including eHealth), medical writing, and library and information science. Moreover, the results of this study can be utilized to stimulate further research about cancer HISB of deafened individuals as well as deafened individuals with high PCR.

CHAPTER II

REVIEW OF LITERATURE

The purpose of this review is to explore literature about HISB among the deafened population, particularly HI sources that deafened individuals utilize and trust. First, this review will provide a background on *Healthy People 2020*, health literacy of Americans, their HISB, and the HI sources Americans utilize. Additionally, this review will report the prevalence of cancer in America, HI sources and cancer HI sources that are available, factors that influence HISB, and the HISB of Americans in general as well as HISB of individuals with high PCR. The review will narrow further in its explanation of the HISB among the deafened population, healthcare experiences of deafened adults, the barriers to appropriate HI sources and cancer HI, as well as HI sources trusted and used among deafened adults. Figure 1 provides a representation of the progression of the review of literature.

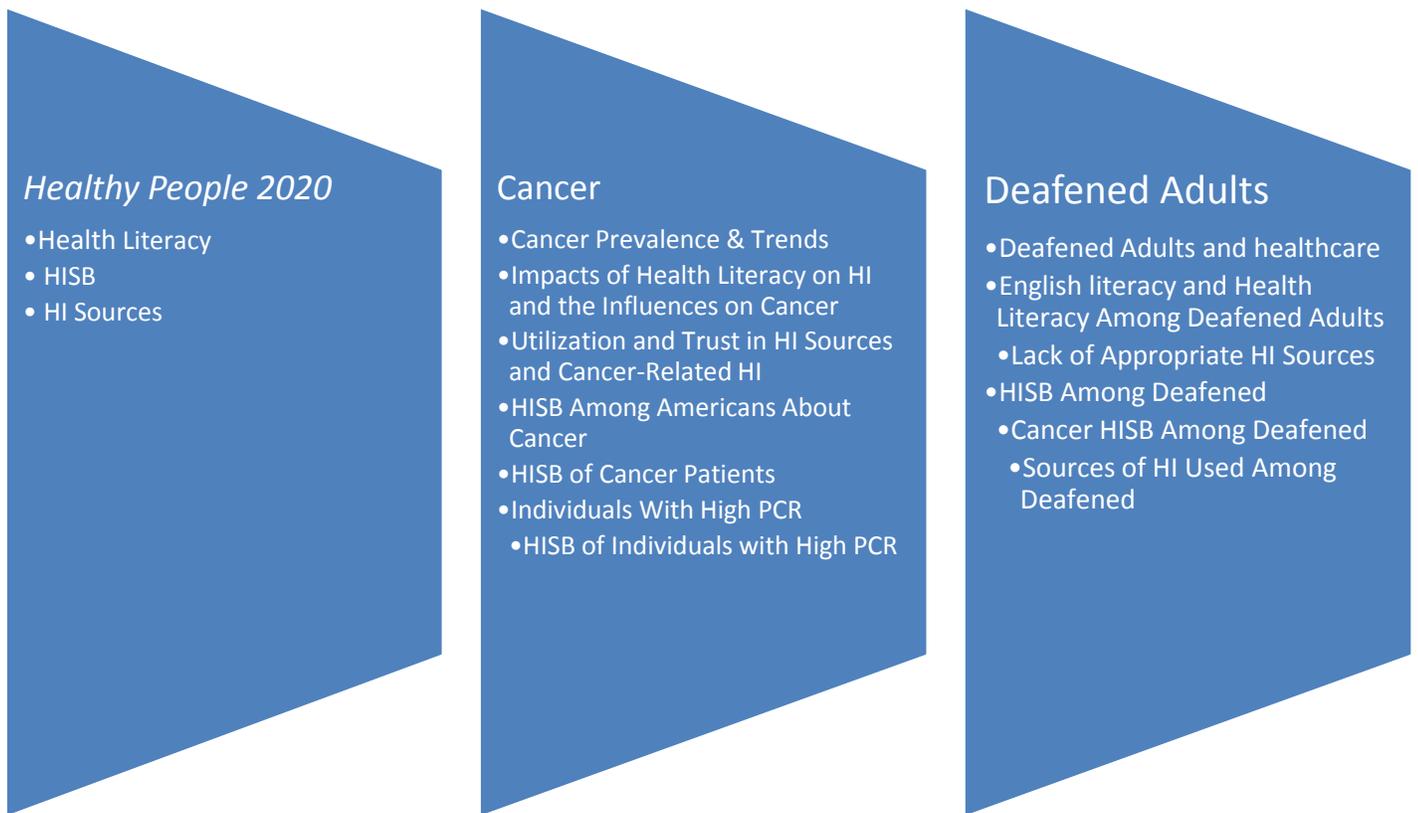


Figure 1: Visual Representation of Literature Review

Healthy People 2020

Healthy People 2020 (HP 2020) is an agenda created by U.S. federal agencies to address diseases, injuries, suicide, preventative health behaviors, mental health, and health outcomes through primary, secondary, and tertiary prevention (Centers for Disease Control and Prevention [CDC], 2014). The agenda set by *HP 2020* is a multiyear process comprised of involvement from multiple organizations and groups (USDHHS-ODPHP, 2014c) with an overarching vision of promoting healthy lives among U.S. citizens (CDC,

2014). *HP 2020* consists of over 1,200 objectives that are decided upon by several federal agencies (USDHHS-ODPHP, 2014c; USDHHS-ODPHP, 2014b). The objectives aim at decreasing morbidity and mortality rates of diseases and disabilities, eradicating some diseases, and improving health behaviors and health outcomes (USDHHS-ODPHP, 2014c). Similar objectives of *HP 2020* are categorized into 42 topics.

A key *HP 2020* topic is Health Communication and Health Information Technology (HCHIT), with the corresponding goal to “use health communication strategies and health information technologies to improve population health outcomes and healthcare quality and health equity” (USDHHS-ODPHP, 2014a, para 1). People have the ability to govern their health and their health behaviors; yet, people need more information and guidance to obtain accurate HI because of the complexity of healthcare and the healthcare system (USDHHS-ODPHP, 2014a). The premise of HCHIT is that health and health behaviors are influenced by communication, information, and technologies people experience and interact with daily. On the other hand, there are individuals who do not utilize certain technologies (e.g., the internet) to make health decisions but rather use other traditional print and media HI sources. Because of the abundance and variety of HI sources available, there is a need to ensure that all HI sources are accurate, accessible, and comprehensible (Patel, Barker, & Siminerio, 2016). Berkman et al., (2011) and Patel, Barker, and Siminerio (2015) explained that disparities in HI access leads to lower utilization of preventive services, lack of

knowledge about chronic disease management, increased rates of hospitalizations, and poorer self-reported health status.

The HCHIT topic consists of 13 objectives (USDHHS-ODPHP, 2014a). Key objectives from the HCHIT include: (a) increase health literacy, (b) increase individuals' access to the internet, (c) increase the proportion of quality health information websites, (d) increase access to online health information, (e) enhance health promotion and disease prevention via social marketing, and (f) increase patients' self-reported satisfaction of healthcare providers' communication skills (USDHHS-ODPHP, 2014a).

Health Literacy

Health literacy has been defined as “the degree to which individuals have the capacity to obtain, process, and understand basic health information and services needed to make appropriate health decisions” (Ratzan & Parker, 2000, p. v). Health literacy leads to improvement in increasing knowledge, changing in motivation and in health behaviors, and improving health outcomes (Cooper et al., 2018; Du et al. 2018; Nutbeam, 2000). Health literacy is inextricably linked to health and quality of life. For example, individuals with low health literacy often experience poorer health and are less likely to use preventative healthcare (Institute of Medicine, 2004). Health literacy is influenced by multiple factors such as the situation or context of the individual, cultural beliefs, knowledge of health, communication styles and skills, comprehension and reaction to HI, and demands of the healthcare system (USDHHS-ODPHP, 2008; USDHHS-ODPHP,

n.d.). For instance, health literacy is impacted by cultural belief systems, communication styles, and comprehension and reaction to HI (USDHHS-ODPHP, 2008).

Because taking care of one's health is a daily occurrence, having the skills to understand how to prevent, treat, or manage health issues is of paramount importance. Therefore, having a solid foundation of health literacy skills is necessary in maintaining and promoting health. Health literacy is comprised of two major skills—literacy and numeracy (CDC, 2016d). Literacy pertains to an individual's ability to comprehend, appraise, and interact with text-based content (CDC, 2016d), whereas numeracy refers to an individual's ability to assess, evaluate, deduce from mathematical information, and communicate that information (CDC, 2016a). In 2003, the National Assessment of Adult Literacy revealed that approximately 89% of Americans were less than proficient in health literacy (Kutner, Greenburg, Jin, & Paulsen, 2006). Additionally, those impacted by low health literacy are ethnic/racial minorities, individuals who did not complete high school, low income individuals, those that are non-native English speakers, and older adults (USDHHS-ODPHP, n.d). However, adults over the age of 76 had lower health literacy than those 65-74 years of age (Vogt, Berens, & Schaeffer, 2018). According to the CDC (2016c), 9 out of 10 adults experience difficulty in comprehending and using HI when the content is unfamiliar, dense, or filled with medical jargon. The most recent report by Program for the International Assessment of Adult Competencies (PIAAC) regarding literacy among U. S. adults explained that

86% of Americans aged 16-65 have less than proficient literacy skills (Rampey et al., 2016). Additionally, the same report indicated that about 90% of American adults have less than proficient numeracy skills (Rampey et al., 2016). To exacerbate the gap of health literacy, a majority of HI sources are over the recommended 6th grade reading level (Badarudeen & Sabharwal, 2010; Kim & Xie, 2017). In fact, most HI is written at a 7th grade reading level or higher (Freda, 2005; Kim & Xie, 2017).

On the other hand, researchers are cautioned not to combine healthy literacy with eHealth literacy as Monkmana et al. (2017) suggested that the two methods of searching and using traditional print HI and eHealth information are dissimilar. Norman and Skinner (2006) defined eHealth as “the ability to seek, find, understand, and appraise health information from electronic sources and apply the knowledge gained to addressing or solving a health problem” (para. 5). According to Pew Research Center’s (2018) latest survey, almost 90% of American adults have access to the internet, which leverages the reach of eHealth. However, low health literacy influences eHealth literacy; therefore, individuals with low health literacy are less likely to use the internet to find HI (Gutierrez, Kindratt, Pagels, Foster, & Gimpel, 2014). Additionally, individuals with low health literacy prefer to use traditional print HI sources. This may be because most eHealth information language is over the suggested 6th grade reading level (Kim & Xie, 2017). Similarly, most HI in written format (including captioned TV and the internet) is targeted toward those with a reading level of 7th grade or higher (Freda, 2005), which

indicates that many (if not most) digital and print HI materials are not suitable for those with low health literacy and low eHealth literacy.

eHealth literacy is also associated with age. In a study by Neter and Brainin (2012), the younger the adults were, the higher the eHealth literacy they displayed. Additionally, Arcury et al. (2018) noted most older adults had low eHealth literacy. Arcury et al. (2018) also found that eHealth literacy is influenced by education level. Adults with lower education levels, such as individuals who did not graduate from high school, exhibited lower levels of health literacy than college graduates (Neter & Brainin, 2012). In particular, adults who completed college exhibited higher levels of eHealth literacy and utilized books, newspapers, magazines, and the internet more than individuals with low eHealth literacy (Neter & Brainin, 2012). Moreover, those with low eHealth literacy obtained less information during internet searches, used fewer HI sources, conducted fewer internet searches, and utilized fewer online search strategies than those with high eHealth literacy (Neter & Brainin, 2012).

Health Information Sources and Health Information-Seeking Behavior

There are multiple sources that individuals use to obtain HI, including traditional print media such as newspapers, magazines, books, and brochures; traditional non-print media such as radio and television (Kutner et al., 2006); family and/or friends; healthcare professionals (Gutierrez et al., 2014); and the internet (Kutner et al., 2006; Spooner, Salemi, Salihu, & Zoorob, 2017). It is not fully understood how HI sources influence

HISB of individuals. To confound this issue, HISB is not clearly defined because there is no specific definition that is used in research studies. Lambert and Loiselle (2007) explained that HISB is derived from different contexts. The three main contexts are coping with a health-threatening situation, participating in medical decisions, and addressing and initiating behavior change and/or preventive behaviors (Lambert & Loiselle, 2007). In addition, Longo (2005) explained that an individual's HISB could be either passive or active. For this study, the researcher used the definition of HISB (noted in Chapter 1) as actions of obtaining HI either passively or actively through various forms of media (Longo, 2005). The next sections focus on the rationale of HISB among Americans, the demographic variables that influence HISB, and how health literacy, health status, and disability status influence HISB.

Pew Research Center is one of the leading U.S. organizations that focuses on HISB. A Pew report regarding online HISB and eHealth information revealed that in a previous HI search, 39% of American adults sought HI based on their own circumstances, another 39% sought HI as it related to another person's health situation, and 15% searched the internet for eHealth information to help themselves and others (Remez, 2013). Another Pew Research Center report stated that over 59% of American adults use the internet to find health information within a 12-month period, and 31% obtain eHealth information via their cell phone (Rainie, 2013). The same study also reported that over 50% of American adults use the internet to find certain information

about a specific disease or medical problem, and over 40% use the internet to find information about medical treatments or procedures. In addition, an estimated 35% of U.S. adults go to the internet to self-diagnose their condition; and of those individuals, 53% discuss their finding of eHealth information with their healthcare professional (Rainie, 2013). Furthermore, eHealth information appears to influence the decisions of American adults. For example, over 55% of American adults reported that eHealth information influenced their approach of health maintenance (Rainie, 2013); and nearly 60% of internet users reported that the HI they found influenced a medical decision pertaining to treatment (Fox, 2006; Rainie, 2013). Moreover, 49% of American adults expressed that eHealth information influenced their preventive behaviors such as diet and exercise, while 38% reported that it changed their methods and routines of coping with a chronic condition or pain (Rainie, 2013).

