

Health Literacy Surrounding Anal Cancer Among Women and the Need for Policy

Changes in Preventive Health Screenings

by

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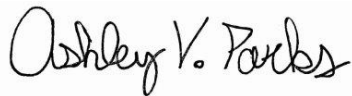
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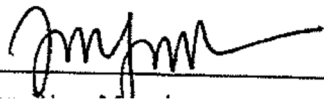
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## Abstract

When examining health literacy across ethnicities and communities, ethnic minority groups are known to be at a higher risk of being below the average health literacy threshold, and limited health literacy has been linked to poor health status and higher mortality rates (Giurca et al., 2018). This study examined health literacy surrounding anal cancer and HPV related preventative health screening behaviors. More specifically, the aim of the study was to bring awareness to low levels of anal cancer related health literacy for women and the need for policy changes regarding preventive health screenings.

The following research questions were explored: (1) What are the common themes and/or beliefs when asked about anal cancer, HPV, and preventive screening? and (2) What are the common themes and beliefs surrounding the severity and susceptibility of contracting anal cancer?. This study utilized a cross-sectional design to survey 26 individuals regarding their knowledge level and perspectives regarding anal cancer and HPV related severity and susceptibility. The student researcher developed and administered an 8-question survey de novo. The survey included open-ended questions constructed based on an application of the Health Belief Model (HBM) elements of perceived susceptibility and perceived severity to anal cancer health literacy.

This study employed thematic analysis and grounded theory to explore critical themes and construct a model to explain health literacy regarding anal cancer and intention to participate in preventive screenings. The fundamental attitudes and themes about health literacy related to anal cancer and the intention to participate in preventative

screenings were elicited using a qualitative descriptive technique. The student researcher utilized the coded data to create open categories, axial codes, and finally selective codes based on higher level themes based on (1) knowledge and (2) perceived risk, both severity and susceptibility. A model for classifying responses, including knowledge levels and perceived severity and perceived susceptibility was created. While the axial and selective codes were created by grouping the themes discovered through open coding, application of the core constructs of the health belief model informed the creation of the groups into the evidence based selective code categories of risk and knowledge. The results from this study may be used to inform practitioners, providers, and policymakers in developing interventions addressing low health literacy rates surrounding anal cancer in support of creating a standardized health screening procedure.

*Key Words: health literacy, anal cancer, human papilloma virus, HPV, cancer screening*

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## Introduction

### Overview

#### *Health Literacy*

Across ethnic groups and communities, inequities in health have been attributed to low health literacy rates. When examining health literacy across ethnicities and communities, ethnic minority groups are at a higher risk of being below the average health literacy threshold, and limited health literacy has been linked to poor health status and higher mortality rates (Giurca et al., 2018). However, evidence-based approaches to improving health literacy through patient education can generate systematic changes via community organization and engagement with healthcare providers (Simmons et al., 2017). It is vital to ensure that healthcare providers are equipped with adequate education, training, and materials for patients throughout the community they serve. The National Institutes of Health (NIH) and the American Medical Association (AMA) propose that patient information be prepared at the sixth and eighth-grade levels, respectively (Weis, 2003).

The definition of health literacy is complex and fluid. The complexities of defining health literacy stem from varying cultural values, beliefs, economic systems, and environmental factors. Three types of health literacy impact individuals' health outcomes: functional health literacy, interactive health literacy, and critical health literacy—each dimension of health literacy aid in understanding the varying health outcomes across communities. Functional health literacy reflects basic reading and writing abilities (Giurca et al., 2018). Interactive health literacy pertains to any skill required to extract and derive meaning from various health information sources, along with the capability to apply it to real-life situations (Giurca et al., 2018). At the same time, critical health literacy refers to a collection of cognitive and social abilities that

enable people to evaluate and determine the applicability of health information to personal circumstances (Giurca et al., 2018). Each dimension of health literacy is equally important, but each is not alone quantifiable. Yet, researchers in the health care setting have defined health literacy as the capacity individuals have to obtain, process, and understand the basic health information and services needed to make appropriate decisions about their health (Simmons et al., 2017).

Low literacy has been highlighted as a national policy issue threatening our economic, social, and defense competitiveness (Berkman et al., 2010). The importance of health literacy in health communication cannot be overstated. With a wide range of definitions, all of which reflect the complexities of what it means to be health literate, and the field of health literacy is growing rapidly and demands more interdisciplinary audiences to recognize the multifaceted structure that comes with health literacy rates.

