Vassar College Digital Window @ Vassar

Senior Capstone Projects

2018

Cervical cancer's undue fatalities: a critical examination of the discrepancy between effective prevention technology and the continuance of cervical cancer incidence and mortality in the United States

Zoe Elizabeth Sweet Vassar College

Follow this and additional works at: https://digitalwindow.vassar.edu/senior capstone

Recommended Citation

Sweet, Zoe Elizabeth, "Cervical cancer's undue fatalities: a critical examination of the discrepancy between effective prevention technology and the continuance of cervical cancer incidence and mortality in the United States" (2018). Senior Capstone Projects. 790. https://digitalwindow.vassar.edu/senior_capstone/790

This Open Access is brought to you for free and open access by Digital Window @ Vassar. It has been accepted for inclusion in Senior Capstone Projects by an authorized administrator of Digital Window @ Vassar. For more information, please contact library thesis@vassar.edu.

Cervical Cancer's Undue Fatalities:

A Critical Examination of the Discrepancy Between Effective Prevention Technology and the Continuance of Cervical Cancer Incidence and Mortality in the United States

> Zoe Elizabeth Sweet April 2018

Senior Thesis Submitted in partial fulfillment of the requirements for the degree of Bachelor of Arts in Science, Technology, and Society

> Vassar College Poughkeepsie, NY

Advisor, Nancy Jo Pokrywka

TABLE OF CONTENTS

CHAPTER 1: INTRODUCTION TO CERVICAL CANCER	
CHAPTER 2: CERVICAL CANCER AS A DISEASE	7
Cervical Cancer: Disease Overview	7
The Pap-Test	9
Screening	11
Conclusions	12
CHAPTER 3: CERVICAL CANCER AS A PUBLIC HEALTH CONCERN	13
Prevention and Public Health	13
Racial-Ethnic Disparities	16
Mortality	19
Access	21
Title X	24
Conclusions	25
CHAPTER 4: BARRIERS TO ACCESS	26
Income	26
Health Insurance	28
Education	34
Health Literacy	37
Immigration Status	40
Stigma	44
Gender Identity	48
Conclusions	50
CHAPTER 5: PLANNED PARENTHOOD UNDER ATTACK	52
Non-sexual Health Services	52
Threat to Planned Parenthood	53
State Defunding	56
Inadequate Alternatives	58
Symbolic Attacks	61
Conclusions	62
CHAPTER 6: CONCLUSION	63

Works Cited	68
Eradication Within Reach	66
The Role of Planned Parenthood in Cervical Cancer Prevention	64
Importance of Cervical Cancer Screening	63
Women's Health	63

CHAPTER 1: INTRODUCTION TO CERVICAL CANCER

Each year approximately 500,000 women will be diagnosed with cervical cancer and 274,000 will die from the disease worldwide, making it the second most common cause of cancer-related death in women.¹ The staggeringly high mortality rate of the disease is largely due to the fact that the disease is asymptomatic in its early stages. Precancerous lesions cause no symptoms at all and early stages of the disease often display unalarming symptoms: spotting between periods, longer and heavier periods, increased vaginal discharge, and unexplained back or pelvic pain.² Given that a woman's menstrual cycle and hormones are subject to fluctuations, some women may not recognize these early signs as symptoms of anything at all. Risk factors for cervical cancer include HPV infection, age, and smoking.³

Cervical cancer is an insidious disease—it quietly develops over years (sometimes decades) only rearing its head once the cancer has reached its later stages or has metastasized and spread to peripheral organs. The disease begins with *cervical dysplasia*, which is characterized by the growth of abnormal cells in the cervix. Precancerous cervical dysplasia is caused by the infection of oncogenic strains of HPV virus. From the time that abnormal cells begin to develop, it usually takes 10-15 years for the precancerous lesions to become malignant. This lengthy timeline between precancer and cancer gives medical providers a large window of time for intervention and prevention treatments. This time frame also allows ample opportunities for cervical cancer screening.

¹ Karjane, Nicole W., MD. "Pap Smear." *Medscape*. Ed. Christine Isaacs. WebMD LLC, 02 Dec. 2016. Web. 19 Jan. 2018.

² "Cervical Cancer: Symptoms and Signs." Cancer.Net. *American Society of Clinical Oncology*, 22 Sept. 2017. Web. 15 Jan. 2018.

³ "Cervical Cancer: Symptoms and Signs"

Cervical cancer is effectively screened by use of the Papanicolaou test and the DNA test for HPV infection, and it is prevented using safe sex practices and the HPV vaccine. In the last four decades cervical cancer incidence decreased by over 50% due to the advent of such screening with cervical cytology. However, the implementation of screening technology has not reduced cervical cancer incidence and mortality (referred to as I&M for the remainder of this document) equitably as roughly 80% of cervical cancer deaths occur in developing nations. Still, given the resources available, screening has drastically reduced cervical cancer I&M in developed countries. This is well demonstrated in the U.S. as incidence from 1975-2012 decreased from 14.8 cases per 100,00 women to only 6.5 as the Pap test became the gold standard across the country. This translates to approximately 10,000 new diagnoses and 4,000 deaths due to the disease annually.

While the significant decrease of cervical cancer I&M in the U.S. may seem to be a promising accomplishment, the 4,000 deaths each year demonstrate that simply *having* screening and prevention technology is not enough. Theoretically, if every woman were to follow screening guidelines, each case of cervical dysplasia would be detected and treated before possibly becoming cancerous, effectively eradicating the cancer in its tracks—especially considering the window of 10-15 years for such detection. Eradication has become even more possible in recent years given the HPV test, which can predict risk, and the HPV vaccine, which prevents infection and therefore cervical dysplasia and cancer. With the prevention and screening tools available then, cervical cancer should no longer exist—except in rare aggressive cases—in the resource-rich U.S.

-

⁴ Karjane 2016

I argue then that it is the implementation inadequacies of such medical technologies that are driving the continuing rates of cervical cancer I&M in the U.S. These inadequacies are due to socioeconomic barriers to access of such technologies, which disproportionately affect women who are low-income, immigrant, and/or people of color.⁵ I will begin with background information regarding the biology of cervical cancer and elaboration of cervical dysplasia, screening, and prevention methods. I will then explore cervical cancer in regards to public health—detailing cervical cancer trends, screening programs, how to access screening, and federal subsidies for screening. Moving forward, I will elucidate seven significant barriers to access of preventative care for cervical cancer including but not limited to income, immigration status, and health insurance. I will then bring together the information from Chapters 2-4 (see Table of Contents) to analyze Planned Parenthood as a case study to assess the effect of reproductive healthcare access on cervical cancer incidence and mortality. Through these analyses, I will utilize Actor-Network Theory, the Sociology of Scientific Knowledge, and the Social Construction of Technology as frameworks of understanding the relationship between science, technology, and society.

The goal of this body of writing is to examine the socioeconomic factors that drive the discrepancy between cervical cancer I&M in the U.S. and the available technologies that should have nearly eradicated incidence and mortality already. The critical examination of this discrepancy is intended to elucidate both the importance of cervical cancer screening and prevention methods *and* the barriers to access of such that continue to take cause preventable deaths.

⁵ De Alba, Israel, et al. "Impact of U.S. Citizenship Status on Cancer Screening Among Immigrant Women." *Journal of General Internal Medicine* 20.3 (2005): 290–296. PMC. Web. 28 Dec. 2017.

Author's Note: When discussing cervical cancer I&M I use the term women in reference to cisgender women with cervixes. Still, it is critical to recognize that not all women have cervixes and that not all people with cervixes identify as women. Gender identity will be briefly explored in Chapter 4: Barriers to Access subsection "Gender Identity." Admittedly, one section does not do justice to the unique host of circumstances that bar access to reproductive healthcare for transgender people with cervixes who are therefore outside of the scope of this thesis. It is nonetheless important to validate the right to cervical cancer screening and prevention for people who are not cisgender women.

Cervical Cancer: Disease Overview

Cervical cancer is a disease in which malignant tumor cells form in the lining of the *cervix*. The cervix is the lower region of the uterus where the organ opens into the vaginal canal. It is subdivided into the upper *endocervix* and lower *ectocervix*. The endocervix is categorized by the presence of glandular cells, while the ectocervix houses squamous cells. Between the two regions is the *transformation zone*, wherein most cases of cervical cancer originate.⁶

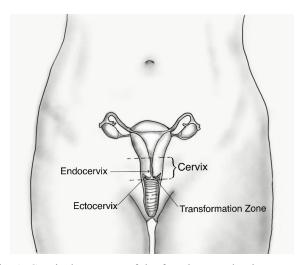


Fig. 1. Cervical anatomy of the female reproductive system.

Nearly 90% of cervical cancers are *squamous cell carcinomas* in the ectocervix, which originate from the transformation zone. Most other cervical cancers are *adenocarcinomas* of the endocervix that originate in glandular cells. Less commonly, the cervix can be affected by *adenosquamous carcinomas* also known as *mixed carcinomas* as they are a mix of both squamous and glandular malignant cells. In rarer cases the cervix can also be affected by melanoma, lymphoma, and sarcoma.⁷ Symptoms of middle to late stage cervical cancer include

⁶ "What Is Cervical Cancer?" *American Cancer Society*. American Cancer Society, 2018.

⁷ "What Is Cervical Cancer?"

"spontaneous or contact bleeding" between normal menstruation, pain in the lymph nodes if affected, backache, and "serosanguineous foul smelling vaginal discharge."

Cervical cancer itself is preceded by *cervical dysplasia*, also known as *cervical intraepithelial neoplasia* (*CIN*)—abnormal, precancerous cells in the lining of the cervix. Cervical dysplasia is most commonly asymptomatic and therefore requires regular screening to be diagnosed. Although dysplasia is a necessary precursor for cervical cancer, only some women with the condition will later develop cancer. ⁹ Cervical dysplasia is caused by a genital infection of oncogenic strains of the human papillomavirus (HPV). ¹⁰

HPV is the most common sexually transmitted infection, affecting 79 million Americans with most sexually active people obtaining at least one strain of the virus. Over 100 strains of HPV have been identified with 30 strains known to cause genital infection. In most cases the virus will naturally clear itself out of the body, though some persistent strains can cause genital warts or produce no symptoms at all. Of the strains known to cause genital infection, 13 strains have additionally been identified as high-risk for causing cervical cancer. When these strains infect the deepest layers of cells, the viruses damages their host cells' DNA and induce rapid cell division. An out of control increase in cell proliferation can then lead to cancer. The risk of contracting HPV can be reduced by using protection during intercourse, such as latex condoms or dental dams, and by being vaccinated for available strains of the virus. The Center for Disease

⁸ Petignat, Patrick, and Roy, Michel. "Diagnosis and Management of Cervical Cancer." BMJ: British Medical Journal 335.7623 (2007): 765. Print.

⁹ "Cervical Dysplasia." MedlinePlus Medical Encyclopedia, U.S. National Library of Medicine, medlineplus.gov/ency/article/001491.htm.

¹⁰ Kitchener, Henry C., et al. "Developing Role of HPV in Cervical Cancer Prevention." BMJ: British Medical Journal 347.7921 (2013): 26. Print.

¹¹ "Human Papillomavirus (HPV)." Centers for Disease Control and Prevention, Centers for Disease Control and Prevention, 17 July 2017, www.cdc.gov/std/hpv/stdfact-hpv.htm.

¹² "HPV and Cancer." Cancer Research UK. N.p., 08 Nov. 2017. Web. 17 Nov. 2017.

Control (CDC) currently recommends vaccination for all children ages 11 to 12, regardless of gender.¹³ For women who were not vaccinated between these ages, a "catch-up" vaccination is recommended between the ages of 13 and 26¹⁴ as people in this age bracket exhibits higher sexual activity with multiple partners, increasing the likelihood of contracting the virus. Though the HPV vaccine primarily aims to prevent cervical cancer, HPV infection can also cause oral, anal, vulvar, vaginal, and penile cancers and genital warts.¹⁵

The Pap-Test

The Papanicolaou smear—known as the Pap test—was developed in 1928 by George Papanicolaou and is now considered the gold standard for cervical cancer screening and prevention. Papanicolaou began his cytopathological research on human reproduction in 1920, which led him to find discernible differences under the microscope between normal and malignant cells taken from the vagina and cervix. These findings were revolutionary in that they provided a low cost, easy to perform screening procedure for cervical cancer. Widespread use of the Pap test began in the 1950s and has since reduced cervical cancer I&M by at least 80%. Presently, the test has a sensitivity (rate of true positives) of 70-80% and a specificity (rate of true negatives) of 95%.