Several factors influence HISB among individuals, including demographics such as race and ethnicity (Lee, Boden-Albala, Larson, Wilcox, & Bakken, 2014; Rooks, Wiltshire, Elder, BeLue, & Gary, 2012), age, gender, education level, income level, caregiver status, health status, and disability status (Fox, 2011b; Jacobs, Amuta, & Jeon, 2017; Lee et al., 2014; Rooks et al., 2012; Weaver et al., 2010). Pertaining to race, non-Hispanics are more likely to seek cancer HI when compared to English-speaking Hispanics and Spanish-speaking Hispanics (Vanderpool et al., 2009). Additionally, Rooks et al. (2012) found that blacks and whites are more likely than Latinos to search

for HI after a medical appointment. In terms of age, fewer than 30% of internet users over the age of 65 search the internet for HI; on the other hand, 71% of adults aged 18-29 typically search the internet for HI (Fox, 2011a). Gender also plays a role in HISB. For example, women are more likely to use the internet for HI in comparison to their male counterparts (Fox, 2011b; Mesch, Mano, Tsamir, 2012). Regarding education level, nearly 75% of adults who did not graduate from high school use other HI sources than the internet (Fox, 2011d), while those with a high school diploma typically use traditional and digital text-based sources (Feinberg et al., 2016). Individuals without a high school diploma are less likely to use text-based sources for HI and use audio-based sources such as radio and television instead (Feinberg et al., 2016). Nearly 80%-90% of college graduates utilize the internet for HI, whereas 70% of high school graduates use the internet for HI and even fewer (38%) individuals with less than a high school diploma use the internet for HI (Fox, 2011b; Fox 2011d). Moreover, income level influences HISB. Reports show that higher-income households tend to have more access to the internet and mobile devices with internet access in comparison to lower-income households, which limits lower-income individuals' access to online HI (Fox, 2011b; Jansen, 2010). Additionally, nearly 88% of caregivers (those unpaid to care for a parent, child, friend, or loved one) who have internet access pursue HI on the internet (Fox, 2011b). Another factor that influences HISB is military status. For example, Sandler (2018) noted that veterans with post-traumatic stress disorder (PTSD) utilize the internet

to find HI on a variety of topics such as tips on returning to work after a mental health diagnosis, diabetes treatments, treatments for post-combat nightmares, treatments and coping skills to maintain anger and PTSD (Sendler, 2018).

Health literacy also plays a role in the HISB of individuals. Americans with low health literacy tend to retrieve most of their HI from written sources such as traditional print HI sources and text-based internet sources, while those with high health literacy consult books and brochures when they choose not to use the internet (Kutner et al., 2006). Nevertheless, those with high health literacy are more likely to use the internet for HI (Kutner et al., 2006).

Reports from Pew Research Center documented that health status is another factor that impacts HISB. According to Fox and Purcell (2010), individuals living with chronic health conditions, such as hypertension, heart conditions, lung disease, diabetes, and cancer, are less likely to have access to the internet compared to those without a chronic disease. However, over 80% of individuals who have internet access and have a chronic disease report that they use the internet for HI (Fox, 2011b). Moreover, those living with chronic diseases are more likely to get HI from healthcare providers (93%), friends, family members (60%), or other traditional printed sources (56%) rather than searching the internet (44%) for HI (Fox & Purcell, 2010). Although individuals with disabilities can experience barriers when using the internet to find HI, nearly 80% of individuals with self-reported disabilities utilize the internet for HI (Fox, 2011b). In the Pew Research

Center report, Fox (2011b) included physical, mental, and emotional impairments in one category rather than focusing on each individual category of disability. Therefore, it is not clear how disability status affects HISB. In fact, a majority of HISB research does not focus on individuals with disabilities.

Cancer

Cancer is the second leading cause of death in the United States (CDC, 2016a) and is projected to become the leading cause of death by 2020 (CDC, 2016b). An estimated 40% of men and women in the United States will be diagnosed with cancer within their lifetime (NCI, n.d.). Other estimates from the American Cancer Society (2016) state that 1 in 2 men and 1 in 3 women will develop cancer. For the year 2016, approximately 1.6 million new cases of cancer were diagnosed; and almost 600,000 people died from cancer. For the year 2018, the American Cancer Society (n.d.) projected that there will be over 1.7 million new cancer cases diagnosed and nearly 610,000 deaths due to cancer. Additional approximations suggest that by 2026 the number of cancer survivors will be over 20 million Americans (American Cancer Society, 2016). Of those 20 million, 10.3 million will be females and the remaining will be males (American Cancer Society, 2016). Yet, cancer survivors have a poorer quality of life because of financial burdens (Guy et al., 2015; Yabroff et al., 2016), difficulties returning to work (de Jong, Tamminga, Frings-Dresen, & de Boer, 2017), psychological distress (Bowen et al., 2007), and social difficulties (Medeiros et al., 2015).

Additionally, the costs associated with cancer not only impact the individual but the nation as whole. For example, the national median of cancer-related missed work days was 6.1 days per employed person with a range of 5.9 days in Utah to 6.3 days in Ohio (Tangka et al., 2013). However, the total annual average of cancer-related missed work days ranged from almost 60,000 days in Wyoming to a startling 3.7 million days in California, with a nation median of over 48,000 days (Tangka et al., 2013). The costs of cancer-related absenteeism ranged from almost \$15 million in Wyoming to over \$915 million in California, with national median of almost \$116 million (Tangka et al., 2013).

Despite having health insurance, the cost of cancer treatment can be a financial drain to individuals as well as their families (Guy et al., 2015; Yabroff et al., 2016). According to Ekwueme et al., (2014), male cancer survivors without a previous history of cancer accumulated an average of \$8,000 per person in annual medical expenses, whereas females accumulated approximately \$8,400 for per person. Moreover, males experienced productivity loss of about \$3,700; and females experienced a productivity loss of about a \$4,000 (Ekwueme et al., 2014). However, those costs nearly doubled for those individuals who had a previous cancer experience. In addition, nearly one-third of cancer survivors reported that cancer caused them to alter their outside-of-work activities; and almost 42% reported they adjusted their work hours and work responsibilities (Ekwueme et al., 2014).

HP 2020 includes a goal to decrease cancer morbidity and mortality rates (USDHHS-ODPHP, 2017). One of the aims of the *HP 2020* objectives in relation to cancer rates is to determine if individuals can comprehend and recall information about cancer screenings (USDHHS-ODPHP, 2014a). To address the *HP 2020* objectives concerning cancer screenings, there is a need to understand cancer health disparities, particularly among the medically underserved. Those who have little or no access to effective healthcare are considered medically underserved (NCI, n.d.). Medically underserved groups are less likely to obtain routine cancer screenings and more likely to be diagnosed with late-stage cancer, both of which increase the possibility of poorer prognoses (NCI, n.d.). Moreover, the medically underserved exhibit health behaviors that increase cancer risk. For example, the medically underserved tend to have higher rates of tobacco use, obesity, excessive alcohol consumption, and lower rates of physical activity and breastfeeding when compared to the medically served (NCI, n.d.).

Impacts of Health Literacy on HI and the Influences on Cancer

Low health literacy is another factor that increases cancer-related health disparities. Low health literacy is associated with chronic disease and negatively affects cancer incidence, mortality, and quality of life (NNLM, n.d.). Low health literacy also hinders cancer-preventive behaviors and preventative screenings (Dolan et al., 2004; Khankari et al., 2007; Scott, Gazmararian, Williams, & Baker, 2002; Zonderman, Ejiogu, Norbeck, & Evans, 2014). A systematic review by Mantwill, Monestel-Umaña, and

Schulz (2015) revealed that although low health literacy is a contributing factor to cancer health disparities, its impact on cancer health disparities is not fully understood.

Additionally, low eHealth literacy is associated with having a chronic illness (Neter & Brainin, 2012). Yet, those with high eHealth literacy tend to participate in physical activity and have a nutritious diet, both of which are cancer-preventive health behaviors (Mitsutake, Shibata, Ishii, & Oka, 2016). Individuals who have adequate eHealth literacy are also more likely to obtain cancer screenings and are more knowledgeable about cancer when compared to individuals with low eHealth literacy (Mitsutake, Shibata, Ishii, & Oka, 2012). Those with high eHealth literacy are also more confident in their ability to locate and understand HI in comparison to those with low eHealth literacy (Park, Moon, & Baeg, 2014). On the other hand, those with low eHealth literacy experience difficulty in locating electronic HI (Norman & Skinner, 2006; Park et al., 2014) and struggle with comprehending cancer HI pertaining to prevention, treatment, and management, which often leads to frustration (Park et al., 2014). To reduce the gap of health disparities among adults who exhibit low eHealth literacy, there is a need to identify the factors influencing low eHealth literacy (Park et al., 2014). Once these factors have been identified, educational programs can be developed to teach individuals how to find, understand, and use accurate and reliable HI (both print and online), including cancer HI (Park et al, 2014; Xie, 2011). For example, Xie (2011) noted that eHealth literacy programs are successful when lessons focus on the following

topics: computer skills, web navigation skills, web-searching procedures, and eHealth literacy. Additionally, educational programs that include instructional materials, in-class activities, individual practice exercises, and supportive content (e.g., a glossary of terminology) have been successful in improving eHealth literacy (Xie, 2011).

In response to rising cancer rates, the quantity of obtainable cancer and cancer preventive HI, including general information on cancer, treatments, symptoms, and side effects, has multiplied swiftly (Nelson et al., 2004; Viswanath et al., 2012). However, most HI is not at an appropriate reading level for a substantial portion of the public. Studies have determined that the reading level for HI in general and cancer HI (ranging from cancer prevention information and treatment information) from various print and digital sources ranges from 9th-15th grade (Badarudeen & Sabharwal, 2010; Friedman & Hoffman-Goetz, 2006; Singh, 2003). More specifically, most internet-based HI about kidney, bladder, breast, prostate, and colon cancer is written at a high school or college reading level (Azer, Alghofaili, Alsultan, & Alrumaih, 2018; Basch et al., 2018; Friedman, Hoffman-Goetz, & Arocha, 2004; Rosenberg et al., 2016; Vargas, Chuang, Ganor & Lee, 2014).

Trust and Utilization of HI Sources and Cancer-Related HI

Rains (2007) posited that trust and perception of the usefulness of a HI source influences how people obtain HI. For example, people who distrust information-oriented media (newspapers and magazines) are more likely to use the internet as the first source

for HI (Rains, 2007). Rains (2007) also noted a trend revealing that when an individual distrusts information from a traditional HI source (mass media or healthcare providers), there is an increased likelihood of that individual using the internet as the primary HI source. Although physicians are the most trusted source for HI, many people still prefer to search for HI online (Hesse, Moser, & Rutten, 2010). However, individuals with high trust in a physician do not tend to use the internet as often for HI. Then too, individuals who distrust HI from their physician tend to rate online HI as useless and prefer to use traditional HI sources (Rains, 2007). Nevertheless, national surveys have shown that overall trust of the internet for HI has experienced a slight decline, while trust in physicians has remained steady (Hesse et al., 2010). Individuals also seek cancer HI from television news sources; however, they perceive HI and cancer-specific HI from local television news sources as vague (Kealey & Berkman, 2010). On the other hand, they perceive HI in newspapers and on the internet as easier to comprehend (Kealey & Berkman, 2010). However, the utilization of HI on the local news was associated with lower PCR (Kealey & Berkman, 2010).

HISB Among Americans About Cancer HI

Health information trends data from HINTS 4 Cycle 3 indicated that approximately 40% of respondents have sought HI related to cancer (Amuta et al., 2017). Data from the same survey also showed that demographic groups more likely to seek cancer HI include females, younger-aged individuals, those with higher education,

and those with higher household incomes (Rutten, Squiers, & Hesse, 2006). Studies have shown that the primary reasons for seeking cancer HI are to decrease stress, enhance the ability to cope with cancer, increase knowledge about cancer, and raise awareness about the need for social support (Robinson & Tian, 2009; Seçkin, 2011; van der Molen, 1999). Individuals also seek cancer HI to increase awareness about prevention behaviors, learn more about treatment options, and/or to find social support for themselves or others (Kelly et al., 2010; Kobayashi & Smith, 2016; Robinson & Tian, 2009; Seçkin, 2011; van der Molen, 1999).

HISB of Cancer Patients

Cancer patients use a variety of sources to obtain information related to treatment, survivorship, quality of life, and other relevant HI. Those who are younger, female, and have higher income and education levels obtain HI from other sources in addition to the HI from healthcare staff involved with their cancer treatment (Boudioni et al., 2001; Carlsson, 2000; Czaja, Manfredi, & Price, 2003; Manfredi et al., 1993; O'Leary, Estabrooks, Olson, & Cumming, 2007; Rutten, Arora, Bakos, Aziz, & Rowland, 2005). Walsh et al. (2010) discovered that almost 96% of cancer patients sought cancer HI, and nearly 70% sought information outside of healthcare staff involved with their cancer treatment. Moreover, 96% of cancer patients stated that at least one cancer-related HI source influenced their treatment decisions; and 60% reported that their treatment decisions were influenced by at least one cancer-related HI source outside of healthcare

staff involved with their treatment. Approximately 43% of cancer patients also reported that family members influenced their treatment decisions. In comparison to other studies, Walsh et al., (2010) concluded that fewer than 35% of cancer patients utilized the internet as a cancer HI source; and only 13% of those individuals noted that internet-based cancer HI sources influenced treatment decisions. Overall, cancer patients who do not consider their treatment team as a viable cancer HI source tend to seek HI from other sources more often than cancer patients who rely on their treatment team as a credible cancer HI source (Walsh et al., 2010).

Individuals With High Perceived Cancer Risk

Individuals with high PCR are more likely to search for HI and cancer HI; however, PCR varies based on sociodemographic factors (Amuta et al., 2017; Hovick, Liang, & Kahlor, 2014; Nan, Underhill, Jiang, Shen, & Kuch, 2012; Orom, O'Quin, Reilly, & Kiviniemi, 2015; Teufel-Shone et al., 2015; Vanderpool & Huang, 2010). For example, Amuta et al. (2017) explained that younger people tend to have higher PCR; and those with a college degree have lower PCR than those without a college degree. Additionally, Hovick, Liang, and Kahlor (2014) noted that education level has a positive correlation with cancer HISB among adults with high PCR. Race and ethnicity also influence PCR and HISB. For example, Hispanics and blacks have a lower PCR when compared to other ethnic groups (Amuta et al., 2017). Yet, Hovick, Liang, and Kahlor (2014) noted that Hispanics seek more cancer HI than whites; and blacks seek

significantly less cancer HI than whites. There is also a noted gap in PCR and HISB among males and females (Manierre, 2015). Nan et al. (2012) discovered that women are more likely to look for cancer HI when they have a high PCR regardless if their PCR involves cancer in general or specifically breast cancer. Females who are parents and have a genetic predisposition of cancer are also more likely to seek cancer HI (Koehly et al., 2009). However, men with high PCR tend to search for more cancer HI sources in comparison to men without high PCR (Manierre, 2015; Nan et al., 2012). Additionally, men are more likely to seek cancer HI if their general PCR and their perceived risk of prostate cancer are both high (Nan et al., 2012). Furthermore, Manierre (2015) suggested that differences in HISB and PCR among males and females might be because women have more of the parenting duties, women are more reactive to HI, and men's self-perception regarding masculinity hinders their need or desire to search for HI. However, Manierre (2015) suggested that PCR alone is not the single motivator of HISB among men or women.

