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Understanding community-based HIV/AIDS service organizations: an invaluable source of HPV-related cancer information for at-risk populations

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Abstract

Objective: To describe non-clinical HIV service providers (NCHSPs) as surrogate seekers and health information mavens for people living with HIV (PLWH), men who have sex with men (MSM), and other vulnerable populations.

Methods: In May/June 2016, we recruited 30 NCHSPs from three community-based HIV/AIDS service organizations. NCHSPs completed a 118-item self-administered, paper-and-pencil survey about HPV, cancer, and health communication. Data were analyzed using Stata/SE 14.1.

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All authors have contributed substantially to the conception, design, analysis, and/or interpretation of the data in this manuscript. LTW - conceived the study, developed and pretested the survey, conducted data collection, performed the data analyses, and led the manuscript writing team.

DBF - provided behavioral science and health communication expertise during the survey development process and contributed to the interpretation of the data.

All of the other co-authors, which included academic researchers and community partners, contributed to the interpretation of the data in this manuscript. Additionally, community partners facilitated Dr. Wigfall's access to their staff for data collection.

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Results: Almost all (97%) NCHSPs were surrogate seekers and had looked for HIV/AIDS (97%), STD (97%), and cancer (93%) information. Most (60%) cancer information seekers had looked for information about HPV. The Internet (97%) and healthcare providers (97%) were health information sources almost all NCHSPs trusted. Nearly all NCHSPs (93%) were completely or very confident about their ability to find health information. The mean health information mavenism score (17.4 ± 2.1) was significantly higher than the scale's high-score cutoff (15.0) ($p < 0.001$).

Conclusions: NCHSPs look for and share health information with the vulnerable populations (e.g., PLWH, MSM) they serve. More research is needed to understand what NCHSPs' know and think about the health information they are sharing with vulnerable populations.

Keywords

human papillomavirus or human papilloma virus or HPV; men who have sex with men (MSM); people living with HIV (PLWH); information seeking; health communication

Introduction

HPV-Related Cancer Health Disparities

Human papillomavirus (HPV) is the main cause of some types of anogenital and oropharyngeal cancers. More than half of the cases of anal, cervical, oropharyngeal, penile, vaginal, and vulvar cancers diagnosed in 2012 – 2016 were attributed to HPV infection (Senkomago et al 2019). At-risk populations such as people living with HIV (PLWH) and men who have sex with men (MSM) are disproportionately affected by HPV-related cancers (Hernández-Ramírez et al 2017, Wang et al 2014, Latini et al 2014). The importance of these HPV-related cancer disparities are underscored by the fact that the Advisory Committee on Immunization Practices (ACIP) previously recommended HPV vaccination for PLWH ages through 26 years (Petrosky et al 2015). It is important to note ACIP's previous recommendation for HPV vaccination among PLWH despite the fact that these individuals have a compromised immune system and are likely sexually experienced (Petrosky et al 2015). Similarly, ACIP's previous HPV vaccination recommendation for males was ages through 21 years for heterosexual males, but was expanded 22–26 years for gay or bisexual males (Petrosky et al 2015). Although ACIP's most recent position on the Food and Drug Administration's (FDA) approval of the HPV vaccine for adults 27–45 years strongly encourages patient-provider communication, the emphasis on the importance of HPV vaccine coverage among at-risk populations (i.e., PLWH, MSM) remains clear (Meites et al 2019).

Community-based HIV/AIDS Service Organizations

Community-based HIV/AIDS service organizations (ASOs) provide various types of services to their clients, which include at-risk populations such as PLWH and MSM that are disproportionately affected by HPV-related cancers. ASOs also serve other sexual and gender minority populations (i.e., transgender persons), and at-risk populations such as injection drug users and high-risk HIV-negative persons who meet pre-exposure prophylaxis (PrEP) eligibility criteria (e.g., tested positive for a sexually transmitted disease (STD)

within the past year). The primary services that ASOs provide to their clients are focused on preventing the transmission of HIV, STDs (e.g., chlamydia, gonorrhea, syphilis), and other infectious diseases (e.g., hepatitis C) through prevention education, confidential HIV/STD testing, and risk-reduction counseling. Examples of other services that ASOs provide to their clients include (but is not limited to): linking clients HIV care, PrEP clinics, substance abuse treatment, and mental health counseling; medical case management; food and clothing; and housing assistance.