### ***Cancer***

Cancer is the leading cause of mortality globally, with approximately 10 million fatalities expected in 2020, accounting for roughly one in every six deaths (World Health Organization, 2022). In low- and middle-income nations, cancer-causing diseases, such as the human papillomavirus (HPV), account for around 30% of cancer cases, with breast, lung, colon, rectum, and prostate cancers being the most frequent malignancies (World Health Organization, 2022). The risk factors for cancer are abundant, yet there is an elevated risk among low and middle-income nations. Some chronic infections are increased cancer risk factors in these areas: Infections such as, *Helicobacter pylori*, human papillomavirus (HPV), hepatitis B virus, hepatitis C virus, and Epstein-Barr virus were responsible for almost 13% of malignancies reported globally in 2018 (World Health Organization, 2022). However, many cancers can be cured if

caught early and appropriately treated. There are varying cancer disparities, which affect all demographic groups in the United States. Particular groups endure a disproportionate burden of cancer relative to others owing to social, environmental, and economic disadvantages.

Cancer disparities result from multiple variables interacting. Social determinants of health, behavior, biology, and genetics all of which can have a substantial influence on cancer risks and outcomes. The National Cancer Institute (NCI) defines cancer health disparities as differences in the incidence, prevalence, mortality, and burden of cancer and related unfavorable health outcomes among demographic groups in the United States (Wallace et al., 2011). The worldwide cancer pattern is not static. Instead, it is dynamic due to changes in population age distribution, advancements in cancer prevention and early diagnosis in wealthier nations, as well as changes in food and lifestyle in some regions of the world. (Wallace et al., 2011).

There is increasing evidence that adults with lower health literacy are less likely to use preventive health services such as cancer screenings, thus having higher mortalities (Morris et al., 2013). Cancer beliefs, information-seeking habits, and perceived control over cancer risks are all linked to low levels of health literacy (Fleary et al., 2018). There is a high correlation between health literacy and education (Kobayashi and Smith, 2016). Thus, it is vital to understand that low health literacy is a social determinant of health significantly associated with cancer-related disparities (Simmons et al., 2017).

### **Anal Cancer.**

Anal cancer is a condition in which the tissues of the anus develop malignant (cancer) cells (National Cancer Institute, 2022). The human papillomavirus (HPV) frequently causes this form of anal cancer. The incidence of anal cancer in the U.S. increases in men and women (American Cancer Society, 2022). According to the National Cancer Institute, anal cancer affects

roughly 8,590 persons in the United States annually (2022), and squamous cells make up about 80% of anal malignancies in the United States. Compared to cancers of the colon or rectum, anal cancer is relatively uncommon; However, anal cancer is rare; the American Cancer Society estimates anal cancer in the U.S in 2022 will be about 9,440 new cases (2022). At the same time, domestic cases of anal cancer for women are 4,909 per year, while cases of anal cancer annually for men are 2,379 (Center for Disease Control and Prevention, 2022).

### ***HPV***

The primary risk factor for anal cancer is human papillomavirus (HPV) infection. Most squamous cell anal tumors are associated with HPV infection. HPV is a collection of more than 150 related viruses that cause cervical cancer and other types of cancer.

HPV has been classified by the International Agency for Research on Cancer as a human carcinogen for several cancer types, including cervical and anal cancer (Grulich et al., 2012). Women who have had cervical cancer (or pre-cancer) have a higher chance of developing anal cancer. More specifically, the incidence of anal cancer in the U.S. increases in both men and women (American Cancer Society, 2022). Although anal cancer is rare, the American Cancer Society estimates anal cancer in the U.S. in 2022 will be about 9,440 new cases (2022).

Increasing evidence indicates that oncogenic strains of HPV, subtypes explicitly HPV-16 and HPV-18, cause anal cancer (Nelson & Benson III, 2016). Annually, there are an estimated 27,000 new cases of anal cancer worldwide, with a ratio of female to male as high as 5:1 (Krzowska-Firych et al., 2018). Anal cancer has numerous similarities to cervical cancers regarding risk factors and HPV infection. Thus, the need for increased awareness of screening for anal cancer precursors is high.

### ***Preventative Screening***

Preventative screening tests can aid in detecting cancer in its early stages before symptoms occur. If discovered early, it may be easier to treat or cure aberrant tissue or cancer. If cancer has grown or spread by the time symptoms have occurred, it can make it more difficult to treat or cure. If anomalies are discovered during screening, more tests should be performed by the individual's primary clinician to obtain a precise diagnosis and a referral for cancer treatment (World Health Organization, 2022).

Between 30 and 50 percent of malignancies can be avoided by avoiding risk factors and using evidence-based preventative measures (World Health Organization, 2022). Early identification of cancer and adequate treatment and care for people who have cancer can help lower the cancer burden. Many cancers have an improving probability of being cured if caught early and treated adequately. Accessible preventive health services such as vaccines and screenings specifically for HPV are vital in ensuring patients can prevent diseases such as anal cancer. Although there is a vaccine to prevent HPV, the vaccine was only recently introduced in 2006 (Center for Disease Control and Prevention, 2022). Thus, leaving older individuals still at risk of developing some form of HPV and HPV-related cancer.