. .

¹³ "Human Papillomavirus (HPV)."

¹⁴ Hachey, Krista J., et al. "Requiring Human Papillomavirus Vaccine for Immigrant Women." Abstract. *Obstetrics & Gynecology* 114.5 (2009): 1135-139. Web.

¹⁵ "The HPV Vaccine: Access and Use in the U.S." The Henry J. Kaiser Family Foundation. *The Henry J. Kaiser Family Foundation*, 19 Oct. 2017. Web.

¹⁶ Tan, Siang Yong, and Yvonne Tatsumura. "George Papanicolaou (1883–1962): Discoverer of the Pap Smear." Singapore Medical Journal 56.10 (2015): 586–587. PMC. Web. 17 Oct. 2017.

¹⁷ "Cervical Cancer Screening." National Cancer Institute, National Cancer Institute, 22 Sept. 2017, www.cancer.gov/types/cervical/hp/cervical-screening-pdq#link/_122_toc.

¹⁸ "Cervical Cancer Screening."

The Pap test involves exfoliating cells from the cervical transformation zone. These cells are obtained by inserting a speculum into the vagina and using a small tool to exfoliate the cells. The sample cells are analyzed using liquid based cytology in which these cells are transferred from a liquid preservative in the cytology lab to a microscope slide. If cervical dysplasia is seen solely from the Pap test, it is referred to as *squamous intraepithelial lesion* (SIL). Dysplasia that is diagnosed by cervical biopsy is referred to as cervical intraepithelial neoplasia (CIN). Subclassifications of these diagnoses are shown in the table below¹⁹:

Types of squamous intraepithelial lesion (SIL)	Types of cervical intraepithelial neoplasia (CIN)
Low-grade (LSIL)	Mild dysplasia (CIN I)
High-grade (HSIL)	Moderate to marked dysplasia (CIN II)
Malignant	Severe dysplasia to cancer in situ (CIN III)
Atypical glandular cells (AGUS)	
Atypical squamous cells	

Table 1. Classifications of cervical dysplasia.

Mild dysplasia (LSIL or CIN I) does not always require immediate treatment, as the disease may clear up on its own over time. The patient must only follow up with more frequent Pap tests unless the abnormalities worsen. Moderate to severe dysplasia or chronic dysplasia is treated by removing the abnormal tissue by cryosurgery, laser therapy, loop electrosurgical excision procedure (LEEP), cone biopsy, or hysterectomy.²⁰ The most common treatment methods for severe or chronic dysplasia are LEEP and cryosurgery which are performed outpatient and have quick recovery times. For each, if abnormal cells are completely removed no further surgical intervention is necessary.²¹

²⁰ "Cervical Dysplasia."

^{19 &}quot;Cervical Dysplasia."

²¹ Mone, Amy. "Cervical Dysplasia Treatment." Kimmel Cancer Center. N.p., 17 July 2017. Web. 17 Nov. 2017.

The Pap test is an extremely powerful screening tool in that dysplasia is not only detected, but classified by severity before the cells become cancerous. The treatment options following an abnormal Pap test are immediate to treat the dysplasia, but also preventative for cervical cancer.

Screening

It usually takes between 10 and 15 years for the abnormal cells in cervical dysplasia to develop into cervical cancer.²² Once the disease has developed in full, the malignant cells can travel to the regional lymph nodes or parametrium (the fibrous tissue that separates the vagina from the bladder). In order to prevent the progression of cervical dysplasia in to cervical cancer, the American Cancer Society recommends screening via the Pap test every three years for women ages 21-29 and every three to five years for women between the ages of 30 and 65. Women with total hysterectomies and women over the age of 65 without any precancerous cells within the last 20 years of screening do not need Pap tests.²³

Screening with the Pap test is a vital health resource for women with its power to drastically reduce cervical cancer I&M. Cervical cancer prevention and screening are currently being further improved with HPV cotesting. The cobas® HPV test was FDA approved in 2014 and is used to detect HPV 16 and HPV 18, along with ten additional high-risk HPV strains. HPV testing should still be performed even if a woman has been vaccinated for the virus. While not officially included in national cervical cancer guidelines, the test can nonetheless help identify

²² "Making Sense of Cervical Cancer." Association of Reproductive Health Professionals, Association of Reproductive Health Professionals,

www.arhp.org/Publications-and-Resources/Patient-Resources/Fact-Sheets/cervical-cancer.

²³ "The American Cancer Society Guidelines for the Prevention and Early Detection of Cervical Cancer." American Cancer Society, American Cancer Society, 2017. Web.

women at higher risk for developing cervical cancer. This test is best used in conjunction with a Pap test as the same cell samples for cytology analysis can be used to detect HPV.²⁴

Like all screening techniques, HPV and Pap cotesting has its limitations. The administration of the Pap test is somewhat limited in that the tool used for specimen collection cannot reach the entirety of the endocervix. The cells are also assessed by individual cytotechnologists, which has an inherent possibility of human error. It is also necessary to recognize the possible psychological distress of patients who receive a false positive lab result or a dysplasia that will clear up on its own.²⁵ Still, the greatest limitation of these screening methods is that although immediate diagnoses can be made, there is no way to differentiate whether abnormalities will clear themselves up or whether they will progress into cancer. This is why following the Pap test guidelines for routine screenings is crucial to the efficacy of cervical cancer prevention.

Conclusions

Organizations like the American Association for Cancer Research are trying to eradicate cervical cancer through the screening methods already available. Cervical cancer is a well-studied disease that is plausibly preventable, yet I&M persist. In the next chapter I will shift my discussion from the biology of cervical cancer to disease screening in relation to public health to begin to elucidate why such a preventable disease is still taking the lives of thousands of American women each year.

²⁴ "Pap and HPV Testing." National Cancer Institute, National Cancer Institute, 9 Sept. 2014, www.cancer.gov/types/cervical/pap-hpv-testing-fact-sheet#q6.

²⁵ "Pap and HPV Testing"

Prevention and Public Health

As discussed in the previous chapter, the key to eradicating cervical cancer is through prevention with the Pap test, HPV vaccine, and HPV test. The Pap test, HPV test, and HPV vaccine are available through primary care physicians, gynecologists, and reproductive health clinics such as Planned Parenthood. While these services are available all across the country, in 2015 only 69% of women aged 18 and older had received a Pap test within the past three years. The inadequate implementation of Pap test is particularly concerning because as Dr. Vicki Benard, the Branch Chief of the Cancer Surveillance Branch in CDC's Division of Cancer Prevention and Control, has stated, "regardless of the improvement in prevention methods, most cervical cancer occurs in women who have not had recent screening."

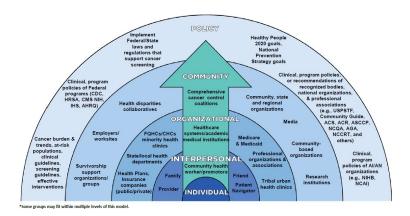
The powers of the Pap test, HPV test, and HPV vaccine are then defined socially in their implementation. Therefore their potential is innately provisional as their successes depend on their utilization. This can be understood by contextualizing these technologies within the STS framework of the *Social Construction of Technology* (SCOT). The SCOT model provides a foundation for understanding the complex relationship between people, society as a whole, and the science and technology in which the society uses. This theory suggests that human behavior shapes a technology while social context shapes its usage. Bruno Latour's *Actor Network Theory* (ANT) further suggests that technology is not socially inanimate but rather has intrinsic

²⁶ "National Center for Health Statistics." Centers for Disease Control and Prevention. Centers for Disease Control and Prevention, 03 May 2017. Web. 24 Nov. 2017.

²⁷ Benard, V. B. et al. "The Effectiveness of Targeting Never or Rarely Screened Women in a National Cervical Cancer Screening Program for Underserved Women." *Cancer causes & control*: CCC 26.5 (2015): 713–719. PMC.

reciprocal and changing relationships with society—technological and scientific advancements interact with humans as both actors comprise a complex network of relationships and functionalities. Using these models to conceptualize cervical cancer prevention services suggests that the power of these advancements depends on their social contexts. In this chapter, I will use this conceptual understanding of cervical cancer preventative services and their implementation to assess areas of interest for public health agencies and programs.

With the existing prevention technology already effective and available, it then becomes a matter of public health to address and improve its use among American women. Never or rarely screened women have disproportionate rates of cervical cancer I&M. These women should then be prioritized by outreach programs that provide access to screening methods. To address this, the CDC created the National Breast and Cervical Cancer Early Detection Program (NBCCEDP) in 1990 to provide "low-income, uninsured, and underserved women access to timely breast and cervical cancer screening and diagnostic services" in order to increase screening use. The NBCCEDP operates under the social ecological model of preventative healthcare as demonstrated below:



²⁸ "National Breast and Cervical Cancer Early Detection Program (NBCCEDP)." Centers for Disease Control and Prevention. Centers for Disease Control and Prevention, 14 Sept. 2017. Web.

Fig. 2. The CDC's social ecological model of preventative healthcare. Source: "Social Ecological Model." *Centers for Disease Control and Prevention*. Centers for Disease Control and Prevention, 27 Oct. 2015. Web.

This model was created to demonstrate the "myriad of factors that affect health outcomes" so that providers and community groups can dynamically implement effective activities and interventions to best serve target populations.²⁹ The social ecological approach practiced by the NBCCEDP reflects the importance of both treating individuals and creating structures to improve long-term accessibility. The NBCCEDP is currently the only national screening program for cervical cancer in the U.S. and provides Pap tests, HPV tests, pelvic exams, diagnostic testing, and referrals for treatment along with mammograms and clinical breast exams. This program receives of a lot clientele nationwide; from July of 2002 to June of 2012, 1,485,251 women received their first Pap test via the NBCCEDP.³⁰

The NBCCEDP is an exemplary outreach program for under-screened women that are particularly at risk for developing cervical cancer. Still, it is only one program and is faced with challenges of developing culturally adaptive materials, limited staff, and limited resources.³¹ As a matter of public health, more programs need to be implemented to specifically target at risk groups and programs such as the NBCCEDP should receive more funding for the possibly life-saving work they do. In the U.S., "older women, racial minorities, and women living in rural areas in the South have a higher disease burden," and should therefore be specifically provided with access and information about screening.³²

-

²⁹ Levano, Whitney, et al. "Public Education and Targeted Outreach to Underserved Women through the National Breast and Cervical Cancer Early Detection Program." *Cancer* 120.S16 (2014): 2591-596. Web.

³⁰ Benard 2015

³¹ Levano 2014

³² Benard 2015

Public health policies and programs must also address the geographical trends in cervical cancer I&M. Southern rural areas are of particular concern for public health programs. There are higher rates of both cervical cancer I&M and women who have not been screened within the past 5 years in the South relative to other census regions.³³

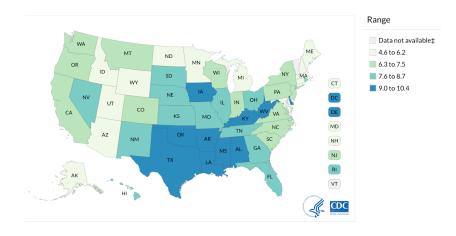


Fig. 3. Cervical cancer incidence rates per 100,000 women in 2014. Source: "Gynecologic Cancers." *Centers for Disease Control and Prevention*. Centers for Disease Control and Prevention, 07 June 2017. Web.

Appalachia, southeastern Atlantic states, the lower Mississippi Valley, and areas along the U.S.-Mexico border display disproportionately high rates of cervical cancer I&M. Data from the 2000 U.S. census has indicated that in relation to non-metropolitan areas, Southern rural areas demonstrate higher poverty, higher unemployment rates, and lower median family incomes—all of which may increase risk of inadequate screening. Targeting rural areas is then essential as resource deprivation and low socioeconomic status have demonstrated to be particularly strong determinants of cervical cancer I&M.³⁴ Affluent Southern communities display similar rates of cervical cancer I&M to metropolitan rates which demonstrates the effects

³³ Benard, V. B., et al. "Vital signs: Cervical cancer incidence, mortality, and screening - united states, 2007-2012.". Atlanta: U.S. Center for Disease Control (2014).

