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EXAMINING HEALTH LITERACY AND PATIENT-CENTERED COMMUNICATION: A SECONDARY ANALYSIS OF U.S. ADULTS WITH A HISTORY OF CANCER

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Abstract

Racial/ethnic communities bear a disproportionate burden when examining cancer mortality and infection-related cancer incidence rates. According to the Office of Disease Prevention and Health Promotion (ODPHP), health literacy and clear communication between professionals and patients are crucial to improving health and the quality of healthcare. This study examined the relationship between personal health literacy and perceived patient-centered communication quality (PPCQ). A secondary data analysis was conducted using the Health Information National Trends Survey (HINTS) 5, Cycle 4 (2020), and STATA/BE 17.0 for Windows. The sample included respondents who have a history of cancer and have seen a healthcare provider within the past 12 months (n=579). Descriptive statistics described how health literacy and perceived PPCQ vary among different racial/ethnic groups. Most respondents self-identified as Non-Hispanic White (78.6%), male (58.3%), aged 50+ (M=67, SD=13), earned $50,000 or less annually (53.9%), and had health insurance (98.8%). This study found no statistically significant differences between racial/ethnic groups concerning health literacy. Black respondents had the highest mean PPCQ score (M=25.8, SD=3). Out of the three health literacy constructs (find, understand, and use), a multiple regression determined that the skills to find and understand information to inform health-related decisions and actions are significant predictors of PPCQ. It is incumbent upon healthcare/public health organizations and policymakers to implement system-level changes to ensure accurate, credible health information is easily accessible, distinguishable, and understandable to foster trust and self-confidence, thereby empowering individuals to improve patient-provider engagement and increase the likelihood of positive health outcomes.

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Dedication

I dedicate this thesis to my mom, a cancer survivor and the strongest person I have the privilege of knowing and loving. I feel so fortunate to have you as my mom, and recognize all of the sacrifices you made to provide us with a better life. Thank you for everything. Thank you for being you. And thank you for teaching me what is truly important in life.

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Chapter 1. Introduction

In 2020, cancer was the second leading cause of death in the United States, following heart disease and accounting for 18% of all deaths (National Center for Health Statistics [NCHS], 2022; Siegal et al., 2023). Cancer is a disease in which a group of cells grow uncontrollably and spread to other organs and organ systems (National Cancer Institute [NCI], 2021). The types of cancer are typically named for the organs or tissues in which the cancers form, amounting to more than 100 types of cancer. Cancer mortality rates are a better indicator of cancer prevention and treatment progress compared to incidence or survival rates because they are less affected by biases resulting from changes in detection practice (Welch et al., 2000). From 1991 through 2020, there was a 33% reduction in cancer deaths, with a mortality rate of 143.8 deaths per 100,000 persons in 2020 (Siegal et al., 2023).

Nevertheless, there is a disproportionate cancer burden among certain racial/ethnic communities. From 2016-2020, the cancer mortality rate was 174.7 deaths per 100,000 persons among Black individuals compared to 154.4 deaths per 100,000 persons among White individuals (Surveillance Research Program, 2022b). Furthermore, when examining specific types of cancers, Asian and Pacific Islander, and Hispanic/Latinx people had higher liver and stomach incidence and mortality rates than their white counterparts from 2015 to 2019. Additionally, the prostate mortality rate among Black men was more than double that of men in every other racial/ethnic group within the same time frame (Surveillance Research Program, 2022a). The data points to a need to investigate contributors to these disparities further.

According to the Office of Disease Prevention and Health Promotion (ODPHP), an office of the United States Department of Health and Human Services, health literacy and clear communication between professionals and patients are crucial to improving health and the quality of healthcare (ODPHP, 2021a). Personal health literacy is defined as “the degree to which individuals have the ability to find, understand, and use information and services to inform health-related decisions and actions for themselves and others” (ODPHP, 2021c, p. 1-2). A cancer diagnosis can be an anxiety-inducing and confusing situation for individuals and their families. Health literacy is integral to navigating the new reality for newly diagnosed cancer patients that may involve complex disease information and medical treatment options (Holden et al., 2021; Koh et al., 2013). Barriers to health literacy among racial/ethnic populations, such as lack of language proficiency and lower socioeconomic statuses, have led to delays in screening tests and treatment (Rogers et al., 2018; Sentell & Braun, 2012; Vince et al., 2022).

Furthermore, patient-centered communication is critical in cancer care. Patient-centered communication recognizes and validates the patients' perspectives, considers their psychosocial context, fosters their understanding of the treatment and health issue, and involves the patients in decision-making as much as they desire (Epstein & Street, 2007). As part of good quality patient-centered communication, the provider must consider the emotional and psychological impacts of the disease, uncertainties associated with the progression or recurrence, and the impact of treatment throughout the cancer care continuum (Coleman et al., 2019; Pozzar et al., 2021). Recognizing that past interactions with clinicians perceived as unfavorable can impact healthcare-seeking behavior and subsequent health outcomes can be critical to patient-centered communication. Moreover, providers' lack of cultural competency and pre-existing implicit biases can become barriers to patient-centered communication and positive health-seeking behaviors (Ayanian et al., 2005; Epstein & Street, 2007; Gonzales et al., 2019; Hoffman et al., 2003; Moreno et al., 2018; Prouty et al., 2014; Street et al., 2018; Wagner et al., 2001).

Research Objective & Significance

Findings are limited in the existing literature investigating health literacy and patient-centered communication among cancer patients. Furthermore, the examination of each construct of health literacy and any potential associations with patient-centered communication does not exist. Since health literacy and patient-provider communication are considered vital to improving health and the quality of healthcare (ODPHP, 2021a), the objective of this study was to examine how health literacy and patient-centered communication vary among racial/ethnic groups and investigate which construct of health literacy is the strongest predictor of patient-centered communication quality. These relationships could have implications for alternative approaches to effective cancer care and future research.

Chapter 2. Literature Review

This chapter will include a review of previous literature, which will provide insight of cancer in the U.S. among racial/ethnic communities and discuss the significance health literacy and patient-centered communication in the cancer care continuum. The literature review will include an overview of cancer in the U.S., a discussion of the health literacy definitions and how three constructs are used in this study, an examination of the relationship between health literacy and patient-centered communication among cancer patients and survivors, an overview of the Social Ecological Model, and descriptions of the gaps in the literature and the purpose of this study.

Cancer Rates in the United States

According to the Centers for Disease Control and Prevention (2022), cancer was the second leading cause of death in the United States in 2020, exceeded only by heart disease. In 2019, 1,752,735 new cancer cases were reported, and 599,589 people died of cancer (U.S. Cancer Statistics Working Group, 2022). In 2015-2019, the incidence rate of cancer was 449.4 new cancer cases per 100,000 persons (Surveillance Research Program, 2022a; Sherman et al., 2022a; Sherman et al., 2022b), while the mortality rate was 149.1 deaths per 100,000 persons (Surveillance Research Program, 2022b). Limited-duration prevalence is the estimated proportion of people diagnosed with the disease on a specific day within the past x years (e.g., x = 5, 10, or 18 years) (NCI, 2022). According to the U.S. Cancer Statistics Working Group (2022), an estimated 12,758,769 (5,558,560 in 5-year limited duration prevalence from 2013-2018) people alive in the United States who were diagnosed with cancer from January 1, 2002, to December 13, 2018 (18-year limited-duration prevalence as of January 1, 2019).

The rates of cancer diagnoses and deaths are impacted by the utilization of screening tests, improvements in treatments, environmental exposure risk, and risk factors (genetically and otherwise). From 1991 to 2020, there has been an overall reduction in the cancer mortality rate by 33%, with an estimated 3.8 million deaths averted (Siegel et al., 2023; Surveillance Research Program, 2022b). As new treatment technologies are developed, patients live longer after cancer diagnoses. Although cancer mortality rates continue to decline, rising incidence rates in breast, prostate, and uterine corpus cancers may slow future progress. Moreover, these cancers, in particular, have the largest racial disparities in mortality (Siegel et al., 2023). Studies have shown that racial disparities in cancer care may partly be attributed to perceived discrimination or breakdowns in communication during patient-provider interactions (Epstein et al., 2017; Gonzales et al., 2019; Prigerson et al., 2015; Street et al., 2019). Therefore, the relationship between the patients and their healthcare providers becomes more significant in maintaining and improving the patient's health statuses.

Disproportionate Cancer Burden in Racial/Ethnic Communities

Moreover, marginalized racial/ethnic communities have a disproportionate cancer burden than their white counterparts. The Black and Latinx/Hispanic populations, in particular, are disproportionately affected by cancer, its adverse consequences, and risk factors for cancer development. The Black population is the third largest racial/ethnic group in the U.S. after the Latinx/Hispanic population and White population, accounting for 13.6% of the total population in the U.S. in 2021 (United States Census Bureau, 2022). However, from 2016 to 2020, the Black community had the second-highest mortality rate at 174.7 deaths per 100,000 persons (following the American Indian and Alaska Native community at 179.3 deaths per 100,000 persons) and the lowest survival of any racial/ethnic group for most types of cancers (Siegel et al., 2023; Surveillance Research Program, 2022b). In comparison, the White population has the third highest mortality rate at 154.4 deaths per 100,000, the Latinx/Hispanic community has the second lowest mortality rate at 108.2 deaths per 100,000 persons, and finally, the Asian American and Pacific Islander community has the lowest mortality rate at 94.5 deaths per 100,000 persons for all cancer types. While the overall Black-White cancer disparity is slowly narrowing (due to a steeper reduction in cigarette smoking by Black people than by White people in the 1970s and 1980s) (Siegel et al., 2022; Surveillance Research Program, 2022a), the breast cancer disparity remains wide (Siegel et al., 2023; Surveillance Research Program, 2022a). Black women are 41% more likely to die from breast cancer than White women despite being less likely to be diagnosed with it (ACS, 2022). In 2022, an estimated 111,990 Black men and 112,090 Black women will be newly diagnosed with invasive cancer (Giaquinto et al., 2022).

Latinx/Hispanic individuals accounted for 18.9% of the population in the United States in 2021, making them the second largest racial/ethnic population (United States Census Bureau, 2022). While Latinx/Hispanic individuals are less likely than non-Hispanic Whites to be diagnosed with the most common cancers (i.e., lung, colorectal, breast, and prostate), they have a higher risk for infection-related cancers (i.e., stomach, liver, cervical) and gallbladder cancer (National Center for Health Statistics, 2021). For example, from 2014-2018, cervical cancer incidence rates were about 30% higher, and liver and stomach cancer incidence rates were about double the rates in Latinx/Hispanic Individuals compared to White individuals (North American Association of Central Cancer Registries [NAACCR], 2021; American Cancer Society [ACS], 2021). However, there are variations in cancer incidence rates among this population by country of origin and nativity. Oftentimes, the data are aggregated, which poses challenges in examining the true burden. For example, prostate cancer incidence is about 15% lower in Latino/Hispanic men overall compared to White men but 44% higher in men residing in Puerto Rico (NAACCR, 2021). Cancer is also the leading cause of death among Latinx/Hispanic people, accounting for 20% of deaths in 2019, at 106.2 deaths per 100,000 persons (National Center for Health Statistics, 2021). The liver and intrahepatic bile duct mortality rate among the Latinx/Hispanic community was 13.1 deaths per 100,000 from 2016 to 2020, following the highest rate of 19.5 deaths per 100,000 persons among American Indian/Alaska Native community, with the third highest rate at 12.9 deaths per 100,000 persons among the Black community. In contrast, Asian American/Pacific Islanders had a mortality rate of 12.5 deaths per 100,000 persons, and the White population had a mortality rate of 8.4 deaths per 100,000 persons (Siegel et al., 2023; Surveillance Research Program, 2022b). Although advances in cancer treatment have resulted in declines in cancer mortality rates overall, increases in specific cancer types are evident once race and ethnicity are examined.

Defining Health Literacy

Many health organizations have defined health literacy over the years. Two prominent definitions have been established by the World Health Organization (WHO) and the Institute of Medicine (IOM). According to the World Health Organization (WHO), health literacy is defined as "the cognitive and social skills which determine the motivation and ability of individuals to *gain access to, understand, and use* information in ways which promote and maintain good health” (Nutbeam, 1998, p. 357). Moreover, the WHO adds, "Health literacy implies the achievement of a level of knowledge, personal skills and confidence to take action to improve personal and community health by changing personal lifestyles and living conditions. Thus, health literacy means more than being able to read pamphlets and make appointments. By improving people's access to health information and their capacity to use it effectively, health literacy is critical to empowerment" (Nutbeam, 1998a, p. 357). This definition underscores health literacy as a *shared* function of social and individual factors.

Furthermore, the culminating report of the Institute of Medicine's Committee on Health Literacy's 2004 meeting, *Health Literacy: A Prescription to End Confusion,* utilized the definition developed for the National Library of Medicine (NLM)-- “the degree to which individuals can obtain, process, and understand the basic health information and services they need to make appropriate health decisions” (Ratzan & Parker, 2000, pp. vi). This definition was used as the foundational basis for the Healthy People 2010 and 2020 initiatives. Although these two definitions were provided by prominent health organizations, Pleasant & McKinney (2011) found a lack of consensus on what health literacy represents. As such, it is crucial to understand and identify a robust and timely definition for health literacy, as the relationship between health literacy and patient-centered communication for cancer patients in the United States will be explored in this literature review.

As the body of health literacy research and practice has grown since the publications of definitions above, we now have a better understanding that health literacy is not only an individual's responsibility but also extends to health promotion, healthcare, and healthcare delivery organizations and professionals that create and deliver health information and services (ODPHP, 2021b). Moreover, improving health literacy is one of the national health initiatives outlined by the Office of Disease Prevention and Health Promotion, as evidenced by the declaration of health literacy as a foundational principle and overarching goal– elevating its importance in Healthy People 2030 (ODPHPH, 2021a).

Healthy People, an initiative spearheaded by the Office of Disease Prevention and Health Promotion (ODPHP) in the U.S. Department of Health and Human Services, provides 10-year, measurable public health objectives and tools to assist in tracking the progress made toward achieving them (Office of Disease Prevention & Health Promotion [ODPHP], n.d.). The Secretary's Advisory Committee on Health Promotion and Disease Prevention Objectives for 2030 proposed expanding Healthy People's perspective on health literacy for Healthy People 2030 (ODPHP, 2021b). As a result, two definitions constitute health literacy– personal health literacy is "the degree to which individuals have the ability to find, understand, and use information and services to inform health-related decisions and actions for themselves and others"; organizational health literacy is "the degree to which organizations *equitably enable individuals* to find, understand, and use information and services to inform health-related decisions and actions for themselves and others" (ODPHP, 2021c). These definitions emphasize the diversity of needs of both the patients and the clinicians, as well as the significance of the interactions between patients, healthcare providers, and healthcare systems. This study employs the definition of personal health literacy as the focus is on individuals with a history of cancer and their interactions with healthcare providers. This definition substantiates the importance of the patient-provider relationship and the consequence of the initial level of understanding the patient brings to each interaction. Since the publication of the two new definitions that comprise health literacy, the Centers for Disease Control & Prevention and the

National Institutes of Health (the agency that includes the National Library of Medicine and the National Cancer Institute – the latter of which the data used in this study was collected) have also adopted these definitions. Currently, there is no agreed metric of health literacy in the United States.