There are preventive measures in place for various types of cancers. There are screening recommendations for cervical cancer; there are no official national screening recommendations for anal squamous cell carcinoma (SCC) (McGovern et al., 2021). With the prevalence rate of cervical cancer at 50 cases per 100,000 before the cytologic screening, guidelines for preventative screening for women was implemented and it is currently 7 cases per 100,000 women after screening began (Mittra and Crane, 2011). Yet, with domestic cases of anal cancer in women rising more than in men, according to the American Cancer Society, anal cancer

screening tests are not usually suggested for everyone. Nonetheless, some specialists advise anal cytology testing for patients at a higher risk of anal cancer (2022).

Anal cancer used to be deadly, but because of advancements in treatment, it is now growing increasingly treatable (Charow et al., 2019). Patients, relatives, and caregivers have substantial information demands that may be satisfied by consumer health information and training from healthcare professionals, whether they have been diagnosed with a curable or incurable cancer (Charow et al., 2019). Yet, currently available evidence indicates that knowledge of anal cancer and its dangers is not widely disseminated (Wheldon et al., 2021). In more recent population-based research of people in the U.S., awareness of anal cancer was found to be generally poor and to have remained so from 2014 to 2017 (Wheldon et al., 2019). These studies' generalizability is uncertain given their dependence on convenience samples drawn without regard to probability. Thus, the creation and effectiveness of specialized health education initiatives aimed at anal cancer require more investigation.

### **Purpose of the Study**

This study examines the impact of health literacy among women surrounding preventative health screening behaviors. More specifically, the aim is to bring awareness to the need for policy changes in preventive health screenings. The results from this study will be used to aid practitioners, providers, and policymakers in developing interventions addressing low health literacy rates surrounding anal cancer in support of creating a standardized health screening procedure. In doing so, health inequities in preventative healthcare will debunk the stigma surrounding anal cancer, health literacy, and social inequities. The overall purpose of this study was to explore common themes and beliefs surrounding anal cancer, preventative screening, and HPV through qualitative methods. Specifically, this study employed thematic



analysis and grounded theory to explore critical themes and construct a model to explain women's health literacy regarding anal cancer and intention to participate in preventive screenings.

### **Research Questions & Hypotheses**

The research questions explored in this study include:

- (1) What are the common themes and beliefs when asked about anal cancer, HPV, and preventive screening?
- (2) What are the common themes and beliefs surrounding the severity and susceptibility of contracting anal cancer?

Low health literacy is hypothesized as the primary barrier to women not understanding the linkage between HPV and anal cancer, thus not acting towards preventative health screenings.

### **Method**

A qualitative descriptive technique elicited the fundamental attitudes and themes about women's health literacy related to anal cancer and the intention to participate in preventative screenings. The following research questions were explored, (1) What are the common themes and beliefs when asked about anal cancer, HPV, and preventive screening? (2) What are the common themes and beliefs surrounding the severity and susceptibility of contracting anal cancer?

### **Design**

To aid in the exploratory processes of examining common themes and elements surrounding anal cancer, preventative screening, and HPV, this study used a cross-sectional design to survey people about their knowledge level and perspectives regarding anal cancer and

HPV severity and susceptibility. The student researcher developed and administered an 8-question survey de novo (see Appendix A). The survey included three questions regarding demographics (age, gender, and ethnicity) and five open-ended questions constructed based on applying the Health Belief Model (HBM) elements of perceived susceptibility and severity to anal cancer health literacy. The HBM encompasses various components theorized to explain why people participate in preventive medicine, screening, and management. Perceived susceptibility and severity of a medical condition are referred to as "perceived threat" combined. Additionally, environmental cues cause behavior and affect personal beliefs, such as perceived advantages and vulnerability. In contrast, self-Efficacy affects perceived danger (perceived susceptibility and severity) and perceived rewards versus perceived barriers, which supports the start of a health behavior change.

### **Participants and Procedures**

The intended population for this study was adults ages 18-99 (male and female) at an underserved family practice clinic in Southern California. Participants were recruited from a predominantly underserved community in Riverside County and primarily included participants insured through managed Medi-Cal benefits offered by Inland Empire Health Plan (IHEP). Participants were asked to participate in a non-identifiable survey via pen and paper and complete it in the clinic office. In total, the study obtained a sample of 26 participants. The inclusion criteria for this study included all adult patients over the age of 18, including both adult men and women, and all age categories. Exclusion criteria include participants who do not meet the proper age requirement, including those who are minors. The participants were given an informed consent form outlining the risks and benefits of the study, study procedures, confidentiality, and voluntary participation before being given the survey.