Information Sharing Between ASO Staff and Clients

In addition to engaging in community outreach efforts that target PLWH and MSM, NCHSPs also provide these at-risk populations with information about HIV/STDs and other health-related topics (e.g., cancer). Seeking and sharing health information is an example of non-clinical services that NCHSPs provide to PLWH and MSM, some of whom have low health literacy (Bynum et al., 2013). Receiving information about health topics from trusted sources of health information like NCHSPs becomes increasingly important for PLWH and MSM who have not disclosed their HIV-positive and/or gay status to family members and friends who may have otherwise provided the health information that was needed. As PLWH and MSM continue to age, their need for health information will increase, both in the context of HPV-related diseases and cancer (National Cancer Institute, 2017), and other HIV-related diseases (e.g., cardiovascular disease, diabetes that are also leading causes of morbidity and mortality (De Wit et al., 2008; Friis-Møller et al., 2003). Thus, it is reasonable to expect that NCHSPs' role as trusted sources of health information for PLWH and MSM will become increasingly important as PLWH and MSM continue to age.

Surrogate Seekers

Most US adult information seekers have also looked for health information for someone in their social network (PEW 2008). Researchers have shown that surrogate seeking is most likely to occur when the seeker has a close relationship with chronically ill person (Sadasiyam et al 2013). Other characteristics of surrogate seekers including sharing health information with others, which could be via social networking sites or online health support groups (Cutrona et al. 2015). Looking for health information on the behalf of others (i.e., surrogate seeking) is one form of social support that NCHSPs may provide for their clients. NCHSPs knowledge about HPV-related cancers, perceptions of their clients health needs, and health information seeking self-efficacy make them ideal surrogate seekers for their clients (Wigfall et al 2018, Grasso & Bell 2015). Beyond seeking and sharing, NCHSPs may also help their clients interpret and understand health information, which is another characteristic of surrogate seekers (Turner et al 2018).

Health Information Mavens

Although NCHSPs are trusted sources of health information for PLWH and MSM, health education professionals and public health practitioners know little about NCHSPs in general, and even less about NCHSPs' health communication behaviors. We seek to fill this gap in the literature by describing NCHSPs' information seeking behaviors and patient-provider (i.e., client-NCHSP) communication related to HPV and cancer, and general health information mavenism. A health information maven, a term coined by Kontos and

colleagues (2011) is a public health concept that mirrors the business and marketing concept of market mavens (i.e., interpersonal sources of communication regarding specific goods or services) (Abratt, Nel, & Nezer, 1995; Feick & Price, 1987). According to Kontos and colleagues (2011), market mavens exhibit two important characteristics: (a) they have *general* knowledge about the topics they share and, in this regard differ from early adopters and opinion leaders who tend to have more specialized, focused knowledge; and (b) they “consider it important to share their knowledge with others in their social network” (p. 3). Researchers have shown that NCHSPs are more knowledgeable about HPV-related cancers than US adults in the general population (Wigfall et al 2018). Additionally, NCHSPs interest and willingness to engage in HPV-related cancer prevention efforts has been established (Guidry et al 2014, Wigfall et al 2018). Therefore, NCHSPs are an ideal target population to further explore how the business and marketing concept of market mavens can be applied to a public health context such as NCHSPs serving in the role of health information mavens for their clients.

Since HPV is the most common sexually transmitted infection and ASO clients (i.e., PLWH, MSM) are disproportionately affected by HPV-related cancers, it seems plausible that ASOs are an ideal delivery setting for integrating HPV prevention education with existing HIV/STD prevention education strategies. However, HPV prevention education and other strategies in delivery settings such as ASOs is not well understood (Guidry et al 2014). In this study, we focus specifically on ASO staff’s human papillomavirus (HPV)-related cancer information seeking behaviors because their MSM and HIV-positive female clients are disproportionately affected by anal and cervical cancers, both of which are almost always attributed to persistent oncogenic HPV infection (National Cancer Institute, 2017). We also use the *Health Information Mavenism* scale to describe ASO staff as valued sources of health information.

Methods

Participants

Our study was conducted at community-based HIV/AIDS service organizations (ASOs) located in South Carolina (SC). SC is located in the South United States (US) Census region – a geographical area with the highest burden of HIV/AIDS in the US (Centers for Disease Control and Prevention, 2017), and is divided into four public health regions: Lowcountry, Midlands, Pee Dee, and Upstate (South Carolina Department of Health and Environmental Control, n.d.). Metropolitan statistical areas (MSAs) of residence fully situated within the SC state line include: Charleston-North Charleston, SC; Columbia, SC; Greenville-Mauldin-Spartanburg, SC.