³⁴ Singh, G. K. (2012). Rural-urban trends and patterns in cervical cancer mortality, incidence, stage, and survival in the united states, 1950-2008. *Journal of Community Health*, 37(1), 217-23.

of poverty, unemployment, and family income have on disease screening and prevention. Thus, Southern-rural women of low socioeconomic standing must be targeted as well as women from other medically underserved areas and high-risk population in metropolitan areas.³⁵

Racial-Ethnic Disparities

Women of color are disproportionately affected by cervical cancer, demonstrating an apparent inverse relationship between privilege and mortality.³⁶ The figure below demonstrates age-adjusted cervical cancer incidence rates by ethnicity in the U.S. from 2009-2013.

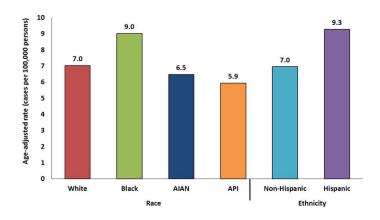


Fig. 4. Cervical cancer incidence per 100,000 women by ethnicity. "AIAN" represents American Indian/Alaska Native and "API" represents Asian/Pacific Islander. Source: "HPV and Cancer." *Centers for Disease Control and Prevention*. Centers for Disease Control and Prevention, 03 Mar. 2017. Web.

Asian/Pacific Islander women and Native American/Alaskan Native women have higher rates of inadequate cervical cancer screening compared to other racial-ethnic groups in the U.S.³⁷ In fact, Vietnamese women have been the most likely group to be under-screened for cervical

³⁵ Singh 2012

³⁶Note: In this section, racial-ethnic qualifiers used are verbatim from their sources. Census data and other longitudinal reports provide options for racial-ethnic categories that may not accurately describe the way in which the women identify.

³⁷ Benard 2014

cancer in recent years.³⁸ Black and Hispanic women also exhibit inadequate rates of screening and consequently cervical cancer I&M compared to white women. However in an attempt to compensate for higher cervical cancer incidence rates for black and Hispanic women relative to white women,³⁹ Asian—especially Asian immigrant—women have unfortunately been neglected by general health campaigns that have otherwise helped the general population.⁴⁰

Of the major racial-ethnic groups in the U.S., Hispanic whites had the highest incidence rate of invasive cervical cancer from 1992-2003.⁴¹ In this time period, premalignant adenocarcinoma was more likely to go undetected among this group than other more frequently screened groups.⁴² In order to address this disparity between non-Hispanic white and Hispanic white women, the state of California implemented public health interventions such as telephone screening reminders and educational messages in Spanish, the use of female physicians and interpreters, and coalitions among trusted community organizations that targeted Hispanic women across the state.⁴³ These interventions have proved successful as cervical cancer trends have recently demonstrated a closing gap between non-Hispanic white and Hispanic white incidence. Still, as of 2014, Hispanic women were the only racial-ethnic group to have cervical cancer as one of the top ten causes of cancer-related deaths.⁴⁴

³⁸ Ponce, Ninez A., et al. "Is There a Language Divide in Pap Test Use?" Medical Care, vol. 44, no. 11, 2006, pp. 998–1004. JSTOR, JSTOR, www.jstor.org/stable/41219554.

³⁹ Benard 2014

⁴⁰ Ponce 2006

⁴¹ McDougall, Jean A., et al. "Racial and Ethnic Disparities in Cervical Cancer Incidence Rates in the United States, 1992-2003." Cancer Causes & Control 18.10 (2007): 1175-86. Print.

⁴² McDougall 2007

⁴³ Schleicher, E. (2007). Immigrant Women and Cervical Cancer Prevention in the United States. Baltimore, MD. Women's and Children's Health Policy Center. Johns Hopkins Bloomberg School of Public Health.

⁴⁴ "United States Cancer Statistics: 1999-2014 Incidence and Mortality Web-based Report." *Centers for Disease Control and Prevention*. U.S. Department of Health and Human Services, 2017. Web. 14 Jan. 2018.

Though cervical cancer incidence rates are particularly high for both black and Hispanic women, death rates are nonetheless highest for black women.⁴⁵ Among a host of detrimental, systemic injustices, black women have historically been medically underserved. Current public health campaigns specifically aimed at increasing screening among low-income minority women have demonstrated progress in reducing this disparity. Since the implementation of such programs, the rate of cervical cancer incidence in black women with median household income at or below \$40,000 has recently decreased.⁴⁶

There are also variations in reported barriers to access of cervical cancer screening among U.S. racial-ethnic groups. In March of 2016, Planned Parenthood surveyed a nationally and ethnically representative sample of 1,104 women at or above the age of 18 across the U.S. The survey was conducted at the University of Chicago and focused on women's experiences, knowledge, and beliefs regarding cervical and breast cancer screening. When asked whether they had ever been screened for cervical cancer, 81% of white women said yes while only 64% of black and Hispanic women said yes. Black, Hispanic, and white women also differed in their reported barriers to access. White women had the lowest rates of citing the any of the six surveyed barriers in response to questions about why they have not been adequately screened.⁴⁷ The following table conveys the rates of reported barriers to access from this study:

⁴⁵ Benard 2014

⁴⁶ Benard 2015

⁴⁷ Results Summary: National Survey of Women's Knowledge of Recommended Screenings for Breast and Cervical Cancer. Rep. Planned Parenthood Federation of America, 2017. Web.

CERVICAL CANCER			
Barriers	Black	Hispanic	White
TIME to go to the doctor	27%	31%	18%
ON DISTANCE to doctor's office	22%	20%	11%
\$ COST of the test	32%	42%	19%
FEAR of the test	29%	29%	12%
FEAR of the results	40%	38%	14%
DON'T think they are at risk	27%	32%	15%

Fig. 5. Perception of barriers to access among black, Hispanic, and white women. Source: *Results Summary:*National Survey of Women's Knowledge of Recommended Screenings for Breast and Cervical Cancer. Rep. Planned
Parenthood Federation of America, 2017. Web.

It is imperative that public health measures to increase cervical cancer screening focus especially on women of color. Outreach programs have proved to effectively reduce racial-ethnic disparities in cervical cancer I&M when specifically addressing these medically underserved populations and they should continue to do so.

Mortality

The most effective method of decreasing cervical cancer mortality is through prevention and early diagnosis. Data from the Surveillance, Epidemiology, and End Results Program (SEER) found the overall 5-year survival rate for cervical cancer patients to be 67.1% from 2007-2013.⁴⁸ The figure below demonstrates the continually decreasing and subsequent plateau in cervical cancer I&M from 1975-2009. It is hypothesized that the rates continued to decrease slowly before the turn of the century as the Pap test was still spreading nationwide as a preventative and diagnostic tool for cervical cancer.

⁴⁸ SEER Cancer Stat Facts: Cervical Cancer. National Cancer Institute. Bethesda, MD, http://seer.cancer.gov/statfacts/html/cervix.html

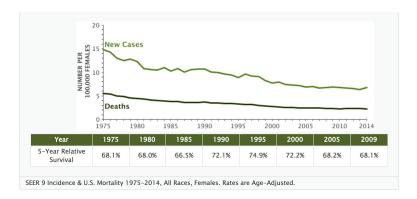


Fig. 6. Trends in 5-year relative incidence, mortality, and survival rates for cervical cancer per 100,000 females. Source: SEER Cancer Stat Facts: Cervical Cancer. *National Cancer Institute*.

Bethesda, MD, http://seer.cancer.gov/statfacts/html/cervix.html

The 5-year survival rate drastically decreases with high cervical cancer staging. The survival rates for localized, regional (cancer has spread to surrounding lymph nodes), and distant (cancer fully metastasized) stages are 91.5%, 57.1%, and 17.3%, respectively.⁴⁹ Due to a lack of symptoms in early stages of the disease, women who are not being regularly screened will not develop signs until late stages and will then have a relatively low survival rate. This demonstrates the importance of following screening guidelines as they offer both prevention and diagnosis of the disease in its early stages without persistent symptoms.

The disparity between early and late stage survival rates demonstrate just one trend cervical cancer mortality. There are also marked mortality trends between age groups and racial-ethnic groups. Cervical cancer is most frequently diagnosed between the ages of 35 and 44 years; 47.6% of new cases from 2010-2014 were in women between the ages of 35 and 54 years. While the median age at diagnosis is 49 years, the median age at death is 58 years. ⁵⁰

As for racial-ethnic groups affected, black women are most likely to die from the disease with 3.8 deaths per 100,000 women, while Asian/Pacific Islander women are least likely to die

21

⁴⁹ SEER Cancer Stat Facts: Cervical Cancer. National Cancer Institute

⁵⁰ SEER Cancer Stat Facts: Cervical Cancer. National Cancer Institute

with 1.7 deaths per 100,000 women.⁵¹ Black women unjustly bear a relatively greater burden of the disease, especially compared to their white counterparts. From 2004-2009, the 5 year survival rate for white women was 63.5% while the survival rate from black women was markedly lower at 55.5%.⁵²

In order to reduce cervical cancer mortality, public health measures must address the most at-risk groups for dying of the disease. Women aged 34-55 years must be screened according to CDC guidelines and public health policy makers must address the systemic racial-ethnic disparities in mortality. Nonetheless, the foundation of decreasing mortality of cervical cancer is with preventative care and public health measures to increase such care.

Access

Those with health insurance or who can otherwise afford preventative healthcare for cervical cancer may use their primary care physician or a local Obstetrics and Gynecology (OB/GYN) practice for Pap tests, HPV tests, and HPV vaccines. For those who are unable to do so, the most reliable options for care are Planned Parenthood (including its affiliates) and Federally Qualified Health Centers (FQHCs). Affiliate Planned Parenthood health centers are locally governed offices that operate under and are funded by the Planned Parenthood Federation of America. Planned Parenthood has over 650 health centers across the U.S. In 2017—the organization's centennial—Planned Parenthood and its partners served 4,900,000 people. 2,470,000 of these patients visited at least one of the 56 Planned Parenthood affiliated health centers. Additionally, Planned Parenthood served 1,500,000 clients in affiliated educational

⁵¹ SEER Cancer Stat Facts: Cervical Cancer. National Cancer Institute

⁵² Benard, V. B., et al. "Cervical cancer survival in the United States by race and stage (2001-2009): Findings from the CONCORD-2 study." *Cancer* 123 (2017): 5119–5137.

programs. Of the patients who use Planned Parenthood for their reproductive and sexual healthcare needs, 75% have incomes at or below 150% of the federal poverty level.⁵³ Furthermore, Planned Parenthood offers services (including Pap tests, HPV tests, and HPV vaccines and treatment or referrals for cervical dysplasia and cancer) primarily to low-income individuals, though these services are available to people of all economic positions.

Similarly to Planned Parenthood, FQHCs provide affordable healthcare for individuals with little or no other access to primary care. FQHCs are "community-based health care providers that receive funds from the Health Resources and Services Administration (HRSA) Health Center Program to provide primary care services in underserved areas." FQHCs accept Medicaid and provide care on a sliding fee scale based on ability to pay. In 2015 there were 1275 FQHCs across the U.S. which received nearly 97 million patient visits. Under the section 330 of the Public Health Service Act (PHSA), FQHCs are required to provide "voluntary family planning," among their other primary care services such as mental healthcare, dentistry, and other preventative care.

-

⁵³ By The Numbers. Rep. Planned Parenthood Federation of America, 2017. Web.

⁵⁴ "Federally Qualified Health Centers." Health Resources & Services Administration. N.p., 01 Apr. 2017. Web. 21 Dec. 2017

⁵⁵ "Community Health Center Delivery Sites and Patient Visits: Total CHCs, 2015." The Henry J. Kaiser Family Foundation. N.p., n.d. Web.

⁵⁶ Best, Alicia L, PhD,M.P.H., C.H.E.S., et al. "Examining the Influence of Cost Concern and Awareness of Low-Cost Health Care on Cancer Screening among the Medically Underserved." Journal of health care for the poor and underserved 28.1 (2017): 79-87. ProQuest. Web. 21 Dec. 2017.

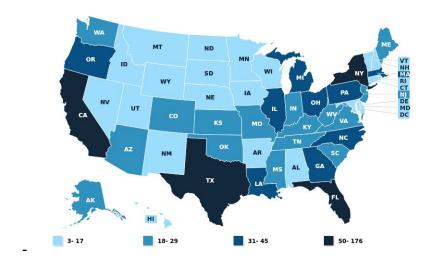


Fig. 7. Number of FQHC locations by state. Source: "Community Health Center Delivery Sites and Patient Visits: Total CHCs, 2015." *The Henry J. Kaiser Family Foundation*. N.p., n.d. Web.