The Categorizations of Health Literacy

The set of skills described by the multitude of health literacy definitions has been categorized in different ways, most notably functional, interactive, and critical health literacy (Nutbeam, 2000; Nutbeam, 2017). These health literacy categories are the outcomes of certain health education approaches and benefit the individual or population. Basic or functional health literacy describes having the ability to obtain and abide by recommendations regarding health risks and benefits from certain health services (Nutbeam, 2017); in other words, having basic skills in reading and writing to function sufficiently in everyday situations (Nutbeam, 2000). Basic or functional health literacy demonstrates the result of traditional health education based on communicating factual information on health risks and how to use health services. Such health education generally benefits the individual and does not foster interactive communication or development in skills or autonomy (Nutbeam, 2000).

Interactive or communicative literacy describes the development of more advanced cognitive and literacy skills required to find, understand, and discern health information from multiple sources and to improve motivation and self-confidence to apply new knowledge to changing circumstances independently (Nutbeam, 2000; Nutbeam, 2017). This type of health education similarly results in individual benefits rather than benefits to the larger society (Nutbeam, 2000).

Finally, critical health literacy is the outcome of more advanced cognitive, social, and literacy skills, used to critically analyze and apply information to exert greater control over life events and situations with effective individual, social, and political action (Nutbeam, 2000). This type of health literacy is associated with individual and population benefits by providing the skills necessary to address social, economic, and environmental determinants of health.

In addition to the three levels described above, health literacy can also be considered a "risk factor" or "asset" dependent upon the two different settings (Martensson, 2012; Nutbeam, 2008; Pleasant, 2008). For example, health literacy can be viewed as a risk factor in clinical settings in terms of hospitalization, visits to the emergency room, ability to apply learned health information in decision-making, and medication adherence. Alternatively, health literacy can be viewed as a public or community health asset, moving beyond solely functional capabilities. Health literacy comprises a set of skills to increase autonomy and empowerment in health-related decisions and actions (Holden et al., 2021; Nutbeam, 2017). Functional capabilities are a foundation for health literacy on which complementary skills can be developed (Nutbeam, 2017).

Key Constructs of Health Literacy

In the personal health literacy definition, there are three skills that individuals must be able to do when making health-related decisions. The consequences of lacking these skills are shown to be associated with difficulties in comprehension of health information, limited knowledge of diseases and their associated risks/symptoms/prognoses, and lower treatment adherence, which contribute to poorer health, higher risk of mortality, insufficient and ineffective use of healthcare services, increased healthcare costs, and health disparities (IOM Committee on Health Literacy, 2004; Berkman et al., 2011; Sheridan et al., 2011; Liu et al., 2020). Each skill is considered a key construct to having high health literacy in this study. The first construct of health literacy that will be assessed is an individual's ability to find information and services to inform health-related decisions and actions for themselves and others. Health literacy is considered a wide range of skills and competencies that individuals develop over their lifetimes, including the ability to seek out health information that can influence health-related decisions and behaviors (Zarcadoolas et al., 2006).

The second aspect of the health literacy definition is the ability to comprehend information to inform health-related decisions and behaviors; therefore, the second construct that will be assessed is an individual's ability to understand information and services. This concept is bidirectional; the patient must be able to comprehend the information, and the information provided must be presented at an appropriate level of understanding for the patient. For example, when an Oncologist is informing a patient of a cancer diagnosis for the first time, it would not be appropriate to communicate at the medical provider's level of understanding. The information must be presented in a way that is appropriate for the audience; in other words, in plain language or "layman's terms."

Finally, the third construct of health literacy that will be assessed is an individual's ability to use information and services to inform health-related decisions and actions for themselves and others. Cancer patients are expected to comprehend the complexities of cancer diagnosis, treatment, and management– they must be familiarize themselves with foreign health terminology, consent to potentially complex procedures and treatment plans, attend and engage in medical appointments on time, and as for help right away when necessary (Holden et al., 2021). Health literacy is integral to navigating these new circumstances (Holden et al., 2021).

Limited data examines the three health literacy constructs individually and their associations with healthcare interactions, issues, and outcomes. Instead, previous studies examine the concept of health literacy as a whole. Comparatively, this study will investigate the roles that each of the constructs plays separately in healthcare interactions by finding which of the three is the strongest predictor of perceived patient-centered communication quality.

Health Literacy Among Cancer Patients and Survivors in the United States

As highlighted in the Affordable Care Act of 2010, patients are expected to successfully engage in their healthcare (Dumenci et al., 2014; Koh et al., 2013). Some examples of engaging in healthcare include being able to adhere to medication and treatment plans, discern scientifically credible medical evidence from myths and misleading information, and effectively communicate issues such as weighing risks and benefits and success rates with their healthcare providers (Dumenci et al., 2014; Koh et al., 2013). A cancer diagnosis can be an anxiety-inducing situation. Health literacy is integral to navigating these new circumstances (Holden et al., 2021).

Patient-centered care is predicated on the healthcare provider explaining complicated health concepts, treatments, and procedures to the patient so that they can make informed decisions during times of physical and emotional distress (Dumenci et al., 2014; Katz et al., 2014; Thome et al., 2013; Walter & Covinsky, 2001). The healthcare providers' expectation of patient engagement in these types of decisions likely increases the burden that cancer patients are already experiencing following a life-changing diagnosis (Dumenci et al., 2014).

*The Association Between Health Literacy, Seeking Care, and Health Outcome*s

The association between health literacy and health outcomes for cancer patients has been vastly investigated. Higher health literacy is associated with a preference for more engaged participation in decision-making (Lillie et al., 2007; Holden et al., 2021) and observed shared decision-making (Yen et al., 2020). Shared decision-making is one of the hallmark components of patient-centered care that encourages and empowers patients to play a proactive role in the self-management of their health (Agency for Healthcare Research and Quality [AHRQ], 2015; Smith, 2016). Higher health literacy is also shown to be associated with increased odds of receiving chemotherapy (Busch et al., 2015), increased likelihood of breast reconstruction (Winton et al., 2016), lower likelihood of receiving unproven treatment (Mahal et al., 2015), higher medication adherence (Jiang et al., 2019; Rust et al., 2015), greater self-efficacy (Gunn et al., 2020; Tagai et al., 2020), greater patient engagement (Post et al., 2020), fewer practical concerns (Tagai et al., 2020), and increased inclination for clinical trial participation to participate (Polite et al., 2019). Lower health literacy was associated with poorer quality of life (Chrischilles et al., 2019; Eton et al., 2019; McDougall et al., 2019; Nilsen et al., 2020; Xia et al., 2019), increased number and duration of hospital admissions (Cartwright et al., 2017), multiplied use of post-operative discharge services (Kappa et al., 2017), and increased likelihood of treatment complications (Scarpato et al., 2016; Holden et al., 2021). No associations were found between health literacy and mortality (Busch et al., 2015), perception of doctors' communication of recurrence risk of breast cancer (Janz et al., 2017), and presentation with early-stage disease (Busch et al., 2015).

Although no associations were found between health literacy and the perception of doctors' communication of the recurrence risk of *breast* cancer, this study explores the relationship between health literacy and the perception of doctors' communication of *any* healthcare-related issues among adults with a history of *any* cancer. While breast cancer is the most common type, it only makes up 15% of all new cancer cases, with 128.3 new cases of female breast cancer per 100,000 women per year (Surveillance Research Program, 2021). In comparison, the incidence rate of all types of cancer in 2019 was 456.1 new cases per 100,000 people (Surveillance Research Program, 2021).

Health Literacy Among Cancer Patients in Different Racial/Ethnic Groups

Further complicating the issue of health literacy is the racial disparities that are associated with and, in turn, affect positive healthcare-seeking behaviors. In a study examining health literacy among cancer survivors, Coughlin and colleagues (2022) found that the adjusted odds ratios for low health literacy among Black and Hispanic participants were 1.4 and 2.5 times that of their white peers, respectively. Moreover, a literature review investigating racial disparities among Black men with prostate cancer revealed that Black men lacked an understanding of medical terminology, were reluctant to seek medical care, and had negative views toward research, possibly contributing to the underrepresentation of Black men in clinical studies (Lillard et al., 2022; Rogers et al., 2018; Vince et al., 2022). Additionally, another study found that Black patients did not know the signs or symptoms of prostate cancer, and had limited knowledge of prostate-specific antigen (PSA) testing, screening age recommendations, and post-prostate cancer treatment quality of life (Ogunsanya et al., 2017). These findings underscore the lack of knowledge and understanding of the type of cancer that heavily impacts Black men.

Language barriers may also contribute to the challenges in the cancer care continuum among communities of color. In a study investigating low health literacy, limited English proficiency, and health status in Asians, Latinos, and other racial/ethnic groups in California, evidence suggested that Chinese and Hispanic individuals had the highest rates of limited health literacy at 68.3% and 45.3%, respectively (Sentell, 2012). By racial/ethnic group, Latinos who reported limited English proficiency and low health literacy had an odds ratio of 2.01 (95% CI: 1.09-3.59), compared with a 4.00 odds ratio (95% CI: 1.53-10.44) in the Vietnamese group, and 3.10 odds ratio (95% CI: 1.85-5.18) in the Other category (Sentell, 2012). These results underscore the need to examine health literacy further, with some regard to language proficiency as a potential barrier among varying racial/ethnic groups.

Understanding Patient-Centered Communication for Cancer Patients in the United States

Patient-centered communication can play an essential role in improving health outcomes among individuals with a history of cancer across the cancer care continuum.

Research shows good patient-centered communication improves interpersonal relationships between patients and their healthcare providers and advances the satisfaction and overall perceived quality of life of cancer patients (Arora et al., 2009; Finney Rutten et al., 2015; Sabee et al., 2015; Trivedi et al., 2021). In addition, evidence suggests that patient-centered communication is associated with improved clinical outcomes in cancer management (Bredart et al., 2005; Mead & Bower, 2002; Trivedi et al., 2021). These outcomes include early cancer detection, medication or treatment adherence, improved health-related quality of life (e.g., minimal side effects), and lower symptom burden (Epstein & Street, 2007; Pozzar et al., 2021).

Patient-centered communication is defined as "that which recognizes and validates the perspectives of the patients, takes into consideration the psychosocial context of the patients, fosters the patient's understanding of the treatment and health issue at hand, and involves the patients in decision-making as much as they desire" (Epstein & Street, 2007; Pozzar et al., 2021).

Six core functions of patient-centered communication comprise the National Cancer Institute Framework for Patient-Centered Communication in Cancer Care (NCI Framework); they entail "exchanging information, making decisions, fostering healing relationships, enabling patient self-management, managing uncertainty, and responding to emotions" (Epstein & Street, 2007, p. 17). The six core functions of the NCI Framework intermingle to affect patient-centered communication and may ultimately impact health outcomes of cancer patients (Epstein & Street, 2007; Levit et al., 2013). Effective communication within these domains has been shown to impact perceived cancer care quality (Arora et al., 2011; Mazor et al., 2013;

Street et al., 2019) and are pathways to improved cancer care outcomes (Arora et al., 2009; Gross et al., 2015; Robinson et al., 2013; Street et al., 2014, 2019; Trudel et al., 2014).

Patient-centered communication is crucial in cancer care. The provider must consider the emotional and psychological impacts of the disease, uncertainties associated with the progression or recurrence, and the impact of treatment throughout the cancer care continuum (Coleman et al., 2019; Pozzar et al., 2021). One qualitative study examining the perceptions of patient-centered communication among individuals with ovarian cancer found that patients who engaged with providers who employed the functions of the NCI Framework reported that greater overall patient-centered communication predicted better overall health-related quality of life and lower symptom burden among individuals with ovarian cancer (Pozzar et al., 2021).

Constructive interactions with healthcare providers are important for achieving quality cancer care delivery and may be associated with improved outcomes for cancer patients (Arora, 2003; Epstein et al., 2017; Stewart, 1995; Street et al., 2009). For instance, improved communication is associated with decreased anxiety (Zwingmann et al., 2017), improved treatment and surveillance adherence (Liu et al., 2013; Tan et al., 2012), and increased discussion of prognosis, treatment alternatives, and patient concerns (Eide et al., 2004; Shields et al., 2009; Sohl et al., 2015). The growing body of evidence of associations between patient-centered communication and health outcomes has led to increased encouragement to enroll providers in patient-centered communication skills training (Littell et al., 2019; Pozzar et al., 2021; Street et al., 2019).

Unfortunately, patient-centered communication in cancer care often falls short (Street et al., 2019). Studies have found that a considerable percentage of patients are dissatisfied with the communication with cancer care providers (Arora et al., 2015; Chawla et al., 2015; Mazor et al., 2016; Street et al., 2019), particularly concerning compassion, receiving well-timed and pertinent information, abiding by the preferences of patients, and ensuring their cancer care is coordinated among different departments and organizations (Epstein & Street, 2007; Street et al., 2019). Street and colleagues (2018) also describe that patient-centered communication includes more than the discussions between patients and one specific healthcare provider– it may also be affected by how the healthcare organization interacts with the patient, such as delays in test results and failure to ensure continuity of care (Epstein & Street, 2007; Wagner et al., 2001; Prouty et al., 2014; Street et al., 2019). Moreover, evidence suggests inadequate communication in advanced cancer care is common with respect to prognosis and treatment options (DesHarnais et al., 2007; Epstein et al., 2017; Parker et al., 2007; IOM Committee on Approaching Death, 2015). Prior studies have found associations between inadequate communication and patients' unrealistic expectations of curability (Weeks et al., 2012), recommendation of aggressive treatment not in line with patients' wishes, and delayed hospice enrollment resulting in little benefit (IOM Committee on Approaching Death, 2014; Prigerson et al., 2015; Mack et al., 2010; Weeks et al., 1998; Weeks et al., 2012; Wright et al., 2008).