Participants included 30 NCHSPs were primarily non-Hispanic Black or African American (83%) and college graduates (77%), including eight (27%) who had earned a Master’s degree. Half were heterosexual females (52%), 22% were heterosexual males, and 26% were lesbian or gay. Less than half were 50 years old (46%), married (37%), and reported having an annual household income \$50,000 (40%).

NCHSPs had worked with PLWH 11.4 years ($SD = 7.8$), and at their ASOs 8.5 years ($SD = 7.1$) where 79% were full-time staff. NCHSPs provided the following types of services to ASO clients: case management/social work (20%); HIV/HCV testing and counseling services (20%); HIV/HCV prevention services (20%); patient navigation/care coordination (20%); community health specialist/community partner (13%); other (medical assistance/intake specialist/data coordination) (10%); and organizational leadership (7%). A few (7%) provided multiple types of service. For example, the HCV/PrEP linkage to care coordinator's role overlapped with HIV/HCV testing and counseling services, HIV/HCV prevention services, and patient navigation/care coordination.

NCHSPs served 89.0 clients on average ($SD = 85.2$). Almost all worked with MSM (96%), 87% worked with PLWH, 83% with people who tested positive for an STD (e.g., chlamydia, gonorrhea, syphilis) in the past year, and 43% worked with other at-risk populations (e.g., HCV-positive, injection drug users, transgender persons).

Measures

For our needs assessment survey, we adapted questions from the Health Information National Trends Survey (HINTS) (National Cancer Institute, n.d.). We also adapted the Kontos and colleagues' (2011) five-item health information mavenism (HIM) scale. Expert reviewers included researchers with expertise in behavioral science, health communication, and infectious disease. A draft of our needs assessment survey was pretested for cultural appropriateness by key stakeholders (i.e., ASO leader, NCHSP, PLWH), and the final version was pretested by graduate students majoring in communication and/or public health. We used data from the needs assessment survey to inform the development of an HPV-related cancer prevention program for high-risk populations (i.e., WLH, MSM).

The main purpose of the 118-item needs assessment survey was to describe NCHSPs' knowledge, attitudes/beliefs, and health communication behaviors related to HPV and cancer. In this study, we focus on a subset of questions from the 118-item needs assessment survey to describe NCHSPs health communication behaviors (i.e., information seeking, patient-provider (i.e., client-NCHSP) communication, health information mavenism).

Information seeking.—We asked NCHSPs if (yes/no) they had ever looked for information about cancer, HIV, STDs, HPV (including the HPV vaccine), and HPV-related cancers (anal/cervical/oropharyngeal/penile/vaginal/vulvar). We also asked NCHSPs if (yes/no) they had ever looked for health information (i.e., surrogate seeking) (Cutrona et al., 2015) for an ASO clients, co-workers, family member or friend, or PLWH.

NCHSPs's information seeking self-efficacy (i.e., confidence about their ability to find health information) was assessed. Response options ranged from 1-completely confident to 5-not confident at all. We also asked NCHSPs to identify sources of health information they trusted (e.g., Internet, doctor or nurse, etc.).

Patient-provider (i.e., client-NCHSP) communication.—We asked NCHSPs if (yes/no) or how often (always/usually/sometimes/never) they talked to ASO clients about general health topics, engagement in HIV care, and HIV/STD risk behaviors. NCHSPs were

also asked if (yes/no) their ASO clients were: HPV vaccine-eligible clients (aged 9–26 years), ever talked to them about the HPV vaccine; initiated or completed the HPV vaccine series; or been diagnosed with an HPV-related disease or cancer. Those worked with MSM and had heard of the HPV vaccine (N=23/30) were asked if (yes/no) they were willing to do the following for their MSM clients: encourage patient-provider communication about the HPV vaccine, promote HPV vaccination, navigate to adult safety net HPV vaccine providers, and influence their MSM clients' HPV vaccine decision-making.

Health information mavenism.—We adapted the Kontos and colleagues (2011) five HIM scale statements to better reflect the relationship between NCHSPs and ASO clients as denoted by brackets { }. NCHSPs were asked how much they agreed/ disagreed with the following five statements: (1) *I like introducing new health topics to my {clients}*; (2) *I like helping {my clients} by providing them with information about health*; (3) *{My clients} ask me for information about health*; (4) *If {my clients} asked where to get the best information about a particular health topic, I could tell {them} where to go*; and (5) *My {clients} think of me as a good source of information when it comes to new information about health*. Response options ranged from 1—*strongly agree* to 4—*strongly disagree*. Each item was reverse coded so that values ranged from 1—*strongly disagree* to 4—*strongly agree*. The HIM scale score range was 5–20. Our adapted scale's score reliability (Cronbach's $\alpha = 0.72$) was similar to the 0.77 reported by Kontos and colleagues (2011).