## **Data Analysis**

### ***Review and Coding of Survey Responses***

Initially, all survey responses were transcribed exactly as written to understand the meaning, mood, context, and intent of the survey responses. Transcribed responses were uploaded and coded in MAXQDA software. Specifically, manual open coding methods were utilized to code all question responses in the MAXQDA qualitative analysis software. Following the initial open coding process, codes were grouped further into axial and selective codes using the principles of thematic analysis and grounded theory.

Survey questions 4, 6, and 7 were primarily utilized to assess levels of participant knowledge regarding anal cancer, HPV, and preventive screening; however, responses were also coded according to levels of perceived severity and susceptibility if this information was provided by respondents. Specifically, responses to survey question 4, which asks, "*What do you think about when you hear the phrase 'anal cancer'?*" were coded according to whether the respondent illustrated no, some, or high levels of anal cancer knowledge. Responses to knowledge questions were also coded based on any statements that indicate low, medium, or high levels of perceived susceptibility or severity. An "unsure of susceptibility" code was also incorporated for those responses that indicated a lack of understanding regarding perceived susceptibility. Responses to survey question 6: "*What do you know about HPV?*" were coded according to whether the respondent illustrated no, some, or high levels of HPV-related knowledge. Responses to survey question 7: "*To the best of your knowledge, explain preventive cancer screening?*" were coded according to low, some, or high levels of screening knowledge.

Survey questions 5 and 8 were created to assess the anal cancer-related perceived susceptibility of participants; however, responses to these questions and the knowledge-related

questions above also provided information regarding perceived severity levels. Survey questions 5: "What do you think is your level of risk to get anal cancer?" and 8: "Do you believe you are vulnerable to contracting anal cancer?" were coded according to unsure, low, some, or high levels of perceived susceptibility. In the case where participants commented on the severity of the condition, results were also coded based on perceived severity.

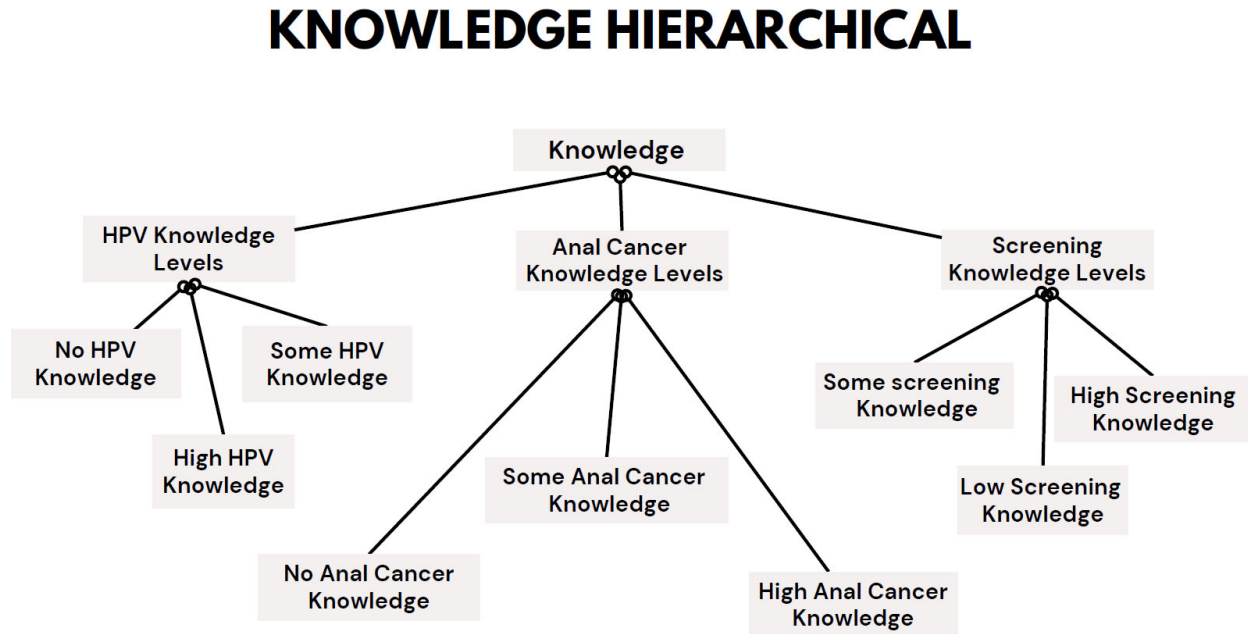
The student researcher reviewed the coding with a secondary researcher and advisor to capture accurate results and reduce the likelihood of researcher bias impacting the coded data. The researchers each worked to identify common themes in responses across surveys using inductive content analysis. The data was then reviewed to determine agreement on the main themes.