Patient-Centered Communication Among Cancer Patients in Different Racial/Ethnic Groups

It is widely known that racial disparities exist within the healthcare system. Implicit biases, language barriers, and communication issues further exacerbate the uneven healthcare provided to various racial/ethnic communities. In 2018, cancer was the leading cause of death for Asian individuals (National Center for Health Statistics, 2019). Comparably, cardiovascular disease is the leading cause of death for most other racial groups in the United States. A contributing factor may be that Asians have lower cancer screening rates (Fane et al., 2022; Lee et al., 2021). The second largest Asian population in the United States resides in California. Yet, Asian women's mammography rate of 72% is lower than that of Non-Hispanic White women (81%), African American (83%), and Latina (77%) women (University of California Los Angeles [UCLA] Center for Health Policy Research, 2014). A survey of Korean American women in Chicago revealed that low mammography rates could be attributed to perceived *healthcare discrimination* and *distrust in providers and the healthcare system* (Fane et al., 2022; Gonzales et al., 2019). Perceived quality of care was also reported to be lower among Asian women, regardless of education, compared to Non-Hispanic White women (Gonzales et al., 2019). Fane and colleagues (2022) suggested that conversations regarding decision-making influences, health literacy assessments, and patient-focused education between healthcare providers and their Asian patients with breast cancer could impact perceived quality of care and improve health outcomes.

Furthermore, Black men had the highest sex-specific cancer incidence rate from 2015 to 2019, primarily due to prostate cancer. Black men had a rate that was 70% higher than White men, two times higher than in American Indian or Alaskan Native (AIAN) and Hispanic men, and three times higher than in Asian American or Pacific Islander (AAPI) men (Siegal et al., 2023). According to Pollack and colleagues (2017), communication issues may explain the racial disparities among U.S. prostate cancer diagnosis and treatment reports (Lillard et al., 2022).

Additionally, Black men more likely to report that they were not given information before prostate-specific antigen (PSA) testing that was necessary for shared decision-making (SDM), and when the information was provided, confusion remained among Black men compared with with their White counterparts (13.1% vs. 4.8%; p = .008) (Leyva et al., 2016; Hewitt et al., 2018; Lillard et al., 2022).

In addition, in a study seeking to identify the psychosocial needs of patients with cancer undergoing radiation therapy to address racial disparities, disparities were found in the amount of cancer literacy education that patients sought between the pre- and post-treatment periods (Kronfli et al., 2022). The unmet needs index (calculated from the results of an unmet needs survey) of cancer literacy did not differ significantly between Black and non-Black patients; however, upon further analysis of the individual survey questions, the results showed that Black patients desired additional information on quitting smoking (a known cancer risk factor) and their cancers compared with the other racial/ethnic groups, as well as sought additional information about pain management and relaxation techniques (Kronfli et al., 2022). These topics may influence future health-related behaviors that could impact cancer recurrence.

In addition to the disparities reported by Black and Asian Americans, Latinx breast, prostate, and colorectal cancer survivors seem to share similar experiences. Latino colorectal and prostate cancer survivors reported lower overall satisfaction with cancer care and additional difficulties accessing and coordinating cancer care (Ayanian et al., 2005; Hoffman et al., 2003; Moreno et al., 2019). Latinx colorectal and breast cancer survivors who have limited English proficiency, in particular, reported lower satisfaction with cancer care and lower trust and confidence in their healthcare providers (Ayanian et al., 2005; Hawley et al., 2008; Moreno et al., 2019). Additionally, Palmer and colleagues (2014) found that both Asian and Hispanic long-term cancer survivors reported significantly lower overall communication scores (overall communication and communication concerning medical tests) compared with White long-term survivors. The results of these studies underscore the need to closely examine perceived patient-centered communication quality among historically marginalized racial/ethnic groups.

The Relationship Between Health Literacy and Patient-Centered Communication for Cancer Patients in the United States

As cancer patients conclude their treatments and enter remission, they experience obstacles in managing their care and continue to need effective communication with healthcare providers and navigating the healthcare system (Coughlin et al., 2022; Wei et al., 2021). In a qualitative study examining providers' perceptions of communication breakdowns in cancer care, providers expressed one concern: the patients' limited understanding of their cancer diagnoses and treatments (Prouty et al., 2014). This circumstance created challenges in patients knowing what questions to ask, prevented further inquiry, and interfered with information exchange between patients and providers– a key factor in the NCI Framework of patient-centered communication in cancer care (Epstein & Street, 2007; Prouty et al., 2014). Similarly, a qualitative study examining communication breakdowns from the patients' perspectives found comparable challenges in effective patient-centered communication (Street et al., 2019). Issues with information overload, lack of guidance in processing the information, perception of biased information, and insensitive, dismissive, inappropriate, or unprofessional statements shared by the providers led to psychological consequences and emotional distress (Street et al., 2019).

Additionally, uncertainty about who to see or speak with regarding cancer care contributed to confusion and distress when making treatment decisions (Street et al., 2019). A prior study indicated that doctors are the first and preferred source of cancer information among cancer patients and survivors (Barnes et al., 2017). When patients experience communication breakdowns, this could lead to confusion, distress, and distrust, ultimately eroding the patient-provider relationship.

Prior research also revealed that patients withhold information/inquiries or refrain from sharing concerns about their cancer care (Frosch et al., 2012; Mazor et al., 2012; Pinquart & Duberstein, 2004; Prouty et al., 2014; Street et al., 2018). From the providers' perspectives, patients may avoid endangering their relationships with their providers by hesitating to share negative opinions about their care to avoid being seen as unintelligent or bothersome (Prouty et al., 2014). These findings suggest that patients may conceal their actual levels of health literacy and support the need for additional data about the relationship between health literacy and patient-centered communication quality.

According to the NCI Framework of Patient-Centered Communication in Cancer Care, patients’ knowledge and understanding may also play a moderating role between patient-centered communication and health outcomes (Epstein & Street, 2007). Patients with a better comprehension of the disease, the available treatment options, and the risks and benefits of each treatment option are more likely to engage in health-related decisions (Epstein & Street, 2007). Additionally, cancer patients often rely on physicians as their preferred source of cancer-related information for effective decision-making (Barnes et al., 2017; Cohen et al., 2013; Eggly et al., 2013; Song et al., 2012, 2014; Schubart et al., 2015). Furthermore, Song and her colleagues (2012) found that patients with insufficient knowledge relinquished decision-making power to their physicians. In the NCI Framework, physicians are instructed to ask about information needs with their patients– the first step in fostering a comfortable, safe environment for patients that ultimately encourages information exchanges, relationship-building, and shared decision-making– core functions of PPCQ and ultimately improves health outcomes (Epstein & Street, 2007; Guimond et al., 2022).

In the "Patient-Centered Communication and Shared Decision-Making" chapter of a report on improving cancer care quality, the authors further describe the difficulties patients often experience while receiving care (Levit et al., 2013). A cancer diagnosis has emotional, financial, and logistical consequences (Song et al., 2014). The limited health literacy levels of cancer patients, the complexity of treatment options, and lack of familiarity with the healthcare system can pose challenges for patients and their families to be actively involved in shared decision-making. These factors highlight cancer patients' challenges during initial diagnosis, treatment, and even in the remission period.

Moreover, prior studies have demonstrated that when patients are involved in their healthcare, satisfaction increases, often associating with better health outcomes (Alston et al., 2012; Center for Advancing Health [CFAH], 2010; Hibbard & Greene, 2013; Lantz et al., 2005; Levit et al., 2013; Maurer et al., 2012; Roseman et al., 2013). Therefore, shared decision-making is an essential characteristic of patient-centered care and appropriately serves as one of the core functions in the NCI Framework for Patient-Centered Communication in Cancer Care.

Shared decision-making is defined as "the process of negotiation by which physicians and patients arrive at a specific course of action, based on a common understanding of the goals of treatment, the risks and benefits of the chosen treatment versus reasonable alternatives, and each other's values and preferences" (IOM, 2011, p. 8; Sheridan et al., 2004; adapted from Levit et al., 2013). The responsibility of managing more significant aspects of healthcare are frequently placed on cancer patients and their families/caregivers because of developments in cancer treatments and changes in healthcare protocols, such as patients being discharged from healthcare organizations sooner (CFAH, 2010; McCorkle et al., 2011). These added responsibilities may include medication adherence, changes to their lifestyles, wound care, and rehabilitation (CFAH, 2010). Healthcare providers assist patients in participating in their own health management, which involves managing the medical and psychosocial parts of cancer care and adjusting to role changes resulting from a cancer diagnosis (Levit et al., 2013; McCorkle et al., 2011). Self-management and autonomy over health-related decisions and actions are the primary objectives of health literacy, according to Nutbeam (2000, 2017). Although previous studies found that educational attainment, not health literacy, was a significant predictor of information needs, the measurement tools for health literacy only assessed literacy and numeracy skills (Matsuyama et al., 2012; Song et al., 2014). Researchers expressed a need for a more comprehensive assessment of health literacy and how different types of health literacy relate to patient-provider communication during cancer treatment and survivorship (Song et al., 2014).

Data is limited in the existing literature that investigates both health literacy and patient-centered communication among cancer patients. Furthermore, the examination of each construct of health literacy and any potential associations with patient-centered communication does not exist. This study investigated these relationships, which may have implications for alternative approaches to cancer care and future research.

Theoretical Framework: The Social Ecological Model

The Social Ecological Model was introduced in 1988 by Kenneth McLeroy, Daniel Bibeau, Allan Steckler, and Karen Glanz. This model combines the theory of individual development with Brofenbrenner’s ecological model and borrows from the work of Belsky and Steuart (McLeroy et al., 1988). There are five principles of ecological perspectives on health behavior: 1) There are multiple levels of influence on health behaviors, 2) environmental contexts are significant determinants of health behaviors, 3) influences on behaviors interact across levels, 4) ecological models should be behavior-specific, and 5) multilevel interventions should be most effective in changing behaviors (Glanz et al., 2015). In the Social Ecological model, the outcome of interest is patterns of behavior, and behavior is viewed as being determined by multiple levels of influence (the model's constructs). The multiple levels of influence on health behaviors include:

- intrapersonal factors, such as one’s knowledge, attitudes, beliefs, self-concept, and skills
- interpersonal factors, such as formal and informal social networks and social support systems (family, work group, and friendship networks)
- institutional factors, such as healthcare systems, state/local health departments, and formal and informal rules and regulations for operation

- community factors, such as relationships among organizations and institutions
- and factors relating to public policy, such as local, state, and national policies and regulations (McLeroy et al., 1988).

This model is relevant for this study because it examines the individual level (patients and their health literacy) and external influences with which the individuals interact (social support network, relationships with healthcare providers)—The topic-at-hand concerns health literacy levels and the potential associations with perceived patient-centered communication quality. Cancer patients who have a better understanding of their diagnosis, the available treatment options, and the risks and benefits of each treatment option will have a higher likelihood of participating more effectively in exchanging information and engaging in the decision-making process (Epstein & Street, 2007). As such, this study focused on the intrapersonal and interpersonal factors of the Social Ecological Model. While additional factors of influence may impact health literacy and PPCQ, only the first two levels of influence can appropriately measure the items selected from the survey. The potential impacts from the remaining levels of influence are shared in the study implications.

Examples of Intrapersonal factors include an individual's knowledge, attitude, beliefs, self-concept, and skills (McLeroy et al., 1988). Personal behaviors like smoking, treatment adherence, and exposure to toxic chemicals can influence cancer risk factors and subsequent health outcomes. A cancer diagnosis is often promoted as a "wake-up call" or opportunity to change health behaviors motivated by a desire to minimize the risk of recurrence or other complications (Arem et al., 2020; Denmark-Wahnefried et al., 2005). Health literacy can be similarly described as the knowledge, attitudes, beliefs, and self-concept that patients bring to their interactions with healthcare providers and healthcare organizations to discuss health status and make informed decisions to address health-related issues. Considering this phenomenon, the intrapersonal construct will measure each component of health literacy–<u>finding</u>, <u>understanding</u>, and <u>using</u> health information and services to inform health-related decisions.

Interpersonal factors involve an individual's social network and social support system (McLeroy et al., 1988). The cancer diagnosis, treatment, and post-cancer survival processes may depend on the patient's social networks and social support systems. These networks and support systems can include family members, friends, and the perceived relationships patients may have with their oncologists, nurses, primary care physicians, and medical technicians. Research shows good patient-centered communication improves interpersonal relationships between patients and their healthcare providers and advances the statisfaction and overall perceived quality of life of cancer patients (Arora et al., 2009; Finney Rutten et al., 2015; Sabee et al., 2015; Trivedi et al., 2021). For this reason, the interpersonal construct will measure perceived patient-centered communication quality.

The purpose of this study was to determine how each construct of health literacy and perceived patient-centered communication quality vary among different racial/ethnic groups and to examine the relationship between health literacy and perceived patient-centered communication quality among adults with a history of cancer in the United States. Limited literature examines the relationship between the three constructs of health literacy and perceived patient-centered communication quality. This study investigated that relationship to fill that gap and guide improvements in the cancer care continuum. At the conclusion of this study, the findings describe implications for approaches to cancer care and future research.

Chapter 3. Methods

This chapter will present the methodology for this study. An overview of the research questions will be presented first. Descriptions of the data source, the Health Information National Trends Survey (HINTS), the methods of data collection, and the study sample will follow. The remainder of the chapter will provide explanations of the study variables, research model, and analytical approach.

Research has shown the benefits of patient-centered communication in healthcare outcomes (Arora et al., 2009; Finney Rutten et al., 2015; Bredart et al., 2005; Mead & Bower, 2002; Sabee et al., 2015; Trivedi et al., 2021). However, limited research exists regarding the relationship between the three measures of health literacy and patient-centered communication, especially among varying racial/ethnic groups. This study investigated that relationship using the HINTS 5, Cycle 4 (2020) to answer the following research questions:

1. *How does health literacy vary among adults with a history of cancer in different racial/ethnic groups in the United States?*

2. *How does perceived patient-centered communication quality vary among adults with a history of cancer in different racial/ethnic groups in the United States?*

3. *Among adults with a history of cancer in the United States, which construct of health literacy is the strongest predictor of perceived patient-centered communication quality: <u>finding</u>, <u>understanding</u>, or <u>using</u> information and services to inform health-related decisions and actions?*

Data Source and Sample

A secondary data analysis was conducted using the Health Information National Trends Survey (HINTS) 5, Cycle 4 (2020). The Health Information National Trends Survey (HINTS) is a nationally representative survey that has been administered since 2003 by the National Cancer Institute (NCI) (Westat, 2020). The target population is civilian, non-institutionalized adults aged 18 and older living in the United States. HINTS provides NCI with “a comprehensive assessment of the American public’s access to and use of information about cancer across the cancer care continuum from prevention, early detection, diagnosis, treatment, and survivorship. The content of each data collection cycle focuses on comprehending the degree to which members of the general population understand vital cancer prevention messages” (Westat, 2020, p. 1). This study analyzed the final round of data collection for HINTS 5, Cycle 4 (2020).