NCHSPs Work Experience.—NCHSPs work experience was described as: number of years working with PLWH and at ASO, employment status at ASO, and type(s) of service provided. Types of ASO clients served included: PLWH, sexual and gender minority populations (MSM, transgender persons), injection drug users, HCV-positive, STD-positive, and other (i.e., adolescents, college students, general population, people who are in active role of addiction).

Sociodemographics.—We assessed age (years) (<50, 50); race/ethnicity (Hispanic, non-Hispanic Black or African American, non-Hispanic White, non-Hispanic multiple races); sexual orientation/sex (heterosexual female, heterosexual male, lesbian or gay); and marital status (married, unmarried).

Socioeconomic Status (SES).—We assessed education (<college graduate, college graduate) and annual household income (<\$50,000/ \$50,000/refused).

Procedure

Eligible ASOs were fully situated within the SC state line and community-based (versus clinic-based) and located in a MSA that had higher HIV/AIDS incidence rates than the US. Eligible MSAs included 11th ranked Columbia, SC (21.7/100,000), 29th ranked (Charleston-North Charleston, SC: 15.2/100,000), and 52nd ranked (Greenville-Mauldin-Spartanburg, SC: 10.7/100,000) in 2016 HIV incidence rates (comparatively, US: 12.3/100,000) (Centers for Disease Control and Prevention, 2017). Similarly, these MSAs ranked 6th (Columbia, SC: 12.6/100,000), 26th (Charleston-North Charleston, SC: 6.7/100,000), and 51st (Greenville-Mauldin-Spartanburg, SC: 4.9/100,000) in 2016 Stage 3 (AIDS) incidence rates

(comparatively, US: 5.6/100,000) (Centers for Disease Control and Prevention, 2017). We excluded two multi-state MSAs (Augusta-Richmond County, GA-SC; Charlotte, Concord, Gastonia, NC-SC) because they were not fully situated within the SC state line. Eligible MSAs were located in the Lowcountry, Midlands, or Upstate SC public health regions (South Carolina Department of Health and Environmental Control, n.d.). No MSAs were located in the Pee Dee SC public health region (South Carolina Department of Health and Environmental Control, n.d.).

After obtaining institutional review board approval for this study, the principal investigator (LTW) attempted to contact organizational leaders at four eligible ASOs: (1) Lowcountry AIDS Services (Charleston-North Charleston, SC); (2) South Carolina HIV Council dba Wright Wellness Center (Columbia, SC); (3) Palmetto AIDS Life Support Services (PALSS) (Columbia, SC); and (4) AID Upstate (Greenville-Mauldin-Spartanburg, SC). Organization leaders of three ASOs (AID Upstate, South Carolina HIV Council dba Wright Wellness Center, PALSS) responded and agreed to participate in our study (AID Upstate, n.d.; Palmetto AIDS Life Support Services, n.d.). Survey response burden was approximately 20 minutes.

Participants in this study included full and part-time staff, volunteers, and community partners of ASOs located in an MSA that was fully situated within the SC state line. Eligible NCHSPs had some level of engagement with PLWH and MSM who received services at the ASO. The principal investigator (LTW) asked ASO leaders to invite eligible NCHSPs to participate in our study.

In May/June 2016, eligible NCHSPs completed a 118-item, self-administered, paper-and-pencil needs assessment survey. The principal investigator (LTW) facilitated one group session at three ASOs: (1) PALSS (May 20, 2016); (2) AID Upstate (May 27, 2016); and (3) South Carolina HIV Council dba Wright Wellness Center (June 6, 2016). Participation was voluntary and NCHSPs (N=30) provided verbal consent before completing the needs assessment survey. This study is based on a subset of the 118 items that were on the needs assessment, which include questions that were focused on the health communication behaviors of NCHSPs who serve WLH and MSM.