HISB of Individuals with High Perceived Cancer Risk

Those with self-reported high PCR display different HISB and preventive actions than those who have low PCR (CDC, 2016a; Nan et al., 2012). According to 2005 HINTS survey data, 53% of Americans (PCR status unknown) looked for cancer HI (Kealey & Berkman, 2010). The same data showed Americans with high PCR searched for HI from television news (10.5%), newspapers (11.1%), and the internet (11.7%) over

a 12-month period (Kealey & Berkman, 2010). According to Amuta et al. (2017), PCR predicts HISB and may be one of the driving factors for how frequently individuals search for cancer HI. HISB can decrease stress and increase an individual's ability to cope, increase knowledge about chronic diseases such as cancer, raise awareness about the need for social support, and influence positive health behaviors such as screenings (Amuta et al., 2017; Robinson & Tian, 2009; Seckin, 2011; van der Molen, 1999). On the other hand, individuals who are uncertain about their PCR of colorectal and breast cancers tend to participate in fewer preventive health behaviors, cancer screenings, and consult fewer cancer HI sources (Waters, Kiviniemi, Orom, & Hay, 2016).

Age also impacts PCR and HISB among individuals. Middle-aged and older adults are more likely to seek cancer HI than their younger counterparts (Vanderpool et al., 2009). This is likely because most cancers normally develop and are diagnosed in older populations. On the other hand, people over the age of 50 with high PCR and worry or anxiety about developing cancer are more likely to avoid doctors; and it is speculated that they also avoid cancer-related HI (Persoskie, Ferrer, & Klein, 2014; Vanderpool et al., 2009).

Deafened Adults

David (2010) explained the concept of deafness as follows:

Deafness and hearing exist as a continuum that ranges from the complete inability to hear or understand speech to the complete ability to hear and

understand speech.... The ability, or inability, to hear or understand normal speech varies from person to person, and depends on both audiometric measures of sound perception and self-perceived hearing ability. Thus, measures of deafness are both objective and subjective... (p. 2).

Additionally, there are variations of how each person becomes deaf or hard of hearing. Age of hearing loss of deafened onset, functional hearing status, education, communication preferences, and cultural identity all contribute to an individual's identity (National Association of the Deaf, 2019). For example, an individual who experiences presbycusis might self-identify as late-deafened; however, someone else with presbycusis might self-identify as experiencing hearing loss rather than self-identifying as late-deafened (National Association of the Deaf, 2019).

The term "deafened" is used to address those who identify as having difficulty hearing but does not qualify the degree of hearing difficulty. Collectively, national data sets do not have a consistent method of recording deafened status (e.g., deaf, Deaf, hard-of-hearing) or when the onset of deafness occurs. The secondary data used in the current study originated from the HINTS 4 Cycle 3 data set and only has information on individuals who self-identified as being deaf or having trouble hearing. Therefore, in this section of the review of literature, the researcher will use the appropriate terminology of the populations being studied in accordance with the published work.

Based on the Survey of Income and Program Participants, data revealed that over 4.8 million adults use hearing aids for normal conversation but do not have difficulty hearing while using hearing aids (Mitchell, 2005). Additionally, 14.1 million American adults experience some difficulty hearing even with a hearing aid, almost 2.5 million cannot hear normal conversation with the aid of a hearing aid, and over 330 thousand individuals are deaf (Mitchell, 2005). More recent data from 2012 indicated that 37.5 million American adults self-reported having difficulty hearing (Blackwell, Lucas, & Clarke, 2014). Additionally, data from the 2001-2008 National Health Examination Surveys reported approximately 30 million Americans over the age of 12 have hearing loss in both ears (Lin, Niparko, & Ferrucci, 2011). More recent data from another study revealed that bilateral hearing loss is at a decline among American adults aged 20-69 (Hoffman, Dobie, Losonczy, Themann, & Flamme, 2017). Despite the decline in the prevalence of bilateral hearing loss, 41% of Americans were noted to have bilateral hearing loss (Hoffman et al., 2017). Researchers also noted that 24.7% of those aged 60-69 experience bilateral hearing loss along with 11.2% aged 50-59 years, 3.4% aged 40-49, 0.9% aged 30-39, and 0.8% aged 20-29 (Hoffman et al., 2017).

Those who are deafened choose to communicate in a variety of methods. For example, individuals who are early-deafened tend to use ASL as their primary method of communication (NIDCD, 2017). On the other hand, individuals who are late-deafened are noted to use their native language of English rather than ASL (Taylor, 2015).

However, one study suggests that late-deafened individuals may learn ASL as an alternative method to communicate but still rely on English as their primary language (Taylor, 2015).

There are other hearing loss differences associated with different demographic traits. For example, male adults aged 20-69 are more likely to experience hearing loss than their female counterparts (Hoffman et al., 2017). Also, those of different races and ethnicities experience different rates of hearing loss (Hoffman et al., 2017). Among adults aged 20-69, non-Hispanic whites are more likely to experience hearing loss, whereas non-Hispanic blacks experience the lowest rate of hearing loss (Hoffman et al., 2017). Moreover, an individual's age is the strongest predictor of hearing loss among adults (Hoffman et al., 2017). Adults 75 and older have the highest rates of disabling hearing loss (50%) (NIDCD, 2018). However, due to the inverse relationship of the rate of disabling hearing loss and age, almost 25% of adults aged 65-74 have disabling hearing loss, 8.5% of adults 55-64 experience disabling hearing loss, and less than 3% of adults aged 45-54 experience disabling hearing loss (NIDCD, 2018). Veterans are another sub-population that can experience hearing loss and/or deafness (CDC, 2011; Healey, 2017; Yong & Wang, 2015). In 2014, over 900,000 veterans were provided disability compensation for hearing loss (U.S. Department of Veteran Affairs, 2016). Currently, the armed forces exclude deafened individuals from joining or enlisting due to hearing requirements (U.S. Government Publishing Office, 2008);

however, the Keith Nolan Air Force Deaf Demonstration Act of 2018 (under congressional review) would allow deaf individuals to enlist in some military service (H.R.5831 - Keith Nolan Air Force Deaf Demonstration Act of 2018).

Deafened Adults and Healthcare

The Deaf community typically experience barriers to health promotion and healthcare (Sadler, Huang et al., 2001; Okoro et al., 2018; Wang et al., 2010). They also are often medically underserved, have unmet healthcare needs, and are excluded from medical research (Barnett et al., 2011; Okoro et al., 2018). Bukowski (2015) explained that language and communication are components of culture that influence an individual's health and health behaviors. Yet, deafened individuals face difficulty in obtaining appropriate HI because of language and communication barriers. Deaf individuals express that they prefer healthcare professionals to be fluent in ASL (Bukowski, 2015), and research has indicated that deaf adults who have access to healthcare personnel fluent in ASL are more likely to participate in preventive services (McKee, Barnett, Block, & Pearson, 2011). However, there are few fluent ASL healthcare professionals and ASL translators to effectively communicate health and medical information to d/Deaf individuals, which exposes a critical gap in healthcare services (Karras, Rintamaki, & Peek, 2011; Kaskowitz, Nakaji, Clark, Gunsauls, & Sadler, 2006; Kushalnagar et al., 2016; Thew, Smith, Chang, & Starr, 2012). Most healthcare providers are not trained in ASL (Karras et al., 2011). In addition, most

providers who are trained in ASL do not use facial and body expressions with ASL, both of which are crucial elements when communicating to d/Deaf individuals (Bukowski, 2015; Pereira & de Carvalho Fortes, 2010). To further compound the problem, healthcare providers tend to speak quickly, look away from the patient, and often turn their backs to the patient, which hinders deafened individuals from lip reading (Bukowski, 2015) and interferes with building rapport and trust that is essential to the patient-provider relationship.

Deaf adults can be wary of the healthcare system because of their negative healthcare experiences (Steinberg, Wiggins, Barmada, & Sullivan, 2002). Deaf individuals tend to have a general distrust towards healthcare professionals, many of whom believe deafness to be a physical ailment rather than a distinct cultural characteristic (Hoang, LaHousse, Nakaji, & Sadler, 2011). Few healthcare professionals possess cultural awareness of the Deaf community (Karras et al., 2011), and some Deaf individuals have reported that physicians can be culturally insensitive and lack cultural competence (Kaskowitz et al., 2006; Lieu, Sadler, Fullerton, & Stohlmann, 2007). As a result, deafened individuals may feel overlooked, disrespected, belittled, and undermined (Iezzoni, O'Day, Killeen, & Harker, 2004; Karras et al., 2011), which can hinder deafened individuals' ability to self-govern and self-manage health behaviors. These barriers can also prevent deafened individuals from receiving appropriate medical services and treatments (Iezzoni et al., 2004; Pereira & de Carvalho Fortes, 2010). In

addition, Deaf patients accompanied by companions, family members, or interpreters at medical appointments can create a confusing situation in terms of the communication process, particularly as it relates to provider-patient communication and interaction. In turn, this uncertainty can prevent Deaf patients from receiving appropriate healthcare (Pereira & de Carvalho Fortes, 2010). In summary, Deaf patients have reported the following communication roadblocks that impede their access to effective healthcare: (a) difficulty receiving adequate healthcare instructions and information because physicians do not provide certified interpreters; (b) lack of communication when physicians communicate with the interpreter or patient representative rather than directly to the patient; (c) healthcare professionals' disclosure of sensitive HI to interpreters when not warranted; (d) medical decisions that are made without allowing Deaf patients to discuss treatment options with trusted individuals (Bukowski, 2015; Iezzoni et al., 2004; Karras et al., 2011); (e) healthcare professionals' lack of eye contact with the patient (Lieu et al., 2007), and (f) lack of information to be knowledgeable about diagnosis (Simons et al., 2018).

English Literacy and Health Literacy Among Deafened Adults

According to the report entitled *Health Literacy: A Prescription to End Confusion* (Institute of Medicine, 2004), more than 90 million American adults have low health literacy. Additionally, the U.S. Census Bureau (2010) indicated that almost 24.5 million American adults possess limited English proficiency (LEP); however, these statistics do

not include Deaf ASL users (Harrington, 2004; Schick, 1988), nor does Census information reflect the broadened definition or scope of the deafened population. Studies have shown that d/Deaf individuals often have LEP and low English reading levels, which increase their risk for health disparities associated with low health literacy (Bukowski, 2015; Pollard et al., 2009; Zazove et al., 2013). Additionally, studies have shown that some Deaf individuals have inadequate health literacy (McKee et al., 2015; McKee, Thew et al., 2012); however, these studies only examined individuals among the Deaf community with no clear demarcation among those who identify as deaf, deafened, or hard-of-hearing. Despite language barriers and health risks experienced by the d/Deaf, this population is often overlooked in research and research funding. For example, a majority of LEP research and research funding focuses on Spanish-speaking populations rather than the d/Deaf community, primarily due to the relatively low number of d/Deaf ASL users in the U.S. population (McKee & Paasche-Orlow, 2012; McKee, Thew et al., 2012; Smith et al., 2012).

Barriers to Deafened Individuals' Access to HI Sources

In addition to limited research pertaining to LEP and health literacy among the deafened, the limited availability of appropriate HI sources exacerbates the situation. For example, most HI sources contain language written above the recommended 6th grade reading level (Freda, 2005; Kim & Xie, 2017) with a majority of HI sources written at a 7th grade reading level or higher (Freda, 2005). However, most d/Deaf individuals read

at a 4th grade reading level (Paul 1998, 2003; Qi & Mitchell, 2007, 2011). Due to a general lack of culturally competent healthcare providers and concomitant communication barriers, Deaf ASL users often turn to other HI sources such as family, friends, books, magazines, and the internet (Karras, 2010; Karras & Rintamaki, 2012; Margellos-Anast, Hedding, & Miller, 2004). Accessible web-based HI is a positive step forward to increase deafened individuals' retrieval of relevant HI, but "accessible" means more than providing an ASL-translated video. Accessible content for Deaf ASL users and deafened individuals also requires a web design that is easy to navigate, captioned videos with appropriate lighting and no distracting background, and well-organized content (Kushalnagar et al., 2015; NIDCD, 2017). Online text content also needs to be at the appropriate reading level to have the highest potential for knowledge attainment (Fajardo, Cañas, Salmerón, & Abascal, 2009). In addition, it is important to remember that deafened individuals have some degree of English proficiency and may not know or use ASL (Jones et al., 2007). Therefore, they too can experience challenges obtaining appropriate HI (Berman et al., 2017; Jones et al., 2007; McKee, 2013; Smith & Kampfe, 1997; Witte & Kuzel, 2000). However, those individuals that are late-deafened In summary, researchers recommend the following strategies to increase access to HI among the d/Deaf, deafened, and hard-of-hearing: (a) healthcare professionals need to be familiar with the communication and language needs of their patients; (b) health education programs need to be tailored for deafened, d/Deaf, and hard-of-hearing; (c) HI

should be developed that is easy to comprehend and promotes maximum attainment of knowledge; and (d) more studies are needed to distinguish HISB among d/Deaf, deafened, and hard-of-hearing individuals (Berman et al., 2017; Jones et al., 2007; McKee, 2013; Smith & Kampfe, 1997; Witte & Kuzel, 2000). It is important to note that most of these studies focused on the HISB among d/Deaf individuals who use ASL and not late-deafened and hard-of-hearing of deaf individuals who speak English. As explained by Smith and Chin (2012), some deaf individuals are underexposed to HI and environmental stimuli connected with HI. For example, a profoundly deaf individual cannot hear a radio segment or public service announcement (PSA) about a health issue, whereas an individual with mild hearing loss can hear a radio segment or PSA, which can serve as a cue for the individual to seek HI on the particular health topic. Therefore, exposure to HI and environmental stimuli that may serve as cues to action vary for each individual.

Additionally, most individuals who are late-deafened or experience age-related hearing loss usually learn English to some degree during their school-aged years and tend not to utilize ASL as their primary form of communication (Taylor, 2015). Therefore, these individuals may possess higher English proficiency, literacy, and health literacy levels than early-deafened individuals. Nevertheless, there appear to be no studies that compare late-deafened individuals' English proficiency, literacy, and health literacy levels with the general population.

HISB Among Deafened

Although few studies have focused on the HISB of the deafened, it has been shown that d/Deaf individuals often consult their parents and Deaf friends for HI (Bukowski, 2015; Karras, 2010; Karras & Rintamaki, 2012; Zazove, Meador, Reed, Sen, A., & Gorenflo, 2009). Karras (2010) and Karras and Rintamaki (2012) focused on the HISB of Deaf adults pertaining to sexual behaviors, sexually transmitted diseases, and flu shots and determined that Deaf individuals often refer to family and friends for HI and are leery of utilizing the internet. Another study by Zozove et al. (2009) indicated that d/Deaf participants use physicians, family, books, friends, the internet, TV, newspapers, nurses, and Deaf organizations to obtain HI. Yet, some Deaf individuals report being skeptical of the quality of HI on the internet and are dissuaded from searching for HI on the internet because of language barriers (Karras, 2010; Karras & Rintamaki, 2012). On the other hand, Deaf individuals may view the internet as a place to start when searching for HI (Bukowski, 2015). Some Deaf individuals with high self-reported English literacy are more likely to find HI online but still have limited understanding of medical vocabulary, which can be frustrating and overwhelming (Smith et al., 2015). This difficulty hinders their understanding of health issues such as cancer, impetigo, colitis, and cardiovascular disease, which can negatively impact their understanding of the progression and prevention of such health issues (Berman et al., 2013; Folkins et al., 2005; Pollard & Barnett, 2009; Smith et al., 2015). In addition, difficulty in

understanding medical vocabulary has the potential to negatively affect cancer incidence and mortality among the deafened population (NNLM, n.d.).