### ***Model Building***

The student researcher utilized the coded data to create open categories, axial codes, and finally, selective codes based on higher-level themes based on (1) knowledge and (2) perceived risk, both severity and susceptibility. Hierarchical models for classifying responses, including knowledge levels and perceived severity, and perceived susceptibility, were created, as shown in Figures 1 and 2 below. While the axial and selective codes were created by grouping the themes discovered through open coding, the application of the core constructs of the health belief model informed the creation of the groups into the evidence-based selective code categories of risk and knowledge.

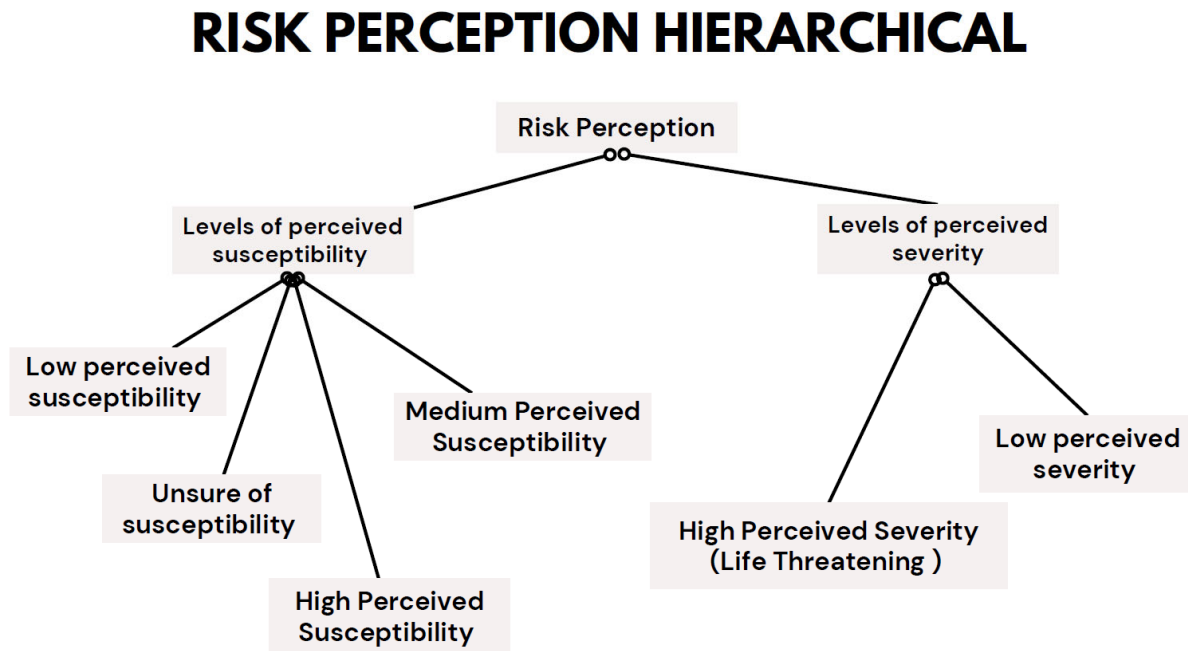
**Figure 1**

*Model of Codes Utilized to Categorize Respondent Knowledge Levels*



**Figure 2**

*Model of Codes Utilized to Categorize Respondent Risk Perception*



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## Results

### Participant Demographics

The survey included 26 adult participants, all of whom were recruited from a predominantly underserved clinic in Riverside County. Of the participants, 18 (69.2%) identified as female, and 8 (30.8%) identified as men. Of the same population, 2 (7.69%) identified as African American, 11 (42.31%) identified as Hispanic, 6 (23.08%) identified as Caucasian, and 6 (23.08%) identified as Asian, and 1 (3.85%) identified as Native American. Of the same sample, the number of participants whose ages ranged from 18-29 was 7 (26.92%), the number of participants whose ages ranged from 30-39 was 5 (19.23%), and the number of participants whose ages ranged from 40-59 was 9 (34.62%), and the number of participants whose ages range from 60+ was 5 (19.23%) (see Table 1).

**Table #: 1**  
*Demographic Details for Survey Participants (n=26)*

		<i>N</i>	<i>%</i>
<b>Gender</b>			
	Male	8	30.8
	Female	18	69.2
<b>Ethnicity</b>			
	African American	2	7.69
	Hispanic	11	42.31
	Caucasian	6	23.08
	Asian	6	23.08
	Native American	1	3.85
<b>Age Ranges</b>			
	18-29	7	26.92
	30-39	5	19.23
	40-59	9	34.62
	60 +	5	19.23

*Note.* N= sample size, %= percentage.