Statistical Analysis

Frequencies and percentages with 95% confidential intervals are reported for categorical variables. Means with standard deviations are reported for continuous variables. HINTS data was used to compare differences in proportions of NCHSPs information seeking behaviors to a population-based sample of US adults. HIM scale mean scores were compared between surrogate seekers and nonseekers using *t*-tests. Similar to Kontos and colleagues (2011), we used 15.0 as our HIM scale high-score cutoff because this was the highest score that could be calculated if a participant responded 3-*agree* for all five items. The HIM scale overall mean score was compared to the 15.0 high-score cutoff. All statistical analyses were performed using Stata/SE 14.1 (StataCorp LP, College Station, TX, USA) (Stata, n.d.).

Results

Information & Surrogate Seeking

The majority of NCHSPs had looked for information about cancer (93%), HIV (97%), and STDs (97%). Compared to data reported from the HINTS 5, Cycle 1 survey that was completed between January and May 2017, the proportion of cancer and information seeking among NCHSPs in our study was significantly higher than US adults: cancer information seeking (93% versus 55.4%, $p<0.001$) and health information seeking (97% versus 78.4%, $p=0.0150$). Most of NCHSPs had looked for information about HPV (including the HPV vaccine) (60%). Although 53% had looked for information about cervical cancer, fewer than half had looked for information about other HPV-associated cancers: anal (43%), vaginal (33%), oropharyngeal (17%), penile (17%), and vulvar (7%). Almost all NCHSPs had searched for health information on behalf of PLWH (97%) and family members or friends (97%). Half had looked for information for an ASO client (53%). Some had also looked for health information for their co-workers (37%), presumably at their ASOs since 79% were full-time staff.

The majority of NCHSPs were either completely (53%) or very confident (40%) about being able to find health information. Only a few were somewhat (3%) or a little confident (3%), and none described themselves as not confident at all. Nearly all NCHSPs identified healthcare providers (97%) and the Internet (97%) as sources of information about HPV and cancer they trusted. Most NCHSPs (70%) identified state and national governmental agencies (e.g., SC Department of Health and Environmental Control, Centers for Disease Control and Prevention). More than half (60%) identified printed educational materials (e.g., books, brochures, or pamphlets), and 60% identified community-based organizations (e.g., American Cancer Society).

Patient-Provider (i.e., client-NCHSP) Communication

Nearly all (97%) NCHSPs said they talk about general health topics with ASO clients. While only 40% said they always talk to ASO clients about their engagement in HIV care, 90% said they always talked to ASO clients about their HIV/STD risk behaviors. Most NCHSPs (60%) worked with clients who had been diagnosed with an HPV-related disease or cancer. Although all worked with ASO clients 9–26 years, only 30% said their HPV vaccine-age eligible ASO clients had ever talked to them about the HPV vaccine. Only 30% and 17% had ASO clients who had initiated and completed (respectively) the 3-dose HPV vaccine series. All NCHSPs who worked with MSM clients and had heard of the HPV vaccine ($N=23/30$) were willing to encourage their MSM clients to at least talk to a healthcare provider about the HPV vaccine. Almost all (96%) were willing to encourage their MSM clients to get the HPV vaccine, 87% were willing to navigate their MSM clients to an adult safety net HPV vaccine provider, and 57% thought they could influence their MSM clients' HPV vaccine decision-making. None of these patient-provider (i.e., client-NCHSP) communication behaviors differed significantly between surrogate seekers and nonseekers.

Health Information Mavenism

NHCSPs mean HIM scale score [17.4 ± 2.1 ; range: 13 (n=1) to 20 (n=7)] was significantly higher than our a priori established high-score cutoff (15.0) ($p < 0.001$). Although NCHSPs' HIM scale scores were slightly higher among surrogate nonseekers, these differences were not statistically significant.

Discussion

Trusted sources of health information can positively affect access to medical care and subsequently disease outcomes for at-risk populations. This is especially important for complex disease outcomes such as cancer and their risk factors such as HPV, of which there are 100s of subtypes, of which only some may cause cancer. As an example, if PLWH and MSM are unaware of the link between HIV infection and increased risk for developing HPV-related diseases and cancers, they will be less likely to access effective cancer prevention tools (e.g., HPV vaccination, Pap tests). This example underscores the importance of NCHSPs' roles as trusted sources of information for PLWH and MSM given the fact that PLWH and MSM are disproportionately affected by HPV vaccine-preventable diseases and cancers. Because HIV-positive women and MSM are disproportionately affected by cervical and anal cancers (respectively), the fact that less than half of the NCHSPs in our study who were surrogate seekers had looked for information about HPV (or the HPV vaccine) for ASO clients suggest that there may be missed opportunities to provide at-risk populations with needed health information. The fact that most NCHSPs worked with ASO clients that had been diagnosed with an HPV-related disease or cancer further underscores this need for information about health topics, including cancer.