Most of the literature noted above pertains to d/Deaf individuals. An extensive literature search revealed no apparent studies that specifically examined HISB of only late-deafened individuals. However, research by Kushalnagar and Keogh (2017) suggested that there are HISB differences between early-deafened ASL users and late-deafened English users. These researchers found that early-deafened adults using ASL trusted doctors, family, and friends less than their late-deafened counterparts who used English. Additionally, the same study noted that there was a statistical significant difference with early-deafened ASL users stating they found HI too difficult to comprehend when compared to late-deafened English users (Kushalnagar & Keogh, 2017).

Cancer, Cancer Knowledge, and Cancer HISB Among Deaf and Deafened Individuals

Jones, Renger, and Firestone (2005) conducted a two-phase study to examine the health education priorities among a Deaf community. In Phase 1, the researchers determined that Deaf individuals might believe they may face cancer and other cancer-related health issues such as hypertension, diabetes, and poor nutrition as health problems. In phase 2, survey results showed that cancer, cancer prevention, and warning signs of cancer were among the top health concerns (Jones et al., 2005). In spite of these

cancer-related health concerns, deafened individuals may lack important cancer prevention knowledge. For instance, Zazove et al. (2009) noted that d/Deaf individuals correctly responded an average of 25% to questions about cancer prevention recommendations. The same study indicated that obtaining HI from different sources increased knowledge about cancer prevention recommendations. For example, d/Deaf individuals who obtained HI from books, physicians, nurses, and the internet had higher scores in cancer prevention knowledge than those that did not obtain HI from those sources (Zazove et al., 2009). Additionally, Zazove et al. (2009) discovered that d/Deaf individuals who were exposed to English in multiple settings scored higher on cancer prevention knowledge than d/Deaf persons with limited exposure to English. Other researchers have indicated that Deaf individuals do not have a fundamental understanding of cancer and cancer prevention (Orsi, Margellos-Anast, Perlman, Giloth, & Whitman, 2007; Steinberg et al., 2002). Zonderman et al. (2014) also noted that mistrust in healthcare professionals, cultural differences, and low literacy and health literacy levels are distinct barriers to cancer prevention knowledge and behaviors among individuals.

To address the gap in cancer-related knowledge, researchers determined that providing video with ASL, English captions, and voice-over are acceptable methods for providing cancer information to d/Deaf individuals and increasing their knowledge and awareness about breast, cervical, colorectal, ovarian, prostate, and testicular cancers (Hickey, Merz, & Gunsauls, 2013; Jensen et al., 2013; Kaskowitz et al., 2006; Sacks et

al., 2013; Shabaik et al., 2010; Yao et al., 2012). Additionally, having face-to-face ASL-translated training sessions (e.g., demonstrations of self-breast examinations to prevent breast cancer) can be effective for increasing cancer knowledge and self-check skills among d/Deaf individuals (Sadler, Gunsauls et al., 2001). Nevertheless, these studies focused on providing educational videos or training sessions in a physical session and were not disseminated on a large scale to the deafened public, such as via the internet, pamphlets, or books.

Additionally, there is insufficient literature regarding the specific cancer HISB among deafened individuals. Two studies about cancer HISB focused on the d/Deaf and the Deaf. One study revealed that most d/Deaf women reported a majority of their HI came from physicians or family and friends; but there was no indication which HI sources were most trusted (Berman et al., 2013). Another follow-up study by Berman et al. (2017) noted that doctors, family and friends were to top two most utilized sources among d/Deaf women. Folkins et al. (2005) revealed that most Deaf males were more likely to trust HI from doctors, followed by Deaf community services, the internet, and health education programs. However, these studies were limited to small and regionally-specific populations. Additionally, there are no known studies examining the HISB of deafened individuals with high PCR on a national level. Most of the research literature specifically focuses on cancer HI among d/Deaf populations and does not distinguish the late-deafened or hard-of-hearing groups. After an extensive search through databases,

there appear to be no studies that specifically examine HISB, cancer HI, and/or PCR status among late-deafened, hard-of-hearing, or deafened who use English. Therefore, the purpose of the current study was to identify which HI sources deafened individuals with high PCR trust and use, which can inform the development of appropriate and accessible HI for deafened individuals.

Summary

In summary, HISB are influenced by several factors such as LEP, demographics, health literacy, and individual influences. Most HI sources are at a high reading level, which poses difficulty to individuals comprehending and utilizing information found in HI sources. Cancer is one of the diseases with the highest rates of mortality and morbidity in the United States. Yet, HI sources in general and cancer HI sources on prevention and treatment are difficult for some individuals to comprehend because of their high reading level. This hinders individuals from using cancer HI to engage in preventive health behaviors or to gain knowledge that is pertinent to treatment, survival, and quality of life. In addition, most research about HI and HISB focuses on mainstream populations rather than those with disparities; and even fewer studies focus on individuals with health disparities such as the deafened. Not much is known about HISB in general and cancer-related HISB among the deafened, particularly those with high PCR. The lack of health surveillance among Deaf ASL users (McKee & Paasche-Orlow, 2012) contributes to this gap in knowledge. The Deaf community perceive cancer to be a

concerning health topic (Jones, Renger, and Firestone, 2005). Nevertheless, no studies focus on deafened individuals with high PCR, their HISB, and the HI sources they trust and use. Therefore, the aim of this study is to examine the HISB of deafened individuals with high PCR and identify the HI sources they trust and use.

CHAPTER III

METHODOLOGY

For this study, the researcher used quantitative analysis of secondary data from the HINTS 4 Cycle 3 English survey. The following chapter describes the population and sample used in the study, the IRB review process, a brief description of the HINTS 4 Cycle 3 instrument, and the statistical analyses completed.

Population and Sample

HINTS 4 Cycle 3 is a national study conducted by the NCI to track health communication and HISB among Americans and collect data about Americans' knowledge of, attitudes toward and perceptions of cancer, use of HI, and health behaviors (NIH & NCI, n.d.). The sample stratification for HINTS 4 Cycle 3 was a two-step process (Westat, n.d.). The first step was an equal-probability sample of addresses selected from within each sampling stratum that consisted of the following: addresses in locations with high density of minorities; addresses in locations with low density of minorities; and addresses within counties comprising Central Appalachia, regardless of race (Westat, n.d.). The second step consisted of selecting one adult residing in the sampled household (Westat, n.d.). The participant selection was stratified to provide a more realistic representation of the U.S. population by utilizing the Decennial Census Summary File results about the race of residents and population density within specific areas (Westat, n.d.). The HINTS 4 Cycle 3 in English was mailed in 2013 to a random

sample of 28,793 U.S. citizens aged 18 and older with a return of 3,185 responses (35.19% response rate) (Westat, n.d.). Materials from HINTS 3 Cycle 3 indicated that 61 of the surveys were only partial completed (Westat, n.d.). For the current study, the researcher only used a HINTS 4 Cycle 3 sample comprised of individuals who self-reported being deaf or having serious difficulty hearing (*HINTS 4 Cycle 3 Codebook*, 2014).

Protection of Human Participants

The HINTS 4 Cycle 3 was a mailed survey specifically addressed to individuals based on information found in the Decennial Census Summary File (Westat, n.d.). The responses from the survey were kept private in accordance to the Privacy Act (1974), and a data management protocol was in place to store completed surveys in a separate file from the data file containing the identifiable data. Documentation from HINTS 4 Cycle 3 indicates that surveys were destroyed after the research project was completed (Westat, n.d.). For the current study, the researcher received approval to perform secondary data analysis by the institution's IRB. The names and other identifiable data were not included in the data set provided by HINTS.gov.

Data Collection Procedures

The data collection process with HINTS 4 Cycle 3 spanned from September 2013 to December 2013 and consisted of four mailings (Westat, n.d.). The initial mailing consisted of a letter of invitation along with the survey. The second mailing was a

reminder postcard to encourage completion and return of the survey. The third and fourth mailings were letters reminding individuals to complete and return the survey if the survey was not returned. Returned surveys were verified and scanned; and data were entered into a data management system, cleaned, edited, and checked for quality. Identifiable data were removed from the data set, saved as data files, and published on the HINTS website (Westat, n.d.).

Instrumentation

The purpose of HINTS is to regularly collect data and track changes pertaining to Americans' health communication, HISB, attitudes, beliefs, and knowledge about cancer, and health behaviors (NIH & NCI, n.d.). The HINTS 4 Cycle 3 survey is the third out of four cycles (Westat, n.d.). The questions within the survey are used to examine demographics, personal health information, HI sources used, HISB, knowledge, perceptions, and attitudes of cancer among Americans (NIH & NCI, n.d.). According to HINTS 4 Cycle 3 documentation, the specific sampling methods (noted in Population and Sample) were used to provide a study sample representative of the U.S. population (Westat, n.d.). The HINTS, like most population-level health surveys, undergoes arduous cognitive testing to ensure construct and content validity of the survey questions; however, the HINTS survey does not lend itself to traditional measures of reliability (B. Keefe, personal communication, July 1, 2018).

Data Analysis

The researcher analyzed secondary quantitative data from HINTS 4 Cycle 3 to assess respondents': (a) demographics, (b) hearing status, (c) PCR, (d) HISB, (c) sources of HI, and (d) trusted sources to obtain HI. The data from the HINTS website was transferred to the Statistical Package for Social Sciences (SPSS) version 23.0 statistical software (IBM Corp., 2015), cleaned, and analyzed. The data in SPSS was saved and stored on the researcher's personal computer that is password-protected.

A priori power analysis was conducted using G*Power version 3.1.7 (Faul, Erdfelder, Buchner, & Lang, 2009) to determine the minimum sample size required to find significance with a desired level of power set at .80, an α -level at .05, and a moderate effect size of .30. Based on the analysis, it was determined that a minimum of 68 participants were required to ensure adequate power for analyses.

Only those who self-reported as having trouble with hearing were included in the analysis. Descriptive statistics were calculated for all variables comprised of means, standard deviations, medians, and minima and maxima for continuous variables, while frequencies and percentages were calculated for all categorical demographic variables. Distributions of the continuous variables were examined to determine if normality assumptions were met and parametric testing was appropriate, or whether transformed data or non-parametric tests should be used. Extreme outliers were investigated for technical or clerical errors. No outliers were identified.

Demographic variables included age, race, ethnicity, gender, marital status, household income, education level, military status, and English speaking status. The variable *high PCR* was re-coded to categorize those who reported they were likely or very likely to get cancer in their lifetime. The variable *low PCR* was re-coded to categorize those who perceived they were unlikely or very unlikely to get cancer in their lifetime. In response to Research Questions 1-4, frequencies were calculated from HINTS 4 Cycle 3 survey questions that include demographics, HI sources, trusted HI sources, and high PCR (likely or very likely). For the null hypothesis, two analyses were completed. First, a correlation analysis was used to examine the relationships between PCR status and the various trusted HI sources. For this analysis, the PCR variable that was examined consisted of five levels of PCR status (very likely, likely, neither likely nor unlikely, and very unlikely). To further examine the relationship between high PCR status and the various trusted HI sources, *t*-tests were completed as the second analysis for the hypothesis. For the *t*-tests, PCR status was categorized into two groups: high PCR and low PCR. *High PCR* were those respondents who perceived they were either very likely or likely to get cancer in their lifetime, and *low PCR* were those respondents who perceived they were unlikely or very unlikely to get cancer in their lifetime. A significant correlation coefficient (Pearson's *r*) with *p* set at .05 indicated that a relationship existed.

Summary

HINTS 4 Cycle 3 is a national data set that obtains information about Americans' HISB, attitudes, beliefs, and knowledge about cancer, and health behaviors (NIH & NCI, n.d.). After IRB approval, the researcher analyzed the (a) demographics, (b) hearing status, (c) PCR, (d) HISB, (c) sources of HI, and (d) trusted sources to obtain HI based on the HINTS 4 Cycle 3 results. Data was analyzed using descriptive statistics and correlation analysis.

CHAPTER IV

RESULTS

This chapter present the results of this study, which analyzed data from HINTS 4 Cycle 3. The primary purpose of this study was to examine the HISB among deafened individuals with high PCR. A second purpose was to identify which HI sources deafened adults with high PCR trust and use. The third purpose was to determine if there was a relationship between PCR status and trust in HI sources.

Demographics

In HINTS 4 Cycle 3, 229 individuals who self-reported being deaf or having serious difficulty hearing submitted an English survey. Of the 229, a majority were white (79.0%), 13.5% were black, 3.9% were American Indian or Alaskan Native, and the remaining participants self-identified as Asian. In addition, 4.4% of respondents self-identified as Mexican, 4.4% self-identified as other Hispanic, 0.4% self-identified as Puerto Rican, while 0.9% self-identified as having multiple Hispanic ethnicities. Of the 229 individuals who self-reported being deaf or having serious difficulty hearing, 44.5% were male, 51.55% were female, and the remaining omitted the question. In terms of employment status, 55.9% were retired, 19.2% of were employed, 14.0% were disabled and unable to work, 7.4% were homemakers, 5.2% were unemployed, and 0.4% were

students. The mean for age for participants was 69.25 years with a standard deviation (SD) 15.12 years. See Table 1 for additional demographic information.

Table 1

Frequencies and Percentages of Demographic Variables of Deafened Adults in HINTS 4 Cycle 3

Demographic Variables	<i>n</i>	%
Gender		
Male	102	44.5
Female	118	51.5
Marital Status		
Married	96	41.9
Previously Married	109	47.6
Never Married	19	8.3
Household Income		
\$0-\$19,999	81	35.4
\$20,000-\$49,999	120	52.4
>\$50,000	23	10.0
Education Level		

< 11 years of school	35	15.3
12 Years Or Graduated High School	75	32.8
Post High School Training	18	7.9
Some College	55	24.0
Graduated College	28	12.2
Postgraduate	15	6.6
Military Status		
Never Served	156	68.1
Training for the Reserves or National Guard	5	2.2
Active Duty or Recent Active Duty	49	21.4
English Speaking Status		
Well	213	93.0
Not Well	6	2.6

Note. Frequencies not summing to $N = 229$ and percentages not summing to 100 reflect missing data.