The HINTS 5, Cycle 4 survey was disseminated and fielded from February 24 to June 15, 2020, with 3,865 completed surveys (Westat, 2020). The sample design included a single-mode mail survey with two stages, and employed the Next Birthday Method to select respondents (Westat, 2020). In the Next Birthday Method, an individual in each household is selected based on whose birthday is next (Salmon & Nichols, 1983)— “In the first stage, an equal probability sample of addresses was selected within each specific sampling stratum. In the second stage, one adult was selected within each selected household. The sampling frame consisted of a database of addresses used by Marketing Systems Group (MSG) to provide random samples of addresses” (Westat, 2020, p. 3).

There were 15,350 total number of addresses selected for HINTS, Cycle 4 (2020). Furthermore, 11,050 addresses resided in areas with high concentrations of the minority population and 4,300 addresses resided in areas with low concentrations of the minority population. According to Westat (2020), "high and low minority strata were created using the Census tract-level characteristics from the 2014-2018 American Community Survey data file. The high-minority stratum comprised of addresses in Census tracts with a 34% or larger population proportion of Hispanic or Black individuals. All the remaining addresses were assigned to the low-minority stratum. The high minority stratum's proportion of the sample was 26.5% and was oversampled so its proportion of the sample increased to 72.0%. The low minority stratum was 73.5% of the sampling frame but comprised 28.0% of the sample" (Westat, 2020, p. 4). Every selected household received one English survey and Spanish surveys were provided upon request via toll-free telephone calls. The survey was disseminated and fielded from February 24 - June 15, 2020. A total of 3,865 completed surveys were collected from the target population, with a response rate of 37% (Westat, 2020).

COVID-19 impacted HINTS 5, Cycle 4 (2020) after the survey was mailed out on February 24, 2020. According to the Methodology Report by Westat (2020), "the World Health Organization's announcement of the COVID-19 pandemic on March 11 impacted the Cycle 4 field period after the first mailing and reminder postcard was sent out. Restrictions from the state of Maryland (the location of Westat's headquarters) led to labor reductions in sending out survey packets and extended lag times between mailings. Regardless of the schedule changes, HINTS 5, Cycle 4 (2020) surveys were returned, inquiries from incoming telephone calls were fulfilled, and completed questionnaires were processed slower than expected” (Westat, 2020, p. 2).

In addition to the impact of COVID-19 on the mailing schedule, surveys received in the later part of the field period occasionally included COVID-related responses (Westat, 2020). For example, numerous respondents included COVID-19 in their responses concerning employment status. A binary pandemic return variable was developed to compare surveys returned early in versus late in the field period for possible COVID-19 consequences (Westat, 2020).

The sample used for this study included respondents who have a history of cancer and have seen a healthcare provider within the last 12 months (n=579). The inclusion criteria for this study were measured by the following questions in HINTS 5, Cycle 4 (2020): "C2. In the past 12 months, not counting the times you went to an emergency room, how many times did you go to a doctor, nurse, or other health professional to get care for yourself?" There are six items to choose: none, 1 time, 2 times, 3 times, 4 times, 5-6 times, or 10 or more times. Respondents who answered none or did not answer the question were omitted from the sample. Additionally, the second question measured the inclusion criteria for this study has a dichotomous answer of yes or no and derives from the question "O1. Have you been ever diagnosed as having cancer? ” (Westat, 2020). Respondents who answered no or did not answer the question were omitted from the sample. After applying the above inclusion criteria, the sample included 579 respondents. This study analyzed anonymous, public-use data and was deemed exempt from review by the Institutional Review Board.

Measures

Reliability

The Cronbach's alpha values of the dependent and independent variables determined the internal consistency or reliability. Values of 0.70 or higher were considered acceptable (Sharma & Petosa, 2014; University of California Los Angeles [UCLA] Advanced Research Computing, 2021).

Dependent Variable

The primary outcome (or dependent) variable was perceived patient-centered communication quality (PPCQ). A single HINTS item with multiple questions assessed perceived patient-centered communication quality. The following questions were included in the HINTS item, "In the past 12 months, how often did your health professional:

- Give you the chance to ask all the health-related questions you had.
- Give the attention you need to your feelings and emotions.
- Involve you in decisions about your health care as much as you want.
- Make sure you understand the things you need to do to take care of your health.
- Explain things in a way you can understand.
- Spend enough time with you?
- Help you deal with feelings of uncertainty about your health or health care?

A 4-point Likert scale followed, with the response options "always, usually, sometimes, and never ."Each question regarding perceived patient-centered communication quality was scored (1 = never, 2 = sometimes, 3 = usually, and 4 = always), then a composite score was created ranging from 7 to 28. Missing responses were given a mean score of 3. Cronbach alpha was 0.926, which indicated high internal reliability of the seven survey items comprising PPCQ.

Independent Variable

The primary predictor (or independent) variable was health literacy. Three constructs comprise health literacy: the skills to find, understand, and use information and services to inform health-related decisions and actions. The find construct had a 5-point Likert scale, while the remaining constructs had 4-point Likert scales.

The ability to find information was measured by the following question: “A3. Overall, how confident are you that you could get advice or information about cancer if you needed it? (Westat, 2020). The score would be 0-4, with 0 indicating “not confident at all,” and 4 indicating “completely confident.” The ability to understand information was measured by the following question: “D10. How easy or difficult was it to understand the health information in your online medical record? (Westat, 2020). The score would be 1-4, with 1 indicating "very difficult" and 4 indicating "very easy." Finally, the ability to use information was measured by the following question: "N2d. How much do you agree or disagree with the following statement? *If I found out from a genetic test that I was at high risk of cancer, I would change my behaviors, such as diet, exercise, and getting routine medical tests* (Westat, 2020). The score would be 1-4, with 1 indicating "strongly disagree" and 4 indicating strongly agree. The Cronbach alpha analysis revealed a scale reliability coefficient of 0.193, suggesting that the three items measuring the health literacy constructs had low internal consistency or reliability; therefore, these items were analyzed separately and not provided in a composite score.

Control Variables

According to the National Cancer Institute (2022b), low income, low health literacy, and lack of health insurance contributed to cancer disparities. Prior studies have demonstrated impacts on patient-provider communication quality by sociodemographic characteristics (DeVoe et al., 2009; Johnson et al., 2004; Street et al., 2014). Therefore, the control variables in this study included sociodemographic variables such as age, gender, education, income, health insurance, and health status.

Analytical Approach

The listed HINTS 5, Cycle 4 (2020) questions above operationalized the constructs of the Social Ecological Model. Table 1 displays an overview of the Social Ecological Model constructs and measures employed in this study and the associated research questions addressed. The intrapersonal level examines individual characteristics that influence behavior, such as knowledge, attitudes, beliefs, and personality traits (McLeroy et al., 1988). This construct measured the HINTS questions that assessed each component of health literacy (Table 1): <u>find</u> (HINTS question A3), <u>understand</u> (HINTS question D10), and <u>use</u> (HINTS question N2). Research questions one and three were answered using these measures. The interpersonal level examines interpersonal processes and primary groups, including family, friends, and peers, that provide social identity, support, and role definition (McLeroy et al., 1988). This construct measured the HINTS question C4 (A-G), described in Table 1. Research questions two and three were answered using these measures.

Table 1. Overview of Constructs, Measures, and Research Questions

Social Ecological Model Construct	Measure: HINTS Question	Associated Research Questions
Intrapersonal	● <u>Find</u>: A3. Overall, how confident are you that you could get advice or information about cancer if you needed it? ● <u>Understand</u>: D10. How easy or difficult was it to understand the health information in your online medical record? ● <u>Use</u>: N2. If I found out from a genetic test that I was at high risk of cancer, I would change my behaviors, such as diet, exercise, and getting routine medical tests.	1. How does health literacy vary among adults with a history of cancer in different racial/ethnic groups in the United States? 3. Among adults with a history of cancer in the United States, which construct of health literacy is the strongest predictor of perceived patient-centered communication quality: <u>finding</u>, <u>understanding</u>, or <u>using</u> information and services to inform health-related decisions and actions?
Interpersonal	C4 (A-G) "In the past 12 months, how often did your health professional: ● Give you the chance to ask all the health-related questions you had ● Give the attention you needed to your feelings and emotions ● involve you in decisions as much as you wanted ● Make sure you understand the things you need to do to take care of your health ● Explain things in a way you can understand ● spend enough time with you ● help you deal with feelings of uncertainty about your health or health care	2. How does perceived patient-centered communication quality vary among adults with a history of cancer in different racial/ethnic groups in the United States? 3. Among adults with a history of cancer in the United States, which construct of health literacy is the strongest predictor of perceived patient-centered communication quality: <u>finding</u>, <u>understanding</u>, or <u>using</u> information and services to inform health-related decisions and actions?

Descriptive Statistics

Descriptive statistics examined the overall sample. More specifically, the frequencies and percentages were calculated for the categorical variables of the sample (i.e., gender, race/ethnicity, education level, income range, employment status, and marital status), as well as the means, standard deviations, and minimum and maximum values for the continuous variable (i.e., age). Additionally, health insurance and health status were assessed. Missing values were given the average response in race/ethnicity, age, education level, income, health status, and health insurance. For example, 10% of responses were missing in race/ethnicity, which would have skewed the analyses. Data was analyzed using STATA/BE 17.0 for Windows (StataCorp LLC, 2021).

Research Question One

Research question one asked: How does health literacy vary among U.S. adults with a history of cancer in different racial/ethnic groups? The frequencies, means, and standard deviations were calculated for each health literacy construct among the racial/ethnic groups in the study. The original racial/ethnic categories included Non-Hispanic White (n=455), Hispanic (n=51), Non-Hispanic Black or African American (n=50), Non-Hispanic Alaska Native or American Indian (n=1), Non-Hispanic Asian (n=11), Non-Hispanic Native Hawaiian or Other Pacific Islander (n=1), Non-Hispanic Multiple Races Selected (n=10). An analysis of variance (ANOVA) was conducted to assess statistically significant differences between the means of each racial/ethnic group and the three health literacy constructs. Due to low sample sizes, Non-Hispanic Alaska Native or American Indian, Non-Hispanic Asian, Non-Hispanic Native Hawaiian or Other Pacific Islander, and Non-Hispanic Multiple Races Selected were recoded into one category, Non-Hispanic Other (n = 23).

Research Question Two

Research question two asked: How does perceived patient-centered communication quality vary among adults with a history of cancer in different racial/ethnic groups in the United States? The frequencies, percentages, means, and standard deviations were calculated for the perceived patient-centered communication quality (PPCQ) levels among the same racial/ethnic groups described above based on the composite scores created for perceived patient-centered communication quality. The following levels of PPCQ were assigned to each racial/ethnic group based on the composite score: high PPCQ with scores of 22-28, average PPCQ with scores of 15-21, and low PPCQ with scores of 7-14. An analysis of variance (ANOVA) was conducted to assess statistically significant differences between the means of each racial/ethnic group and PPCQ. The racial/ethnic groups in research question one were also used in the analysis for research question two.

Research Question Three

Research question three asked: Among adults with a history of cancer in the United States, which construct of health literacy is the strongest predictor of perceived patient-centered communication quality: finding, understanding, or using information and services to inform health-related decisions and actions? A multiple regression was conducted to investigate the strongest predictor of patient-centered communication quality (dependent variable). The predictors (independent variables) included the three constructs of health literacy: find, understand, and use. The scores for each predictor and the composite score for PPCQ were used to calculate the multiple regression.

Table 2. Overview of Research Questions and Data Analysis

Research Question	**Data Analysis**
1. How does health literacy vary among adults with a history of cancer in different racial/ethnic groups in the United States?	Descriptive statistics – frequencies, percentages, means, and standard deviations of each construct of health literacy among • Non-Hispanic White (n=455) • Non-Hispanic Black or African American (n=50) • Hispanic (n=51) • Non-Hispanic Other (n=23)
2. How does perceived patient-centered communication quality vary among adults with a history of cancer in different racial/ethnic groups in the United States?	Descriptive statistics – frequencies, percentages, means, and standard deviations of PPCQ composite scores, among the racial/ethnic groups described above
3. Among adults with a history of cancer in the United States, which construct of health literacy is the strongest predictor of perceived patient-centered communication quality: <u>finding</u>, <u>understanding</u>, or <u>using</u> information and services to inform health-related decisions and actions?	A multiple regression to investigate the strongest predictor of PPCQ (dependent variable). Predictors variables: <u>find</u>, <u>understand</u>, and <u>use</u>. Scores of each predictor variable and the PPCQ composite scores were calculated for the multiple regression.

The research model is as follows:

Y_t (perceptions of patient-centered communication quality) = β_0 + β_1<u>find</u> construct of health literacy + β_2<u>understand</u> construct of health literacy + β_3<u>use</u> construct of health literacy + $\beta_i$control variables

where Y = perceptions of patient-centered communication quality; β_0 = constant; $\beta_{1,2,3}$ = <u>find</u>, <u>understand</u>, or <u>use</u> construct of health literacy; and β_i = coefficients of control variables. Figure 1 shows the relationships between the constructs of health literacy and perceived patient-centered communication quality.

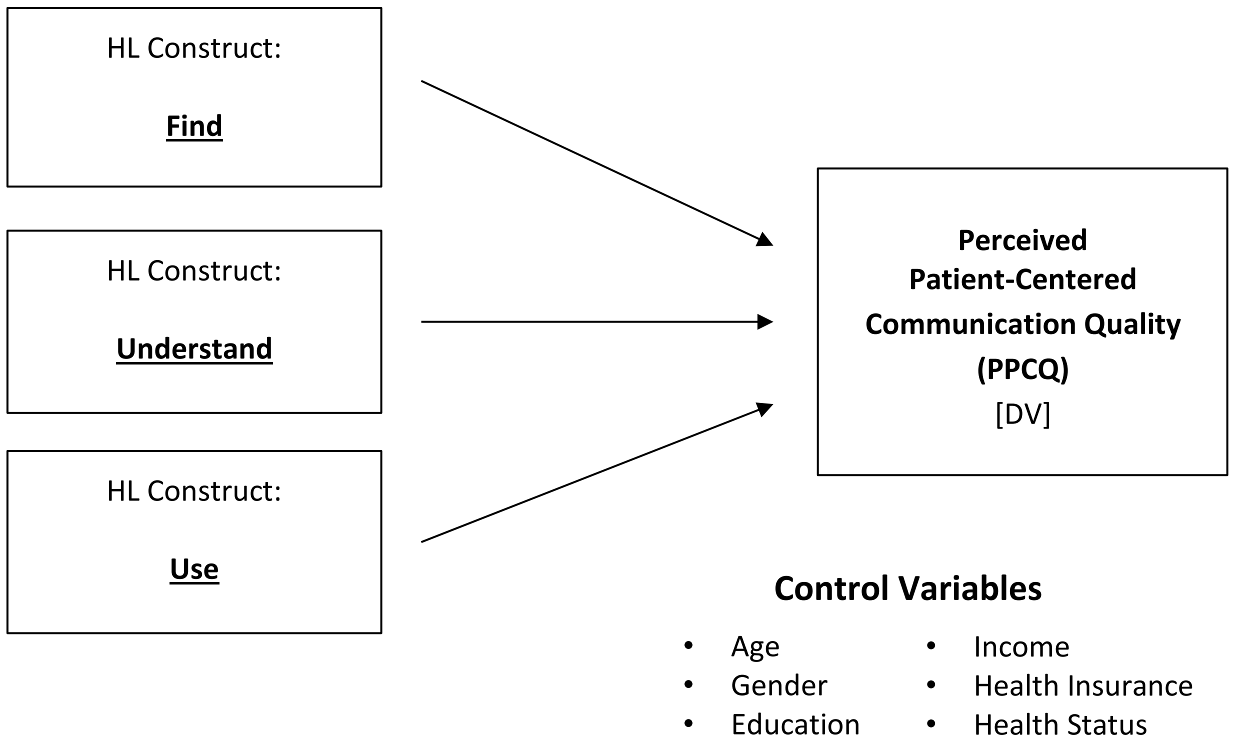

Figure 1. Conceptual Model for Research Question 3. This figure illustrates the relationships between health literacy constructs and PPCQ.