Health information from NCHSPs may also be needed for PLWH as they age, as well as for individuals who may not have disclosed their HIV-positive or gay status to family members and friends. PLWH are living longer due to advancements in treatment and as a result, many will find themselves managing other health conditions in addition to HIV/AIDS. Additionally, PLWH and MSM may not disclose their HIV-positive and or gay status for fear of stigma and therefore, cannot count on family members or friends to meet their health information needs. Within this scenario, NCHSPs are able to meet PLWH and MSM's unique need for health information as surrogate seekers. Our study's findings suggest that not only is cancer and health information seeking more prevalent among our study participants compared to US adults, but that NCHSPs are also more likely to be surrogate seekers who are very confident in their ability to find health information (Cutrona et al., 2015; National Cancer Institute, n.d.). Persons with low health literacy (Diviani, van den Putte, Giani, & van Weert, 2015) are less likely to have the self-efficacy needed to find health information. Further, researchers have shown that low self-efficacy may be a positive predictor of ambiguity about HPV-related information, which warrants further study beyond just understanding low knowledge (Ellis, Ferrer & Klein 2018). For PLWH and MSM with low health literacy (Bynum et al., 2013), having NCHSPs as surrogate seekers becomes a necessity for improving patient-provider communication, making informed health decisions, and engaging in HIV treatment (e.g., antiretroviral therapy) and preventative care (e.g., PrEP).

Despite their valuable roles as trusted sources of health information, little is known about the health communication behaviors (e.g., surrogate seeking, health information mavenism) of NCHSPs. In particular, how NCHSPs may function as ‘mavens’ of health information for at-risk populations served at ASOs has not been explored (to the best of our knowledge). Regardless of surrogate seeking, almost our entire sample of NCHSPs had positive attitudes toward their role as health information mavens for their clients, which is also reflected in the high mean HIM scale scores. It is at least plausible that the high prevalence of cancer and health information seeking and high mavenism scores among our study participants could be attributed (at least in part) to their high education levels, as nearly one-third of the NCHSPs that participated in our study had a Master’s degree. However, it is important to note that Cutrona and colleagues (2015) did not find any differences in education levels between US adults who only looked for health information for themselves compared to those who were surrogate seekers.

Despite high prevalence of information seeking and positive attitudes about mavenism, the small numbers of NCHSPs who had looked for information about HPV (including the HPV vaccine) and HPV-associated cancers underscored the need for cancer prevention and control efforts at ASOs given the high burden of HPV-related diseases and cancers among PLWH and MSM clients. For instance, HIV-positive MSM carry a disproportionate burden (25-fold increase) of anal cancer, one of the several HPV-vaccine-preventable cancers (National Cancer Institute, 2017; Silverberg et al., 2015; Wang, Silverberg, & Abrams, 2014). Moreover, 73% of NCHSPs worked with ASO clients who are eligible to get the HPV vaccine, yet only 60% of NCHSPs reported that their ASO clients had talked to them about the HPV vaccine, only very few had at least initiated the 3-dose HPV vaccine series. These findings are not entirely unexpected because a decade after its first approval by the FDA for women/girls, only 60% of US adults have heard of the HPV vaccine (National Cancer Institute, n.d.). However, our findings raise public health concerns and point to the need for developing and/or adapting evidence-based HPV vaccination programs to reduce HPV-related disease and cancer disparities among PLWH and MSM.

Study Limitations

Although our sample size was small, it is important to note that this exploratory, cross-sectional study was used to obtain provider-level data and not patient- or population-level data. That said, a limitation of our study’s is that these findings are not generalizable to the US adult population, or for NCHSPs at ASOs located in other MSAs outside of SC. The absence of variability in HIM scale scores limited our ability run multivariable regression models. Self-reported data also represent a potential limitation, yet no other format allows for efficient assessment of NCHSPs’ perceptions.

