



A reproductive justice approach to understanding women's experiences with HPV and cervical cancer prevention



Beth Sundstrom^{a,*}, Ellie Smith^b, Cara Delay^c, John S. Luque^d, Caroline Davila^e, Bailey Feder^a, Vincenza Paddock^a, Jessie Poudrier^a, Jennifer Young Pierce^f, Heather M. Brandt^g

^a Department of Communication, College of Charleston, Charleston, SC, USA

^b College of Public Health and Human Sciences, Oregon State University, USA

^c Department of History, College of Charleston, Charleston, SC, USA

^d Institute of Public Health, Florida A&M University, USA

^e Department of Public Health Sciences, Medical University of South Carolina, USA

^f Mitchell Cancer Institute, University of South Alabama, USA

^g Arnold School of Public Health, University of South Carolina, USA

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ABSTRACT

Cervical cancer is a preventable disease. HPV infection has been linked to more than 90% of cervical cancers. A vaccine to prevent the acquisition of HPV has been available since 2006. The purpose of this study was to investigate women's perceptions of cervical cancer prevention, including HPV vaccination. A reproductive justice framework guided data collection and analysis.

In 2016, researchers conducted 70 in-depth, semi-structured qualitative interviews with women aged 19–78 years in South Carolina. A purposive sampling approach was employed to maximize requisite variety based on social, economic, and environmental axes of inequality. Participants self-identified as white (53%), African American (33%), and Hispanic (9%). Data analysis included an inductive constant comparative method to identify patterns and themes across the interviews. Misinformation about the prevalence and risk of HPV and cervical cancer led to “othering” of women with HPV-related diagnoses based on the flawed assumption of not being at risk.

Participants described a lack of knowledge about the effectiveness and safety of the HPV vaccine. Social norms influenced participants' perceptions of HPV vaccination and cervical cancer, including concerns about sexual activity and intergenerational communication. Participants' social construction of identity, including race/ethnicity, socioeconomic position, ability, age, gender, sexual orientation, and immigration status, impacted their perceptions of cervical cancer screening and the HPV vaccine. In particular, participants believed that the HPV vaccine was “only for girls” and identified gender norms that limited uptake. Participants described barriers to accessing health care and cervical cancer screening, including cost, health insurance, and life changes (e.g., pregnancy, relocating). Many participants experienced an abnormal Papanicolaou test and described follow-up care, including biopsies and treatment for cervical dysplasia.

Findings from this study offer insight into women's identity and perceptions of cervical cancer prevention. Results provide practical recommendations to increase women's agency in the development of successful public health interventions.

1. Introduction

The human papillomavirus (HPV) is the most common sexually transmitted infection (STI) in the United States (CDC, 2017b; McQuillan et al., 2017; Satterwhite et al., 2008). According to the Centers for Disease Control and Prevention (CDC), HPV is ubiquitous and almost

everyone who is sexually active will be exposed to the virus (CDC, 2016b). Approximately 14 million individuals are newly infected with HPV each year (Markowitz et al., 2014; Satterwhite et al., 2008), with a total of about 79 million Americans infected with HPV (Markowitz et al., 2014; Satterwhite et al., 2008). In 2014, the prevalence of HPV was 42.5% among all U.S. adults ages 18–59 (45.2% among men and

* Corresponding author. 66 George St., Charleston, SC, 29424, USA.

E-mail address: BLS@cofc.edu (B. Sundstrom).

39.9% among women) with high-risk HPV prevalence at 22.7% in the total population (25.1% among men and 20.4% among women) (McQuillan et al., 2017).

HPV infection has been linked to more than 90% of cervical cancers (CDC, 2017a). Each year, over 30,000 men and women are diagnosed with HPV-related cancers in the United States. Although cervical cancer is a relatively rare outcome, the numbers of pre-cancerous lesions are significant and lead to abnormal Papanicolaou (Pap) tests and anxiety, which remains a common experience for many women (Moyer, 2012). Each year, approximately 400,000 women present with abnormal Pap test results. A vaccine to prevent the acquisition of HPV has been available since 2006. The latest vaccine, HPV-9 prevents approximately 90% of HPV-related cancers (FDA, 2014). In 2016, the CDC and the Advisory Committee on Immunization Practices (ACIP) recommended that 11–12 year old boys and girls receive only two doses of the HPV-9 vaccine six months apart. Older adolescents ages 15–26 still need three doses of the HPV vaccine (CDC, 2016a). Since 2010, the Affordable Care Act (ACA) requires most private health insurance plans to cover all vaccines recommended by the ACIP without cost-sharing. The Vaccines for Children (VFC) program provides vaccines for children who are uninsured and Medicaid-eligible.

2. Background and conceptual frameworks

2.1. Gender, the body, and biopolitics

This study incorporates a postmodern approach to HPV and cervical cancer prevention, which explores meanings of gender, the body, and biopolitics. Foucault (1978) argued that biopolitics led to the medicalization of women's reproduction, which assigned natural processes to the biomedical paradigm. Scholars define medicalization as the pathologizing of women's bodies, allowing medical authorities to define illness by identifying objective signs and symptoms (Bush, 2000; Martin, 2001; Pollock, 1999). The medicalization of the body, which was largely complete by the mid-twentieth century, enabled the medical establishment to secure its power over health and illness (Kline, 2011). Extant research has explored the role of biopolitics in the dissemination of the HPV vaccine (Paul, 2016). The role of biopolitics as a regulatory control of the body and reproduction (Foucault, 1978) provides a lens to investigate women's personal and social identity related to health behaviors (Cline, 2011).