However, Planned Parenthood and FQHCs each face inherent limitations in providing care. There are nearly twice as many FQHCs than Planned Parenthood centers nationwide. Planned Parenthood centers are most concentrated in metropolitan areas and offer limited access in rural areas. The organization faces difficulties when attempting to expand in and open new locations in certain areas of the U.S. due to backlash against its abortion services. Its health centers are also often located in discreet areas for patient confidentiality and protection. Moreover, Planned Parenthood locations must grapple with anti-choice protests that may endanger the mental and physical well-being of its patients.

FQHCs are more accessible in the U.S. than Planned Parenthood locations, though their services are only available to low-income Americans rather than accepting any and all patients. FQHCs are also frequently "the only source of mental health care, dental care, and treatment for patients with serious and chronic health conditions such as hypertension, cardiovascular disease, and diabetes," and so most staff members are not specialized in women's healthcare. ⁵⁷ Because

⁵⁷ Rosenbaum, Sara. J.D. "Planned Parenthood, Community Health Centers, And Women's Health: Getting The Facts Right," Health Affairs Blog, September 2, 2015.

24

of this, there is also a larger patient population for FQHCs than Planned Parenthood which results in increased waiting time for appointments and limited amount of time that a patient has with their healthcare provider. Though there is a large presence of FQHCs across the country, the medically underserved are still undertreated due to lack of awareness and community outreach. A 2015 study of FQHC use among medically underserved populations found that over 66% of the participants were not aware of their local low-cost health services.⁵⁸

Planned Parenthood and FQHCs are both primary care and OB/GYN office alternatives with the resources to provide cervical cancer preventative care for low-income women. Within the public health lens, their services must be made more accessible by "increas[ing] awareness of available resources among medically underserved populations" in order to expand the use of Pap tests, HPV test, and HPV vaccine among women. ⁵⁹ Though this does not fix the more complex issues that each resource faces, public awareness of their services and the importance of preventative care that they both offer is a necessary step in reducing cervical cancer I&M. Planned Parenthood and its preventative services for cervical cancer will be further elaborated upon in *Chapter 5: Planned Parenthood Under Attack*.

Title X

The Title X Family Planning program was introduced in the 1970s under the Nixon administration as a part of the PHSA. Title X, Medicaid, and Section 330 of PHSA together are the foremost sources of federal funding for more than 10,000 safety-net clinics that provide

-

⁵⁸ Best 2017

⁵⁹ Best 2017

reproductive health services to low-income individuals nationwide.⁶⁰ The program specifically supports health centers that provide contraceptive and preventative care to low-income, uninsured, young women of diverse racial-ethnic backgrounds.⁶¹ The Title X program targets medically underserved individuals and communities that are often non-white; about 21% of Title X patients identify as black and 32% identify as Latinx.⁶²

In 2015 more than 4,000 clinics across the nation received Title X funding, including Planned Parenthood centers, FQHCs, health departments, and private non-profits specializing in family planning. In 2015, Title X-funded health centers provided care for 3.6 million women, 743,000 of whom were screened for cervical cancer —though this figure (~20%) may seem low, it is important to remember that Pap tests are recommended every 3-5 years based on patient age and medical history, so not all women need to be screened annually. In short, Title X funding is an important, widespread public health measure that provides reproductive and preventative healthcare to medically underserved women. A crucial aspect of the program is that it funds various organizations that serve uninsured women, such as Planned Parenthood and FQHCs; public health funding must be inclusive of all providers of cervical cancer screening and prevention services in order to combat government biases towards more controversial or lesser known providers.

-

⁶⁰ Ranji, Usha, et al. "Financing Family Planning Services for Low-income Women: The Role of Public Programs." The Henry J. Kaiser Family Foundation. N.p., 31 May 2017. Web.

⁶¹ Fowler C, et al. Trends in Cervical Cancer Screening in Title X-Funded Health Centers — United States, 2005–2015. MMWR Morb Mortal Wkly Rep 2017;66:981–985.

⁶² Ranji 2017

⁶³ Ranji 2017

⁶⁴ Fowler 2017

Conclusions

This chapter discussed racial-ethnic and geographical trends in cervical cancer I&M as a framework for improving public health measures to increase screening. Evidently, non-white and Southern rural women are particularly at risk for inadequate access to preventative diagnostic tools and should accordingly be targeted for improvement in Pap test use. Additionally, Planned Parenthood and FQHCs exemplify clinical focus on providing adequate care for women otherwise unable to afford Pap test through primary care or OB/GYN offices. Title X supplies funding for clinics that offer family planning services, which cervical cancer prevention methods are included under. With this foundation of public health information regarding cervical cancer, I will specifically elaborate on significant barriers to access of preventative care of the disease in the following chapter.

CHAPTER 4: BARRIERS TO ACCESS

In this chapter I will analyze and discuss lower levels of income, health insurance, education, and health literacy, as well as immigration status, stigma, and gender identity as significant barriers to access of cervical cancer screening and preventative care. Each of the following barriers to access contributes to the prevalence of cervical cancer I&M that would otherwise be nearly eradicated given equal and substantial access to such care.

Income

Income is an appreciable determinant of nearly all aspects of American life, including women's healthcare. On a national scale, low-income populated low-resource areas consistently have cervical cancer screening inadequacies.⁶⁵ Statistically, low-income women are less likely to have received a Pap test within the last three years in accordance with the CDC screening guidelines for cervical cancer.⁶⁶ Due to insufficient access to screening and healthcare, women of low socioeconomic status also (unfortunately) exhibit relatively higher mortality rates from the disease.⁶⁷

Medically underserved populations cite high cost and lack of awareness as significant barriers to access of healthcare even when referred to low-cost services at FQHCs.⁶⁸

⁶⁵ Blumenthal, P. D., et al. "Training for Cervical Cancer Prevention Programs in Low-Resource Settings: Focus on Visual Inspection with Acetic Acid and Cryotherapy." International Journal of Gynecology & Obstetrics 89: S30–S37(2005). Web.

⁶⁶ "Cancer Trends Progress Report." National Cancer Institute. National Cancer Institute, Jan. 2017. Web.

⁶⁷ Du, Ping, et al. "The Roles of Social Domains, Behavioral Risk, Health Care Resources, and Chlamydia in Spatial Clusters of US Cervical Cancer Mortality: Not all the Clusters are the Same." Cancer Causes & Control 21.10 (2010): 1669-83. Print.

⁶⁸ Best 2017

Additionally, though the HPV vaccine may be readily available at little to no cost through programs that are designed to provide healthcare to low-income individuals such as Medicaid, women of low-socioeconomic standing are most likely to have limited or no knowledge regarding the vaccine and its relation to cervical cancer.⁶⁹ Income unjustly dictates both a woman's access to cervical cancer prevention and her knowledge regarding critical prevention methods such as the HPV vaccine.

The Alliance for Cervical Cancer Prevention (AACP) has attempted to combat the relatively higher risk of cervical cancer I&M among low-income women by adjusting screening methods to be more cost effective in low resource areas. For Pap test providers with limited funding such as free clinics, the AACP has recommended a focus on visual inspection methods that cost less than traditional Pap tests. The use of acetic acid and Lugol's iodine for visual inspection may reduce resource allocation for cervical cancer screening, yet requires special additional training for nurses and physicians that is a "time-consuming learning process." This is thematic of common measures to reduce long-term treatment and resource costs as this measure requires initial monetary investment in medical training that low resource areas may not have.

Income, an evident mediating factor for cervical cancer I&M, has also displayed trends in cervical cancer staging upon diagnosis. Women in low-income areas are significantly more likely to be diagnosed with the disease once it has already metastasized, a probable explanation for the relatively higher mortality rates among low-income women.⁷¹ Moreover income trends in

⁶⁹ Breitkopf, Carmen R., et al. "Poor Knowledge regarding the Pap Test among Low-Income Women Undergoing Routine Screening." Perspectives on Sexual and Reproductive Health 37.2 (2005): 78-84. Print.

⁷⁰ Blumenthal 2005; S31

⁷¹ Mitchell, Janet B., and Lauren A. McCormack. "Time Trends in Late-Stage Diagnosis of Cervical Cancer: Differences by Race/Ethnicity and Income." Medical Care 35.12 (1997): 1220–1224.

cervical cancer have been prevalent for decades as lower-income women have exhibited higher rates of disease incidence. The income disparities are powerful enough that as incidence rates have steadily declined among middle and high income women, low-income women have faced periods of simultaneous increase in incidence. From 1976-1990, high-income and middle-income women exhibited a 1.2% and 1.3% *decrease* (respectively) of late stage diagnosis of the disease. Meanwhile, during the same time period low-income women demonstrated a 2.0% *increase* in late stage diagnosis.

While cervical cancer I&M have decreased drastically since the introduction of the Pap test, low-income women (among other disenfranchised groups) have been left behind. Income has prevailed as a barrier to access of preventative care for the disease even though the Pap test has been proven to be effective at a relatively low price. The effects of income on health insurance and Pap test use are explored further in the following section.

Health Insurance

Without universal healthcare in the U.S., whether or not one can afford health insurance determines the adequacy of their medical care. In the absence health insurance, a Pap test costs \$50-200⁷², the full dosage of the HPV vaccine costs \$390-500⁷³, and the DNA HPV tests costs \$80-100⁷⁴ depending on the healthcare provider. Thus, co-testing for cervical cancer—the most recommended screening method—could cost up to \$300 per screening visit. Low-income Americans without health insurance may be unwilling or unable to afford screening and

⁷² Fayed, Lisa. "How Much Does a Pap Smear Cost Without Insurance?" *Verywell*, Verywell, June 2017, Web.

⁷³ Fayed, Lisa. "Does Insurance Cover HPV Vaccine Costs?" *Verywell*. Verwell, 27 Apr. 2017. Web.

⁷⁴ Chura, Justin, MD. "FDA Approves HPV DNA Test for Cervical Cancer Screening." Cancer Treatment Centers of America. Cancer Treatment Centers of America, 1 May 2014. Web.

therefore go without adequate preventative care. This is evident by the fact that, statistically, uninsured or underinsured women have Pap tests and mammograms less frequently than insured women.⁷⁵

Approximately of 13% of adult American women are uninsured, with certain groups disproportionately affected by lack of insurance including black women (15%), Latina women (24%), and low-income women (26%).⁷⁶ Medically underserved women are less likely to be screened for cervical cancer. Between 2007-2012 11.4% of American women had not been screened for cervical cancer. Of these women that had not been screened, 23.1% did not have health insurance and 25% did not have a regular healthcare provider.⁷⁷ Women with a continuous source of healthcare through a regular provider are strikingly 55% more likely to have been screened for cervical cancer than women without.⁷⁸

Women without health insurance or a regular healthcare provider have limited options for accessing care. One way that women may access Pap tests and other cervical cancer prevention methods is through free clinics. There are over 1,200 free and charitable clinics in medically underserved areas across the U.S. that provide care to nearly 2 million people annually. Free and charitable clinics differ from FQHCs because they are privately funded (through donations, grants, etc.) and care is provided primarily if not exclusively by volunteer medical professionals

-

⁷⁵ Karliner, Leah, et al. "Reducing Health Care Disparities for Minority Women in the Era of the Affordable Care Act: Opportunities within Primary Care." *Journal of health care for the poor and underserved* 27.2 (2016): 392-415. ProQuest. Web.

⁷⁶ Karliner 2016

⁷⁷ Benard 2014

⁷⁸ Schleicher, E. (2007). Immigrant Women and Cervical Cancer Prevention in the United States. Baltimore, MD. *Women's and Children's Health Policy Center*. Johns Hopkins Bloomberg School of Public Health.