Despite limitations, our study is (to the best of our knowledge) one of the first attempts at portraying NCHSPs as surrogate seekers and health information mavens for PLWH and MSM. The descriptive data we report herein represent a valuable first step in characterizing NCHSPs as surrogate seekers and health information mavens for the at-risk populations they serve. Thus, our study adds valuable insights into NCHSPs’ health communication behaviors. Our study also functions as a provider-level needs assessment related to

potentially missed opportunities to disseminate cancer information to at-risk populations who are disproportionately burdened by HPV-related diseases and cancers. Finally, our sample belonged to both racial/ethnic (82% non-Hispanic Black or African American) and sexual minority populations (40% identified as lesbian or gay) who, in turn, served at-risk clients from similar minority groups. These demographic characteristics render this study's sample unique and worthy of further study.

Public Health Implications

While some researchers have explored ways to promote tobacco control interventions at ASOs (Burkhalter et al., 2013; Guidry et al., 2014), health education and public health professionals require additional data to better understand the health communication behaviors of NCHSPs. Some of our findings (e.g., the low levels of HPV vaccine information-seeking), however, suggest educational interventions are needed to increase NCHSPs knowledge and beliefs about effective cancer prevention strategies (e.g., HPV vaccination). In future studies, we would do well to explore – as Kontos et al. (2011) did – whether NCHSPs' knowledge and beliefs aligned themselves with clinical guidelines and evidence-based intervention strategies. Understanding the knowledge and beliefs of NCHSPs will become increasingly important as we seek to make the most of these potentially missed opportunities at ASOs to promote cancer prevention and control research efforts among at-risk populations (Damschroder et al., 2009).

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Abbreviations:

MCHES[®]	Master Certified Health Education Specialist
FGSA	Fellow of the Gerontological Society of America
PA	Physician Assistant
LISW-CP/AP	Licensed Independent Social Worker Clinical Practice/ Advanced Practices

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Table 1.

Sample Characteristics, NCHSPs (N=30)

	<i>n</i>	% (95% CI)
Sociodemographic		
Aged <50 years (Mean age in years= 47.7±12.5, N=28)	15	54 (34-72)
Sexual orientation (and sex)		
Heterosexual		
Female	12	40 (23-59)
Male	6	20 (9-39)
Lesbian or gay	12	40 (23-59)
Marital status (=married)	11	37 (21-56)
Race/ethnicity (=NH Black or African American)	25	83 (64-93)
Socioeconomic Status		
Education (=college graduate or higher) ¹	23	77 (57-89)
Annual household income (\$50,000)	12	40 (23-59)
Work Experience		
With PLWH (Mean #years= 11.4±7.7, N=30)	---	---
At community-based ASO (Mean #years= 8.5±7.1, N=28)	---	---
Employed full-time at community-based ASO	22	79 (58-91)
Areas of service current roles served at community-based ASO		
Organizational leadership	2	7 (2-25)
Case management/social work	6	20 (9-39)
Community health specialist/community partner	4	13 (5-32)
HIV/HCV testing and counseling services	6	20 (9-39)
HIV/HCV prevention services	6	20 (9-39)
Patient navigation/care coordination	6	20 (9-39)
Other types of services ²	3	10 (3-28)
Multiple types of services		7 (2-25)
At-risk Populations Served (Mean #clients= 89.0±85.2, N=25)		
PLWH	25	83 (64-93)
Sexual and gender minority populations		
MSM	29	97 (78-100)
Transgender persons	6	20 (9-39)
Injection drug users	2	7 (2-25)
Other infectious diseases		

	<i>n</i>	% (95% CI)
HCV+	1	3 (<1-22)
STD+	25	83 (64-93)
Other types of clients ³	3	10 (3-28)

Notes: ASO (AIDS service organizations); CI (confidence interval); HCV (hepatitis C virus); MSM (men who have sex with men); NCHSPs (non-clinical HIV service providers); NH (non-Hispanic); PLWH (people living with HIV); STD (sexually transmitted disease) |

¹ Graduate degrees (n=8)

² Medical assistance, intake specialist, data coordination

³ adolescents, college students, general population, people who are in active role of addiction.

Table 2.