Table 2 presents the demographics for deafened adults with high PCR. Of the 229 respondents, 46 noted having high PCR (likely or very likely to get cancer within their lifetime). The mean age of this sub-group was 65.38 years with a SD of 13.21 years. Of those deafened with high PCR, 43.5% were male and 50.0% were female, which 6.3% omitted the question. In terms of race, 78.3% were white, 19.6% were black, and 2.2% were American Indian or Alaska Native. Regarding ethnicity, over 78% self-reported not being of Hispanic origin, 6.5% of respondents self-identified as Mexican, 4.3% self-identified as other Hispanic, 2.2% self-identified as Puerto Rican, while 2.2% self-identified as having multiple Hispanic ethnicities. Additionally, the self-reported employment status was as follows: 47.8% retired, 23.9% employed, 17.4% disabled and not working, 8.7% unemployed, 6.5% homemaker, and other occupational status was 2.2%.

Table 2

Frequencies and Percentages of Demographic Variables of Deafened Adults With High PCR in HINTS 4 Cycle 3

Demographic Variables	<i>n</i>	%
Gender		
Male	20	43.5

Female	23	50.0
Marital Status		
Married	21	45.7
Previously Married	22	47.8
Never Married	2	4.3
Household Income		
\$0-\$19,999	17	37.0
\$20,000-\$49,999	26	56.5
>\$50,000	3	6.5
Education Level		
< 11 Years of School	6	13.1
12 Years or Graduated High School	21	45.7
Post High School Training	4	8.7
Some College	10	21.7
Graduated College	3	6.5
Postgraduate	1	2.2
Military Status		
Never Served	29	63.0
Active Duty or Recent Active Duty	10	21.8
English Speaking Status		

Well	44	95.6
Not Well	1	2.2

Note. Frequencies not summing to $N = 46$ and percentages not summing to 100 reflect missing data. PCR= perceived cancer risk.

Research Questions and Null Hypothesis

This section addresses the research questions and hypotheses and the respective findings. For Research Questions 1-4, individuals with high PCR are respondents who perceived they were either likely or very likely to get cancer in their lifetime. Research Question 1 asked which HI source deafened adults with high PCR accessed first in their most recent search (see Table 3). Almost 30% of deafened adults with high PCR searched the internet first, and the next HI source was a doctor or healthcare professional at 21.7%.

Table 3

Frequency Table of Deafened Adults With High PCR and HI Sources First Accessed in Latest Search

Source	<i>n</i>	%
Traditional Print Sources (Books, Brochures, Pamphlets, and Magazines)	4	8.7
Family, Friends, Co-Workers	2	4.4
Doctor or Healthcare Professional	10	21.7
Internet	13	28.3

Note. Frequencies not summing to $N = 46$ and percentages not summing to 100 reflect missing data. PCR= perceived cancer risk; HI = health information

In the HINTS 4 Cycle 3 survey, the responses for degree of trust of HI were categorized as *a lot, some, a little, and not at all*. These same categories are used in the upcoming results to stay consistent with the survey. The aforementioned categories are noted in the text and in the tables for Research Questions 2-4 and the Hypothesis.

Research Question 2 asked what top three HI sources deafened adults with high PCR trusted the most. Table 4 shows the HI source and the degree of trust expressed by deafened adults with high PCR. Research Question 2 asked what top three HI sources deafened adults with high PCR trusted the most. Table 4 shows the HI source and the degree of trust expressed by deafened adults with high PCR. For this analysis, to determine the order of rankings, the percentage for each categories *a lot* and *some* were examined individually followed by the examination of cumulative percent of *a lot* and *some*. Rankings were based on which HI source had the highest percentage in the *a lot* category, and the cumulative percent was examined as well. Doctors were identified as the HI source that deafened adults with high PCR trusted the most. Approximately 70% of respondents stated they trusted doctors *a lot*, and about 28% trusted doctors *some*, which indicates that most of the respondents (97.8%) trusted doctors *a lot* or *some* for HI. The second most trusted HI sources were *family and friends* and *health and medical magazines*. Approximately 15% of respondents identified trusting HI from family and friends *a lot*, while 32.6% stated they trusted HI from family and friends *some*. Collectively, almost half (47.8%) of the participants reported they trusted their family and friends *a lot* and *some* when obtaining HI. Then too, 15.2% of deafened adults with high PCR trusted HI from health and medical magazines *a lot*, while 34.8% trusted HI from health and medical magazines *some*. Thus, 50% of deafened adults with high PCR trusted HI from health and medical magazines *a lot* and *some*. The third most

trusted HI source was the internet, with 54.6% of respondents stating they trusted HI from the internet either *a lot* (13.3%) or *some* (41.3%).

Table 4

Frequency and Percent of Trust in HI Sources Among Deafened Adults With High PCR

Source	<i>n</i>	%	Cumulative Percent
Doctor			
A Lot	32	69.6	69.6
Some	13	28.3	97.8
A Little	1	2.2	100.0
Not At All	0	0	100.0
Total	46	100.00	
Family and Friends			
A Lot	7	15.2	15.2
Some	15	32.6	47.8

A Little	18	39.1	86.9
Not At All	4	8.7	95.6
Total	44	95.6	
Online Newspapers			
A Lot	0	0	0
Some	13	28.3	28.3
A Little	6	13.0	41.3
Not At All	20	43.5	84.8
Total	39	84.8	
Print Newspapers			
A Lot	1	2.2	2.2
Some	12	26.1	28.3
A Little	13	28.3	56.6

Not At All	15	32.6	89.2
Total	41	89.2	
Health & Medical Magazines			
A Lot	7	15.2	15.2
Some	16	34.8	50.0
A Little	14	30.4	80.4
Not At All	5	10.9	91.3
Total	42	91.3	
Radio			
A Lot	1	2.2	2.2
Some	15	32.6	34.8
A Little	12	26.1	60.9
Not At All	15	32.6	93.5

Total	43	93.5	
Internet			
A Lot	6	13.3	13.3
Some	19	41.3	54.6
A Little	11	23.9	78.5
Not At All	5	10.9	89.4
Total	41	89.4	
Local TV			
A Lot	1	2.2	2.2
Some	15	32.6	34.8
A Little	17	37.0	71.8
Not At All	9	19.6	91.4
Total	42	91.4	

National or Cable TV

A Lot	2	4.3	4.3
Some	16	34.8	39.1
A Little	16	34.8	73.9
Not At All	7	15.2	89.1
Total	41	89.1	

Government Health Agencies

A Lot	5	10.9	10.9
Some	18	39.1	50.0
A Little	14	30.4	80.4
Not At All	5	10.9	91.3
Total	42	91.3	

Charitable Organizations

A Lot	2	4.3	4.3
Some	12	26.1	30.4
A Little	15	32.6	63.0
Not At All	13	28.3	91.3
Total	42	91.3	
Religious Organizations And Leaders			
A Lot	3	6.5	6.5
Some	14	30.4	36.9
A Little	14	30.4	67.3
Not At All	11	23.9	91.2
Total	42	91.2	

Note. Frequencies not summing to $N = 46$ and percentages not summing to 100 reflect missing data. PCR = perceived cancer risk; HI = health information.

Research Question 3 asked which were the top three HI sources that deafened females with high PCR trust the most. Research Question 4 asked which were the top three HI sources that deafened males with high PCR risk trust the most. For these questions, the degree of trust was averaged to indicate which HI sources had the highest rank among male and female respondents. In the HINTS 4 Cycle 3, the numeric representation of the *some*, *a lot*, *a little*, and *not at all* were as follows: *a lot* = 1, *some* = 2, *a little* = 3, and *not at all* = 4. When calculating the Trust Mean for each of the HI sources, the lower the average, the higher the degree of trust in the HI sources. Table 5 shows which HI sources were the most trusted among deafened males and females with high PCR.

Table 5

Most Trusted HI Sources Ranked for Males and Females

	Rank 1	Average	Rank 2	Average	Rank 3	Average
Male	Doctor	1.35	Internet	2.39	Family and Friends	2.47
Female	Doctor	1.26	Health and Medical Magazines	2.14	Government Health Agencies	2.19

Note. HI = health information

The following null hypothesis was tested at the 0.05 level of significance:

There will be no relationship between deafened adults with high PCR and their degree of trust regarding HI sources. Pearson's correlations were conducted to examine the relationship between deafened adults with five categories of PCR status (very likely, likely, neither likely nor unlikely, unlikely and very unlikely) and their degree of trust regarding HI sources. The results revealed that there was no relationship between high PCR to the level of trust in HI sources. Table 6 shows the Pearson's r for the PCR status and the degree of trust in HI sources.

Table 6

Correlation Pearson's r Between PCR Status and Trust in HI Sources

HI source	Pearson's r	N
Doctor	-.067	158
Family and Friends	-.043	150
Online Newspapers	.129	135
Print Newspapers	.134	141
Health or Medical Magazine	.016	144

Radio	.025	142
Internet	-.028	143
Local Television	-.024	145
National or Cable Television	.036	142
Government health agencies	.070	142
Charitable Organizations	.102	142
Religious Organizations/Leaders	-.010	144
Trust Mean	.039	158

Note. * $p < .05$, ** $p < .01$. PCR = perceived cancer risk; HI = health information

To further explore the level the relationship between high PCR status and degree of trust in HI sources, a *t*-test was completed on each of the 12 HI sources and the trust mean of each HI source. The *t*-tests compared the level of trust in all 12 HI sources and the trust mean between those with high PCR (very likely or likely to get cancer) to those with low PCR (unlikely and very unlikely to get cancer). Of the 12 *t*-tests and the Trust Mean of each HI source, none were statistically significant. The results are in Table 7.

Table 7

Independent T-Test: PCR Status and HI Sources With Equal Variances Assumed

Variable	<i>N</i>	<i>M</i>	<i>SD</i>	<i>t</i>	<i>p</i>
Doctor				.954	.395
High PCR	41	1.44	.709		
Low PCR	46	1.33	.519		
Family and Friends				.367	.715
High PCR	38	2.50	.797		
Low PCR	44	2.43	.937		
Online Newspapers				-.958	.342
High PCR	32	2.97	.933		

	Low PCR	39	3.18	.914		
Print Newspapers					-1.115	.268
	High PCR	35	2.80	.868		
	Low PCR	41	3.02	.880		
Health or Medical Magazines					-.216	.830
	High PCR	36	2.36	.867		
	Low PCR	42	2.40	.912		
Radio					-.062	.951
	High PCR	34	2.94	.814		
	Low PCR	43	2.95	.899		
Internet					.599	.551

	High PCR	34	2.50	1.052		
	Low PCR	41	2.37	.888		
Local Television					.435	.665
	High PCR	35	2.89	.718		
	Low PCR	42	2.81	.804		
National Television or Cable					-.303	.763
	High PCR	35	2.63	.731		
	Low PCR	41	2.68	.820		
Government Health Agencies					1.071	.288
	High PCR	35	2.23	.973		
	Low PCR	42	2.45	.861		
Charitable Organizations					-1.164	.248

	High PCR	35	2.69	.932	
	Low PCR	42	2.93	.894	
Religious Organizations/					
	Leaders			.215	.830
	High PCR	36	2.83	1.028	
	Low PCR	42	2.79	.925	
					.6
	Trust Mean			-.398	.91
	High PCR	41	2.43	.697	
	Low PCR	46	2.49	.684	

Note. * $p < .05$, ** $p < .01$. PCR = perceived cancer risk; HI = health information

Summary

Data from HINTS 4 Cycle 3 were cleaned and analyzed using quantitative methods. From this data set, a total of 46 respondents self-identified as deafened with a high PCR status. Of the deafened adults with high PCR, 43.5% were male and 50% were female; over 70% were white, over 45% were married, over 50% had an income of \$20,000-\$49,999, over 80% completed high school or had some form of college and post high school training, and approximately 63% never served in the military. During the last HI search, most of the deafened adults with high PCR consulted the internet first (28.3%), followed by doctors and other healthcare professionals (21.7%). Additionally, 97.8% of deafened adults with high PCR reported trusting doctors and other healthcare professionals *a lot or some* to provide reliable HI. Furthermore, 54.6% reported trusting the internet *a lot or some* when obtaining HI. Males and females differed in their responses concerning most trusted HI sources. Both genders ranked doctors and other healthcare professionals as the most trusted HI source. However, males ranked the internet as their second most trusted source, while females ranked health and medical magazines as their second most trusted source. Further analysis using Pearson's r correlation revealed that there was no relationship between level of PCR among deafened adults and trust in HI sources. Additional analysis using t -tests on all 12 HI sources with

level of PCR revealed no statistically significant relationship between high PCR and trust in HI sources.

CHAPTER V

CONCLUSIONS AND RECOMMENDATIONS

This chapter will examine study results, particularly as they compare to the research questions, hypothesis, and related literature. Additionally, implications for health educators, healthcare professionals, librarians, and creators of health information will be discussed as well as study limitations and recommendations for future research.

Summary and Discussion

This study was a cross-sectional, secondary analysis of HINTS 4 Cycle 3 data, which was obtained from a stratified sample of households based on a U.S. Census and population density. The researcher downloaded the publicly available data set from the HINTS website, then cleaned and analyzed the data. The primary purpose of this study was to examine (a) the HISB of deafened adults with high PCR, (b) which HI sources deafened adults with high PCR trust, and (c) whether there is a relationship between high PCR and HISB among deafened adults. Another study aim was to determine if there was a relationship between level of self-reported PCR and trusted HI sources.

HINTS 4 Cycle 3 Participants

For this study, HINTS 4 Cycle 3 data included 229 deafened respondents, of whom 46 self-reported having high PCR. The average age of deafened adults with self-reported high PCR was almost 66 years. Of the deafened adults with high PCR, the majority (78.3%) were white and 50% were female. More than 39% of the deafened

adults with high PCR attended some type of higher education or trade school after high school. Additionally, approximately 24% of deafened individuals with high PCR were employed, 47.8% were retired, 45.7% were married, and over 63% never served in the military.