In summary, this study aimed to shed light on the associations between health literacy and perceived patient-centered communication quality among adults with a history of cancer in the United States. More specifically, this study analyzed which construct of health literacy– the ability to <u>find</u>, <u>understand</u>, and <u>use</u> information and services to inform health-related decisions and actions– is the strongest predictor of perceived patient-centered communication quality through a multiple linear regression. Furthermore, this study assessed the varying levels of health literacy for each construct and perceived patient-centered communication quality among different racial/ethnic groups from the chosen sample. The statistical software employed to create the composite scores, conduct descriptive statistics, and analyze the multiple linear regression was STATA/BE 17.0 for Windows (StataCorp LLC, 2021).

Chapter 4. Results

This chapter will present the results from the data analyses calculated in STATA/BE 17.0 to answer three research questions for this study. Descriptive characteristics of the study sample will be presented first. Next, the characteristics of the study measures will follow. The remainder of the chapter will then provide an investigation of the three research questions and their associated data analyses.

Descriptive Characteristics of the Study Sample

Descriptive characteristics of the study sample are presented in Table 3. The study sample included 579 respondents whose ages ranged from 19 to 104, with a mean of 67 years of age (*SD* = 13). Most of the respondents self-identified as Non-Hispanic White (78.6%), male (58.3%), married (48.5%), and retired (52.2%). Almost three-quarters of the respondents had post-high school training or education (73.4%), and over half earned $50,000 or less annually (53.9%). Most respondents also indicated having health insurance (98.8%) and generally good health (72%).

Table 3. Demographics of Study Sample

Variable	Frequency	Percent
Gender		
Male	338	58.4
Female	238	41.1
Missing	3	0.52
Age Group		
18-34	11	1.90
35-49	42	7.25
50-64	157	27.1
65-74	203	35.1
75+	166	28.7
Mean Age (SD)	67 (13)	19-104 *(Min-Max)*
Race/Ethnicity		
Non-Hispanic White	455	78.6
Non-Hispanic Black or African American	50	8.64
Hispanic	51	8.81
NH American Indian or Alaska Native (AIAK)	1	0.17
Non-Hispanic Asian	11	1.90
NH Native Hawaiian or other Pacific Islander (NHPI)	1	0.17
Non-Hispanic Multiple races selected	10	1.73
Non-Hispanic Other (i.e., AIAK, NH Asian, NHPI, and NH Multiple races)	23	3.97
Marital Status		
Married	281	48.5
Living as married or living with a romantic partner	16	2.76
Divorced	97	16.8
Widowed	94	16.2
Separated	9	1.55
Single, never been married	67	11.6
Highest Level of Education		
Less than 8 years	12	2.07
8 through 11 years	24	4.15
12 years or completed high school	115	19.9
Post-high school training other than college	44	7.06
Some college	135	23.3
College Graduate	137	23.7
Postgraduate	112	19.3
Employment Status		
Employed full time	156	26.9
Employed part-time	27	4.66
Homemaker	28	4.84
Student	2	0.35
Retired	302	52.2
Disabled	40	6.91
Unemployed less than 1 year	5	0.86
Unemployed 1 year or more	5	0.86
Other	4	0.69
Income Level		
Less than $20,000	90	15.5
$20,000 to < $35,000	73	12.6
$35,000 to < $50,000	149	25.7
$50,000 to < $75,000	89	15.4
$75,000 or More	178	30.7
Health Insurance		
Yes	572	98.8
No	7	1.21
General Health Status		
Poor	28	4.84
Fair	124	21.4
Good	222	38.3
Very Good	171	29.5
Excellent	34	5.87

Characteristics of Study Measures

This study consisted of four measures, including PPCQ and the three constructs of health literacy (find, understand, use). Table 4 displays the characteristics of the study measures. The dependent variable, perceived patient-centered communication quality (PPCQ), was measured by seven sub-questions with a four-point Likert scale ranging from "Never" with a score of 1 to "Always," with a score of 4. The summation of the seven sub-questions provided a composite score of 7 to 28. The summation of the seven sub-questions provided a composite score of 7 to 28. The mean for PPCQ was 23.9 (*SD*=4.37), in the “high PPCQ” range.

Table 4. Characteristics of Study Measures

Measure	*Items*	*Observed Range*	*n*	*M*	*SD*
Perceived Patient-Centered Communication Quality (PPCQ)	*7*	*7-28*	579	23.9	4.37
Health Literacy: Find	5	1-5	573	3.92	0.92
Health Literacy: Understand	4	1-4	289	3.34	0.63
Health Literacy: Use	4	1-4	565	3.38	0.73

The independent variables were measured by three questions, making up the three health literacy constructs: finding, understanding, and using information to make health-related decisions or actions. The measure for the health literacy construct, find, consisted of a five-point Likert scale with responses ranging from "Completely confident" with a score of 5 to "Not confident at all" with a score of 1. The mean was 3.92 with a standard deviation of 0.92, with the majority response being "Very confident" (Table 4).

The measure for the health literacy construct, understand, consisted of a question with a four-point Likert scale with responses ranging from "Very easy" with a score of 4 to "Very difficult" with a score of 1. The mean was the lowest of the three constructs at 3.34 (*SD*=0.63), with a majority response of "Somewhat easy" (Table 4).

The measure for the health literacy construct, use , consisted of a sub-question with a four-point Likert scale with responses ranging from "Strongly disagree" with a score of 1 to "Strongly agree" with a score of 4. The mean was 3.38 (*SD*=0.73), with the majority response of "Somewhat agree" (Table 4). This mean indicates that respondents would change their behaviors, such as diet, exercise, and getting routine medical tests, if they found out from a genetic test that they were at high risk of cancer.

Examination of the Research Questions

This study had three research questions that were guided by the Social Ecological Model. The following sections will discuss each research question and their corresponding statistical analyses.

Research Question One

Research Question One assessed health literacy constructs (find, understand, and use) among U.S. adults with a history of cancer in different racial/ethnic groups. Table 5 presents the descriptive statistics of each health literacy construct among four racial/ethnic categories in the study sample: Non-Hispanic White, Non-Hispanic Black or African American, Hispanic, and Non-Hispanic Other (including Non-Hispanic American Indian or Alaska Native, Non-Hispanic Asian, Non-Hispanic Native Hawaiian or other Pacific Islander, and Non-Hispanic Multiple Races Selected). The results for the health literacy construct, find, are presented first. Respondents who identified as "Non-Hispanic Black or African American" had the highest mean of 4.02 (*SD*=0.94). Respondents who self-identified as Hispanic had the lowest mean of 3.3 (*SD*=1.02). All racial/ethnic groups had a mean response of “Very confident.” For the second health literacy construct, understand, among all racial/ethnic groups, the mean was around 3, with a mean response of "Somewhat easy." For the third health literacy construct, respondents in the Non-Hispanic White category had the lowest mean of 3.35 (*SD*=0.74). Respondents in the Non-Hispanic Black or African American category had the second to highest mean of 3.6 (*SD*=0.61), rounding up to “Strongly agree.”

Table 5. Health Literacy Among U.S. Adults with a History of Cancer by Race/Ethnicity

Health Literacy Construct: Find					
Question: A3. Overall, how confident are you that you could get advice or information about cancer if you needed it?					
Frequencies (Percentages)	Non-Hispanic White	NH Black	Hispanic	Non-Hispanic Other	Total
Not confident at all	6 (1.0%)	0	0	0	6 (1.0%)
A little confident	16 (2.8%)	1 (0.2%)	9 (1.6%)	2 (0.3%)	28 (4.8%)
Somewhat confident	114 (19.7%)	18 (3.1%)	12 (2.1%)	6 (1.0%)	150 (25.9%)
Very confident	178 (30.7%)	10 (1.7%)	19 (3.3%)	10 (1.7%)	217 (37.5%)
Completely confident	141 (24.4%)	21 (3.6%)	11 (1.9%)	5 (0.9%)	178 (30.7%)
Total	455 (78.6%)	50 (8.6%)	51 (8.8%)	23 (4.0%)	579 (100%)
Statistics	Non-Hispanic White	NH Black	Hispanic	Non-Hispanic Other	Total
Mean	3.949451	4.02	3.627451	3.782609	3.920553
Standard deviation	0.905	0.9365591	1.019035	0.9023465	0.9210583
Median	4	4	4	4	4
Minimum value	1	2	2	2	1
Maximum value	5	5	5	5	5
Mean response	Very confident	Very confident	Very confident	Very confident	Very confident

Health Literacy Construct: Understand					
Question: D10. How easy or difficult was it to understand the health information in your online medical record? Criteria description: Participants who have accessed any medical records in the past 12 months.					
Frequencies (Percentages)	Non-Hispanic White	NH Black	Hispanic	Non-Hispanic Other	Total
Very difficult	1 (0.3%)	0	0	0	1 (0.3%)
Somewhat difficult	19 (6.6%)	1 (0.3%)	1 (0.3%)	1 (0.3%)	22 (7.6%)
Somewhat easy	114 (39.4%)	10 (3.5%)	12 (4.2%)	7 (2.4%)	143 (49.5)
Very easy	102 (35.3%)	7 (2.4%)	7 (2.4%)	7 (2.4%)	123 (42.6%)
Total	236 (81.7%)	18 (6.2%)	20 (6.9%	15 (5.2%)	289 (100%)
Statistics	Non-Hispanic White	NH Black	Hispanic	Non-Hispanic Other	Total
Mean	3.34322	3.333333	3.3	3.4	3.342561
Standard deviation	0.6431278	0.5940885	0.5712406	0.6324555	0.6321439
Median	3	3	3	3	3
Minimum value	1	2	2	2	1
Maximum value	4	4	4	4	4
Mean response	Somewhat easy	Somewhat easy	Somewhat easy	Somewhat easy	Somewhat easy
Health Literacy Construct: Use					
Question: N2d. How much do you agree or disagree? If I found out from a genetic test that I was at high risk of cancer, I would change my behaviors, such as diet, exercise, and getting routine medical tests.					
Frequencies (Percentages)	Non-Hispanic White	NH Black or African American	Hispanic	Non-Hispanic Other	Total
Strongly disagree	13 (2.2%)	1 (0.2%)	2 (0.3%)	0	16 (2.8%)
Somewhat disagree	33 (5.7%)	0	1 (0.2%)	2 (0.3%)	36 (6.2%)
Somewhat agree	193 (33.3%)	17 (2.9%)	20 (3.5%)	9 (1.6%)	239 (41.3%)
Strongly agree	216 (37.5%)	32 (5.5%)	28 (4.8%)	12 (2.1%)	288 (49.7%)
Total	455 (78.6%)	50 (8.6%)	51 (8.8%	23 (4.0%)	579 (100%)
Statistics	Non-Hispanic White	NH Black	Hispanic	Non-Hispanic Other	Total
Mean	3.35	3.60	3.45	3.43	3.38
Standard deviation	0.74	0.61	0.73	0.66	0.73
Median	3	4	4	4	3
Minimum value	1	1	1	2	1
Maximum value	4	4	4	4	4
Mean response	Somewhat agree	*Strongly* agree	Somewhat agree	Somewhat agree	Somewhat agree

Lastly, Table 6 presents the analysis of variance of the health literacy constructs, find, understand, and use, and race/ethnicity. The number of observations included in the study was 289. The R-squared value was 0.12 with an adjusted R-squared of -0.005. The root mean squared error was 0.83. The F value for the model was 0.96, and the p-value was 0.54. For each health literacy construct, the analysis revealed no statistically significant differences between the racial and ethnic groups.

Table 6. ANOVA of Health Literacy Constructs and Race/Ethnicity

ANOVA of Health Literacy Constructs and Race/Ethnicity					
		Number of Obs	289	R-squared	0.1205
		Root MSE	0.827703	Adj R-squared	-0.0052
Source	Partial SS	df	MS	F	Prob>F
Model	23.647434	36	0.65687317	0.96	0.5408
Find	2.0966204	4	0.52415509	0.77	0.5488
Understand	0.27786283	3	0.09262094	0.14	0.939
Find & Understand	5.4891149	5	1.097823	1.6	0.1599
Use	2.1081822	3	0.7027274	1.03	0.3818
Find & Use	8.5354161	8	1.066927	1.56	0.1381
Understand & Use	0.94010872	5	0.18802174	0.27	0.9269
Find, Understand & Use	5.8181839	8	0.72727299	1.06	0.3907
Residual	172.64322	252	0.68509216		
Total	196.29066	288	0.68156478		

Research Question Two

Research Question Two inquired about the varying levels of perceived patient-centered communication quality (PPCQ) among U.S. adults with a history of cancer in different racial/ethnic groups. Table 7 presents the descriptive statistics of the PPCQ composite scores among the four racial/ethnic categories in the study sample. Non-Hispanic Black and Non-Hispanic Other respondents had the highest and second-highest means of 25.8 (*SD*=3.00) and 24.1 (*SD*=5.10), respectively. Among these racial/ethnic groups, 90% of Black respondents had high PPCQ, and Non-Hispanic Other respondents had a median score two points higher than the next group (median = 27, compared to 25 among Non-Hispanic White individuals). Almost half of all respondents who identified as Non-Hispanic Other had a PPCQ score of 28 (47.8%, m = 24.1, SD = 5.1). Respondents who identified as Hispanic and Non-Hispanic White also had relatively lower means of 22.8 (*SD*=5.75) and 23.8 (*SD*=4.23), respectively. Despite these findings, all racial/ethnic categories (71.9% of all respondents) had PPCQ scores between 22-28, suggesting high levels of PPCQ.