⁷⁹ "Clinics." *NAFCC*. National Association of Free and Charitable Clinics, 2016. Web.

rather than employed clinic staff.⁸⁰ These clinics offer a variety of health services including women's health. In 2016, 58% of free and charitable clinic patients were women.⁸¹ Though this may seem to be a viable and reliable option for uninsured and underinsured women, free clinics do not have their own resources to provide care. Rather, they rely entirely community resources and donations. More troubling however is that free clinic patients report lower health-related qualities of life and more specifically, female free clinic patients also report lower utilization of Pap tests and HPV vaccination than national statistics.⁸²

As previously mentioned in *Chapter 2: Cervical Cancer as a Disease*, the NBCCEDP provides uninsured, low-income women with preventative women's health care. Uninsured and underinsured women between the ages of 21 and 64 years with income at or below 250% of the federal poverty level are eligible for NBCCEDP services. 11.1% of American women qualify for the program, yet it only serves 6.5% of eligible women. Perhaps due to lack of awareness of the program, reservations about entering it, etc. it is clearly being underutilized across the U.S. Still, 140,073 women *were* screened for cervical cancer through the NBCCEDP in 2016. Of these women, 171 were diagnosed with invasive cervical cancer and 5,919 were diagnosed with premalignant lesions—39% of which were high grade and thus necessitated treatment via removal of the abnormal tissue (for methods of removal, see *Chapter 2: Cervical Cancer as a Disease* subsection "The Pap-Test").⁸³ Evidently, diagnoses of malignant cervical cancer indicates a long-term lack of screening of these women as the disease takes 10-15 years to

⁸⁰ Comparison of Free & Charitable Clinics to Federally Funded Clinics. Alexandria, VA: National Association of Free and Charitable Clinics, n.d. PDF.

^{81 &}quot;Clinics" 2016

⁸² Kamimura, A., et al. (2015). Women in free clinics: An assessment of health-related quality of life for prevention and health education. *Journal of Community Health*, 40(4), 793-801.

⁸³ "National Breast and Cervical Cancer Early Detection Program (NBCCEDP)" 2017

develop once abnormal cells appear. The NBCCEDP must be made more accessible to women unaware of the program as it has demonstrated that medically underserved women eligible for the program have shown patterns of infrequent or inadequate cervical cancer screening.

In order to reduce financial barriers to screening for uninsured and underinsured women, the Affordable Care Act (ACA) of 2010 required that all cancer screening be covered without copay for women enrolled in the insurance program and that private insurance programs must cover the HPV vaccine, Pap test, and HPV testing, often without cost-sharing as well.⁸⁴ This includes breast cancer genetic testing and chemoprevention for women at high risk of developing breast cancer, mammography screenings every 1-2 years for women over the age of 40, cervical cancer screening for sexually active women, and HPV tests for women aged 30 years or older that have had previous normal cytological Pap test results.⁸⁵ Additionally, the ACA has prohibited discontinuation of insurance coverage due to a new diagnosis or pre-existing condition, such as cervical dysplasia and cancer.

A remarkable consequence of ACA provisions is that it has increased usage and full dose completion of the HPV vaccine. A recent study reported that 30% of surveyed unvaccinated adult women were unwilling to pay the approximately \$390 total price for the recommended three doses of the vaccine but *would* choose to receive the vaccine if it were free or at a greatly reduced cost. After the 2010 implementation of the ACA, coverage and prevention provisions demonstrated a "significant increase in the percentage of young adult women who had initiated"

⁸⁴ Results Summary: National Survey of Women's Knowledge of Recommended Screenings for Breast and Cervical Cancer

⁸⁵ "Preventive Care Benefits for Women." *HealthCare.gov*. U.S. Department of Health & Human Services, n.d. Web. 19 Dec. 2017.

⁸⁶ Lipton, B. J., & Decker, S. L. (2015). ACA provisions associated with increase in percentage of young adult women initiating and completing the HPV vaccine. Health Affairs, 34(5), 757-764,1-6.

and completed the HPV vaccine three-dose series," suggesting that cost was notable barrier—even amongst insured women—to access of the prevention method.⁸⁷ The national likelihood of HPV vaccination initiation and completion increased by 7.7 and 5.8 percentage points, respectively, among women aged 19-25 years. This translated to approximately 854,000 women completing the full vaccination series. 88 These findings prove the ACA to be a positive factor in decreasing socioeconomic disparity trends in cervical cancer I&M by preventing the spread of HPV infection among low-income women.

The ACA has also implemented Medicaid expansion to broaden the services and eligibility measures for those who qualify. Adults covered by Medicaid under ACA expansion can receive the HPV vaccine, HPV testing, and Pap tests without cost-sharing in qualifying states. The Vaccines for Children (VFC) program additionally provides the HPV vaccination without cost for children under the age of 18 who are either eligible for Medicaid, uninsured/underinsured, or who identify as American Indian or Alaska Native.⁸⁹

Though the ACA and its Medicaid expansion have the ability to decrease insurance-based barriers to access for cervical cancer preventative care, it is nonetheless a limited and provisional resource for women's healthcare. This is due to both eligibility qualifications and the tentative nature of the ACA under the current White House administration. Medicaid only covers some low-income individuals and families based on income and resources (Medicaid expansion eligibility is based solely on income). Financial qualifications for Medicaid are based on an individual's relation to the federal poverty level.

Number of Household Individuals	Federal Poverty Level for	138% of Federal Poverty Level*
---------------------------------	---------------------------	--------------------------------

⁸⁷ Lipton 2015; 5

⁸⁸ Lipton 2015

^{89 &}quot;The HPV Vaccine: Access and Use in the U.S."

	Household Annual Income	
Single Individual	\$12,060	\$16,643
2	\$16,240	\$22,412
3	\$20,420	\$28,180
4	\$24,600	\$33,948
5	\$28,780	\$39,717
6	\$32,960	\$45,485
7	\$37,140	\$51,254
8	\$41,320	\$57,022

Table 2. 2017 U.S. federal poverty levels for annual incomes of individuals and households. Source: "Federal Poverty Level (FPL)." *HealthCare.gov.* U.S. Centers for Medicare & Medicaid Services, n.d. Web. 09 Jan. 2018.

As demonstrated in the table above, the federal poverty level is quite low considering the cost of living in the U.S. Individuals and households at or below the federal poverty level are financially, socially, and medically underserved, though there are millions of economically disadvantaged people above that line also deserving of otherwise unaffordable healthcare. In short, being above the federal poverty level does not ensure the ability to afford health insurance.

The Trump administration campaigned on the promise of repealing the ACA (often pejoratively referred to as "Obamacare" by Republicans that did not favor the Obama administration) and attempted multiple times to keep this promise within President Trump's first year in office. The ACA is promising for cervical cancer eradication as it provides the necessary screening and prevention methods with little or no copay charges to help low-income women. Trump's 2017 signing of a sweeping tax bill has already repealed the ACA's individual mandate (effective in 2019) and has additionally cut subsidies, insurance enrollment periods, and certain

^{*138%} of the federal poverty level is the income-based criteria for Medicaid under states with expanded coverage.

provisions from the 2010 policy. If the ACA and Medicaid expansion are to be completely repealed, those who depend on its provisions for cervical cancer screenings will face a substantial financial barrier to access of the Pap test, HPV test, and HPV vaccine. Providing universal health-care would ideally eliminate this barrier to access, though the possibility of such a program is unlikely in the U.S. currently.

Free clinics and the NBCCEDP strive to provide considerable healthcare for low-income individuals, though due to funding and public health reasons are unable to equitably allot access to women's health services. Those relying on the ACA and Medicaid expansion are also provisionally provided healthcare coverage given the political threats to repeal such policies. A lack of adequate health insurance prevents women unable to afford preventative services from receiving the care that they deserve. Without affordable women's health services, cervical cancer I&M will continue to prevail among the uninsured and underinsured.

Education

In order to utilize the power of cervical cancer screening and prevention methods, one must first have the knowledge of how and when to use them. Though the CDC has clear recommendations and guidelines for screening, the information is inadequately disseminated to the public. Often, the only access to this information is through primary care visits. Access to scientific and technological information is not egalitarian. A quintessential pillar of STS is the *Sociology of Scientific Knowledge* (SSK) theory that conceptualizes science as a social activity, as scientific and medical information do not exist outside of the context of society. Access and dissemination of knowledge is unequivocally linked to a variety of political, historical, cultural,

and economic factors. Thus, the promulgation of information regarding cervical cancer screening guidelines and treatment options define the potency of the Pap test, HPV vaccine, and HPV test.

In the aforementioned Planned Parenthood survey (see *Chapter 2* subsection "Racial-Ethnic Disparities") 73% of respondents claimed to understand how often they must been screened for cervical cancer—yet only 9% were able to correctly answer that "that the average 21-29 year old woman should be checked every 3 years, or that the average 30-64 year old woman should be checked every 3-5 years." The overwhelming misunderstanding of screening guidelines is concerning as a lack of education does not only decrease Pap test use, but the ability to conceptualize what an abnormal results means and how to proceed. The lack of accessible knowledge of cervical cancer further results in many people not knowing that HPV—the most common STD in the U.S.—causes the disease. In the absence of such knowledge, the onus is unjustly placed upon women to encourage one another to receive Pap tests. Still, only 52% of surveyed women reported encouraging other women in their lives to be screened for cervical cancer. Women deserve to know the importance of the Pap test, HPV, and co-testing in order to protect themselves from cervical cancer.

Moreover, sexual health education in school is frequently the first formal information that adolescents receive regarding their reproductive anatomy and sexuality. Currently, only 24 states and the District of Columbia mandate sex education and only 13 states require that sex education be medically accurate. ⁹² There are no federal or state laws that require women's health education. This is particularly troubling as knowledge about HPV and Pap testing must be disseminated

-

⁹⁰ Results Summary: National Survey of Women's Knowledge of Recommended Screenings for Breast and Cervical Cancer

⁹¹ Results Summary: National Survey of Women's Knowledge of Recommended Screenings for Breast and Cervical Cancer

^{92 &}quot;Sex and HIV Education." Guttmacher Institute. Guttmacher Institute, 02 Jan. 2018. Web.

earlier rather than later as younger women are at greater risk for contracting HPV than older women.⁹³ Additionally, 37 states require that information on abstinence be required, 26 of which require it be stressed as the best prevention for unplanned pregnancy and STIs.⁹⁴

A lack of comprehensive sex or sexual health education leaves adolescents unaware of the most effective practices for safe sex. While Pap testing is a highly effective screening tool, the best way to prevent cervical cancer is by not contracting HPV. Thus, students who are not given information on Pap tests, HPV, and STI protection methods are at risk for cervical cancer later in life as they are not adequately prepared to practice safe sex, get the HPV vaccine, or receive proper healthcare when they become sexually active. Studies have demonstrated a statistically significant positive effect on sexual risk reduction with proper sexual health education, particularly for socially and disadvantaged women—a phenomenon with the potential effect to reduce HPV transmission and consequent cervical cancer incidence.⁹⁵

When sexual health education *is* provided in schools it is primarily catered to heterosexual students. Only 12 states require discussion of sexual orientation; 9 states require it to be inclusive and 3 states require any discussion be negative. While the use of condoms for heterosexual intercourse is effective in preventing the spread of HPV, queer women are rarely if ever taught how to prevent STIs. Therefore a lack of queer education has the ability to put queer women at risk for contracting HPV. HPV can be transmitted through skin-to-skin contact and is common among queer women—sexual transmission of HPV then likely occurs between female

_

⁹³ Breitkopf 2005

^{94 &}quot;Sex and HIV Education"

⁹⁵ Shepherd, J., et al. "Cervical Cancer and Sexual Lifestyle: A Systematic Review of Health Education Interventions Targeted at Women." Health Education Research 15.6 (2000): 681-94. Web.

^{96 &}quot;Sex and HIV Education"

sex partners.⁹⁷ Plausibly due to the lack of STI prevention information for queer women, the use of barrier protection such as gloves for digital sex, condoms for sex toys, and latex or plastic barriers for oral-genital sex between women is infrequent.⁹⁸ This same lack of information may also contribute to the significantly lower rates of timely Pap testing among lesbian and bisexual women.⁹⁹ General sexual health education is especially important for lesbian and bisexual women, as many do not necessitate birth control—birth control prescriptions are the most common reason for OB/GYN visits where screening information is readily available.¹⁰⁰

Though sexual and women's health education is most effective in preventing the spread of HPV and cervical cancer screening when taught at younger ages before the initiation of sexual activity, the information should also be provided outside of the classroom. Organizations such as Planned Parenthood provide educational outreach programs and accessible online information regarding STI protection, cervical cancer, and screening guidelines. Free clinics may as well provide health education programs on cervical cancer prevention. In order to inform women effectively, these programs should focus on perceptions of the disease, preventative interventions, and treatment options as well as the dissemination of factual knowledge. ¹⁰¹

A lack of education and knowledge regarding cervical cancer screening guidelines and the disease's connection to HPV infection causes another barrier to access of cervical cancer prevention. Without widespread understanding of cervical cancer screening and prevention it

⁹⁷ "Special Populations." *Centers for Disease Control and Prevention*. Centers for Disease Control and Prevention, 25 Jan. 2017. Web.