The HINTS 4 Cycle 3 does not have an item in the survey that indicates ASL use or onset of deafness; however, the data of HINTS 4 Cycle 3 alludes that most of the participants within the data set were late-deafened (P. Kushalnagar, personal communication, December 16, 2018). This assumption is based on factors noted in the data: age of the participants, military status, and their self-reported ability to speak English. The average age of the deafened participants in the HINTS 4 Cycle 3 was 69.25 years and the average age of those deafened with high PCR was 65.38 years. Additionally, over 56% of the deafened individuals with high PCR were 65 years and older. The NIDCD (2018) explained that age-related hearing loss is common and is most frequently experienced among older and elderly adults. In fact, estimates suggest that one third of adults between 65 and 74 and nearly 50% of adults over the age of 75 experience hearing loss or have difficulty hearing (NIDCD, 2018). Those who become deafened later in life may identify themselves as late-deafened (National Association of the Deaf, 2019). Furthermore, the data revealed that almost 20% of the deafened participants who were deafened at some point worked in the armed forces. Additionally, over 21% of the deafened participants with high PCR were in the armed

forces. Currently, the armed forces requirements for hearing exclude deafened individuals from joining (U.S. Government Publishing Office, 2008). This suggests that those deafened individuals experienced deafness either during or after their military service. Research indicates that military personnel can experience hearing loss and deafness depending on their department of service (CDC, 2011; Healey, 2017; Yong & Wang, 2015). However, according to the U.S. Government Publishing Office (2008), some individuals with functional hearing loss are allowed in the military and appropriate treatment programs are in place should hearing loss be detected among military personnel (McIlwain, Gates, & Ciliax, 2008). Additionally, there is a push to allow deaf individuals to enlist in military service as outlined in the Keith Nolan Air Force Deaf Demonstration Act of 2018, which was presented to U.S. Congress in May of 2018 (H.R.5831 - Keith Nolan Air Force Deaf Demonstration Act of 2018). Moreover, over 90% of the deafened individuals in HINTS 4 Cycle reported that they spoke English well or very well and over 95% of the deafened individuals with high PCR spoke English well.

These participant characteristics are important as they can impact how participants seek and obtain HI. For example, late-deafened individuals are probably comfortable speaking to and obtaining HI from their doctors and healthcare providers. Kushalnagar and Keogh (2017) demonstrated that those who are late-deafened trust HI from their doctors and healthcare provider, whereas those who are early-

deafened and use ASL are less likely to trust HI from a doctor healthcare provider. Therefore, the level of trust in HI sources among those with high PCR may differ according to whether they are late-deafened or early-deafened. Because HINTS 4 Cycle 3 data suggests that a majority of the deafened participants were late-deafened and/or spoke English, it stands to reason that they had the potential of being exposed to different health-related environmental stimuli and HI in comparison to the profoundly deaf who used ASL. Additionally, most studies noted in this discussion pertain to d/Deaf individuals using ASL, who typically exhibit different HISBs than individuals who are late-deafened and/or deafened English speakers. There are also no known studies that exclusively examine HISB of late-deafened or English-speaking deafened individuals, although Kushalnagar and Keogh (2017) compared early-deafened ASL users to late-deafened English users in a poster presentation at a professional conference.

Research Questions and Hypothesis

The following discussion focuses on the research questions and hypothesis that guided the current study.

Research Question 1: Which HI sources did deafened adults with high PCR access first on their most recent search?

The data from HINTS 4 Cycle 3 alludes that most of the deafened participants were late-deafened; and as Kushalnagar and Keogh (2017) pointed out, there is a difference in trust between early-deafened ASL users and late-deafened English users.

Therefore, to give a well-rounded view of the HISB of the deafened population, there will be focus on other literature that relates to HISB of d/Deaf populations as well as the general population. In the current study, deafened individuals with high PCR (28.3%) went to the internet first for their most recent HI search. These results complement findings from other studies. For example, Kushalnagar and Kushalnagar (2018) discovered that 55% of deaf ASL users refer to the internet first for HI. Karras and Rintamki (2012) reported that some Deaf individuals utilize the internet as a HI source but also experience skepticism concerning the accuracy of online HI. This may help explain why Berman et al. (2013) and Berman et al. (2017) noted that the internet is the fourth most frequently used HI source among Deaf women. On the other hand, the general population also consults the internet for HI. For example, Pew Research Center report stated that almost 60% of American adults use the internet to find HI and over 50% of American adults use the internet to find certain information about a specific disease or medical problem (Rainie, 2013). Moreover, 53% of Americans who consult the internet for HI discuss their finding of eHealth information with their healthcare professional (Rainie, 2013). Furthermore, Kealey and Berkman, 2010 noted that over 11% Americans with high PCR did utilized the internet when searching for HI. Additionally, LaCoursiere, Knobf, and McCorkle (2005) noted that cancer patients, although eager to find cancer HI, viewed unknown online sources with skepticism. Some professionals assert that a degree of skepticism is healthy when reviewing online HI sources and

suggest consulting a clinician to clarify potentially inaccurate online HI (*Healthy skepticism' advised for online medical information*, 2008).

A doctor or healthcare provider was the second most frequently used source in the most recent HI search by deafened individuals with high PCR (21.7%). These results are similar to other study findings. For example, Berman et al. (2013) and Berman et al. (2017) explained that d/Deaf women identify doctors as the most frequently used HI source. In another study, Deaf individuals explained that they prefer to get HI from their primary care physician (Karras & Rintamki, 2012). Furthermore, Kushalnagar and Kushalnagar (2018) noted that 12% of deaf signers consult a doctor first for HI. The general populations had higher rates of utilizing a doctor or healthcare provider for HI. Physicians are the most trusted source for HI; however, many people still prefer to search for HI online (Hesse et al., 2010). Individuals with high trust in a physician do not tend to use the internet as often for HI (Hesse et al., 2010). Yet, national surveys have indicated a slight decline in the trust of the internet for HI, while trust in physicians has remained steady (Hesse et al., 2010).

Traditional print sources (books, brochures, flyers, and health and medical magazines) were the third most utilized source in the most recent HI search by deafened individuals with high PCR (8.7%). However, Berman et al. (2013) and Berman et al. (2017) discovered that d/Deaf women utilize book, magazines, and newspapers for HI the internet. Folkins et al. (2005) discovered that Deaf males initially obtained HI from

books and pamphlets less often than HI from doctors and the internet; but after an educational video, they consulted books and pamphlets more often. However, in general populations, individuals who distrust HI from their physicians tend to rate online HI as useless and prefer to use traditional HI sources (Rains, 2007). Additionally, Rains (2007) explained that when an individual distrusts information from a traditional HI source (mass media or healthcare providers), there is an increased likelihood of that individual using the internet as the primary HI source. Another study indicated that individuals with his PCR sought HI from newspapers (Kealey & Berkman, 2010). Moreover, over 50% of those living with chronic diseases are likely to get HI from traditional printed sources (Fox & Purcell, 2010).

In addition, individuals with high PCR are less likely to first seek HI from family, friends, and co-workers. Similar findings were noted in other studies (Berman et al., 2013; Folkins et al., 2005; Karras & Rintamki, 2012). Folkins et al. (2005) discovered that Deaf men selected family and friends as their third and fourth choices for HI prior to a video health intervention about prostate cancer. In contrast, Berman et al. (2013) and Berman et al. (2017) noted that family and friends are the second most used HI source among D/deaf women. Although there is a willingness to seek HI from family and friends (Karras & Rintamki, 2012), some deaf ASL users tend to request help from family and friends to aid in their comprehension of HI or to simplify HI content (Berman et al., 2013). However, Kushalnagar and Keogh (2017) noted that early-deafened ASL

users were less likely to trust HI from their family and/or friends than late-deafened English users. Review of literature from general populations indicates that family and friends are utilized as a HI source among those with low health literacy (Gutierrez et al., 2014). Additionally, 60% individuals living with chronic diseases, such as cancer, obtain HI from family and friends (Fox & Purcell, 2010). Moreover, approximately 43% of cancer patients reported that family members influenced their treatment decisions (Walsh et al., 2010).

Research Question 2: What are the top three HI sources that deafened adults with high PCR trust the most?

Deafened individuals with high PCR noted doctors as their top most trusted HI source (69.6%). Because the majority of the deafened participants in HINTS 4 Cycle 3 spoke English well, they may have trusted doctors more because of their ability to communicate with their doctors in English. In contrast, deafened ASL users often experience communication barriers because of the lack of ASL-fluent healthcare providers and certified ASL interpreters in the healthcare setting (Karras et al., 2011). Karras (2010) determined that Deaf respondents' views varied regarding the utility of the information provided by doctors, depending on the context of the HI. For example, respondents thought HI about drugs and alcohol was least valuable in comparison to information about flu shots (most valuable) (Karras, 2010). In another study, Smith et al. (2015) discovered that Deaf adolescents trusted HI from doctors about cardiovascular

health; however, participants experienced communication barriers as doctors mainly communicated with their parents who were interpreting the information. However, the general populations note that the most trusted source for HI are doctors; however, many individuals prefer to find HI on the internet (Hesse et al., 2010). Nevertheless, individuals with high trust in a physician do not utilize the internet for HI as often (Hesse et al., 2010). Additionally, national surveys have shown a decline in the trust HI found online, while trust in physicians has remained steady (Hesse, et al., 2010).

Results from the current study revealed a tie for the second most trusted HI source among deafened adults with high PCR, which were family and/or friends and health and/or medical magazines. Other literature reflects varying results. For example, in studies by Karras (2010) and Karras and Rintamki (2012), Deaf individuals placed more value on HI from interpersonal sources such as family and friends than other HI sources. Folkins et al. (2005) found that Deaf males selected traditional printed items such as books and pamphlets as their second choice for HI. Additionally, participants in other studies (Berman et al., 2013; Berman et al., 2017) ranked books, magazines, and newspapers as third and fourth most frequently used HI sources, respectively. The HISBs among the general population reveal some similarities and differences with HISBs of deafened individuals from the study. For example, family and friends are utilized as a HI source among those with low health literacy (Gutierrez et al., 2014). Additionally, approximately 60% of Americans surveyed living with chronic diseases obtain HI from

family and friends (Fox & Purcell, 2010). Furthermore, one study identified over 40% of cancer patients self-reported that family members influenced their treatment decisions (Walsh et al., 2010). Pertaining to HISB use of traditional printed HI among general populations, Americans with low health literacy tend to retrieve most of their HI from written sources such as traditional print HI sources, while those with high health literacy consult books and brochures when they choose not to use the internet (Kutner et al., 2006). Moreover, over 50% of those living with chronic diseases are likely to get HI from traditional printed sources (Fox & Purcell, 2010).

The internet ranked as the third most popular choice for first HI searches among deafened adults with high PCR, while other studies report mixed findings. For example, Folkins et al. (2005) and Kushalnagar and Kushalnagar (2018) showed that the internet ranked first among Deaf adults, whereas research results from Berman et al. (2013) and Berman (2017) displayed the internet ranked as fourth and fifth, respectively, among d/Deaf. However, research conducted by Folkins et al. (2005), Berman et al. (2013), and Berman et al. (2017) did not focus on *trust* of HI sources; and Kushalnagar and Kushalnagar (2018) examined whether demographic variables predicted trust in HI sources. In terms of a more balanced view of HISBs, there are similarities and differences between deafened individuals and the general population. For example, if an individual distrusts information from a traditional HI source (mass media or healthcare providers), there is an increased likelihood of that individual searching the internet for HI

(Rains, 2007). Additionally, surveys of general populations have noted a decline in trust of HI from the internet; yet, the internet is a widely used HI source among general populations (Hesse et al., 2010). Furthermore, individuals who distrust information-oriented media (newspapers and magazines) are more likely to use the internet as the first source for HI (Rains, 2007).

Research Question 3: What are the top three HI sources that deafened women with high PCR trust the most?

Deafened females with high PCR trusted HI from doctors the most. Additionally, health and medical magazines were the second most trusted HI source followed by government health agencies (third) and the internet (fourth). Similarly, Berman et al. (2013 and 2017) explained that d/Deaf women reported a majority of their HI came from physicians or family and friends; but there was no indication which HI sources were most trusted. Then too, Kushalnagar and Kushalnagar (2018) noted that demographic variables, such as gender, did not predict ASL users' distrust of online HI. Most studies noted in this section were with d/Deaf populations rather than late-deafened or deafened English speakers, which blurs comparisons with the current study. Yet research of HISB among general populations provides a different outlook on HISB behaviors. For example, one study noted that individuals that are females, younger, and have higher income and education levels obtain HI from other sources in addition to the HI from healthcare staff involved with their cancer treatment (Boudioni et al., 2001; Carlsson,

2000; Czaja et al., 2003; Manfredi et al., 1993; O’Leary et al., 2007; Rutten et al., 2005).

Additionally, women are more likely to use the internet for HI in comparison to their male counterparts (Fox, 2011b; Mesch et al., 2012). Moreover, women tend to have a higher level of trust HI from internet and most other HI sources such as healthcare providers, family and friends, and print compared to men (Brown-Johnson et al., 2018).

Research Question 4: What are the top three HI sources that deafened men with high PCR risk trust the most?

Similar to deafened females, deafened males with high PCR trusted HI from doctors the most. The internet was the second most trusted HI, followed by family and friends (third) and health and medical magazines (fourth). These results are parallel to another study by Folkins et al. (2005), which revealed that most Deaf males were more likely to trust HI from doctors, followed by Deaf community services, the internet, and health education programs. Folkins et al. (2005) also noted that Deaf males trust family and friends for HI, whereas HI from books and brochures are among the least trusted HI sources. Additionally, Kushalnagar and Kushalnagar (2018) showed that being male did not predict trust in online HI. However, as previously noted, the aforementioned studies primarily focus on d/Deaf populations and do not focus on late-deafened or deafened English users. One study does explain that late-deafened English users are more likely to trust HI from their family/friends than early-deafened ASL users (Kushalnagar & Keogh, 2017). To provide a balance to the discussion the following information pertains to HISB

among general populations. For example, men, women are less likely to use the internet for HI in comparison to their female counterparts (Fox, 2011b; Mesch et al., 2012). Moreover, men tend to have a lower level of trust HI from internet and television, internet, and social media than women (Brown-Johnson et al., 2018).

Hypothesis: There will be no relationship between deafened adults with high PCR and their degree of trust regarding HI sources.

This section discusses the analyses for the hypothesis. For the Pearson's r , the number of participants required for the power analysis was met for each of the HI sources. The results of Pearson's r indicated no relationship between deafened adults with high PCR and their degree of trust regarding HI sources; therefore, the null hypothesis was not rejected. Further analysis utilizing t -tests of the 12 HI sources revealed no statistically significant relationship between high PCR and trust in HI sources; therefore, the null hypothesis was not rejected. At this time, the researcher is not aware of any literature relating to the level of PCR and the degree of trust in HI sources. However, related studies have shown that PCR predicts HISB among individuals and may be one of the driving factors for how frequently individuals search for HI (Amuta et al., 2017; Hovick et al., 2014; Nan et al., 2012; Orom et al., 2015; Teufel-Shone et al., 2015; Vanderpool & Huang, 2010).