Table 7. Perceived Patient-Centered Communication Quality (PPCQ) Among U.S. Adults with a History of Cancer by Race/Ethnicity

Frequencies & Statistics of PPCQ Composite Scores (from 7 survey items)					
Frequencies (Percentages)	Non-Hispanic White	NH Black	Hispanic	Non-Hispanic Other	Total
Low (scores of 7-14)	16 (3.5%)	0 (0%)	6 (11.8%)	1 (4.4%)	23 (4.0%)
Average (scores of 15-21)	118 (26.0%)	5 (10.0%)	11 (21.6%)	6 (26.1%)	140 (24.1%)
High (scores of 22-28)	321 (71.6%)	45 (90.0%)	34 (66.7%)	16 (69.6%)	416 (71.9%)
Total	455 (100%)	50 (100%)	51 (100%)	23 (100%)	579 (100%)
Statistics	Non-Hispanic White	NH Black	Hispanic	Non-Hispanic Other	Total
Mean	23.8	25.8	22.8	24.1	23.9
Standard deviation	4.2	3.0	5.8	5.1	4.4
Median	25	28	24	27	25
Minimum value	11	17	7	11	7
Maximum value	28	28	28	28	28
Mean PPCQ Level	High	High	High	High	High

Table 8 presents the analysis of variance (ANOVA) of perceived patient-centered communication quality composite scores and race/ethnicity to determine if there is a statistically significant difference between the means. The number of observations was 579, with an R-squared value of 0.06, an adjusted R-squared value of 0.02, and a root mean squared error of 0.80. The F-value for the model was 1.74, with a p-value of 0.02, revealing statistical significance ($p < 0.05$).

Table 8. Analysis of Variance (ANOVA) of PPCQ and Race/Ethnicity

ANOVA of PPCQ and Race/Ethnicity					
		Number of obs	579	R-squared =	0.0586
		Root MSE	0.797146	Adj R-squared =	0.0249
Source	Partial SS	df	MS	F	Prob>F
Model	22.069541	20	1.1034771	1.74	0.0246*
PPCQ	22.069541	20	1.1034771	1.74	0.0246*
Residual	354.5764	558	0.63544158		
Total	376.64594	578	0.65163658		

**p < 0.05 **p < 0.01 ***p<0.001*

Research Question Three

Research Question Three examined which health literacy construct was the strongest predictor of perceived patient-centered communication quality among U.S. adults with a history of cancer. The F value (22, 265) for the multiple regression model was 4.07 and showed statistical significance ($p < 0.001$). The total number of observations in the model was smaller than expected (n = 289) due to the response criteria of accessing one's medical record within the past 12 months (health literacy construct: understand). The R-squared value revealed that approximately 26% of the variance in PPCQ was due to health literacy. After adjusting for the number of cases and variables, the adjusted R-squared was 0.1951, or approximately 20% variance. The root mean squared error was 3.9. Two health literacy constructs, find and understand, showed statistically significant relationships ($p < 0.001$) with PPCQ. The strongest predictor of PPCQ was the ability to understand health information to inform health-related decisions and actions (*B* coefficient = 1.54, *SE* = 0.38, CE: 0.79, 2.3).

The following results describe the control variables in the multiple linear regression model. Self-identifying as Hispanic had a statistically significant inverse relationship with PPCQ

($p < 0.05$), with the reference category being Non-Hispanic White. Age also showed a statistically significant relationship ($p < 0.05$), with a mean age of 67. Finally, having a relatively poorer health status had a statistically significant inverse relationship with PPCQ ($p < 0.01$). Table 9 presents the results of the multiple regression analysis.

Table 9. Multiple Regression Analysis Examining the Impact of Three Health Literacy Constructs on PPCQ for U.S. Adults with a History of Cancer

Multiple Linear Regression Analysis						
					95% CI for *B*	
	B	*S.E.*	t	*p*	LL	UL
Health Literacy: <u>Find</u>	1.075884	0.2872833	3.75	0.000***	0.5102264	1.641543
Health Literacy: <u>Understand</u>	1.543941	0.3840503	4.02	0.000***	0.7877496	2.300132
Health Literacy: <u>Use</u>	0.540877	0.334537	1.62	0.107	-0.1178233	1.199577
Race/ethnicity (reference = White)						
Non-Hispanic Black or African American	1.25297	1.018168	1.23	0.220	-0.7517932	3.257734
Hispanic	-2.413043	0.96282	-2.51	0.013*	-4.308827	-0.5172597
Non-Hispanic Other	-0.2317786	1.071272	-0.22	0.829	-2.341103	1.877545
Sex/Gender	(reference = Male)					
Female	0.2645317	0.4956394	0.53	0.594	-0.7113775	1.240441
Age	0.0480658	0.0204243	2.35	0.019*	0.0078506	0.0882811
Highest Education Level Achieved (reference = Postgraduate)						
College Graduate	0.1331632	0.6771716	0.2	0.844	-1.200181	1.466508
Some college	0.6526282	0.6985154	0.93	0.351	-0.722742	2.027998
school	1.07277	1.011608	1.06	0.290	-0.9190758	3.064616
years or	0.8925129	0.8025991	1.11	0.267	-0.687797	2.472823
8 through 11 years	0.7670701	2.413977	0.32	0.751	-3.986027	5.520167
Less than 8 years	4.841805	4.121408	1.17	0.241	-3.273208	12.95682
Income Level (reference = $75,000 or more)						
$50,000 to $75,000	-0.6498251	0.6738662	-0.960	0.336	-1.976661	0.677011
$35,000 to < $50,000	-0.3411386	0.63255	-0.540	0.590	-1.586623	0.9043462
$20,000 to < $35,000	0.8050974	0.966683	0.830	0.406	-1.098292	2.708487
Less than $20,000	0.3482979	0.869399	0.400	0.689	-1.36354	2.060136
Health Insurance (y/n)	4.986261	2.917243	1.71	0.089	-0.7577626	10.73028
General Health Status (reference = Excellent)						
Very good	-1.382767	0.9690111	-1.43	0.155	-3.29074	0.5252069
Good	-2.689168	0.9734876	-2.76	0.006**	-4.605956	-0.7723806
Fair	-3.232566	1.098411	-2.94	0.004**	-5.395327	-1.069806
Poor	-5.195613	1.477753	-3.52	0.001**	-8.105295	-2.285931
_cons	6.638565	4.079747	1.63	0.105	-1.394417	14.67155

*$p < 0.05$ **$p < 0.01$ ***$p<0.001$

Chapter 5. Discussion

The purpose of this study was to determine how three health literacy constructs (find, understand, and use) and perceived patient-centered communication quality vary among different racial/ethnic groups, as well as to examine the relationship between health literacy and perceived patient-centered communication quality among adults with a history of cancer in the United States. The Social Ecological Model, provided the theoretical framework for this study, leading to development of three research questions to examine these relationships. This chapter will discuss the significant findings of this study, how these findings relate to prior research, the limitations of this study, the implications of these findings for professional practice or applied settings, and recommendations for further research. This chapter will then close with a conclusion summarizing the practical implications of the findings of this study.

Health Literacy and Race/Ethnicity among U.S. Adults with a History of Cancer

The first research question inquired how health literacy varies among U.S. adults with a history of cancer in different racial/ethnic groups. Three health literacy-related items identified from the survey were used as the three health literacy constructs (find, understand, and use health-related information to inform decisions and actions). Across all racial/ethnic communities, the majority of adults indicated they were “very confident” in their ability to find advice or information about cancer, they thought it was “somewhat easy” to understand their health information in their online medical records, and they "somewhat agreed" that they would change their health-related behaviors if a genetic test indicated a high risk of cancer. Unlike Coughlin and his colleagues (2022), this study found no statistically significant differences in health literacy levels when comparing Black or Hispanic individuals to their White counterparts. The most frequent responses to each survey item, comprising of the three health literacy constructs, were the same across all racial/ethnic groups, with the exception that self-identified Black individuals strongly agreed (while the other three racial/ethnic groups somewhat agreed) that they would change their health behavior if they were at high risk of cancer, genetically. This finding suggests that the Black individuals in the sample believed changing their health-related behavior is necessary in the face of strong evidence and need.

In Coughlin and his colleagues' study (2022), the classification of low health literacy was assigned to respondents who reported difficulty with one or more of three basic health literacy-related tasks (i.e., finding and understanding communication and written health information). Within the context of Coughlin’s study, health literacy is viewed as a risk factor measured by basic, functional tasks. In comparison, this study viewed health literacy as an asset, measured by functional (find and understand), interactive, and critical (use) tasks. In addition, health literacy is seen as an opportunity to develop basic, social, and cognitive skills to improve self-empowerment and autonomy over health-related decisions and actions. Improved self-empowerment and autonomy would benefit the individual patient *and* their support networks in enhanced engagement and increase the likelihood of favorable health outcomes (Busch et al., 2015; Gunn et al., 2020; Jiang et al., 2019; Lillie et al., 2007; Mahal et al., 2015; Nutbeam, 2017; Polite et al., 2019; Post et al., 2020; Rust et al., 2015; Tagai et al., 2020; Yen et al., 2020).

Although no statistically significant differences were found between racial or ethnic groups, a difference in frequencies was observed between Non-Hispanic Black individuals and the other racial/ethnic groups, of whom selected that they strongly agreed to change their health behaviors if they were found at high risk of cancer (Table 5). According to Nutbeam (2017), health literacy is content and context-specific– a person's ability to access health information and their motivation and skills to use information is greatly influenced by their age and circumstances in life and the context in which information might be applied. However, this study found no statistical differences between racial and ethnic groups.

These results are not consistent with the work of Rencsok and colleagues (2020), who found that Black men in the U.S. were severely underrepresented in seventy-two phase 3 prostate cancer clinical trials– 83.4% of participating men were White compared to 6.7% of participating men who were Black. Factors accounting for lower enrollment of Black men that have been observed include mistrust in the healthcare system and clinical research, a lack of awareness and access to prospective clinical trials, lack of representative diversity in clinical trial research teams, lack of education or bias of healthcare providers to recommend definitive therapies or access to clinical research, and reluctance to receive medical care (Kaplan et al., 2015; Lillard et al., 2022; McKay et al., 2021; Rencsok et al., 2020; Rogers et al., 2018; U.S. Food and Drug Administration [FDA], 2020). Health Literacy may not differ among different racial/ethnic groups in this study, but differences are documented in previous literature listed above. Low sample sizes may explain the conflicting results in racial/ethnic groups other than White and the lack of standardized health literacy definitions and measurement tools.

The findings from research question one are consistent with the intrapersonal factors that influence health-related behavior in the Social Ecological Model. Intrapersonal factors examine a person's knowledge, attitudes, beliefs, self-concept, and skills (McLeroy et al., 1988).

The pre-existing knowledge of health topics and the ability to develop the skills necessary to find, understand, and use information to make health-related decisions and actions constitute a patient's health literacy. These skills involve previously held beliefs regarding their health and healthcare and the confidence to act on learned information. Therefore, intrapersonal factors appropriately measure personal health literacy. However, health literacy is also affected by the accessibility of health information (Inglehart et al., 2016), medical discrimination (Lillard et al., 2022), and socioeconomic factors (Busch et al., 2015; Freedman et al., 2015; Gonzales et al., 2019; Halverson et al., 2013; Halverson et al., 2015; Jiang & Hong et al., 2018), which can be considered interpersonal, institutional, and social factors in the Social Ecological Model. Health Literacy may not differ among different racial/ethnic groups in this study, but differences are documented in previous literature listed above. The utilization of differing health literacy definitions and measurements may explain the conflicting results.

Perceived Patient-Centered Communication Quality and Race/Ethnicity Among U.S. Adults with a History of Cancer

The second research question inquired how perceived patient-centered communication quality varies among adults with a history of cancer in different racial/ethnic groups in the United States. The PPCQ scores relate to the “NCI framework of Patient-Centered Communication in Cancer Care: fostering healing relationships, exchanging information, responding to emotions, managing uncertainty, making decisions, and enabling patient self-management” (Epstein & Street, 2007, p. 17). These six core functions are neither independent nor hierarchical– they overlap and interact, resulting in communication that can impact vital health outcomes (Epstein & Street, 2007). The measurements of this framework are self-reported from the patients' perspectives (*perceived* patient-centered communication quality). Hispanic respondents had the lowest mean score of PPCQ, and Non-Hispanic Black respondents had the highest mean score of PPCQ (m = 22.8, *SD* = 5.75 and m = 25.8, *SD* = 3.00, respectively). This study's findings were similar to those found by Palmer and colleagues (2014) in that lower communication scores were observed among Hispanic cancer survivors. These results confirm known disparities and highlight opportunities for improvement in PPCQ among Hispanic individuals regarding overall communication and health education, cultural competency with those with limited English proficiency, perceptions of confidence and trust in their medical providers, and satisfaction with their cancer care.

However, the findings in this study differed from previous research that revealed communication quality that fell short in terms of likeliness to report good physician-patient communication concerning conversations and shared decision-making about prostate-specific antigen (PSA) screening and confusion among Black men with prostate cancer compared to White men (Pollack et al., 2017). A study that examined the psychosocial needs of patients undergoing radiation therapy also found that Black patients desired and requested more information about their types of cancer, how to address a known cancer risk factor (smoking), and symptom-coping techniques (Kronfli et al., 2020). Moreover, in a qualitative study of Black breast, colorectal, and lung cancer survivors, participants stressed the importance of clinicians discussing potential causes of their cancer (including genetic information), treatment options, schedules, and potential impacts on life (Eggly et al., 2013, 2017; Guimond et al., 2022).

Song and her colleagues (2014) also found significant associations between perceived racism, trust in physicians, and patient-provider communication, although they failed to find evidence that these relationships varied by race. These findings were inconsistent with this study's results that suggested higher levels of PPCQ across all racial/ethnic groups. Black respondents had the highest median and mean PPCQ scores compared with the other racial/ethnic groups, with 90% of Black respondents accounting for high PPCQ scores of 22-28. The previous studies described racial/ethnic disparities in patient-centered communication quality among Black men, yet this study suggests improvements have been made with respect to PPCQ. These contrasts could be explained by the smaller sample sizes among self-identified people of color compared to their White counterparts.

The results of this study are also consistent with the interpersonal factors of the Social Ecological Model. Intrapersonal factors that may influence PPCQ include previous knowledge and understanding and language proficiency. Prior research established issues with information exchange occur when patients do not feel comfortable with their providers or care (Frosch et al., 2012; Mazor et al., 2012; Pinquart & Duberstein, 2004; Prouty et al., 2014; Street et al., 2019). Minimizing communication breakdowns by fostering trust and following the six core functions of the NCI Framework for Patient-Centered Communication is vital. Interpersonal factors include effective communication between health providers, patients/families/caregivers. A qualitative study aimed at understanding health literacy in patients who received hematopoietic stem cell transplantation (HCST) indicated that family or those who have undergone similar treatment helped in individual comprehension (Cohen et al., 2013). Lastly, potential institutional factors that seem to impact PPCQ include issues with healthcare institutional issues such as communication breakdowns between providers involved in continuity of care, perceived implicit biases, and institutional racism affecting trust and confidence in health providers (Gonzales et al., 2019; Lillard et al., 2022; Street et al., 2018).