## Major Findings

Manual open coding techniques in the MAXQDA qualitative analysis program were utilized to code every response to a question. By using the concepts of theme analysis and grounded theory, codes were further categorized into axial and selected codes after the first open coding procedure. The analysis revealed several findings when asked open-ended questions related to severity, susceptibility, and knowledge.

### *Themes Identified Regarding Anal Cancer, HPV, and Preventive Screening Knowledge*

Several findings were revealed when investigating research question 1: "*What are the common themes and/or beliefs when asked about anal cancer, HPV, and preventive screening?*" The findings revealed that the participants shared common beliefs when questions about anal cancer, HPV, and preventative screening were presented (see Table 3). Some of the participants shared the same common ideas and conceptions when asked about anal cancer. One participant's response to the question, "what do you think about when you hear the phrase 'anal cancer'?" was "*cancer in or around the anal*" (Female, 33). Participants were also asked, "what do you know about HPV?" to which many participants shared similar responses. In contrast, only one participant (Female, 42) out of the 26 had a thorough understanding of HPV, including its prevention via vaccination and its link to cervical cancer. Only four people demonstrated a high degree of screening knowledge, and one of them replied, "FOBT, or fecal occult blood test," (Female, 35) when asked, "*to the best of your four knowledge, describe preventive cancer screening.*"

When examining female responses against male participants, only 6% of the female responses were coded as having high HPV knowledge. In contrast, none of the male responses could be coded as having a high level of HPV knowledge. When coding for screening

knowledge, half of the females (50%) responses could be coded as having a low level of screening knowledge. On the other hand, when coding for levels of anal cancer knowledge, specifically for some anal cancer knowledge, men (50%) had remarkably more knowledge than women (22%). Overall, the significant findings indicate very low levels of anal cancer health literacy—13 coded segments (13 surveys- 50%) show no familiarity with or comprehension of HPV, and four coded segments indicate no familiarity with anal cancer. In addition, 15 respondents (57%) had low or no preventive or screening-related knowledge.

### ***Themes Identified Regarding Perceived Severity and Susceptibility***

Several findings were revealed when investigating research question 2: "*What are the common themes and beliefs surrounding severity and susceptibility of contracting anal cancer?*". The findings revealed that participants showcased similar beliefs around the severity and susceptibility of contracting anal cancer, which was coded as risk perception. Participants' perceptions of their vulnerability to anal cancer were measured specifically by survey questions 5 and 8. However, the researcher classified any replies to all survey items that indicated a level of susceptibility or severity (low, medium, or high). Responses to these and the knowledge-related questions above also revealed how severe respondents believed the disease to be. Survey questions 5: "*What do you think is your level of risk of getting anal cancer?*" and 8: "*Do you believe you are vulnerable to contracting anal cancer?*" along with any responses to other questions indicating a degree of susceptibility were categorized as unsure, low, some, or high levels of perceived susceptibility. The results were also classified according to the condition's perceived severity when participants commented on its seriousness.

A larger portion of participants (46%) responded with comments that indicated high perceived severity. While there were half as many respondents indicating high levels of



perceived susceptibility (23%), the total female responses coded were 27%.; however, when analyzing female versus male respondents for perceived severity, over half of the responses that were coded for having high perceived severity (61%) were from female participants. Remarkably, the same percentage of women believed they had a low level of susceptibility. In total, 15 out of 26 (58%) surveys contained coded segments indicating low perceived susceptibility, and 6 out of 26 (23%) contained coded segments indicating high levels of perceived susceptibility. On the other hand, 12 surveys (46%) contained coded segments indicating high perceived severity. Only one respondent included a response that indicated a low level of perceived severity which stands in stark comparison to the 15 respondents who indicated lower levels of perceived susceptibility.

While a large portion of participants indicated high perceived susceptibility when asked, "*What do you think is your level of risk of getting anal cancer?*" and "*Do you believe you are vulnerable to contracting anal cancer?*" comments such as "dangerous cancer," indicating high perceived severity, was paired with "not high, for it does not run in my family," indicating low perceived susceptibility (Female, 34). Another example of this dissonance was found in another survey, in which the participant stated "terminal," indicating high perceived severity and "not that likely (hopefully [smiley face])" when asked about personal risk (Female, 47).