It is important to note that of the 229 individuals within HINTS 4 Cycle 3 who self-identified as being deafened, only 46 were categorized as having high PCR. In fact,

several of those who self-identified as being deafened had missing data (71) for the particular question, “How likely are you to get cancer in your lifetime?”. This omission may be due to a lack of knowledge among d/Deaf, minorities, and the general population regarding cancer and cancer prevention, which, in turn, can affect their understanding of cancer risk and health behavior risks related to cancer (Ashing-Giwa et al., 2004; Costas-Muniz et al., 2013; Gany et al., 2013; Haggerty et al., 2017; Hickey et al., 2013; Jensen et al., 2013; Kaskowitz et al., 2006; Orsi et al., 2007; Sacks et al., 2013; Shabaik et al., 2010; Steinberg et al., 2002; Yao et al., 2012). Due to the fact that the majority of deafened respondents did not answer the item regarding perceived cancer risk, the research findings may not portray an accurate picture of the relationship between high PCR and degree of trust in HI sources among the deafened.

Cultural Gap and Healthcare

Results from this study suggest that deafened adults with high PCR trust HI from healthcare professionals the most. However, other studies have indicated that there is a mistrust of medical professionals among deaf individuals. For example, Steinberg, Barnett, Meador, Wiggins, and Zazove (2006) discovered that deafened patients had negative experiences with healthcare personnel interactions. More specifically, these patients reported experiencing fear, mistrust, and frustration with healthcare professionals (Steinberg et al. (2006). Similar experiences have been documented for Deaf Brazilians’ healthcare experiences (Pereiria & de Carvalho Fortes, 2010) s and in a

literature review by Kuenburg, Fellingner, and Fellingner (2016). Based on the results of this study, it is unclear why deafened individuals with high PCR trust healthcare providers for HI. However, Kushalnagar and Keogh (2017) proposed that the deafened participants in HINTS 4 Cycle 3 are late-deafened and therefore more comfortable obtaining HI from doctors and healthcare providers versus deaf individuals who are ASL users and generally do not trust doctors as much as deaf individuals who speak English. Nevertheless, there is evidence suggesting that because of the mistrust, negative experiences, and communication barriers that deaf individuals experience with healthcare providers, they often consult HI from other sources (Margellos-Anast et al., 2004). Steinberg et al. (2006), Pereira and de Carvalho Fortes (2010), and Kuenburg, Fellingner, and Fellingner (2016) explained that Deaf individuals express more trust in healthcare providers when: licensed ASL interpreters are available, healthcare providers use ASL, healthcare providers make a genuine effort to communicate with them, and healthcare professionals are culturally sensitive. Additional studies have shown that the general U.S. public has a lower trust in their physicians compared to other countries (Blendon, Benson, & Hero, 2014; Huang, Pu, Chou, & Huang, 2018). This alludes to the possibility that the cultural distrust of physicians among the deafened may be somewhat similar to the distrust felt by the general U.S. public, at least in comparison to other countries.

First HI Search Versus Most Trusted HI Source

Study results indicated that there is a contradiction between which HI sources deafened adults with high PCR utilize first in their latest search and their most trusted cancer HI sources. The sources deafened adults with high PCR first accessed in their most recent HI search were the internet, doctors or healthcare providers, and then the traditional print sources of books, brochures, flyers, and health and medical magazines. In comparison, the most trusted HI sources were doctors, family and friends, health and medical magazines, and the internet. The reason deafened adults consult the internet first to locate HI may be primarily due to its ubiquitous influence and the range of devices with internet access. In 2016, 89% of American households had a device that could access the internet; and over 80% had access to broadband internet (Ryan, 2018). Although deafened adults trust healthcare providers the most for HI, Americans visit their doctors less than in the past (U.S. Census Bureau, 2012). Additionally, doctors and healthcare providers are unavailable after office hours, which is probably why individuals consult the internet first. To add to the situation, the cultural gap between deafened individuals and doctors (Bukowski, 2015) may also influence deaf individuals' HI information searches. Individuals who have difficulty accessing healthcare services are also more likely to report using the internet to obtain HI (Amante, Hogan, Pagoto, English, & Lapane, 2015). Then too, deafened individuals with high PCR might be preparing for their doctor's visit and plan to review their concerns, questions, treatment

options prior to their appointment (Rains, 2013; Tan & Goonawardene, 2017) or confirm their skepticism of online information (Karras & Rintamki, 2012).

Gender Differences in Trusted HI Sources

Studies have indicated that males and females with cancer-specific high PCR are more likely to search for HI (Koehly et al., 2009; Manierre, 2015; Nan et al., 2012). Manierre (2015) explained that HISB among males and females with high PCR differed based on frequency of HI searches. Manierre (2015) also suggested that PCR alone is not the single motivator of HISB among men and women. The results of the current study showed that deafened males and females with high PCR view doctors as their most trusted source of HI. There were minimal differences in the rankings of the other trusted HI sources among deafened males and females. Future research could indicate why there is a difference if there is a significant difference degree of trust in HI sources among males and females, which would enable health educators and health communication specialists in the development of cancer specific information for males and females.

Literacy and Trust

Results of this study indicated that deafened adults with high PCR trust online HI slightly less than *family and friends* and *health and medical magazines*. This may be due to the level of English literacy (rather than their ability to speak English) among the study participants. Clayman et al. (2010) explained that Hispanics who had higher English

literacy trusted online HI more than those with less English literacy. Additionally, Berman et al. (2013) suggested that some deaf ASL users request help from family and friends to aid in their comprehension of HI or simplify the content, which may partially explain why deafened individuals with high PCR ranked the internet first and family and friends second in terms of trusted health information sources in their study.

Study Limitations and Recommendations for Future Research

This study had limitations. The HINTS 4 Cycle 3 is one of the few national data sets that includes questions specifically about HISB and hearing status; however, the sample size from the current study was small because the data for HINTS 4 Cycle 3 is stratified by population density and race/ethnicity and not on population density, race/ethnicity, and hearing status. Although there was an adequate number of deafened participants, several responses were missing (71) pertaining to PCR status, which limited the sample of those who self-reported a high PCR. Therefore, the small sample size impacts the internal validity of this study. In addition, due to stratified sampling used for HINTS 4 Cycle 3, the data do not accurately represent the total population of deafened individuals within the U.S., thereby limiting external validity.

The age of the participants in the HINTS 4 Cycle 3 study may also be considered a limitation. The average age of the deafened adults who participated in the HINTS 4 Cycle 3 study was almost 68 years. Yet, the range of ages of deafened adults in the HINTS 4 Cycle 3 was 19-105 years. Previous research has indicated that age and PCR

are inversely related (young adults tend to have lower self-reported PCR versus compared to middle-aged and older adults) (Persoskie et al., 2014; Vanderpool et al., 2009).

Despite the limitations, this study makes important contributions to the knowledge base. The researcher examined a national data set that consisted of stratified population sampling based on population density, whereas most other HI research among deaf, Deaf, and hard-of-hearing populations has focused on local data. Findings from the current study identified which HI sources deafened individuals with high PCR go to first in their most recent HI searches and which HI sources are trusted the most among males and females. These results can be utilized in devising a strategic plan for a mass media health communication plan for deafened adults with high PCR. More precise plans can also be created for disseminating HI specifically targeting men or women. Additionally, this study confirms that deafened individuals with high PCR trust healthcare professionals for HI, which is similarly reflected in national studies (Kushalnagar & Kushalnagar, 2018) as well as other localized studies (Folkins et al. 2005; Berman et al., 2013, 2017). Overall, this study adds to the body of knowledge pertaining to deafened individuals and their HISBs. In turn, this information can be used to enhance existing health education and health communication strategies and programs and develop new strategies, programs, and campaigns that assist the deafened in obtaining appropriate and accessible HI. More specifically, the findings from this study can be used to increase access to cancer-specific HI among deafened individuals with high PCR.

Future Research

Although this study focused on deafened individuals with high PCR, there is also a need to know which cancer HI sources are trusted and used by the deafened population in general. Therefore, the following recommendations apply to both groups— deafened individuals in general and deafened individuals with high PCR. For future research, a larger sample size of deafened individuals will enhance internal validity and possibly external validity. Future studies also need to include assessment of functional communication and functional hearing abilities among participants, which can be accomplished by including a question regarding hearing status that includes definitions and response options for the terms “deaf,” “Deaf,” and “hard-of-hearing.” Furthermore, d/Deaf, deafened and hard-of-hearing individuals who use HI and eHealth information exhibit varying degrees of proficiency in English and ASL, which affects their access and use of HI among various sources (Berman 2013; Folkins et al., 2005; Karras, 2010; Karras & Rintamki, 2012; Kushalnagar & Kushalnagar 2018). Therefore, studies that include assessment tools such as the EPL, Short Assessment of Health Literacy-English (SAHL-E) and/or eHealth Literacy Scale (eHEALS) can help determine the differences in HISB among the deaf, Deaf, and hard-of-hearing based on their EPL, health literacy, and eHealth literacy. In turn, this information can enable health educators and health communication specialists tailor HI content to specific audiences based on their hearing status and/or their EPL, health literacy level, and eHealth literacy level. Other possible

research can focus on the differences of HISB of early deafened and late-deafened individuals compared to the general population, which would better determine HI needs of each specific population. Additional research examining why there is a difference between the preferred HI sources during a first search and most trusted cancer sources can also be beneficial in determining HI needs. Moreover, there are no known studies at this time pertaining to deafened individuals' attitudes about health education and their experiences with health education/health promotion programs, including their level of trust in those programs. Such research efforts can inform efforts to strategically connect with this population and establish a foundation of mutual trust that will benefit future health education and health communication interventions.

Implications for Practice

The data from this study revealed that deafened adults with high PCR rank doctors as their most trusted HI source yet are more likely to go to the internet first for HI. Deaf educators need to be aware of the HISB of deafened adults with high PCR because the information might influence the information they teach deafened children and adults pertaining to health and health behaviors. In addition, this data also adds to the body of knowledge for librarians and related professional organizations such as the Association of Specialized, Government and Cooperative Library Agencies (ASGCLA), which helps members of the American Library Association “build capacity” to more effectively serve special populations (ASGCLA, 2018). In turn, librarians can work with

health educators, deaf educators, health communication specialists, and healthcare professionals to create appropriate and accessible HI content for deafened adults via the internet as well as health and medical magazines. Kushalnagar et al. (2016) discovered that simplifying content about cancer with captions and ASL options are helpful for Deaf individuals. Therefore, creating video content can help ensure that online HI is relevant and accessible. It is also important for deaf education and library science professionals to collaborate in the development of educational programs aimed at teaching deafened adults *how* to effectively locate credible HI on the internet and in print materials.

Implications for Deaf Educators

Despite a majority of the deafened participants being able to speak English in the HINTS 4 Cycle 3, deaf educators can still play a critical role in meeting the health education and health communication needs and interests of the deafened population. As such, deaf educators can develop strategies and programs to teach deafened individuals across the lifespan how to locate credible and relevant HI they can trust and use. Deaf educators can also teach related life skills such as self-help (locating a healthcare provider), discernment of appropriate situations to contact a healthcare provider, and how to appropriately consult the doctor or healthcare professional to gain HI. There is an additional need for curriculum development in the areas of literacy, health literacy, and eHealth literacy that incorporates appropriate ASL signs for specific health terms and health topics (C. Smith, personal communication, October 31, 2018). Considering some

deaf individuals are underexposed to environmental stimuli to cue the HI-seeking process (Smith & Chin, 2012), deaf educators can collaborate with health education specialists to provide experiential learning opportunities designed to increase health awareness, enhance health knowledge, and stimulate positive HISBs. Pertaining to the late-deafened, deaf educators can also aid deaf educators can aid in the development of English-based curriculum development in the areas of literacy, health literacy, and eHealth literacy.

Implications for Healthcare Professionals

Results from this study indicated that healthcare professionals are the most trusted source of HI among deafened individuals with high PCR. Yet, studies have shown that there is mistrust among some Deaf individuals pertaining to their experiences with healthcare professionals (Kuenburg et al., 2016; Pereira & de Carvalho Fortes, 2010; Steinberg et al., 2006). Deledda, Moretti, Rimondini, and Zimmerman (2013) explained that adult patients desire their healthcare professional to be friendly, respectful, and sensitive and also treat them as a fully functioning and competent person. For effective communication, it is important for healthcare professionals to speak slowly while facing d/Deaf, deafened, and hard-of-hearing patients to provide them the option of lip-reading (Bukowski, 2015). However, since lip-reading is often difficult to understand, it is pertinent to provide other methods to relay information to these patients (Lieu et al., 2007). Because there are few ASL healthcare professionals and ASL translators within

healthcare settings (Bukowski, 2015; Karras et al., 2011; Kaskowitz et al., 2006; Kushalnagar et al., 2016; Pereira & de Carvalho Fortes, 2010; Thew et al., 2012), healthcare professionals and pre-service students can take the initiative to learn some basic ASL and utilize appropriate facial expressions when communicating with these patients. Healthcare professionals and health organizations can also employ certified ASL translators to effectively communicate HI to d/Deaf, deafened, and hard-of-hearing patients. Moreover, healthcare professionals and health organizations can take steps in fostering positive healthcare experiences among d/Deaf, deafened, and hard-of-hearing patients by becoming culturally sensitive (Karras et al., 2011; Kaskowitz et al., 2006; Lieu et al., 2007). Duggan and Street (2013) suggested that effective provider-patient communication has the potential to enhance trust, positive health behaviors, and patients' ability to make appropriate medical decisions. Additionally, as physicians are the most trusted HI source within the deafened population, they should ask patients about their HISB, validate or refute the information (including that which is located online), and provide patients with a list of credible and accessible HI sources (including those that are web-based). Having such a list prepared for their patients, providing certified ASL interpreters, and communicating effectively with deafened patients can build rapport, cultivate positive patient-provider relationships, and garner more mutual trust (Cappell, 2009; Tan & Goonawardene, 2017).

Implications for Health Educators and Public Health Professionals

This study also connects with the Areas of Responsibility for Certified Health Education Specialists as defined by the National Commission for Health Education Credentialing, Inc. (NCHEC, 2015). The Seven Areas of Responsibility, along with competencies and sub-competencies, outline essential roles of Certified Health Education Specialists. The following are the Seven Areas of Responsibility (AOR):

- Area I: Assess Individual and Community Needs for Health Education
 - Area II: Plan Health Education Strategies, Interventions, and Programs
 - Area III: Implement Health Education Strategies, Interventions, and Programs
 - Area IV: Conduct Evaluation and Research Related to Health Education
 - Area V: Administer Health Education Strategies, Interventions, and Programs
 - Area VI: Serve as a Health Education Resource Person
 - Area VII: Communicate and Advocate for Health and Health Education
- (NCHEC, 2015, para. 4).

Furthermore, this study connects with some of the competencies from the Council on Education for Public Health (CEPH). The following competencies are from the MPH Foundational Competencies (FC) in section D2:

- 7. Assess population needs, assets and capacities that affect communities' health

- 8. Apply awareness of cultural values and practices to the design or implementation of public health policies or programs
- 9. Design a population-based policy, program, project or intervention
- 18. Select communication strategies for different audiences and sectors
- 19. Communicate audience-appropriate public health content, both in writing and through oral presentation
- 20. Describe the importance of cultural competence in communicating public health content
- 21. Perform effectively on interprofessional teams (CEPH, 2016, p.17-18).