^{98 &}quot;Special Populations"

⁹⁹ Solazzo, Alexa L., et al. "Cancer Screening Utilization among U.S. Women: How Mammogram and Pap Test use Varies among Heterosexual, Lesbian, and Bisexual Women." Population Research and Policy Review 36.3 (2017): 357-77. ProOuest. Web. 28 Dec. 2017.

¹⁰⁰ Petterson, Stephen M., et al. "Trends in Office-Based Care for Reproductive-Aged Women According to Physician Specialty: A Ten-Year Study." *Journal of Women's Health* 23.12 (2014): 1021-026. Web.

cannot be expected that women will receive Pap tests that meet the CDC screening guidelines.

Therefore, in order to remove this barrier and increase Pap test use, there must be public health campaigns and women's health education to make cervical cancer knowledge more accessible.

Health Literacy and Access for Non-English Speakers

Health literacy is a "critical skill set that enables an individual to navigate the healthcare system," for both native and non-native English speakers. Health literacy provides patients with the capacity to comprehend basic health information and communicate within their healthcare systems. Having this skill is vital for knowing when to seek care, how to communicate with medical professionals, and most importantly, for making informed healthcare decisions for oneself and family. Given that the U.S. is culturally and linguistically diverse, health literacy and access to resources to improve these skills are necessary for non-native English speakers who are seeking care. As screening guidelines fluctuate and follow up appointments are recommended within the context of cervical cancer screening and prevention, health literacy has become an important component of comprehensive access to such care. It has therefore become a potential determinant for fundamental reproductive healthcare.

A meta-analysis of English-language studies before May 2014 measuring health literacy and cervical cancer screening by Johns Hopkins School of Nursing found a "significant positive correlation between health literacy and Pap test receipt across ethnically diverse samples." Women with higher health literacy were found more likely to receive cervical cancer screening regardless of ethnicity and language abilities. This shows that those affected by a lack of health

¹⁰² Kim, Kyounghae, et al. "Potential Links between Health Literacy and Cervical Cancer Screening Behaviors: A Systematic Review." *Psycho-oncology* 25.2 (2016): 122-30. Print.

¹⁰³ Kim 2016; 125

literacy are not necessarily non-native English speakers, but also women without proper education in healthcare navigation and terminology. The study suggested that healthcare providers "tended to overestimate their patients' reading levels," leaving many inadequately informed on cervical cancer prevention and the meaning of abnormal test results. Women that do not fully understand their test results and physician recommendations may be too embarrassed or linguistically unable to ask for clarifications. This lack of communication can result in negative adherence to screening guidelines and follow up recommendations that, within a more linguistically inclusive system, could save lives.

Access to medical language and health literacy skills is necessary to improve adherence to screening guidelines across language barriers. It is inappropriate and neglectful for healthcare professionals and public health campaigns to assume a universal baseline of health literacy as it is impacted by both education and language proficiency levels. In order to alleviate this barrier to access to cervical cancer preventative care, medical professionals and community health organizations must understand health literacy inequalities among patient populations and tailor efforts for providing adequate care to varying levels of health literacy.

A secondary data analysis of California Health Interview surveys from 2001-2003 demonstrated that measures to improve health literacy across language barriers is an effective method for improving cervical cancer screening. During this time, Latinx focused public health campaigns targeted native Spanish speakers through providing comprehensive reproductive healthcare and stressing the importance of access to Spanish speaking physicians. Communication in one's language of choice had a strong impact on adherence to screening

_

¹⁰⁴ Kim 2016; 126

guidelines: Latinas interviewed in Spanish were 1.65 times more likely to have had a Pap test within the last three years than those interviewed in English.¹⁰⁵ This elevated adherence to screening guidelines signifies the need for linguistically inclusive healthcare. Providing information and care in Spanish is critical in areas heavily populated by native Spanish speakers because 65% of Hispanics have basic or below basic health literacy, while only 28% of their non-Hispanic white counterparts have basic or below basic health literacy.¹⁰⁶ Subsequent efforts beyond the 2001-2003 health campaigns have successfully tackled the Spanish language barrier to reproductive healthcare access as the gap between Hispanic and white use of the Pap-test is continually closing.¹⁰⁷

However, Spanish is but one of many language barriers that affects Pap test use among American women. While California has increased Latinx use of the Pap-test, there is still much improvement to be made for women that primarily speak Mandarin, Cantonese, Korean, and Vietnamese. Asian immigrant populations speaking languages other than English particularly struggle with health literacy. The aforementioned California study found that nearly 75% of native Korean speakers have difficulty understanding basic medical words and about 70% of native Chinese have difficulty understanding both written information from their doctor and instructions on prescription bottles.¹⁰⁸

For non-native English speakers in the U.S., language barriers may cause difficulty communicating and existing within spaces that are linguistically exclusionary. Access to cervical cancer screening and preventative tools should not be determined by a woman's English

¹⁰⁵ Ponce 2006

¹⁰⁶ Kim 2016; 123

¹⁰⁷ Ponce 2006

¹⁰⁸ Kim 2016; 123

proficiency. In order to effectively increase adherence to cervical cancer guidelines in medically underserved communities, the language barrier to reproductive healthcare access must be tackled through efforts to increase health literacy for all women and specifically help non-native English speakers to communicate with their healthcare provider. Efforts must be made to increase all women's health literacy as it is a foundational step towards promoting screening. Cervical cancer education can only be effective if women have a foundational health literacy to comprehend it.

Immigration Status

In 2010, 13% of the U.S. population was foreign born and that figure has since increased.

109 In an era of marked right-wing xenophobia and racism, immigrants are often a vulnerable group socioeconomically; this is true as well in the context of cervical cancer I&M. A survey by the National Institutes of Health (NIH) found that between 2001-2004, only 61% of recent immigrants to the U.S. reported having a Pap test in the past 3 years as opposed to the 83% of U.S. born women that had done so. 110 Immigrant women are disadvantaged in their reproductive healthcare access by language barriers, lack of insurance, and lack of primary, continuous sources of healthcare that further decrease their rates of regular Pap test use and knowledge of the CDC's screening recommendations. 111 This has resulted in disproportionate rates of I&M of the disease among foreign-born American and U.S.-residing (noncitizen) women.

Immigrants to the U.S. are often subject to lack of education, insurance, and primary care. 112 As previously discussed, one's access to health insurance is a significant determinant of

¹⁰⁹ Reyes, Adriana M., and Patricia Y. Miranda. "Trends in Cancer Screening by Citizenship and Health Insurance,

43

^{2000-2010.&}quot; Journal of Immigrant and Minority Health 17.3 (2015): 644-51. ProQuest. Web. 27 Dec. 2017.

110 De Alba 2005

¹¹¹ Schleicher 2007

¹¹² Ponce 2006

Pap test use and reproductive healthcare as whole. Noncitizen women residing in the U.S. have low rates of insurance coverage even in relation to foreign-born U.S. citizens. In fact, foreign-born non-citizens have 25% lower coverage rates than their foreign-born citizen counterparts. This is likely due to income disparities between foreign-born and native-born Americans as one's income is a strong predictor of the extensiveness of health insurance coverage. Though immigrants have lower levels of unemployment in the U.S., their median weekly income is only 81.3% of the median weekly income of native-born people. Additionally, non-citizen women are as a whole less likely to receive Pap tests than immigrant citizen women, even when data is adjusted for healthcare access, English proficiency, time lived in the U.S. and other sociodemographic factors.

As well as unequal access to health insurance, immigrant women face acculturation, cervical cancer knowledge, symptom awareness, the concept of preventative care, and culture-specific beliefs as barriers to reproductive healthcare. Aforementioned health literacy is a weighty part of the acculturation process of entering the U.S. for non-native English speakers. For immigrants with low health literacy, access as well as adequate patient-provider communication can make receiving a Pap test quite challenging. Moreover, immigrant women of various countries of origin face their own unique barriers to access of cervical cancer preventative care and Pap test use. The NIH study found that lack of cervical cancer knowledge and symptom awareness among immigrant women has resulted in many women reporting absence of symptoms as a major factor for not having a regular Pap test, particularly among

_

¹¹³ Reyes 2015

¹¹⁴ Gillespie, Patrick. "America's Immigrant Economy: More Work, Less Pay." *CNNMoney*, Cable News Network, 19 Aug. 2016, money.cnn.com/2016/08/19/news/economy/us-immigrant-economy/index.html.

¹¹⁵ De Alba 2005

¹¹⁶ Schleicher 2007

Latina and Korean immigrants; Latinas and Vietnamese women display the belief that proper genital hygiene negates the need for a Pap test; Latinas and Southeast Asian women exhibit fatalistic views of the disease and karma, respectively, as factors that undermine prevention strategies.¹¹⁷

The cultural and citizenship specific components of immigrant barriers to access of preventative and diagnostic care of cervical cancer has resulted in striking disparities in I&M of the disease between immigrant and native-born women in the U.S. This stems from relatively lower rates of cervical cancer screening and consultation with healthcare providers among immigrant women that concerningly result in failure to detect and diagnose the disease in a timely manner. Cervical cancer trends among foreign-born and U.S.-born Hispanic women are demonstrative of the impact that immigration has on screening and diagnosis. SEER data from 1998-2008 found that foreign-born Hispanic women were more likely to be diagnosed with cervical cancer in its later stages than U.S.-born Hispanic women. This fact is further substantiated by the fact that rates of cervical cancer greater than 27 per 100,000 have been observed among Hispanic women living in counties with higher proportions of foreign-born residents. Overall, non-citizen Latinx immigrants are as well less likely to attend primary care visits—which are one way to access Pap tests—than the general U.S. population.

¹¹⁷ Schleicher 2007

¹¹⁸ Mcdonald, James Ted, and Jeremiah Neily. "Race, Immigrant Status, and Cancer among Women in the United States." *Journal of Immigrant and Minority Health* 13.1 (2011): 27-35. ProQuest. Web. 27 Dec. 2017.

¹¹⁹ Montealegre, Jane R., et al. "Nativity Disparities in Late-Stage Diagnosis and Cause-Specific Survival among Hispanic Women with Invasive Cervical Cancer: an Analysis of Surveillance, Epidemiology, and End Results Data." *Cancer Causes & Control* 24.11 (2013):985–1994. JSTOR.

¹²⁰ McDougal 2007

¹²¹ Health care for unauthorized immigrants. Committee Opinion No. 627. American College of Obstetricians and Gynecologists. *Obstetrics & Gynecology* 2015;125:755–9.

Among the burdens placed upon immigrants to the U.S., cervical cancer I&M has proved substantial and pervasive. While the rates of cervical cancer mortality among U.S.-born women declined by 17% from 1985-1996, foreign-born mortality continued to increase by 22% during this time. 122 A lack of access to adequate healthcare, insurance, and education has proved a lack of citizenship to be a significant barrier to access of cervical cancer screening. The American College of Obstetrics and Gynecology has advocated for a universal healthcare package for all women, regardless their immigration status—a policy that would include undocumented U.S. residing women as well—in addition to the elimination of barriers to access of health insurance to prevent undue deaths due to breast and gynecological diseases such as cervical cancer. 123 Until major policy and immigrant-targeted outreach programs are adjusted to benefit the rising numbers of immigrants to the U.S., "citizenship will continue to add to the existing disparity affecting the uninsured" and further, disparity affecting cervical cancer I&M. 124

Stigma

While there are various financial and external factors barring access to preventative care for cervical cancer, internalized biases also cause women to delay or refuse care. Stigma about gynecological cancers, using Medicaid, and the HPV vaccine undermine opportunities for cervical cancer prevention for those who otherwise have access to such measures. Firstly, there is an innate discomfort in discussing female reproductive health and behavior within the heteropatriarchal structure of American society. The female reproductive system is something that is not openly discussed among many women. For example, period-shaming by the media,

¹²² Schleicher 2007

¹²³ Health care for unauthorized immigrants. 2015

¹²⁴ Reyes 2015

men, and even other women has led menstruating women to silence their pain and discomfort of PMS symptoms and hide the fact that they are menstruating at all. Reactions of disgust, surprise, and anger towards women talking freely about menstruation further extend to any public discussion of female reproductive health.