Effective patient-centered communication means answering questions, addressing uncertainty, shared decision-making, responding to emotions, and empowering patient self-management. Respondents in this study revealed that they experienced high levels of PPCQ with their healthcare providers within the past year. Although there are some differences between racial/ethnic groups, these results mean they felt generally satisfied with their interactions with their healthcare providers. When healthcare providers practice patient-centered communication, previous studies have shown associations between decreased anxiety (Zwingmann et al., 2017) and improved treatment and surveillance adherence (Liu et al., 2013; Tan et al., 2012); and increased discussion of prognosis, treatment alternatives, and patient concerns (Eide et al., 2004; Sohl et al., 2015; Shields et al., 2009).

Health Literacy and Perceived Patient-Centered Communication Quality Among U.S. Adults with a History of Cancer

Lastly, the third research question inquired which construct of health literacy is the strongest predictor of perceived patient-centered communication quality (<u>finding</u>, <u>understanding</u>, or <u>using</u> information and services to inform health-related decisions and actions) among U.S. adults with a history of cancer. The multiple linear regression analysis revealed that the health literacy construct, <u>understand</u>, is the strongest predictor of PPCQ ($p < 0.001$). The health literacy construct, <u>find</u>, was also found to be a significant predictor of PPCQ

($p < 0.001$). These results suggest that the ability to find and understand health-related information impacts perceived patient-centered communication quality in a meaningful way. Previous research has established that health literacy and PPCQ affect health behaviors and health outcomes in various ways, such as treatment adherence and clinical trial enrollment (Alston et al., 2012; Aroraet al., 2009; Bredart et al., 2005; Center for Advancing Health [CFAH], 2010; Finney Rutten et al., 2015; Hibbard & Greene, 2013; Lantz et al., 2005; Levit et al., 2013; Liu et al., 2013; Mead & Bower, 2002; Maurer et al., 2012; Rencsok et al., 2020; Roseman et al., 2013; Sabee et al., 2015; Tan et al., 2012). This study suggests that having the skills to find and comprehend pertinent health information is significantly associated with higher-quality patient-centered communication in cancer care.

These results are consistent with findings from previous research (Epstein & Street, 2007; Prouty et al., 2014), which revealed a significant relationship between health literacy and patient-centered communication. According to Holden, Wheelwright, Harle, & Wagland (2021), health literacy is essential for informed and shared decision-making (Sorensen et al., 2012; Edwards et al., 2012) and is closely associated with person-centered care, which aims to develop patients’ knowledge, skills, and self-confidence to engage in a partnership with their health providers (Health Foundation, 2014). A qualitative, secondary analysis also indicated that relationships between African American patients and their providers eroded upon the patients' perceptions that a clinician does not care if they understand the communicated information (Guimond et al., 2022; Song et al., 2012). The confirmation of these associations supports that active engagement in medical discussions and shared decision-making are relevant, especially in cancer care, where patients often face tough, life-changing decisions that are heavily reliant on patients’ preferences and beliefs (Cohen et al., 2013; Holden et al., 2021; Guimond et al., 2022).

The findings from this study were also consistent with a qualitative study examining the perceptions of clinical trial participation of varying health literacy levels among participants who completed a phase 2 clinical trial for early-stage breast cancer (Burks et al., 2019). Researchers found that higher health literacy (measured by reading, writing, and comprehension skills with health-related materials) were possibly associated with more significant research into treatment options because of more access to information, familiarity of what information to seek, comprehension of personal knowledge gaps, and understanding of pertinent information concerning diagnosis and treatment (Burks et al., 2019; Koh et al., 2013; Morris et al., 2013). Most participants ' relationships with their providers affected the decision-making process, with 90% reporting confidence in their surgeons encouraged clinical trial enrollment. A number of clinical trial participants felt so assured in the information provided by their healthcare providers that they did not feel the need to seek out additional details or conduct additional research prior to their decision. These results could potentially be associated with trust built between themselves and their healthcare providers, leading to an abdication of their decision power. Patients with limited health literacy may need help determining what additional information is necessary when making health-related decisions (Burks et al., 2019).

One study with differing results found that participants' health literacy levels concerning basic skills did not affect patient-centered communication for men with prostate cancer (Song et al., 2014). The measurement of health literacy utilized in Song's study (2014) was the short form of Rapid Estimate of Adult Literacy in Medicine (REALM), which assesses the ability to recognize and pronounce 66 medical terms (Davis et al., 1993). Neither numeracy nor other functions of health literacy were assessed, prompting the authors to note that further research is needed to include a more comprehensive assessment of health literacy and an examination of how different domains of health literacy are related to patient-provider communication among cancer survivors (Song et al., 2014).

This study aimed to contribute to that growing body of literature by assessing three health literacy constructs outlined by a widely accepted definition and examining the relationship between those constructs and PPCQ. Although this study found that the health literacy constructs, find and understand (both considered functional health literacy), were the strongest predictors of perceived patient-centered communication quality, the other domains and perceptions of health literacy must also be considered. Interactive and critical health literacy, in addition to the two concepts of health literacy as an asset versus a risk factor, may be influential factors on PPCQ and, ultimately, health outcomes.

Furthermore, these study findings and existing literature support the Social Ecological Model constructs and their influence on health-related behaviors. Intrapersonal factors include the patient's ability to find and understand health-related information (the outcome being functional health literacy [Coughlin et al., 2022; Hawley et al., 2010]) and the ability to discern credible health information from less trustworthy sources. Interpersonal factors in patient-provider communication include weighing risks and benefits (Burks et al., 2020), addressing emotions, psychological impacts, and uncertainties associated with progression or recurrence

(Coleman et al., 2019; Pozzar et al., 2021), and employing metaphors for better comprehension compared to plain language (Krieger et al., 2016). Moreover, patients' limited understanding of their cancer diagnoses and treatment options from the perspectives of healthcare providers has contributed to challenges in patient interactions and interference in information exchange (Prouty et al., 2014). These findings are supported by descriptions of similar challenges in patient-centered communication and shared decision-making, a core function described in the NCI Framework for Patient-Centered Communication in Cancer Care (Levit et al., 2013). In addition, Street and colleagues (2019) have also described institutional factors that can influence PPCQ, such as delays in test results and failure to ensure continuity of care (Epstein & Street, 2007; Wagner et al., 2001; Prouty et al., 2014; Street et al., 2019). The combination of personal knowledge, attitudes, and beliefs, the quality of interactions between individuals and their social network or support system, and the institutional values and implemented procedures can all impact the relationship between health literacy and PPCQ.

Limitations

Some limitations should be considered in this study. This study was a secondary data analysis that used a single database of self-reported data from one year (2020), which may be a source of potential recall or response biases. The COVID-19 global pandemic also impacted the collection of this study's self-reported data. These factors could have introduced sampling biases, either self-selection or nonresponse biases.

This secondary data analysis did not apply any weighting; therefore, it does not accurately represent the U.S. population. There was also an observed lack of racial/ethnic and age diversity among the study sample. Due to the lack of weighting and diversity, these findings are not generalizable. Additionally, further stratification of the data could not occur due to the low sample sizes, particularly in racial/ethnic groups, resulting in the combining of the following groups into one group: Non-Hispanic Other: Non-Hispanic Asian, Non-Hispanic American Indian Alaska Native, Non-Hispanic Native Hawaiian or Other Pacific Islander, and Non-Hispanic Multiple races selected. As a result, the listed data from the listed racial/ethnic groups could not be assessed or compared to other studies. These considerations can help encourage researchers to minimize these limitations by considering larger, more accurately representative data sources.

Additionally, the lack of evidence of significant differences between racial/ethnic groups in each health literacy construct made comparisons between race/ethnicity challenging despite known disparities (Kieffer Campbell, 2020; Coughlin et al., 2022). Most respondents scored relatively high in the health literacy measures, raising the question of whether the measures lack the sensitivity to identify a more complete construct of health literacy. Moreover, conducting a secondary data analysis limited the ability to measure and compare health literacy and its constructs to other studies. Despite these limitations, this study revealed meaningful associations between health literacy and patient-centered communication quality, contributing additional data to an area of study that needs further research.

Study Implications

Despite the limitations, the findings in this study have implications for current and future cancer patients, healthcare providers, healthcare systems, federally qualified health centers, and healthcare delivery services-related organizations. This study demonstrated a statistically significant relationship between health literacy, specifically the ability to find and understand health-related information to inform health-related decisions and actions, and perceived patient-centered communication quality. Furthermore, findings revealed minor but statistically significant differences among PPCQ scores between self-identified Non-Hispanic Black or African American individuals and other racial/ethnic groups. However, there was no evidence to suggest differences in health literacy among racial/ethnic groups.

Healthcare practitioners and healthcare delivery services-related organizations should focus on the two constructs of health literacy, find and understand, to improve patient-centered communication quality. During the global COVID-19 pandemic, populations worldwide witnessed the successes and pitfalls of disconnected health communication, particularly during the roll-out of the novel mRNA vaccines and the subsequent booster doses. These findings suggest that healthcare providers, healthcare institutions, health delivery-related organizations, and public health organizations should take particular care in providing easier access to health information in understandable ways to individuals and communities of varying levels of health literacy, language proficiency, physical accessibility, and socioeconomic status, as well as assisting individuals and communities in discerning accurate, credible health information from non-evidence-based health information from unvalidated sources. People use many possible sources to find health information and medical advice– websites, social media accounts, podcasts, video blogs, and others (Barnes et al., 2017). Some small sample studies have investigated successful interventions regarding question prompt lists (Eggly et al., 2013) and tailored education-coaching (Epstein et al., 2017; Street et al., 2010) and shed some light on communication best practices (Krieger et al., 2016). Based on the strongest predictors of PPCQ, it is incumbent upon healthcare/public health organizations and policymakers to implement system-level changes to ensure accurate, credible health information is easily accessible, distinguishable, and understandable to foster trust and self-confidence, thereby empowering individuals to improve patient-provider engagement and increase the likelihood of positive health outcomes.

Recommendations for Further Research

Few studies examine the relationship between health literacy constructs and patient-centered communication quality, particularly among cancer patients and survivors. Results from this study can guide healthcare providers and organizations, healthcare delivery service researchers, and public health practitioners in improving health literacy and patient-centered care to ultimately empower patient autonomy and increase positive health outcomes. Although the findings of this study shed light on which aspects of health literacy should be the focus with hopes of impacting PPCQ and health outcomes, challenges remain in producing comprehensive and comparable findings and recommendations due to the lack of standardized definitions and measurement tools.

Numerous studies have investigated factors associated with functional health literacy, but few have investigated all three levels of health literacy. The Health Literacy Questionnaire (HLQ), developed Osborne and colleagues (2013) in Australia, is a valid and reliable instrument that examines Nutbeam’s dimensions of health Literacy (2000, 2008). The HLQ has been reported to measure all three levels of health literacy (functional, interactive, and critical) and characterize health literacy needs that can be addressed in the clinical setting, particularly concerning valuable communication between patients with cancer and healthcare providers (Kieffer Campbell, 2020; Goodwin et al., 2018; Hawkins et al., 2017; Kayser et al., 2015; Osborne et al., 2013). Therefore, further research into health literacy utilizing the Health Literacy Questionnaire in diverse U.S. populations with higher cancer burdens is warranted.

Conclusion

Racial/ethnic communities are disproportionately burdened when examining cancer mortality and infection-related cancer incidence rates. According to the Office of Disease Prevention and Health Promotion [ODPHP] (2021a), health literacy and clear communication between professionals and patients are vital to improving health and the quality of healthcare. Three health literacy constructs were ascertained from the Healthy People 2030 personal health literacy definition: "the degree to which individuals have the ability to <u>find</u>, <u>understand</u>, and <u>use</u> information and services to inform health-related decisions and actions for themselves and others" (ODPHP, 2021c). The National Cancer Institute Framework for Patient-Centered Communication in Cancer Care provided the measurements of perceived patient-centered communication quality. This study aimed to determine how each construct of health literacy and perceived patient-centered communication quality vary among different racial/ethnic groups and to examine the relationship between health literacy and perceived patient-centered communication quality among U.S. adults with a history of cancer.

The Social Ecological Model provided a theoretical framework to examine the relationship between the three health literacy constructs and patient-centered communication quality in this study. Although there were no differences in health literacy among different racial/ethnic groups, there were observed differences in levels of PPCQ between self-identified Black respondents compared to their self-identified White, Hispanic, or Other counterparts. The findings suggest that the health literacy constructs find and understand are the strongest predictors of PPCQ. These findings, guided by the Social Ecological Model's levels of influence on health behavior, can serve as a foundation for developing strategies to provide easily accessible health information in understandable ways to individuals of varying levels of health literacy, language proficiency, physical accessibility, and socioeconomic status, as well as assist individuals and communities in discerning accurate, credible health information from non-evidence-based health information from unvalidated sources; thereby, fostering trust, self-confidence, and empowering individuals to make informed health-related decisions and actions throughout cancer treatment and survivorship.

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Curriculum Vitae

KIMBERLY ANN TOMAS, MPH

katomas21@gmail.com

EDUCATION:

University of Nevada, Las Vegas, Las Vegas, NV
School of Public Health
August 2017 – September 2023

Master of Public Health, Social and Behavioral Health, GPA: 3.92
September 2023

Thesis: Examining Health Literacy and Patient-Centered Communication Quality: A Secondary Analysis of U.S. Adults with a History of Cancer

Graduate Certificate in Infection Prevention
Conferred on May 16, 2020

Research Topics:

- The Significance of a Multi-Disciplinary Antimicrobial Stewardship Program in Acute Care Hospitals
- Infections Occurring in Outpatient Dialysis Centers: Causes & Interventions
- Carbapenem-resistant *Enterobacteriaceae*
- The Implementation and Monitoring Strategies of Low-level Disinfection, High-Level Disinfection, and Sterilization in General Acute Care Hospitals

California Polytechnic State University, San Luis Obispo, San Luis Obispo, CA
September 2012 - June 2015

Bachelor of Science in Microbiology

- Senior Proposal: Effectiveness of Chitosan-based Films Incorporating GRAS Antimicrobials in Controlling *Listeria monocytogenes* Growth on Cold-Smoked Salmon

Minor in Music

College of the Canyons, Santa Clarita, CA
August 2010 - June 2012

Associate of Science in Biological & Physical Sciences
Certificate of Achievement in Biotechnology

PROFESSIONAL EXPERIENCE:

Steven Hirsch & Associates, Fountain Valley, CA
February 2020 – December 2022
Infection Prevention and Control Consultant

- Created and maintained the Infection Prevention and Control Program, including surveillance of hospital-associated infections, surveillance of hand hygiene and PPE use, reporting Title 17 CCR §2500, §2593, §2641.5- 2643.20, and §2800-2812 Reportable Diseases and Conditions, data analysis, reporting and implementing mitigation strategies with Hospital Leadership in a 68-bed acute psychiatric hospital.
- Responsible for all Infection Prevention and Control Program services, including the surveillance, data analysis, and reporting for a 132-bed acute psychiatric hospital, a 68-bed acute psychiatric hospital, a 32-bed psychiatric health facility, and a 48-bed inpatient rehabilitation hospital in different counties and jurisdictions across Southern California.
- Created and maintained COVID-19 mitigation and prevention programs in all four client hospitals/facilities—including case reporting and collaboration with local public health departments.
- Created and maintained Mpox mitigation and prevention programs in two acute psychiatric client settings—including case reporting and collaboration with local public health departments.
- Consulted and recommended surveillance data, data analysis and interpretation, inspection, intervention, and education services to facility leadership and medical staff.
- Provided four primary functional areas to all healthcare clients: Education, Surveillance, Quality Improvement, and Program Maintenance.