Vaccination offers a particularly relevant health behavior related to women's personal and social identity, including race/ethnicity, socio-economic position (SEP), ability, age, gender, sexual orientation, and immigration status. Recent research shows that vaccine refusal may be linked to an emphasis on natural health, concerns about science and technology, and distrust of profit-driven pharmaceutical companies (Reich, 2016; Sobo, 2015). The recent backlash against vaccines may be traced to Dr. Andrew Wakefield's fraudulent 1998 study that falsely linked autism with the Measles, Mumps, and Rubella (MMR) vaccination. The modern anti-vaccination movement relies on overstating the frequency of adverse events, misrepresenting the risks of vaccines, understating the benefits of vaccination and the risks of vaccine preventable diseases, and relying on conspiracy theories (Kaufman and Kaufman, 2018). Although the safety of the HPV vaccine has been well established (Andrews et al., 2017; Arnheim-Dahlström et al., 2013), achieving high rates of HPV vaccination globally has been hindered by access, cost, moral or religious concerns about sexual activity, and sensational media coverage of unproven adverse side effects (Sipp et al., 2018). In 2013, anti-vaccination campaigns in Japan led the Ministry of Health, Labor and Welfare to suspend its recommendation for the HPV vaccination, causing vaccination rates to drop from approximately 70% to less than 1% (Hanley et al., 2015).

The field of feminist science studies explores the intersection of technology with nature and its implications related to gender (Paul, 2016; Weber, 2014; Wyer et al., 2014). Scholars have criticized the

false duality of the natural versus the technological, which often results in the subjugation of individuals with subjectivities that differ from the dominant hegemonic discourse, such as women, people of color, and those who identify as LGBTQ (Haraway, 2003). Perpetuating a dichotomy between nature and technology misconstrues how technology may empower women by providing an escape from the reproductive economy (Sundstrom, 2015). Science and technology offer the potential to move beyond essentialism, including the resulting misogyny and homophobia, revealing the harmful consequences of "back to nature" movements, including anti-vaccination (Aengst and Layne, 2014; Haraway, 2003). The impact of biopolitics on gender and the body requires the reconceptualization of normative "natural" processes of women's reproduction.

Gender interacts at the level of the individual, family and community to impact personal health (Bird and Rieker, 2008). Social constructs regarding reproduction contribute to women's understanding of their bodies and health. Butler (2010) suggested that locating social constructions that form women's identities provides an opportunity to intervene and implement subversive strategies. Ultimately, these strategies may empower women to take control of their health through informed, value-based decision-making. Research suggests that women engage in active negotiation and occasional resistance related to cervical cancer screening. Bush (2000) argued that cervical cancer screening discourse should move beyond maintaining medical power through control of women's bodies and encourage communication that empowers women to choose Pap tests because they have a complete understanding of the risks and benefits.

The current U.S. Preventive Services Task Force (USPSTF) Pap test recommendations include screening women ages 21–30 every three years with the opportunity to lengthen screening intervals to 5 years at age 30 with HPV co-testing. Current recommendations caution against the potential harms of overscreening, such as the risk of false positives, invasive diagnostic procedures, overtreatment, and elevated levels of anxiety and stress due to abnormal results (Moyer, 2012). False positive Pap test results, misdiagnosis, and unnecessary treatment cause significant harms, including distress and clinically detectable levels of anxiety, which impacts women's mental health and future screening decisions (Cooper, 2011; Drolet et al., 2012). Recent research suggests that screening for HPV alone may provide more accurate results than Pap test alone or co-testing and may lead to decreased false positive screening results (Huh et al., 2015). Furthermore, false positive (and false negative) Pap test results may be related to the skill of the health care provider or laboratory. Research demonstrates the need for standardization of quality assurance (QA), monitoring and evaluation of cervical cancer screening programs (Elfström et al., 2015).

2.2. A reproductive justice approach

A reproductive justice approach argues that women maintain the right to decide if, when, and how to become a parent (Solinger, 2016). This conceptual framework incorporates the social, environmental, and economic contexts that determine women's ability to raise children in a healthy environment (Kluchin, 2016). According to Ross (2016), a reproductive justice approach considers political and economic factors, including equal pay, access to health care, and freedom from violence by individual and institutional actors (Ross, 2016). The reproductive justice movement acknowledges the complicated intersections of gender, race/ethnicity, and SEP as sources of reproductive oppression and systems of social inequality, including sexism, racism, and classism (bell hooks, 1984; Berger and Guidroz, 2010; Roberts, 1997).

The reproductive justice framework highlights the intersection of race/ethnicity, immigration status, age, SEP, gender, sexual orientation, and ability. These dimensions of social inequality lead to oppression based on racism, xenophobia, ageism, classism, sexism, heterosexism, and ableism. This approach acknowledges the complex ways that biological, political, social, and economic contexts influence health

inequities and limit reproductive justice. Reproductive decision making is explored within the social, cultural, political, legal, and economic contexts of women's lived experiences (Macleod et al., 2018). Scholars have argued in favor of employing a reparative or reproductive justice approach without appropriating it in movements that have historically valued cisgender, educated, able, and white individuals by addressing marginalized issues and considering biological, social, and economic inequities (Macleod et al., 2017; Pirotte, 2016). Price (2011) calls for reproductive justice research to investigate why African-American, Latina, and Asian-American women maintain low rates of cervical cancer screening. Limited extant research has applied the reproductive justice framework to investigate women's experiences with sexually transmitted infections (STIs), including HPV (Stephens et al., 2012). The reproductive justice framework fills a gap in the literature by illuminating the interaction between intersectional identities and systems of social inequality. This improved understanding offers an opportunity to empower women's reproductive decision making and address health disparities.