The stigmatization of the female reproductive system and sexual behavior has the power to evoke aversion towards gynecological care, even when that care is cancer prevention. Survey research by the gynecological research charity, The Eve Appeal, has shown that 39% of women believe that there is a greater stigma about gynecological cancers than other cancers. There is a rampant, fallacious notion that promiscuity is a cause for gynecological cancers, even though no associations between the two have been scientifically documented. Having multiple sexual partners does not increase the risk of cervical cancer—rather it is whether safe sex is practiced with their partners. The same survey also revealed that 34% of women believe they would be more comfortable discussing gynecological health issues if there was less stigma surrounding them. 126

As previously discussed in *Chapter 2: Cervical Cancer as a Disease*, the CDC currently recommends that children receive the HPV vaccine between ages 11 and 12, presumably before they become sexually active. Still, the 2013 National Immunization Teen Survey indicated that of adolescents aged 13-17, only 37.6% of girls and 13.9% of boys had completed the three dose series of the vaccine. While financial barriers to access have an influence on these low numbers, it is crucial to consider the role of the parents in these scenarios. Most parents cite

¹²⁵ Olaitan, Adeola. "Gynaecological Cancer: 'Women Are Literally Dying of Embarrassment'." *The Guardian*. Guardian News and Media, 08 Sept. 2015. Web.

¹²⁶ Olaitan

¹²⁷ Benard 2014

perceived lack of adequate research on the vaccine for delaying its administration to their adolescent children. 128 Surveyed pediatricians and family practice physicians have reported negative reactions of parents of adolescents upon recommendations that their children receive a vaccine against a sexually transmitted disease. Other hesitant parents worried that vaccinating their children would encourage sexual activity. 129 While these cases are not among the majority of reasons why parents refuse the vaccine, it is nonetheless important to recognize that sex-negative attitudes and the stigmatization of adolescent sexual activity inhibits children from receiving an effective prevention method against cervical cancer. It is critical that younger children, whose parents are more likely to refuse the vaccine for sexual reasons than older adolescents, receive the vaccine before initiating sexual activity because it is most effective when implemented before possible HPV exposure. Beginning the vaccination series at a young age in tandem with screening programs has been estimated to reduce cervical cancer incidence by 93%. While rare, aggressive cases of cervical cancer are inevitable, as the vaccination series and prevention technology improve this number may further increase towards complete eradication. Children deserve the most effective preventative care against cervical cancer, which should not be impeded upon by unhealthy attitudes and stigma regarding teen sexual behavior.

The final case of stigma discussed in this section is shame among Medicaid users. Shame is a significant nonfinancial barrier to all types of medical care that has been long and well documented sociologically. Whether due to internalized or externalized stigma, some Medicaid

¹²⁸ Frances, DiAnna Kinder. "Parental Refusal of the Human Papillomavirus Vaccine." *Journal of Pediatric Health Care* 30.6 (2016): 551 - 557. Print.

¹²⁹ "Accelerating HPV Vaccine Uptake: Urgency for Action to Prevent Cancer: Goal 2: Increase Parents', Caregivers', and Adolescents' Acceptance of HPV Vaccines." *National Institutes of Health*. U.S. Department of Health and Human Services, n.d. Web.

¹³⁰ Benard 2014

users cite the pathologization of poverty as a reason for delaying healthcare. A 2014 study at Columbia University's School of Social Work, Providence Health & Services found that the use of Medicaid and its state-level programs evoked shame in those seeking care and that stigmatizing experiences among patients were associated with lower perceptions of quality of healthcare and with greater unmet medical needs.¹³¹

Medicaid users noted that "every interaction with the healthcare system reminded them they could not afford care without assistance," which has the power to shame people into delaying or refusing care all together. One surveyed Medicaid user claimed that "the kind of insurance you have identifies you as what group you fall in...broke, poor class, the class that is welfare class," which is particularly damaging when visiting a middle-upper class doctor as it invokes the fear that the doctor sees the patient coming in and thinking "man, I'm paying for this." Though this stigma is an internalized fear for some, others are literally told by physicians that they are wasting taxpayer dollars by seeking medical care. Some participants in this study were even told not to use Medicaid for preventative care, even though expanding the use of such care has been one of the goals of the ACA. The shame inflicted upon Medicaid users is then furthered when compounded with the fact that in 2011, one-third of doctors were not accepting new Medicaid patients. 134

Among the participants in the revealing Columbia study, one woman exemplified the effect of Medicaid stigma on cervical cancer prevention in particular. The participant had recently qualified for the Oregon Health Plan (OHP)—an Oregon state Medicaid program

¹³¹ Allen, Heidi, et al. "The Role of Stigma in Access to Health Care for the Poor." *The Milbank Quarterly*, vol. 92, no. 2, 2014, pp. 289–318. JSTOR, JSTOR, www.jstor.org/stable/24369969.

¹³² Allen 2014; 296

¹³³ Allen 2014; 298

¹³⁴ Allen 2014; 304

available to adults who earn up to 138% of the federal poverty level. 135 She went in for a long overdue Pap test at her first primary care visit since being put on OHP. She described her experience as such:

"I felt like I was being judged for not having insurance and for not taking care of me.... I didn't like how he made me feel at all. When I left there, I was just real sad. I was supposed to reschedule an appointment. But since he was rude to me, I didn't reschedule that appointment." 136

Unfortunately, following her negative experience, she did not reschedule or receive a Pap test. The cases reported in the study demonstrate that removing financial barriers is not enough to ensure equal access to healthcare and preventative medicine. American capitalism projects blame on those receiving government subsidies rather than the systems of inequalities that keep people in vulnerable economic positions. Medicaid stigma exemplifies the additional social barriers to preventative care for cervical cancer that remain as other barriers are negated.

Gender Identity

In the age of a powerful emergence of LGBT civil rights activism, *all* people with cervixes must be included in any conversations about preventative care for cervical cancer. This includes transgender men (transmen) and non-binary people that were assigned female at birth (afab). Though the preceding rhetoric of this thesis has conflated *woman* with *having a cervix*, it is necessary to nonetheless recognize that all afab people are both at risk of developing cervical

-

¹³⁵ "Apply for OHP." Oregon Health Authority. Oregon.gov, n.d. Web. 28 Dec. 2017.

¹³⁶ Allen 2014; 304

cancer and are deserving of preventative services. Eradication of cervical cancer is only possible if afab people of all genders are able to access the Pap test, HPV tests, and HPV vaccine.

The majority of transmen do not undergo genital gender affirmation surgery until later in life, if at all, and will then have a cervix for a substantial part of their lives. ¹³⁷ The American College of Obstetricians and Gynecologists has therefore recommended that transmen follow the same cervical cancer screening guidelines as cisgender women. The CDC has also recommended that providers acknowledge the anatomic diversity among transmen and afab non-binary people as many retain a vagina and cervix, leaving them just as at risk for bacterial STDs, cervical HPV, and cervical cancer as cisgender women. ¹³⁸ Consequently, anyone with a cervix, regardless of gender identity, must be screened for cervical cancer.

There is a plethora of circumstances that prevent transmen and afab non-binary people from receiving Pap tests that are outside the scope of this thesis, so this section will focus solely on gender dysphoria and unique difficulties in Pap test analysis for non-cisgender people with cervixes. Gender dysphoria is a documented psychological disorder that "involves a conflict between a person's physical or assigned gender and the gender with which he/she/they identify." Gender dysphoria can cause extreme stress for the individual with the power to completely deter afab trans people from receiving cervical cancer preventative services, which are classified as a part of *women's* health. Gynecologic exams and procedures have been reported by transmen to trigger detrimental dysphoria as they are "often a unique time when extreme emotional

¹³⁷ Peitzmeier, Sarah M., et al. "Female-to-Male Patients have High Prevalence of Unsatisfactory Paps Compared to Non-Transgender Females: Implications for Cervical Cancer Screening." *Journal of General Internal Medicine* 29.5 (2014): 778-84. ProQuest. Web. 28 Dec. 2017.

^{138 &}quot;Special Populations"

¹³⁹ Parekh, Ranna. "What Is Gender Dysphoria?" *American Psychiatric Association*, American Psychiatric Association, Feb. 2016, www.psychiatry.org/patients-families/gender-dysphoria/what-is-gender-dysphoria.

conflict between self-perceptions and physical anatomy are heightened because of physical touch."¹⁴⁰ In efforts to avoid gender dysphoria, transmen may avoid any kind of gynecological exams and Pap tests.

Pap tests are also uniquely challenging for transmen in that there is greater difficulty in obtaining adequate samples for cytological analysis. Inadequate Pap test samples cannot be tested due to insufficient cell counts or obstructions, such as the presence of blood, that prevent cytopathologists from obtaining an adequate analysis and/or diagnosis. Transmen that opt for hormone replacement therapy (HRT) as a part of their transition process are subject to gynecological side effects. Long-term use of intramuscular androgen injections induce vaginal atrophy that causes painful speculum insertion and epithelial atrophy that mimics cervical dysplasia. Testosterone use causes changes in the cervical epithelium and amenorrhea (absence of menstruation) that is likely to cause bleeding and obscure the sample, especially when there is patient/provider discomfort during the test. 141

These challenges cause transmen to be 8.3 times more likely to have an inadequate Pap test sample with a higher likelihood of multiple inadequate tests as well—this is particularly concerning due to the fact that cisgender women with inadequate Pap tests are more likely to develop cervical cancer and conversely, women diagnosed with cervical consequences are more likely to have previously had an inadequate Pap test. Though this cannot be avoided for those on HRT, physicians must be aware of the distinctive biological circumstances that may impact results. Additionally, efforts must be made by reproductive and preventative healthcare providers to foster an environment that provides transmen and afab non-binary people with adequate care

¹⁴⁰ Peitzmeier 2017

¹⁴¹ Peitzmeier 2017

¹⁴² Peitzmeier 2017

and understanding to alleviate as much gender dysphoria as possible. Non-cisgender people with cervixes must also be included when discussing cervical cancer prevention and treatment because one's gender identity should not continue to bar people from life-saving medical practices.

Conclusions

This chapter has demonstrated the influence of income, health insurance, education, health literacy, immigration status, stigma, and gender identity as barriers to access of Pap tests and preventative care for cervical cancer (as well as reproductive healthcare as a whole). Lower income levels and lack of health insurance are powerful financial determinants of cervical cancer I&M trends, while immigration status, health literacy, stigma, and gender identity are demonstrative of social and group-specific trends. While these injustices must be tackled in order to drastically reduce if not eradicate cervical cancer in the U.S., the foundation of increasing Pap test use is through public and private health education. Without readily available access to CDC screening guidelines and knowledge regarding one's own healthcare responsibility, women will continue to by systemically underscreened and further barred from access to Pap tests, HPV tests, and the HPV vaccine—especially women without a continuous healthcare provider to remind and educate them about Pap testing and pelvic exams. The aforementioned barriers to access in this chapter signify the critical need for adjustments in the healthcare system, education system, and social notions regarding women's bodies. In the following chapter I will use Planned Parenthood as a case study to examine the detrimental impact of decreasing access to reproductive healthcare as a demonstration of these barriers.

Non-sexual Health Services

Planned Parenthood and its affiliate health centers are widely known for providing STD testing, contraceptive care and more controversially, abortions. However, the organization offers a wide range of non-sexual health services including, but not limited to, general healthcare and screening for breast, cervical, ovarian, and testicular cancers. The CDC lists the most common female reproductive health concerns to be endometriosis, uterine fibroids, gynecological cancers (cervical, ovarian, uterine, vaginal, and vulvar), HIV/AIDS, interstitial cystitis, polycystic ovary syndrome, sexually transmitted diseases, and sexual violence¹⁴³; Planned Parenthood is able to diagnose and/or offer treatment or referrals for each of these concerns. The organization offers highly specific services that patients may not have other access to, such as LGBTQ health and sexual violence services. Planned Parenthood uniquely caters to and educates LGBTQ patients and even offers hormone replacement therapy for transgender patients in select areas. To combat sexual violence, Planned Parenthood offers immediate care, rape counseling, referrals to sexual assault specialists, and information regarding women's rights, consent, and how to support a loved one who has been a victim of sexual or domestic violence.

Planned Parenthood provides additional care outside of contraceptive and protective services. Its cancer prevention services provide over 295,000 Pap tests annually. 144 Controversy regarding the organization unfortunately fails to recognize the significant number of patients who receive preventative healthcare that is critical for cervical cancer treatment and eradication.