In terms of implementing the NCHEC AOR and CEPH Foundational

Competencies, health educators and public health professionals can use findings from this study as part of a needs assessment to determine which HI sources deafened individuals use and trust (NCHEC AOR I and sub-competency 1.1). Additionally, this study utilized existing data and identified gaps in the secondary data such as health literacy level and eHealth literacy level, which needs to be further examined in future research (NCHEC AOR I and sub-competency 1.2). This study also assessed that there is a gap between where deafened adults with high PCR search first for HI and which HI sources they trust (NCHEC AOR I sub-competency 1.2 and CHEP FC 7). Moreover, this study uncovered health education/health promotion needs for deafened individuals and deafened individuals with high PCR (NCHEC AOR I and sub-competencies 1.6 and 1.7). The

results of this study are a preliminary report of the assessment findings but will be further reported via publication in a journal (NCHEC AOR I and sub-competency 1.7). Study results can also be utilized in the planning, implementation, and evaluation, of health education programs tailored to deafened adults in general and those with high PCR. For example, study results can help inform a mass media campaign of HI or tailored cancer-related HI for deafened individuals with high PCR. Study results can also be used to help interdisciplinary professionals create websites and other HI sources that doctors can utilize and share with their deafened patients (NCHEC AOR VI and CEPH FC 18). Additionally, this study points to the need for more stringent evaluation of internet-based HI and HI delivered through health and medical magazines to ensure that deafened individuals can fully access and comprehend credible HI, including cancer-related HI (NCHEC AOR IV). To accomplish the aforementioned interventions and programs, interdisciplinary collaboration among key stakeholders such as health educators, deaf educators, late-deafened individuals, Deaf community members, researchers, and librarians will be required. Such collaboration can enhance the development, implementation, and evaluation of quality content to ensure that health education and health communication programs are educationally sound, culturally competent, and culturally sensitive (NCHEC AOR IV, NCHEC AOR II sub-competency 2.3.4., NCHEC AOR III sub-competency 3.3.4, and CEPH FC 21). Furthermore, the results of this study can be used to advocate for health, health education, and HI source advancement among

late-deafened, d/Deaf, deafened, and hard-of-hearing (NCHEC AOR VII). There is a need to increase cultural competence and cultural sensitivity in communicating HI to late-deafened, d/Deaf, hard-of-hearing, and deafened individuals via multiple forms of media (NCHEC AOR II sub-competency 2.3.4., NCHEC AOR III sub-competency 3.3.4, CEPH FC 8, 18, 19, and 20).

In some instances, late-deafened individuals might self-identify with the Deaf community, which a cultural gap may be present within a group of late-deafened or late-deafened individuals and their healthcare providers. To address the potential cultural gap noted that often exists between the Deaf community and healthcare professionals, it can be beneficial to incorporate a model for cultural competence within health education and health promotion programs tailored for the Deaf community and for individuals who are late-deafened. For example, the PEN-3 Model (Airhihenbuwa, 1995; 2007) can be used to integrate essential aspects of the culture in the development, implementation, and evaluation of health education and health promotion programs. Health educators and other public health professionals can incorporate pertinent sociocultural aspects into the nine PEN-3 Model categories within the three overarching domains of cultural empowerment, relationships and expectations, and cultural identity (Airhihenbuwa, 1995; 2007). The PEN-3 Model can also be infused into pre-service curricula for university students preparing to enter careers in such fields as public health, health education, deaf education, and healthcare (including allied health). Similarly, the PEN-3 Model can be

included in continuing education for professionals in these fields to enhance cultural competence of those working with the late-deafened and Deaf community. Increasing cultural competence can help bridge the cultural and communication gaps between healthcare professionals and late-deafened, d/Deaf, deafened, and hard-of-hearing individuals. Such efforts have the potential to increase utilization of preventive services and preventive health behaviors, which can lead to positive health outcomes among deafened individuals with high PCR as well as late-deafened, d/Deaf, deafened, and hard-of-hearing individuals as a whole.

Additionally, programs based on the PEN-3 Model can be used to educate late-deafened, d/Deaf, deafened, and hard-of-hearing individuals with high PCR on how to obtain and critically evaluate cancer-specific HI. Because health literacy is impacted by cultural belief systems, (USDHHS-ODPHP, 2008), culturally sensitive programs can be devised to enhance the health literacy and eHealth literacy of deafened individuals. Moreover, other programs can be developed to enhance efforts to provide the deafened with accurate and accessible HI sources, particularly HI sources found on the internet and in health and medical magazines. However, accessible HI and cancer HI is needed for all members of the late-deafened, d/Deaf, deafened, and hard-of-hearing community. Such HI should include a 4th- 6th grade reading level for text, captions for videos, and ASL interpreted content in videos if ASL is a preferred language. Due to notable differences among deafened individuals based on functional hearing, functional

communication, and HISB (National Association of the Deaf, 2019; Kushalnagar & Keogh, 2017), health educators and public health professionals working with deafened populations should identify which communication method is preferred for the group and/or individual (Health Literacy Consulting, 2019; Hearing, Speech & Deaf Center, 2019). Prior to developing and implementing a health promotion program, health educators and public health professionals should assess and identify the preferred method of communication and tailor HI to that communication preference. For example, ASL is typically used with those who are early-deafened; however, those who are late-deafened may prefer written English (Clark, Office of Special Education Programs, U.S. Department of Education and the PEPNet-Northeast Regional Center, 2010; Hearing, Speech & Deaf Center, 2019; Taylor, 2015).

There are other recommendations that should be considered by health educators and public health professionals when working with deafened ASL users. For example, certified ASL translators should be hired or part of the health education and public health team rather than relying on volunteers (Health Literacy Consulting, 2019). The rationale is that some volunteers are untrained in communicating medical information, which can lead to misunderstanding as well as confidentiality and privacy concerns (Health Literacy Consulting, 2019). In terms of the communication process, there are important factors to keep in mind. For example, the space needs to be well-lit for ASL users to watch and communicate with the ASL interpreter (Health Literacy Consulting, 2019; Hearing,

Speech & Deaf Center, 2019). Also, speakers should avoid covering their mouths and use body language and facial expressions when communicating (Health Literacy Consulting, 2019; Hearing, Speech & Deaf Center, 2019). Moreover, it is essential to consult with deaf educators when designing health education materials and interventions for the Deaf community, prelingually deaf individuals, or deafened ASL users.

There are also recommendations that should be considered by health educators and public health professionals when working with deafened English users. The space needs to be well-lit for the participants to view the speakers; it also needs to be free of overbearing noises (Health Literacy Consulting, 2019; Hearing, Speech & Deaf Center, 2019). English is the primary language of deafened English users; therefore, providing speech-to-text, captions, and transcripts will enhance the communication process (Clark, Office of Special Education Programs, U.S. Department of Education and the PEPNet-Northeast Regional Center, 2010). Text-based HI is another communication option, which can be presented via traditional print materials, such as pamphlets or brochures, or digital text on a website. Such HI should be at or under the recommended 4th- 6th grade reading level and have a readability test prior to distribution. When creating content, health educators and public health professionals should consult adult learning theories specialists such as instructional designers and college/university instructors.

When working with deafened ASL users and/or deafened English users, health educators and public health professionals should consider the following

recommendations. Ensure that the space is well-lit so people can clearly see the speaker, text, or ASL interpreter; this space should also be free of overbearing noises (Health Literacy Consulting, 2019). Additionally, have the speaker(s) clearly articulate and enunciate for the ASL interpreter and/or the audience members (Health Literacy Consulting, 2019; Hearing, Speech & Deaf Center, 2019). Speakers should face the individual or group, make eye contact, and speak slowly (Bukowski, 2015; Clark, Office of Special Education Programs, U.S. Department of Education and the PEPNet-Northeast Regional Center, 2010; Hearing, Speech & Deaf Center, 2019). Speakers should avoid covering their mouth to provide the opportunity for individuals to lip read; however, lip-reading is not easily understood by most deafened individuals (Hearing, Speech & Deaf Center, 2019; Lieu et al., 2007; Taylor, 2015). Although providing written text is a method of communicating, written materials may not be beneficial based on literacy levels and health literacy levels (Health Literacy Consulting, 2019; Hearing, Speech & Deaf Center, 2019). Additionally, whenever there is more than one speaker, it is prudent to direct the group or individual to the current speaker (Clark, Office of Special Education Programs, U.S. Department of Education and the PEPNet-Northeast Regional Center, 2010; Hearing, Speech & Deaf Center, 2019), which can be accomplished by simply gesturing toward the new speaker. When working with late-deafened individuals or deafened individuals who speak English, there is a need to provide HI and cancer-related HI at the recommended 4th-6th grade reading level because this is the general

recommended level for audiences (Badarudeen & Sabharwal, 2010; Eltorai, Ghanian, Adams, Born, & Daniels, 2014; Stossel, Segar, Gilatto, Fallar, & Karani, 2012;

. Because there is an array of methods to communicate, health educators and public health professionals could take time to confirm the comprehension of the HI being presented with the individual or group (Health Literacy Consulting, 2019). Health Literacy Consulting (2019) recommends having individuals paraphrase HI in their own words to confirm understanding. If there is an instance when HI is unclear or there is a lack of understanding, consider rephrasing the HI rather than repeating the information verbatim (Health Literacy Consulting, 2019; Hearing, Speech & Deaf Center, 2019).

Based on findings from the current study, it is important for health educators and public health professionals to target HI sources that d/Deaf, hard-of-hearing, and deafened access first and trust the most. The internet is the first accessed HI source among deafened individuals with high PCR; thus, health educators and public health professionals could aim at creating and ensuring that online HI and cancer-related HI is accessible and accurate. To accomplish this, health educators and public health professionals can partner with organizations and groups that possess expertise in online educational delivery to create web-based HI content. Health educators and public health professionals who create their own HI and cancer-related HI can assess the current content to confirm that it is appropriate for d/Deaf, hard-of-hearing, and deafened individuals who are ASL users as well as English users. Also, considering doctors were

the second HI source for the most recent HI search and the most trusted HI source among deafened English users with high PCR, health educators and public health professionals can partner with physicians and certified ASL translators to devise programs that deliver appropriate and accessible HI and cancer-related HI. Such programs should aim at providing information about cancer risk, cancer prevention, cancer treatment, and maintaining quality of life after cancer treatment. Additionally, health educators and public health professionals need to consider the differences between men and women with high PCR in terms of trusted HI sources. For example, the current study revealed that deafened English-speaking men with high PCR trusted HI from the internet second to doctors; thus, providing online HI and cancer-related HI for these men may have a notable impact. However, a similar approach may not be effective for deafened English-speaking women with high PCR because their second and third most trusted sources are health and medical magazines and government health agencies. To meet the HI interests and needs of these women, health educators and public health professionals can publish HI and cancer-related HI in relevant health and medical magazines and partner with government health agencies to deliver HI and cancer-related HI.

Overall, it is important to conduct needs assessments concerning functional hearing, functional communication, preferred communication methods, education level, eHealth literacy, health literacy, and English proficiency to appropriately tailor HI and cancer-related HI for the deafened population. Additionally, professionals can

intentionally engage in interdisciplinary and collaborative partnerships to plan, implement, and evaluate health promotion programs for the deafened. Ideally, programs and efforts aimed at enhancing accessible HI and cancer HI sources will correlate with the topics and objectives of *HP 2020* designed to decrease morbidity and mortality of cancer, improve health literacy and eHealth literacy, and potentially increase utilization of preventive services.

Conclusion

According to this study, deafened adults with high PCR are more likely to do a first search for HI online but are more likely to trust HI coming from their healthcare professionals. More research is needed to identify if there are differences among the deaf, Deaf, and hard-of-hearing because each group has the potential to exhibit varying degrees of English proficiency and ASL usage, which can affect their access and use of HI among various sources (Berman 2013; Folkins et al., 2005; Karras, 2010; Karras & Rintamki, 2012; Kushalnagar & Kushalnagar 2018). Additionally, there is a need to understand what factors influence deafened individuals' trust in various HI sources. Such information can be beneficial in creating HI and eHealth information for this special population. Moreover, understanding if there is a relationship between PCR status and degree of trust of HI sources can help narrow the forms of media that deafened individuals with high PCR utilize. Such efforts have the potential of providing more

accessible HI to the deafened population as well as influence health behaviors to prevent cancer within this medically underserved population.

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APPENDIX A

IRB Approval Letter



Institutional Review Board
Office of Research and Sponsored Programs
P.O. Box 425619, Denton, TX 76204-5619
940-898-3378
email: IRB@twu.edu
<http://www.twu.edu/irb.html>

DATE: February 27, 2018
TO: Ms. Amanda Hinson-Enslin
Health Studies
FROM: Institutional Review Board (IRB) - Denton

Re: *Exemption for Cancer Information and Health Information Sources: What do Deafened Adults with High Perceived Risk of Cancer Trust and Use? (Protocol #: 20017)*

The above referenced study has been reviewed by the TWU IRB (operating under FWA00000178) and was determined to be exempt from further review.

If applicable, agency approval letters must be submitted to the IRB upon receipt PRIOR to any data collection at that agency. Because a signed consent form is not required for exempt studies, the filing of signatures of participants with the TWU IRB is not necessary.

Although your protocol has been exempted from further IRB review and your protocol file has been closed, any modifications to this study must be submitted for review to the IRB using the Modification Request Form. Additionally, the IRB must be notified immediately of any adverse events or unanticipated problems. All forms are located on the IRB website. If you have any questions, please contact the TWU IRB.

cc. Dr. Roger Shipley, Health Studies
Dr. Marilyn Massey-Stokes, Health Studies
Graduate School

APPENDIX B

Title Modification Approval



Institutional Review Board
Office of Research and Sponsored Programs
P.O. Box 425619, Denton, TX 76204-5619
940-898-3378
email: IRB@twu.edu
<https://www.twu.edu/institutional-review-board-irb/>

DATE: February 22, 2019
TO: Ms. Amanda Hinson-Enslin
Health Promotion & Kinesiology
FROM: Institutional Review Board - Denton

Re: *Notification of Approval for Modification for Health Information Sources that Deafened Adults with High Perceived Risk of Cancer Trust and Use: A Pilot Study (Protocol #: 20017)*

The following modification(s) have been approved by the IRB:

The title of the study has changed.
Original Title: "Cancer Information and Health Information Sources: What do Deafened Adults with High Perceived Risk of Cancer Trust and Use?"
New Title: "Health Information Sources that Deafened Adults with High Perceived Risk of Cancer Trust and Use: A Pilot Study"

cc. Dr. Marilyn Massey-Stokes, Health Promotion & Kinesiology