2.3. Human papillomavirus (HPV) and cervical cancer

In the United States, women of color are more likely to develop cervical cancer and to be diagnosed with a later stage disease compared with white women (Banister et al., 2013). In South Carolina, new cervical cancer diagnoses between 1996 and 2013 were about 40% higher among African-American women (11.8 cases per 100,000) compared to white women (8.4 cases per 100,000) (SCDHEC, 2016). Moreover, the cervical cancer death rate from 1996 to 2014 was more than two times higher among African-American women (5.1 deaths per 100,000) compared to white women (2.2 deaths per 100,000) (SCDHEC, 2016). These disparities may be exacerbated in rural areas where lower SEP creates barriers to HPV vaccination uptake and cervical cancer screening (Keating et al., 2008). Marginalized populations, including women of color, uninsured and underinsured individuals, and immigrants face increased risks for HPV infection and HPV-related cancers compared to their white counterparts (De and Budhwani, 2017; Burdette et al., 2017; Banister et al., 2013; Bond et al., 2016).

A growing literature has investigated racial and ethnic disparities in HPV vaccination and cervical cancer screening among African-American and Hispanic populations (e.g., Bellinger et al., 2015; Bellinger et al., 2015; Luque et al., 2012; Maness et al., 2016). Through an intersectional approach, Agenor et al. (2014) found that sex of sexual partners, race/ethnicity and other socioeconomic factors impacted cervical cancer screening disparities. Studies show that race/ethnicity, culture, and geography intersect with health care access, age, and SEP to determine HPV vaccination uptake and cervical cancer screening behaviors (Bellinger et al., 2013, 2015). Scholars argue in favor of a new culture-centered approach to studying and addressing health disparities that incorporates various components of social inequality (Bellinger et al., 2013; Galbraith et al., 2016). A culture-centered theoretical approach interrogates the dominant communicative processes that marginalize subaltern communities based on race/ethnicity, SEP, and gender (Dutta, 2015b). In this framework, culture is defined as the local context where the experiences and meanings of health and illness are negotiated and co-constructed based on shared practices, values, and norms (Dutta, 2014, 2015a).

Galbraith et al. (2016) suggested that in order to develop effective interventions, future research should incorporate culture-centered theories, such as the reproductive justice framework, to move beyond health behavior change theories focused on attitudes and awareness. For example, in one integrative review of factors associated with HPV vaccine acceptability among African-American and Hispanics in the U.S., there were parental concerns that HPV vaccination could lead to adolescent sexual activity combined with an attitude of low perceived risk of HPV infection among their daughters (Galbraith et al., 2016). A focus group study in Colorado reported that Hispanic parents with

daughters who had not initiated the HPV vaccine believed that HPV vaccination might encourage premarital sex, which was considered sinful because of Christian religious beliefs. However, the study also noted that lack of effective communication from health care providers to Hispanic parents about the need to complete the 3-dose series and education about the vaccine was a barrier to both completion and initiation (Albright et al., 2017). In another study with Mexican immigrant women in Georgia using cultural consensus analysis, perceptions of risk related to sexual behaviors and HPV as causative factors for cervical cancer were ranked higher than genetic or behavioral factors (Luque et al., 2015). Health communication and social marketing campaigns that incorporate the voices of the target audience throughout development and implementation of health education on HPV and cervical cancer provide increased acceptability and uptake of health behaviors (Cates and Coyne-Beasley, 2015; Dempsey and Zimet, 2015).

The purpose of this study was to investigate women's perceptions of cervical cancer prevention using an intersectional framework and reproductive justice approach. A reproductive justice approach responds to the call by scholars to conduct culture-centered, intersectional research to improve understandings of health disparities in HPV vaccination and cervical cancer screening. Furthermore, this study fills a gap in the study of cervical cancer prevention by incorporating a post-modern approach that explores meanings of gender, the body, and biopolitics. Findings from this study offer insight into women's identity, including race/ethnicity, SEP, ability, age, gender, sexual orientation, and immigration status, and perceptions of cervical cancer prevention, including HPV vaccination. Results provide practical recommendations to increase women's agency in the implementation of successful public health interventions.

3. Methods

This qualitative study was part of a larger oral history project designed to preserve the reproductive health experiences of women in South Carolina. In-depth individual interviews were conducted with 70 women, ages 18 and older from April through December 2016. The purpose of this study was to investigate women's perceptions of cervical cancer prevention, including HPV vaccination. A methodology of listening through conversation reflected a culture-centered approach to elevate the voices of marginalized communities and achieve social justice (Dutta, 2014, 2015b). Participants received a gift bag to thank them for their time. The College of Charleston's Institutional Review Board (IRB) approved this study in accordance with ethical principles involving human participants.