SUPERVISION AND PROGRAM MANAGEMENT EXPERIENCE:

Rebel Wellness Zone, University of Nevada, Las Vegas, Las Vegas, NV
August 2017 - May 2018
Programming Graduate Assistant for Wellness Promotion

- Advised 11 leadership team members and 35+ peer educators on leadership development, event planning, and evidence-based practices in health.
- Assisted with hiring, scheduling, training, supervising, and evaluating 15+ new student peer educators and 5 interns.
- Developed, implemented, and assessed health and wellness programming in the areas of alcohol and other drugs, mental health, safer sex, stress management, and nutrition for the campus community.
- Facilitated discussions and created documents (agendas, timelines, and evaluation forms) for trainings, retreats, weekly meetings, and team-building activities the Leadership Team.
- Provided pre-HIV test counseling for approximately 10 students a month, including education on HIV transmission, condom use, and the rapid HIV test.

Student Engagement & Diversity, University of Nevada, Las Vegas, Las Vegas, NV
March 2017 - June 2017
Assistant Coordinator for Service Programs

- Promoted to Letter of Appointment position upon completion of the AmeriCorps VISTA service year**.**
- Retained all of the responsibilities of my previous position, AmeriCorps VISTA for Service Programs**.**
- Chaired a search committee for the position, Program Coordinator of Alternative Breaks, consisting of three professional staff and provided recommendations for over 30 candidates**.**
- Contributed to annual strategic planning and reporting**.**

January 2016 - February 2017

AmeriCorps VISTA for Service Programs

- Recruited, screened, and managed 21 volunteers in the student organization, UNLVolunteers.
- Advised volunteers in 4 separate committees on service program development & facilitation, marketing, and volunteer recruitment.
- Led a committee to educate participants on hunger & homelessness in Las Vegas bi-weekly, and packed over 5000 meals total for the Las Vegas Rescue Mission.
- Led a committee to bridge two departments and plan three university-wide days of service, partnering with 20 nonprofit organizations and recruiting over 300 volunteers.
- Developed capacity-building tools for the Delivering & Serving Hope (DASH) and DASH Dinner Discussions programs, including checklists, planning timelines, training manuals, and informational worksheets.
- Led 3 Alternative Break trips in San Diego, San Francisco, and Catalina Island acting in the risk management and co-facilitator role with over 35 students.
- Led 11 students to attend the *Change the Status Quo* conference at California Polytechnic State University, San Luis Obispo, acting solely in the risk management and co-facilitator role.

RESEARCH EXPERIENCE:

School of Public Health, University of Nevada, Las Vegas, Las Vegas, NV

May 2018 - November 2019

Graduate Research Assistant

- Literature Reviews using PubMed, Academic Search Premier, Google Scholar, ABI/INFORM Collection & Mendeley.
    - The Impact of Perceived Patient-Provider Communication Quality and Perceived Electronic Cigarette Harmfulness: The Role of Race/Ethnicity
    - The Association between Adoption Levels of Electronic Health Records (EHR) and Patient Safety and Quality
- Collaborated with the Principal Investigator, Dr. Soumya Upadhyay on a mixed method study investigating electronic health record presence and

hospital quality outcomes: the role of safety culture in healthcare organizations by recruiting and interviewing participants.

- Edited the following manuscripts:
    - Hospital Staffing Patterns and Safety Culture Perceptions: The Mediating Role of Perceived Teamwork and Perceived handoffs
    - Improving Healthcare Quality in the United States Healthcare System: A Scientific Management Approach
- Appointed as the Teaching Assistant for HCA 300 Management of Health Services Organizations and HCA 703 Management of Health Services Organizations and Systems in Fall Semester 2018.

INTERNSHIPS AND VOLUNTEER EXPERIENCE:

Keck Medical Center of USC, Los Angeles, CA
June 2019 – December 2019
Infection Prevention Intern

- Created and updated educational materials and audit tools, including but not limited to presentations, orientation training, Infection Prevention/Life Safety Measures Checklist, nursing unit audit tool, and ambulatory audit tool.
- Coordinated performance improvement project regarding bed bath compliance among nursing units to decrease CLABSI rate.
- Assisted with surveillance and prevention activities, data collection and analysis, reporting of data concerning hospital-acquired infections as required by regulatory agencies, and education of hospital-wide staff.

Immunize Nevada, Las Vegas, NV
January 2018 - June 2019
Intern | Volunteer

- Created a survey with undergraduate interns to explore the knowledge, attitudes, and beliefs regarding the influenza vaccine among healthcare providers in Southern Nevada Adult Mental Health Services (SNAMHS).
- Disseminated and analyzed survey results through Microsoft Excel, culminating in a report and poster with suggested interventions to increase influenza immunization rates at SNAMHS.
- Assist with outreach events, look up immunization records via Nevada WebIZ, present on topics regarding influenza vaccine project results, vaccines for those living with HIV, HPV and the HPV vaccine.

CONFERENCE PRESENTATIONS:

Tomas, K.A., Thompson-Robinson, M., Upadhyay, S., Gakh, M., Weisman, A., & Cross, C., (2023, November 15) *Examining Health Literacy and Patient-Centered Communication Quality: A Secondary Analysis of U.S. Adults with a History of Cancer* [Conference roundtable session]. American Public Health Association (APHA) 2023 Annual Meeting & Expo, Georgia World Conference Center, Atlanta, GA, United States.

Tomas, K.A., Upadhyay, S., Opoku-Agyeman, W., & Weech-Maldonado, R. (2019, November 5). *Hospital Cultural Competence and Financial Performance* [Oral presentation]. American Public Health Association (APHA) 2019 Annual Meeting & Expo. Philadelphia, PA, United States.

Tomas, K.A., Upadhyay, S., & Opoku-Agyeman, W. (2019, November 4). *The Association between Adoption Levels of Electronic Health Records (EHR) and Patient Safety and Quality* [Poster presentation]. American Public Health Association (APHA) 2019 Annual Meeting & Expo. Philadelphia, PA, United States.

Tomas, K.A., Upadhyay, S. (2019, November 4). *The Impact of Perceived Patient-Provider Communication Quality and Perceived Electronic Cigarette Harmfulness: The Role of Race/Ethnicity* [Poster presentation]. American Public Health Association (APHA) 2019 Annual Meeting & Expo. Philadelphia, PA, United States.

Tomas, K.A., Upadhyay, S., Opoku-Agyeman, W., & Weech-Maldonado, R. (2019, June 3). *Hospital Cultural Competence: Competitive Advantage and Financial Performance* [Poster presentation]. AcademyHealth 2019 Annual Research Meeting, Walter E. Washington Convention Center, Washington D.C., United States.

Tomas, K.A., Upadhyay, S., & Opoku-Agyeman, W. (2019, June 3). *The Association between Adoption Levels of Electronic Health Records (EHR) and Patient Safety and Quality* [Poster presentation]. AcademyHealth 2019 Annual Research Meeting, Walter E. Washington Convention Center, Washington D.C., United States.

Tomas, K.A., Upadhyay, S. (2019, June 3). *The Impact of Perceived Patient-Provider Communication Quality and Perceived Electronic Cigarette Harmfulness: The Role of Race/Ethnicity* [Poster presentation]. AcademyHealth 2019 Annual Research Meeting, Walter E. Washington Convention Center, Washington D.C., United States.

Tomas, K.A., Upadhyay, S., & Weech-Maldonado, R. (2018, November 12). *Staffing, Teamwork, and Handoffs: How are they related to patient safety culture?* [Oral presentation]. American Public Health Association (APHA) 2018 Annual Meeting & Expo. San Diego Convention Center, San Diego, CA, United States.

Tomas, K.A., Upadhyay, S., & Weech-Maldonado, R. (2018, November 13). *Hospital Cultural Competency and Patient Safety Culture* [Poster presentation]. American Public Health Association (APHA) 2018 Annual Meeting & Expo. San Diego Convention Center, San Diego, CA, United States.

Tomas, K.A., Upadhyay, S., & Weech-Maldonado, R. (2018, September 26) *Hospital Cultural Competency and Patient Safety Culture* [Oral presentation]. Nevada Public Health Association Annual Conference. Alexis Park Resort, Las Vegas, NV, United States.

Ayele, S., Raja, M., Medina, S.P., Purkey, K., **Tomas, K.A.**, & Tran, L. (2017, November 19). *Humans of UNLV: Developing Resilience through Digital Connections* [Oral presentation]. BACCHUS Initiatives of NASPA General Assembly, Denver Marriot City Center, Denver, CO, United States.

Tomas, K.A., & Tran, L. (2017, November 16). *What Makes You Thrive? Collaborating with the University as Change Agents for Mental Health* [Oral presentation]. BACCHUS Initiatives of NASPA General Assembly, Denver Marriot City Center, Denver, CO, United States.

INVITED PRESENTATIONS:

Clarke, D., Njoku, C., & **Tomas, K.A.** (2020, October 13). *Public Health Job Opportunities During a Pandemic* [Panel presentation], BSPH Fall Seminar Classes, University of Nevada, Las Vegas.

Tomas, K.A. (2019, April 26). *Interventions to Increase Influenza Vaccination Rates among Healthcare* Personnel [Poster presentation]. UNLV School of Public Health Internship Final Project/Poster Presentation. University of Nevada, Las Vegas.

Daniels, M., Williams, S., **Tomas, K.A.**, & Cruz Lopez, E. (2018, November 29). Girls' Day Camp [Panel presentation], Gaining Early Awareness and Readiness for Undergraduate Programs (GEAR UP), University of Nevada, Las Vegas.

Tomas, K.A. Upadhyay, S., & Weech-Maldonado, R. (2019, September 24). *The Association between Hospital Cultural Competency & Financial Performance* [Oral presentation]. Nevada Public Health Annual Conference, Whitney Peak Hotel, Reno, NV, United States.

Tomas, K.A., Upadhyay, S., & Opoku-Agyeman, W. (2019, September 24). *The Association between Adoption Levels of Electronic Health Records and Quality and Patient Safety* [Poster presentation]. Nevada Public Health Annual Conference, Whitney Peak Hotel, Reno, NV, United States.

Tomas, K.A. & Upadhyay, S. (2019, September 24). *The Impact of Perceived Patient-Provider Communication Quality and Perceived Electronic Cigarette Harmfulness: The Role of Race/Ethnicity* [Poster presentation]. Nevada Public Health Annual Conference, Whitney Peak Hotel, Reno, NV, United States.

PUBLICATIONS:

Tomas, K.A., Thompson-Robinson, M., Upadhyay, S., Gakh, M., Weisman, A., & Cross, C., (2023). *Examining Health Literacy and Patient-Centered Communication Quality: A Secondary Analysis of U.S. Adults with a History of Cancer* (Manuscript in preparation). School of Public Health. University of Nevada, Las Vegas.

Tomas, K.A. (2021, March 16). Potential Control Measures of SARS-CoV-2 Transmission in the Healthcare Environment. *Steven Hirsch & Associates Accreditation News, 13,* 1, 3-4.

Tomas, K.A. (2020, December 18). Common CMS Infection Control-Focused Survey Findings. *Steven Hirsch & Associates Accreditation News, 12,* 4, 3-4.

Tomas, K.A. & Woodard, D. (2020, September 3). CMS Revises Infection Control "Conditions of Participation." *Steven Hirsch & Associates Accreditation News, 12,* 3, 1-2.

Tomas, K.A. (2020, June 5). Principles of Adult Education for Infection Control Professionals. *Steven Hirsch & Associates Accreditation News, 12*, 2, 3.

SOFTWARE LITERACY:

- Productivity Tools: Microsoft Office Suite | Google Workplace
- Statistical Software Tools: STATA | SPSS

- Electronic Health Record Systems: Aura | BESTCare | Cerner
- Clinical Surveillance Software: TheraDoc

SCHOLARSHIPS, HONORS, & AWARDS:

2023	Awarded the UNLV Graduate Professional & Student Association (GPSA) Research, Travel, & Professional Development Sponsorship for APHA
2021	Invited to join Phi Kappa Phi Honors Society
2019	Inducted into Delta Omega Public Health Honor Society
2019	Awarded the UNLV Graduate Professional & Student Association (GPSA) Research, Travel, & Professional Development Sponsorship for AcademyHealth & APHA
2019	Awarded the UNLV School of Public Health Student Travel Award for APHA
2018	Awarded the UNLV Graduate Professional & Student Association (GPSA) Research, Travel, & Professional Development Sponsorship for APHA
2018	Awarded the UNLV School of Public Health Student Travel Award for APHA & NPHA
2018	Awarded full travel and lodging scholarship to Population Action Fund's *Capitol Hill Days* Reproductive Rights Lobbying Conference in Washington, D.C.
2018	Awarded Chi Delta Theta Beta Chapter Alumni of the Year
2017	Awarded the Outstanding Program Award for Humans of UNLV at the BACCHUS General Assembly in Denver, CO
2015	California Polytechnic State University, San Luis Obispo Dean's List
2012	College of the Canyons President's List
2008	Awarded Simi Valley Education Foundation Scholarship
2008	Awarded Coldwell Banker Scholarship
2008	Awarded Royal High School Brigade High Woodwind Award

PROFESSIONAL ASSOCIATIONS AND MEMBERSHIPS:

American Public Health Association (APHA), 2018 – present
Los Angeles Mycological Society (LAMS), 2022 – present
Chi Delta Theta Alumni Association, 2015 – present
Chi Delta Theta Sorority, Inc., 2009 – present
Asian Pacific American Labor Alliance, AFL-CIO, 2021 – 2022
Association for Professionals in Infection Control & Epidemiology (APIC), 2019 – 2022
AcademyHealth, 2019 – 2020
Nevada Public Health Association, 2018 – 2020