Information Seeking, NCHSPs (N=30)

	<i>n</i>	% (95% CI)
Health Information Seeking		
<i>Have you ever looked for information about...? (Response=Yes)</i>		
Cancer	28	93 (75-98)
HIV/AIDS	29	97 (78-100)
HPV (including the HPV vaccine)	18	60 (41-77)
HPV-associated cancers		
Anal	13	43 (26-62)
Cervical	16	53 (35-71)
Oropharyngeal	5	17 (7-36)
Penile	5	17 (7-36)
Vaginal	10	33 (18-53)
Vulvar	2	7 (2-25)
STDs	29	97 (78-100)
Surrogate Seeking		
<i>Have you ever looked for information about health or medical topics from any source for...? (Response=Yes)</i>		
Clients	16	53 (35-71)
Co-workers	11	37 (21-56)
Family members or friends *	29	97 (78-100)
PLWH	29	97 (78-100)
Someone else	28	93 (75-98)
Self-Efficacy		
<i>Overall, how confident are you that you could get advice or information about health or medical topics if you needed it?</i>		
Completely confident	16	54 (35-71)
Very confident	12	40 (23-59)
Somewhat confident	1	3 (<1-22)
A little confident	1	3 (<1-22)
Not confident at all	---	---
Trusted Sources of Health Information		
Researcher	10	33 (18-53)
Internet	29	97 (78-100)
Social media	1	3 (<1-22)
Doctor or nurse	29	97 (78-100)

	<i>n</i>	% (95% CI)
Books, brochures, pamphlets, etc.	18	60 (41-77)
Family member or friend	2	7 (2-25)
Co-worker	9	30 (26-50)
Magazine or newspaper	4	13 (5-32)
Radio or television show	2	7 (2-25)
Telephone information number (or hotline)	6	20 (9-39)
Community-based organization (e.g., American Cancer Society)	18	60 (41-77)
Faith-based organization or leader	1	3 (<1-22)
Government agency (e.g., DHEC, CDC, National Cancer Institute)	21	70 (50-84)

Notes: CI (confidence interval); CDC (Centers for Disease Control and Prevention); DHEC (Department of Health and Environmental Control); HCP (healthcare provider); HIV/AIDS (human immunodeficiency virus/acquired immune deficiency syndrome); HPV (human papillomavirus); MSM (men who have sex with men); NCHSPs (non-clinical HIV service providers); PLWH (people living with HIV); STDs (sexually transmitted diseases) |

* Spouse/partner, parent, child, other family member.

Table 3.

Patient-Provider (i.e., Client-NCHSP) Communication among NCHSPs who were aware of HPV vaccine, N=23

	Did surrogate seeking for clients, n=14	Did not do surrogate seeking for clients, n=9	
	n (%)	n (%)	p-value *
Ask about their health in general (=yes)	13 (59)	9 (41)	0.609
<i>Always</i> ask about most recent health visit	6 (60)	4 (40)	0.637
<i>Always</i> talk about reducing HIV/STD risk	14 (67)	7 (33)	0.142
NCHSPs served clients aged 9-26 years (=yes) and that had...	14 (61)	9 (39)	---
...talked to them about HPV vaccine (=yes)	4 (57)	3 (43)	0.582
...initiated the HPV vaccine series	4 (57)	3 (43)	0.582
...completed the HPV vaccine series	4 (100)	0 (0)	0.127
...been diagnosed with HPV-related disease (genital warts or cancer)	7 (58)	5 (42)	0.567
NCHSPs who worked with MSM clients			
Willing to encourage clients to get HPV vaccine	14 (64)	8 (36)	0.391
Think clients more likely to get HPV vaccine if they recommended it	8 (62)	5 (38)	0.637
Willing to encourage clients to talk to their HCP about HPV vaccine	14 (61)	9 (39)	---
Willing to help clients access adult safety net HPV vaccine providers	13 (65)	7 (35)	0.538

Notes: NCHSPs (non-clinical HIV service providers) |

* Fisher's exact 1-sided tests.

Table 4.

Health Information Mavenism, NCHSPs (N=30)

	Did surrogate seeking for clients, n=16	Did not do surrogate seeking for clients, n=14	t-test *
	M±SD	M±SD	p-value
Strongly agree/agree with the following statements:			
<i>I like introducing new health topics to my {clients}.</i>	3.25±0.19	3.57±0.14	0.1981
<i>I like helping {my clients} by providing them with information about health.</i>	3.69±0.12	3.79±0.11	0.5600
<i>My clients} ask me for information about health.</i>	3.38±0.13	3.57±0.14	0.2982
<i>If {my clients} asked where to get the best information about a particular health topic, I could tell {them} where to go.</i>	3.38±0.13	3.43±0.23	0.8326
<i>My {clients} think of me as a good source of information when it comes to new information about health.</i>	3.31±0.12	3.43±0.23	0.6435
Mean HIM scale score	17.0±0.52	17.79±0.56	0.3093

Notes: HIM (Health Information Mavenism) scale; NCHSPs (non-clinical HIV service providers) |

* Independent samples, two-sided tests