3.1. Sample

The CDC ranked South Carolina 11th in cervical cancer incidence and 9th in cervical cancer mortality (CDC, 2017a). In South Carolina, where African-Americans comprise 28% of the population, cervical cancer disparities are reflected in incidence, late-stage cancer diagnosis and mortality rates (Luque and Young Pierce, 2016). In HPV vaccination uptake, South Carolina (54% girls, 35% boys) falls below the average for the rest of the United States (63% girls, 50% boys) (Reagan-Steiner et al., 2015). In 2016, South Carolina maintained the lowest rate of HPV vaccine completion among adolescent girls in the United States (30.8%) and one of the lowest rates for up-to-date vaccination among adolescent boys (27.4%) (Walker et al., 2017).

Purposive sampling, a nonprobability sampling technique, was used to recruit participants based on predetermined criteria (Berg and Lune, 2012). Inclusion criteria included women living in South Carolina with a history of cervical cancer screening and/or eligibility for HPV vaccination or caring for a dependent eligible for HPV vaccination. Theoretical sampling improved maximum variation based on factors relevant to reproductive justice, such as age, race/ethnicity, and

immigration status (Corbin and Strauss, 2008). Researchers asked participants to refer other women, providing a “snowball” sampling approach to maximize requisite variety (Berg and Lune, 2012). Participants were recruited from community locations, including libraries, churches, beauty salons, and fairs. Participants completed informed consent and an anonymous demographic survey to ensure recruitment of a diverse sample of women.

3.2. Data collection

In-depth interviews were conducted in English and Spanish at locations convenient for participants. Interviews were robust in length and depth, lasting between 1 h and two and half hours. Researchers with graduate-level qualitative methodology training conducted the interviews. To increase trust with participants and reliability of the results, the research team included interviewers who shared a common background with the participants (e.g., gender, age, race/ethnicity, language, etc.). The reproductive justice conceptual framework and the extant literature informed the development of the semi-structured interview protocol (Rubin and Rubin, 2012). Researchers pilot tested the guide with five women living in South Carolina, including one Spanish speaker. Minor changes were made to the word choice and flow of questions. The semi-structured interview guide provided flexibility in the number and order of questions explored with each participant (Berg and Lune, 2012; Rubin and Rubin, 2012). This allowed participants to develop their own health narrative in conversational partnership with the interviewer. Interviews continued until theoretical saturation was reached, indicating that the themes emerging from these data were robust and fully conceptualized.

3.3. Interview guide

Participants were asked a comprehensive sequence of questions regarding cervical cancer screening and HPV. Questions about cervical cancer screening explored experiences with Pap tests (including frequency, follow-up care, and treatment), access to specialty care, and relationships with health care providers. Questions about HPV covered awareness, knowledge, and decision-making regarding the virus and the vaccine.

3.4. Data analysis

Interviews were digitally recorded and transcribed verbatim. Spanish language interviews were transcribed and then translated into English prior to analysis. Qualitative data analysis software HyperRESEARCH 3.7.3 was used to assist with the analysis and coding of each transcript. Researchers shared memos and observer comments in HyperRESEARCH to maintain self-reflexivity and facilitate a team-based qualitative data analysis approach (Rubin and Rubin, 2012). In 2008, Corbin and Strauss provided a mechanism for researchers to incorporate a theoretical framework while maintaining the benefits of a grounded theory approach. The reproductive justice framework provided the conceptual lens for data analysis. An inductive analytic approach was utilized by researchers to highlight the voices and experiences of each participant (Corbin and Strauss, 2008). Researchers employed a constant comparative method to identify patterns and themes across the interviews (Corbin and Strauss, 2008). The reproductive justice framework and line-by-line open coding was used to develop an initial codebook. Researchers coded social, economic, and environmental concepts, such as gender, sexual orientation, race/ethnicity, SEP, immigration status, age, and ability (See Fig. 1). In line with an intersectional approach, Fig. 1 demonstrates how researchers systematically compared themes across subgroups using axial coding to identify patterns and concepts emerging from the data. The research team met frequently to discuss coding and ensure unanimous agreement of coded transcripts. Finally, researchers collectively identified

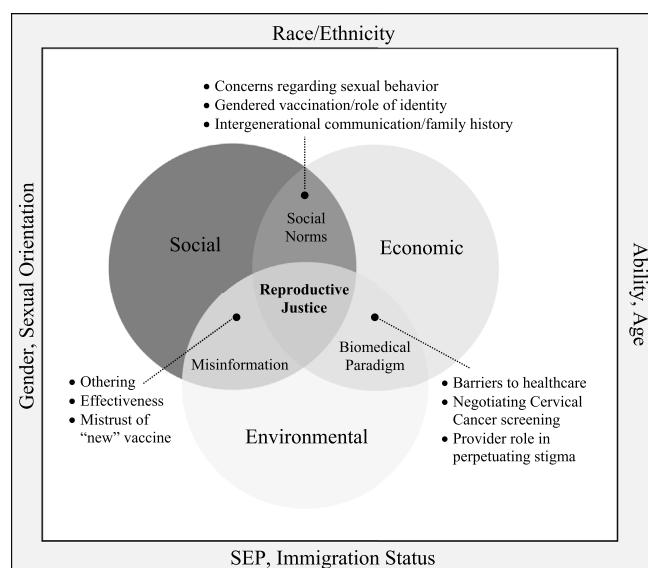


Fig. 1. A reproductive justice approach to HPV vaccination and cervical cancer screening.

themes and conclusions based on these data.