When asked, "*What do you believe is your degree of risk to have anal cancer?*" some individuals gave comments that suggested they were unclear about their perceived susceptibility. Responses included comments such as "I don't know enough to make a guess" (Male, 23), "I have no idea" (Male, 24), and "no idea" (Female, 85). Additionally, according to the individual survey coding, low levels of perceived susceptibility are associated with a lower level of awareness, as shown by the statement, "Since I never hear about it, I would consider my risk

level is quite low" (Male, 24). In short, a large portion of respondents believed anal cancer was life-threatening, but only a smaller portion believed they themselves could be impacted. A sampling of quotes from survey respondents has been provided in Appendix A: Table 2 to further illustrate the low levels of knowledge and perceived susceptibility.

## Discussion

### Summary of Major Findings

The coding of the responses from participants was based on the Health Belief Model's (HBM) application of the perceived susceptibility and severity components to anal cancer health literacy. The analysis revealed several findings when asking open-ended questions related to severity, susceptibility, and knowledge. Some of the participants shared the same common ideas and conceptions when responding to questions on anal cancer, HPV, and preventive screening knowledge. At the same time, alternatively, the findings regarding perceived severity and susceptibility revealed that participants responded similarly to questions that indicated high levels of severity. While the responses to the questions indicated levels of susceptibility showcased, those participants felt they had low levels of contracting anal cancer. These findings highlight the HBM's constructs of perceived severity and susceptibility, which define perceived severity as an individual's ideas on the seriousness of contracting an illness or disease. In contrast, perceived susceptibility is referred to an individual's subjective perception of the risk of acquiring an illness or disease.

According to the HBM, people who perceive high susceptibility and severity would be more inclined to act in the direction of avoiding the disease as long as the health advantages outweigh the barriers and they feel they have the capacity to participate in the activity (Luquis and Kensinger, 2019). There has been conflicting and ambiguous research on the effect of the notions of perceived susceptibility and perceived severity. The notion of perceived seriousness was the focus of earlier studies, but it had no meaningful impact on self-care measures (Luquis and Kensinger, 2019). In general, many people's perceptions of their own susceptibility are underestimated, even though some research suggests that beliefs about perceived susceptibility

are predictive of engaging in health-promoting behaviors like healthy eating and exercise, quitting smoking, self-examinations, and dental care (Abraham and Sheeran 2011).

Overall, low levels of knowledge were demonstrated in the survey questions, which were in line with low levels of susceptibility; however, high levels of severity were shown in the coded replies. In summary, a considerable proportion of respondents, especially the female respondents, believed anal cancer was fatal. The contradiction around anal cancer, HPV, and preventative screening knowledge is illustrated by the fact that a lesser percentage of people thought they might personally be affected.

### **Public Health Implications**

The low levels of perceived susceptibility highlighted in this study should inform efforts to create patient education materials and inform policy change to increase patient understanding of their own personal risk. The findings in this study are impactful to help address the importance of health literacy concerning preventative health behaviors such as health screenings, vaccinations, and lifestyle choices. Yet, when addressing health literacy, which includes both health promotion and disease prevention activities, it is essential to note that health literacy is a crucial component of a woman's capacity to comprehend, interpret, and act on health-related information. Poor health literacy influences women, their offspring, and their households.

With the appropriate allocation of adequate resources for both patients and clinicians, health literacy rates can be improved. Ensuring that healthcare providers are provided adequate education, training, and materials for patients throughout all communities. Collaborating with policy writers, healthcare professionals, community-based organizations, and professional organizations such as the American Medical Association (AMA) and National Institute of Health

(NIH) to develop policies and provide funding for new initiatives that promote access to and capability of health resources.

For example, according to the National Academies of Science, Engineering, and Medicine (2019), there is a grassroots alliance called the Oklahoma Health Equity Campaign that was established in 2008 and increased its focus on health literacy in 2011. Its goal is to address the reality that Oklahoma routinely ranks last in national health rankings. Additionally, the Health Care Institute (HCI) provides health education and prevention programs that draw 80% of families to outreach activities and provide culturally sensitive materials that family members can understand and use to take action to improve their families' health, the Health Care Institute's mission is to strengthen the managerial capacity of Head Start agencies (National Academies of Science, Engineering, and Medicine, 2019). The program promotes parental knowledge of health warning signals, encourages parental reaction to early indicators of sickness, and directs parents to the right use of health reference resources for first-line assistance, according to qualitative assessments of results for families and staff (National Academies of Science, Engineering, and Medicine, 2019).

Future research should investigate preventive screening intentions and self-efficacy as well. Any strategy for tackling health literacy must increase service accessibility, create and strengthen efficient programs and policies, and promote the efficiency of the healthcare system (Corrarino, 2013). By bringing together, a variety of stakeholders who can each provide a skill set that can help to increase the integration of health literacy into healthcare, healthcare professionals may be proactive in creating partnerships to solve this issue. In doing so, improvement of health literacy will lead to greater self-efficacy and potentially lower perceived susceptibility paired with high

levels of perceived severity, which according to the HBM, are the best predictors of actions that promote health.