4. Results

Participants ranged in age from 19 to 78 years, with an average age of 49.3 ± 14.7 years. The majority of participants (53.6%; n = 37) identified as White with 33.3% (n = 23) identifying as African American/Black and 8.7% (n = 6) as Hispanic. The demographic characteristics of participants generally approximated the overall demographics of South Carolina (U.S. Census Bureau, 2016). In addition, 16.4% of participants (n = 11) were immigrants from various countries, including Honduras, Mexico, Jamaica, and Bulgaria, among others. Additional demographic information is presented in Table 1. In the analysis, three primary themes emerged regarding HPV, HPV

Table 1
Selected demographic characteristics.

	Sample (N = 70)
Age	
19–78 years (average: 49.3 years; SD: 14.7)	
Race	
White	37 (53%)
Black/African American	23 (33%)
Hispanic	6 (9%)
Other	3 (4%)
Employment status	
Employed	37 (53%)
Self-employed	11 (16%)
Retired	16 (23%)
Other	5 (7%)
Education	
High school diploma or less	8 (11%)
Some college	13 (19%)
Four-year college degree	28 (40%)
Graduate degree	18 (26%)
Relationship status	
Married	35 (50%)
In a relationship	4 (6%)
Divorced	14 (20%)
Widowed	3 (4%)
Separated	4 (6%)
Never married	9 (13%)

Listed as n (%). Frequencies that do not sum to total represent rounding or missing data.

vaccination, and cervical cancer: misinformation, social norms, and the role of the biomedical paradigm. Fig. 1 contextualizes themes and sub-themes by social, economic, and environmental concepts, including gender, sexual orientation, race/ethnicity, SEP, immigration status, age, and ability.

4.1. Misinformation about HPV, HPV vaccination, and cervical cancer

4.1.1. The impact of “othering” women with HPV and related diagnoses

Participants described HPV and HPV-related cervical cancer as something “other people” face. Many participants underestimated the prevalence of HPV and cervical cancer. According to a 38 year-old African American participant, “with cervical cancer, it may sound horrible but I don’t know that a lot of people get it. I know that it’s hard to detect and it’s horrible, but I don’t know that tons of women get it.” Some participants also described misinformation that condoms could fully protect against the transmission of HPV. According to a 45 year-old African American participant, “you should always use protection during sex … I feel like that’s the only way that you can ward off against the HPV virus.” Many participants believed that lifestyle choices, such as monogamy, could prevent HPV and cervical cancer. A 49 year-old white participant described this perspective, “well, I only have one partner, so I don’t think I would necessarily need it [HPV vaccination]. If I were single and active then yeah, I’d get it.” Overall, participants underestimated the prevalence of cervical cancer and overestimated their personal ability to prevent it without the HPV vaccination.

4.1.2. Effectiveness of the HPV vaccine

Many participants perceived that they lacked adequate knowledge about HPV and the HPV vaccination. Without adequate information, participants expressed uncertainty about the effectiveness of the HPV vaccine. Even participants who reported regular health care access suggested that they did not know enough about HPV and cervical cancer and wondered if the vaccine actually prevented HPV. Although many participants chose to vaccinate their children, some participants decided against HPV vaccination because they lacked comprehensive information about the vaccine and HPV-related cancers. According to a 38 year-old African American participant, “I just think it’s very strange that everyone should be vaccinated against it … my son isn’t getting it. My daughter won’t get it either. My 10-year-old.” A 40 year-old Hispanic participant expressed her concern regarding the vaccine, “I’m doubtful. I heard about the vaccine - that it wasn’t good to give it to them.”

4.1.3. Mistrust of “new” HPV vaccine

Many participants described a mistrust of the HPV vaccine based on their perception of it as a “new” vaccine. These participants described the vaccine as “really new.” According to a 38 year-old African American participant, “I think it’s interesting how HPV is the new thing that everyone needs to be vaccinated against. I’m skeptical of it.” A 55 year-old African American participant described HPV as “just the newest boogeyman medical thing” deterring her from seeking the vaccination. Some participants described resisting the “pressure” they experienced from health care providers to receive the vaccination. These participants suggested that they did not know enough about the vaccine and could not be forced to accept it.

4.2. Social norms: HPV, HPV vaccination, and cervical cancer

4.2.1. Concerns regarding sexual behavior

The majority of participants linked HPV and the HPV vaccine with sexual health and behavior. Most participants described HPV as “introduced or exacerbated by sexual activity” (age 54, white). According to a 38 year-old African American participant, “it strikes me as this way of protecting young girls who are having sex from this potential, sexual infection.” This relationship caused concern for some participants

because HPV is associated with sexual behavior. Participants described how influential others in their social networks impacted their vaccination decisions. A 47 year-old African American participant, who reported having health insurance and regular health care, described how the social implications of a positive HPV diagnosis motivated her to complete the HPV vaccination series, “the reputation of some of the girls from high school who had been around [sexually active] … I don’t want to be that girl.”

4.2.2. Gendered HPV vaccination

While participants correctly linked the HPV vaccine with cervical cancer, they were unaware of other HPV-related cancers. Many participants did not know the current HPV vaccine recommendations for boys and young men. They shared their perception of the vaccine as “only for girls.” According to a 30 year-old African American participant who reported having a daughter, “somewhere a few months ago, I found out that guys can get it … I don’t know any in-depth information.” Gender played a unique role on knowledge about the HPV vaccination. One 47 year-old African American parent said, “I don’t think I have received an adequate amount [of information]. Probably because I don’t have girls.” Other participants who reported regular access to reproductive health care agreed, “I don’t have daughters and it doesn’t apply to me” (66, Native American) and “I thought it was only for girls” (32, African American).

Participants linked resistance to the HPV vaccine for boys and young men with gender norms. One 30 year-old African American participant stressed, “people need to be aware, especially … our young men because they’re a little more brave than females are because they sort of kind of feel invincible.” Participants identified gender bias against vaccination linked to gender norms and identity. One 32 year-old African American participant explained:

There is no man that I have known in life that would be that ahead of the game with protecting themselves … So I would be very surprised to see anyone that would take their son … But the way I see them viewing sexual health, I would be very surprised if that caught on at all.

Participants’ gender impacted their health knowledge and negatively impacted their decisions regarding the HPV vaccine.

4.2.3. Intergenerational communication and family history of cervical cancer

The meaning of the HPV vaccine and cervical cancer screening differed across generations. According to a 47 year-old white participant who immigrated to the United States, “I’ve seen it [HPV vaccine] but not really discussed it in relation to myself. I’ve discussed it more in relation to my daughters. I have three girls.” Similarly, a 40 year-old Latina participant who immigrated from Mexico explains generational differences as cultural, “But in Mexico, in the ranches it’s very-hushed … moms don’t talk about it with their kids.” Many participants who were above the target age for HPV vaccination (ages 27 and above) described a lack of knowledge about the HPV vaccine even though they supported it in principle. According to a 47 year-old white participant, “this day and age, girls might be starting to be active [sexually] earlier … So maybe it’s a good idea to start preventive care earlier than I would have growing up.” Although most older participants, ages 50 and above, were active in the lives of their children and grandchildren and were in a position to offer health recommendations, they often dismissed HPV and cervical cancer screening as “something younger people would experience.”

Family history of cervical cancer also impacted participants’ knowledge, attitudes, and behaviors related to cervical cancer and the HPV vaccine. According to a 37 year-old white participant, “my great-grandmother died from cervical cancer, and they’re [health care providers] pretty sure that’s [HPV] probably what the cause was, I mean, now, so that’s what most of it’s caused by.” Participants with a family

history of cervical cancer strongly supported the HPV vaccine for themselves and their children.

4.3. The role of the biomedical paradigm in HPV vaccination and cervical cancer screening

4.3.1. Barriers to reproductive health care

Participants described barriers to accessing HPV vaccination and cervical cancer screening, including cost, health insurance, and life changes. Many participants described interruptions in access to health care, including yearly exams and screening. According to a 54 year-old white participant who also reported not having a primary health care physician, "I've not had a gynecological exam in probably five years." Many participants described cost and lack of health insurance as barriers to care. According to a 49 year-old white participant who lacked health insurance coverage:

Most challenging was that there isn't very good accessibility to women in lower poverty and no insurance situations, who maybe don't have insurance to go to a private doctor to get the regular health care. It has been difficult, actually, to get the health care that I needed. To get mammograms and Pap smears and that sort of thing.

Participants believed that pregnancy increased access to health care. A 39 year-old Hispanic participant who immigrated to the United States described her experience, "The Pap smear? Yes. I had it done, but I haven't had it done again since she [my daughter] was born." Other barriers to health care included residing in rural areas and limited access to health care facilities.

4.3.2. Negotiating cervical cancer screening

Participants described limited knowledge about the risk of cervical cancer. Although many participants typically followed their doctor's advice about Pap testing, some participants preferred annual screening. Participants said, "I go annually to have them," and "[I] make sure I come every year, annually, to get a Pap smear." Many participants described an active approach to cervical cancer screening as a preventive measure. According to a 46 year-old African American participant who reported participating in consistent, recommended screenings, "I don't want to be walking around here with cancer or something I don't know about. That's why it's good to get your annual, your Pap smear every year. It's good they do it."

Most participants described the experience of an abnormal Pap test and follow-up care, including biopsies and treatment for cervical dysplasia. A 54 year-old white participant described how a challenging experience and the lack of communication with her physician as a young woman led her to stop seeking care during her early reproductive years:

I had some dysplasia. I had to go through cryosurgery and I did do all that. And it was, he was actually, um, pretty standoffish, um, so there was no relationship. So there was no communication with him. He had to do a biopsy, which was not very comfortable and then the cryosurgery was not a very comfortable process. So, the next time that I went to an OB/GYN was when I was pregnant.

A 28 year-old African American participant said, "I know they can freeze your cervix to get the cells off. I've had that done before." Many participants did not link abnormal Pap tests with HPV or cervical cancer. According to a 41 year-old white participant who reported following screening recommendations, "I had an abnormal Pap, they never talked about what that was. I had to go so far as to do a colposcopy."

Some participants described these experiences as distressing and humiliating. According to a 28 year-old white participant:

I had actually had HPV but it never really registered because [my doctor] never really, I don't know, laid it out in layman's way for a young person and I had to go through a few surgeries because I had

a rare strand and that was a traumatic thing for me.

A 54 year-old white participant said, "It was horrible and I was really afraid of needles, so he did the exam which was humiliating because he just, you know, this old man that I didn't know in this very clinical, cold, sterile environment." Participants described the impact of multiple surgeries on their future fertility, identity, and relationships. A 38 year-old white participant who reported a previous abnormal Pap test result explained, "It did surprise me to learn that it was HPV for the results at the time ... I was in a steady relationship, so ... did I get this from my husband?"