### **Study Limitations**

One of the limitations that came along with the study includes self-report bias. Self-reporting bias is a methodological challenge that occurs when researchers rely on interviewing participants about their ideas, feelings, or behaviors rather than directly and objectively quantifying these. Concerning the study, self-reporting bias occurs due to the qualitative nature of the study. In addition, social desirability bias is the inclination or tendency for people to display themselves in ways that other people will find favorable and is also noted as a limitation within the study because the survey analyzed in the study involves self-reporting questions and the study was executed in an environment that was not a natural setting.

The limited sample size was also a limitation of the study. This is important because the power of the investigation is decreased, and the margin of error is raised with a small sample size. However, due to the nature of the study, sample sizes are typical in qualitative research to facilitate the in-depth case-oriented analysis that is central to this type of inquiry (Vasileiou et al., 2018). Limitations also come along with the framework of the HBM. The HBM brings limitations because it does not offer a plan for altering activities relating to one's health and is more descriptive than explicative. Early research on preventive health practices revealed that perceived susceptibility, advantages, and obstacles were regularly linked to the desired health activity, although perceived severity was less frequently connected. Depending on the health result of interest, each individual construct is essential; however, for the model to be used most effectively, it should be combined with other models that take the environmental context into consideration and offer change-management techniques.

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## Appendix A: Themes and Coded Extracts

Table 2. Themes that emerged related to anal cancer and HPV related knowledge and risk perceptions

Theme - Selective Code	Axial Code - Category	Selective Code - Sub Category	Extracts - Coded Segments from Surveys
<b>Risk Perception</b>	Levels of Perceived Susceptibility	High Perceived Susceptibility	Yes, i have polyps and therefore am high risk Female, 40
			anybody can get it, probably for any reason could be your intestines become bad, maybe secreting poison out your hole, things you've eaten, places you've been, toxins you've been around. it can happen to anyone Female, 68
			Yes Male, 45
		Medium Perceived Susceptibility	i think so, didn't know about it until now, but considering I do have an anus, I'm sure I'm just as susceptible as anyone Female, 24
			moderate, im a current smoker and can be prone to any cancer Female, 33
			medium- it was always a risk Male, 63
		Low Perceived Susceptibility	zero percent Female, 75
			i do not perform anal sex, so containing HPV is unlikely this way Male, 40
			not that likely (: Female, 47
			Unsure of Susceptibility
		honestly, no idea. maybe low Female, 27	
		i dont know enough to make a guess Male, 18	
	Levels of Perceived Severity	Low Perceived Severity	i guess i think its pretty self explanatory, i also think of how ive never really heard anyone talk about it Male, 24
		High Perceived Severity - Life threatening	life-threatening Female, 40
			i have a fear. believe it or not, i fear your a-hole falling out Female, 75
			dangerous cancer Female, 34
			terminal Female, 47

<b>Knowledge</b>	HPV Knowledge Levels	High HPV Knowledge	HPV causes cervical cancer and can be prevented thru vaccinations given in teenage years Female, 42
		Some HPV Knowledge	virus that causes cancer and herpes Female, 40 Happopavarillian virus? something in that nature? a virus? Female, 40 very common STI that can cause warts and cervical cancer Female, 33
		No HPV Related Knowledge	what is HPV? Female, 75 dont know anything about it Female, 85 not very much at all Male, 22
	Anal Cancer Knowledge Levels	High Anal Cancer Knowledge	neoplastic changes in the tissue of the anus, the terminal sphincter of the GI tract, the basement membrane of the epithelium is invaded Male, 40
		Some anal cancer knowledge	cancer in or around the anal Female, 33 i think about someone suffering with cancer Female, 27 tumors around the butt Male, 18
		No Anal Cancer Related Knowledge	i never realized that anal cancer existed Female, 34
	Screening Knowledge Levels	High Screening Knowledge	ive never heard of it phrase as anal cancer, reading it i think what treatment is there for it Female, 46
			pap smears, mammograms, colonoscopy, and exams to check for cancer Female 34 FOBT Female, 35 preventative cancer screenings are performed according to age and can be requested if cancer runs in family members Female, 42
		Some Screening Knowledge	Goes over your family history and risk assessment to get necessary testing done Female, 40 asking questions about sexual activities and other questions regarding family medical history Male, 22
Low Screening Knowledge	it is to screen your body for any possible abnormalities that could lead to cancer and catch to prevent Female, 34 no clue Female, 85		