4.3.3. Health care provider role in perpetuating stigma

Many participants described a lack of counseling and understanding from health care providers regarding HPV and cervical cancer. Several participants described "a little bit of judgment" and a lack of sensitivity regarding HPV diagnosis and treatment of abnormal Pap tests. Some participants described how their clinicians perpetuated stigma associated with HPV and abnormal Pap tests. According to a 28 year-old white participant, "[my doctor said], 'well depending on what kind of partners,' ... just the way I contracted it, and [I] felt like there was judgment [of] the kind of lifestyle I was living." Some participants described their health care provider's communication or "bedside manner" as "standoffish," "very poor," or "crass" during diagnosis and treatment following an abnormal Pap test.

However, many participants described the importance of health care providers supporting and recommending the HPV vaccine. A 51 year-old white participant explained how her provider started a conversation that helped her make the decision to vaccinate her children, "you know, when your children get to that age, here's something you should really consider and this is why." Other participants described the persistence of gendered vaccination practices in health care settings. According to a 54 year-old white participant, "my daughter and son were at the same pediatrician ... I felt like it [the pediatric practice] encouraged me to have the vaccine ... For her."

5. Discussion

Researchers conducted in-depth interviews with 70 women between 19 and 78 years old to investigate women's perceptions of cervical cancer prevention, including HPV vaccination. This study answered the call for culture-centered, intersectional approaches to studying health disparities (Agenor et al., 2014; Bellinger et al., 2013; Galbraith et al., 2016). Through a culture-centered approach, this study revealed the voices of women in South Carolina that are often not heard because of marginalization based on race/ethnicity, immigration status, ability/age, SEP, and gender, sexual orientation, thereby illuminating health inequities and the co-construction of meaning about HPV vaccination and cervical cancer screening (Dutta, 2014; Dutta 2015a; Dutta, 2015b). To summarize, participants described misinformation about the prevalence and risk of HPV and cervical cancer, as well as the effectiveness and safety of the HPV vaccine. Social norms influenced participants' perceptions of HPV vaccination and cervical cancer, including concerns about sexual activity, the role of identity and gender, and intergenerational communication. Participants described barriers to health care, negotiating cervical cancer screening, and the role of health care providers in perpetuating stigma. Fig. 1 identifies a reproductive justice approach to HPV and cervical cancer prevention.

Many participants reported a lack of knowledge about cervical cancer, HPV and the HPV vaccination. Participants underestimated the prevalence of cervical cancer and overestimated their personal ability to prevent it without receiving the HPV vaccine. This finding reflects extant research that knowledge of HPV and cervical cancer risk is low (Bellinger et al., 2015). This misinformation led some participants to engage in "othering," whereby individuals impacted by HPV and cervical cancer were perceived to differ from themselves in significant

Table 2
Practical implications of a reproductive justice approach to cervical cancer prevention, including HPV vaccination.

Reproductive Justice Concepts	
To increase women's agency in the development of successful public health interventions and communication campaigns:	
Themes Misinformation	Race/Ethnicity Address systemic racism in health care that leads to mistrust, including the perception of the HPV vaccination as "new" and untested.
Social Norms	Incorporate sex-positive messages and address concerns regarding sexual behavior and promiscuity. Extricate the HPV vaccine from gender.
Biomedical Paradigm	Address the ways medicalization disempowers women, including the frequency of abnormal Pap tests and how women's experiences of follow-up care may be distressing and humiliating, leading some participants to stop seeking healthcare.
Ability, Age	SEP, Immigration Status Move beyond awareness to incorporate the audience's values and needs, including health literacy and patient advocacy, while addressing risks and benefits of vaccination, screening and treatment.
	Implement culturally appropriate community-based interventions that recognize cultural identity, geography, and socioeconomic status impact decisions about vaccination, screening and treatment.
	Address barriers to accessing HPV vaccination and cervical cancer screening, including cost, health insurance coverage, and other economic realities that limit access to care.
	Support negotiation of cervical cancer screening by discussing the potential harms of overscreening. Provide comprehensive information about risk to help women make the best choice for themselves.
	Foster intergenerational communication about cervical cancer prevention, including discussions about family history.
	Educate clinicians to provide equal access to services for all women and to avoid perpetuating stigma associated with HPV and abnormal Pap tests.

ways. Some participants distanced themselves from the burden of HPV and cervical cancer and one participant described it as a "boogeyman." Since a boogeyman is traditionally invoked to frighten children to behave in a proscribed manner, this term offers important insight into understandings of medical recommendations regarding HPV vaccination and cervical cancer screening. This finding elaborates the role of medicalization and reproductive justice (Ross, 2016; Solinger, 2016; Stephens et al., 2012) in addressing misinformation and mistrust related to women's reproductive health. Specifically, women deserve comprehensive, accurate information about their personal risk (e.g., absolute risk) that is easier to understand than population estimates of risk (e.g., relative risk). A reproductive justice approach to communicating about risk should contextualize how inequities across many areas of daily life compound cervical cancer risk. Table 2 outlines practical implications of a reproductive justice approach to increase women's agency in the development of successful cervical cancer prevention interventions.

Although the U.S. Food and Drug Administration (FDA) approved the first HPV vaccine over a decade ago, campaign planners must address systemic racism in health care that leads to mistrust, including the perception of the HPV vaccination as "new" and untested. This finding builds on recent research that vaccine refusal reflects concerns about science and technology as antithetical to natural health (Reich, 2016). The implications of this finding suggest that effective public health interventions will reconceptualize normative "natural" processes by countering the false duality of natural and technological related to vaccination, screening and treatment. This finding urges campaign planners to move beyond increasing awareness, which studies show is not sufficient to increase vaccine uptake (Galbraith et al., 2016). The activist role of patient advocacy groups is another strategy in raising awareness of the benefits of the HPV vaccine separate from vaccine manufacturer's commercial advertising (Gottlieb, 2013). Health communication and social marketing campaigns that rely on the target audience's input throughout development and design, as well as strategies congruent with the audience's values and needs offer an effective approach to address risks and benefits to increase vaccine uptake (Cates and Coyne-Beasley, 2015; Dempsey and Zimet, 2015). Implementing innovative and accessible approaches to education (e.g., telehealth, social media) and health communication campaigns that include a focus on health literacy and patient advocacy may help to counter systemic racism, classism, ableism, ageism, and xenophobia.

Participants negotiated complex beliefs about HPV as a sexually transmitted infection (STI), while concerns regarding sexual behavior and promiscuity remained prevalent. To increase women's agency, campaigns should incorporate sex-positive messages and address concerns about sexual health. Participants with a family history of cervical cancer strongly supported the HPV vaccine for themselves and their children. The meaning of the HPV vaccine and cervical cancer screening differed across generations. This finding supports recent research showing that cervical cancer screening declined with increasing age (Bellinger et al., 2013). To address ableism and ageism, public health professionals and communication campaigns should foster intergenerational communication about cervical cancer prevention, including discussions about family history. Participants' social construction of gender and identity impacted their perceptions of cervical cancer screening and the HPV vaccine. In particular, participants believed that the HPV vaccine was "only for girls" and identified gender norms that limit uptake of vaccination. This finding reinforces the importance of extricating the vaccine from gender, a strategy that has been successful in Europe and Australia (Paul, 2016; Smith and Canfell, 2014).

Participants described barriers to accessing HPV vaccination and cervical cancer screening, including cost, health insurance, and life changes. Nationally, adolescents enrolled in Medicaid are significantly more likely to be vaccinated against HPV than those with private health insurance (Walker et al., 2018). Overcoming these barriers to HPV

vaccination and cervical cancer screening involves addressing classism and the economic realities that limit access to care. In particular, these women struggled with continuity of care due to rural location, limited access to health care facilities, and reproductive health status (e.g., participants received improved access to health care during pregnancy). Lack of access to health care may be compounded by modifiable risk factors for cervical cancer, including smoking, STIs, overweight, and a diet low in fruits and vegetables. These risk factors intersect with race/ethnicity, geography, and SEP suggesting that health inequities, including access to affordable healthy food, may be related to cervical cancer disparities (Diehl et al., 2017; Lana et al., 2017). Raising the voices of marginalized women and sharing their stories may help to address discrimination and systemic racism. This finding elaborates a reproductive justice approach and extends research showing the importance of implementing culturally appropriate community-based interventions that recognize culture, immigration status, geography, and SEP in order to impact decisions about HPV vaccination, cervical cancer screening, and treatment (Bellinger et al., 2013, 2015).

Participants negotiated cervical cancer screening with divergent preferences for more or less medical intervention, situating technology as simultaneously liberating and as a threat to bodily autonomy, which echoes women's experiences historically with products such as thalidomide. Despite counseling and recommendation by their physician to follow updated screening guidelines to mitigate these risks, some participants preferred annual screening. Many participants experienced abnormal Pap tests and described follow-up care, including biopsies and treatment for cervical dysplasia. Participants described these experiences as distressing and humiliating, which lead some participants to stop seeking health care. Several participants described how clinicians perpetuated stigma associated with HPV and abnormal Pap tests. These findings demonstrate how medicalization disempowers women and reaffirms the need for public health interventions to support negotiation of cervical cancer screening by providing comprehensive information about risk, including the potential harms of overscreening, to help women make the best choice for themselves (Bush, 2000; Martin, 2001; Pollock, 1999). To address ableism, public health interventions should educate clinicians to provide equal access to services for all women and to avoid perpetuating stigma associated with HPV and abnormal Pap tests.

5.1. Limitations and future research

In-depth interviews with 70 women between 19 and 78 years old provided a unique opportunity to understand women's perceptions of cervical cancer prevention, including HPV vaccination. Although 11 participants (16.4%) identified as immigrants, future reproductive justice research should focus on immigrant populations to better understand issues of access to health care (MacLeod et al., 2017, 2018). Although the majority of our sample reported at least some higher education, extant research suggests that HPV vaccine completion rates do not differ significantly based on level of education (Suryadevara et al., 2016). This study provides an intersectional, reproductive justice framework for future research to improve understandings of other health behaviors and disparities.

Findings map the social, economic, and environmental axes of inequality by multiple dimensions, including race/ethnicity, SEP, ability, age, gender, sexual orientation, and immigration status (See Fig. 1). Results identify social constructions that form women's identities, creating opportunities to intervene and implement subversive strategies to empower women to take control of their health through informed, value-based decision-making (Butler, 2010). Findings from this study provide practical implications for a reproductive justice approach to increase women's agency in the development of successful public health interventions and communication campaigns to address cervical cancer prevention, including HPV vaccination.

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