¹⁴³ "Common Reproductive Health Concerns for Women." *Centers for Disease Control and Prevention*. Centers for Disease Control and Prevention, 08 July 2015. Web. 28 Dec. 2017.

¹⁴⁴ By The Numbers 2017

Threat to Planned Parenthood

In 1976, the House of Representatives passed the Hyde Amendment which withholds federal Medicaid funding for abortion services—with the exception of cases of rape, incest, or when the mother's life is at risk— nationwide. Most of Planned Parenthood's federal funding is from Medicaid reimbursements and Title X grants which prevent the association from using any federal funding for abortions. Anti-choice groups and right-wing politicians have threatened to "defund" Planned Parenthood, which is in actuality a misleading term. There is no federal budget to *fund* the organization—instead the term defunding refers to blocking funding by Medicaid and Title X reimbursements for patients seeking the reproductive healthcare services offered by Planned Parenthood. Given that approximately 60% of Planned Parenthood clients rely on this funding, these cuts disproportionately affect people that are low-income, living in rural areas, and people of color. Amidst the nationwide debate over abortion, actions have been made to cut funding towards Planned Parenthood due to their offering of abortion services—even though only 3% of its provided services are for abortions, 147 none of which are federally subsidized.

In 2007, then congressman Mike Pence sponsored the first bill to defund Planned Parenthood. The bill was unsuccessful due to reproductive rights groups advocating against it. Though it did not pass on the national level, states like Indiana, Wisconsin, and Texas took this example to defund at the state level. After subsequent efforts to defund nationally failed, in 2017

¹⁴⁵ "How Federal Funding Works at Planned Parenthood." *Planned Parenthood Action Fund.* Planned Parenthood Action Fund, Inc., 2018. Web. 13 Jan. 2018.

¹⁴⁶"Defunding' Planned Parenthood Defined." *I Stand With Planned Parenthood*. Planned Parenthood Federation of America Inc. and Planned Parenthood Action Fund, Inc., 2018. Web. 14 Jan. 2018.

¹⁴⁷ Strickland, Ashley. "Planned Parenthood: Fast Facts and Revealing Numbers." *CNN*. Cable News Network, 01 Aug. 2017. Web.

Mike Pence—now vice president—made the tie-breaking vote to repeal ACA protection of Planned Parenthood patients receiving care by Title X funding.¹⁴⁸ The ramifications of Texas's decision to cut family-planning funding that caused the closure of many Planned Parenthood and its affiliate clinics will be discussed in the following section, "State Defunding."

Movements to defund Planned Parenthood indisputably threaten the health of its patients, which in the case of cervical cancer screening may even result in unnecessary disease and death. The Congressional Budget Office (CBO) estimated in 2015 that defunding Planned Parenthood would result in 400,000 people losing care and 150,000-650,000 patients facing reduced access to care without any increase in federal revenue in return for the budget cuts. Reducing clinic funding would undoubtedly limit access to contraceptive services, STI screening and treatment, primary care services, and cervical and breast cancer screening for low-income women.

In 2016, 617,677 breast and cervical cancer screenings were performed in Planned Parenthood clinics, of which 75,040 (12.15%) detected cancer or abnormalities in their early stages. Nearly 2,000 women received LEEP and cryotherapy procedures for their moderate to severe cervical dysplasia *in office* at their local Planned Parenthood clinic others were referred to external care providers for treatment. It is not uncommon for abnormalities and cancer diagnoses to be detected at Planned Parenthood and its affiliate centers. The organization prides itself on providing these possibly life-saving services; the value of which inspired five

^{148 &}quot;'Defunding' Planned Parenthood Defined" 2018

¹⁴⁹ Pugh 2017

¹⁵⁰ Ranii 2017

¹⁵¹ Planned Parenthood Annual Report 2016-2017. Rep. Planned Parenthood Federation of America, n.d. Web. 14 Jan. 2018

¹⁵² Planned Parenthood Annual Report 2016-2017

women whose cancer was detected at Planned Parenthood to launch The Cancer Survivors Network for Planned Parenthood (CSN4PP).

CSN4PP organizes and provides support for people who have been diagnosed with gynecological or breast cancer (or who have been touched by either) to stand united in support of Planned Parenthood's cancer screening services. The association launched in opposition to defunding threats to convey just how impactful Planned Parenthood's cancer screenings are. Advocates and members of CSN4PP have shared their stories about how screening at Planned Parenthood saved their lives:

Cervical Cancer survivor Gay Norman, 2015: "I would be dead if it hadn't been for [Planned Parenthood]...There are so many women that don't know about it that could use it." 153

Cervical Cancer survivor Christy Miceli, 2017: "During a routine Pap smear and physical when I was 24, Planned Parenthood detected my cervical cancer. I was young and uninsured, and without a resource such as Planned Parenthood, I would not have been able to afford the lifesaving care I received. I would not have been able to afford the diagnostic testing, the various LEEP and cryotherapy procedures, and the extensive follow-up care....I was lucky. The early detection and the surgeries and procedures that followed saved my life. I did not become just another statistic."¹⁵⁴

¹⁵⁴ Miceli, Christy. "Miceli: Paul Ryan Needs to Hear My Planned Parenthood Story." *Milwaukee Journal Sentinel*. Milwaukee Journal Sentinel, 08 Apr. 2017. Web.

¹⁵³ Culp-Ressler, Tara. "Cancer Survivors Who Relied On Planned Parenthood's Treatment Tell Texas Not To Defund It." *ThinkProgress*. ThinkProgress, 30 Mar. 2015. Web.

Evidently, Planned Parenthood and its affiliate clinics have saved lives through early detection of breast and gynecological cancers, especially for black and Latinx clients who bear a relatively staggering burden of cervical cancer I&M nationwide. Threats to defund the organization put the lives of hundreds of thousands of women at risk by reducing if not eliminating their access to cancer prevention services. Given that 54% of Planned Parenthood health centers are located in areas with health professional shortage, rural areas, and/or medically underserved areas, the organization has proved vital in efforts to eradicate the greatly preventable disease of cervical cancer in the U.S. Thus, attacks on Planned Parenthood are also attacks on women with already substantial barriers to access to Pap tests, HPV tests, and HPV vaccines.

State Defunding

While funding efforts have not yet been cut nationally, some states have passed motions to defund or greatly reduce funding to Planned Parenthood locations. Though an anti-choice effort to reduce the rate of abortion, the state decisions to defund Planned Parenthood have had consequently destructive effects on other aspects of reproductive healthcare, including screening for cervical cancer.

The aftermath of Texas's efforts to defund Planned Parenthood statewide demonstrate the deleterious effects on cervical cancer screening that reducing women's access to reproductive healthcare has caused. In 2011, Texas legislature cut state funding to family planning clinics by 66% while redistributing the remaining grant funding away from dedicated family-planning and reproductive healthcare providers including Planned Parenthood.¹⁵⁵ This resulted in the

¹⁵⁵ Stevenson, Amanda J., et al. "Effect of Removal of Planned Parenthood from the Texas Women's Health Program." *New England Journal of Medicine* 374.9 (2016): 853-60. Web.

subsequent closure of 82 clinics—a third of which were Planned Parenthood clinics and affiliates.¹⁵⁶ What came next was, as two members of the Texas Policy Evaluation Project reported in the Washington Post, "the network of health-care providers [fell] apart and women [lost] access to essential preventive services."¹⁵⁷

With a decrease in reproductive healthcare supply and a stagnant demand, Texas had a disastrous downfall in women's health services that resulted in a decrease in Pap tests and sharp increase in pregnancy-related maternal deaths. Following the mass closure of Planned Parenthood centers in Texas and Wisconsin (another state that made efforts to defund Planned Parenthood), average distance to the nearest health center increased by 100 miles. This resulted in a 9% decrease in Pap tests among the affected women. Meanwhile, maternal deaths in Texas nearly doubled from 2011-2016—a figure rarely seen in the absence of destruction due to war, natural disaster, or severe economic disruption.

It is unlikely coincidental that Texas, a state with disproportionately limited access to family-planning and reproductive health centers such as Planned Parenthood, is one of the states with the highest rates of cervical cancer. In 2014, Texas had the 6th highest rate of cervical cancer incidence and 5th highest rate of cervical cancer mortality. Still, senior Texas senator John Cornyn denied the negative consequences of the defunding, rather claiming that a defunding of Planned Parenthood would actually *increase* access to women's healthcare defunding.

_

¹⁵⁶ Ackerman, Todd. "Texas Pregnancy-Related Deaths Double." *Houston Chronicle*, 18 Aug. 2016. Web.

¹⁵⁷ Potter, Joseph E., and Kari White. "Defunding Planned Parenthood Was a Disaster in Texas. Congress Shouldn't Do It Nationally." *The Washington Post.* WP Company, 07 Feb. 2017. Web. 13 Jan. 2018.

¹⁵⁸ The Urgent Need for Planned Parenthood Health Centers. Rep. Planned Parenthood Federation of America, 2017. Web.

¹⁵⁹ Ackerman 2016

^{160 &}quot;Gynecological Cancers" 2017

¹⁶¹ Reid: A Vote Against Planned Parenthood is A Vote Against Critical Women's Health Care Services. Washington: Federal Information & News Dispatch, Inc, 2015. ProQuest. Web. 13 Jan. 2018.

statement that is blatantly *false*. Regardless of the misinformation and anti-choice propaganda supporting the closure of Planned Parenthood and its affiliated clinics, the upheaval in Texas women's healthcare has clearly demonstrated that defunding such clinics may result in death for women that rely on such services. Cervical cancer cannot be eradicated if efforts are made to reduce access to reproductive healthcare—Texas's dwindling rates of Pap test use have proven just that.

Inadequate Alternatives

Planned Parenthood advocates and critics of plans to defund the organization have argued that low-income women will not otherwise have access to reproductive healthcare and gynecological cancer prevention without it. In 2017, Republican leaders supported House Speaker Paul Ryan's response to such criticisms by claiming that the solution lies with FQHCs.

162 Anti-Planned Parenthood organizations such as the Charlotte Lozier Institute—an anti-choice group known for criticizing abortions, stem cell research, and genetic research—have infamously released maps showing the disparity between FQHC locations and Planned Parenthood locations across the country. These maps have been used push the notion that defunding Planned Parenthood will have negligible effects on reproductive healthcare access because of the relatively greater number of FQHC locations available. This however is at best misleading as experts at the American Congress of Obstetricians and Gynecologists and the National Partnership for Women and Families have maintained their position that FQHCs simply *cannot*

¹⁶² Thomson-DeVeaux, Amelia. "How Defunding Planned Parenthood Could Affect Health Care." *FiveThirtyEight*, FiveThirtyEight, 9 Mar. 2017. Web.

take on all of Planned Parenthood patients. The executive director of the American Public Health

Association has even gone so far as to describe this claim as "ludicrous." ¹⁶³

FQHCs are excellent in that they have repeatedly demonstrated efficiency on modest budgets, but it is unwise to assume such efficiency will be able to compensate for sudden closings of Planned Parenthood clinics. 164 Due to high patient demand, not all FQHCs are able to accept new patients—and those that are accepting new patients are likely to have longer wait times for appointments. 165 Unfortunately, as wait times lengthen at FQHCs, care is delayed and in some cases simply unavailable. 166 Pap tests are most effectively preventative, rather than acute care tools. The problem therein lies with the fact that lengthy wait times are more likely to be tolerated for acute conditions rather than those for preventative care as the latter is seemingly nonessential to daily life. Additionally, FQHCs already struggle with high turnover of employees due to a shortage of healthcare workers that overloads existing staff.¹⁶⁷ Moreover, federal law requires that FQHCs be located in communities with few other healthcare providers. 168 Therefore, the presence of Planned Parenthood clinics deters FQHCs from being built in those areas. If an FQHC has not been opened in a location with a local Planned Parenthood, the closure of the Planned Parenthood clinic will leave community members without a reproductive healthcare provider in the area.

The previously discussed closure of Planned Parenthood locations in Texas has demonstrated that relying on FQHCs to provide the care otherwise offered by Planned

¹⁶³ Reid: A Vote Against Planned Parenthood is A Vote Against Critical Women's Health Care Services 2015

¹⁶⁴ Rosenbaum 2015

¹⁶⁵ Thomson-Deveaux 2017

¹⁶⁶ Pugh, Tony. "If GOP Defunds Planned Parenthood Clinics, Health Centers Can't Handle Patient Flood." Miamiherald. The Miami Herald, 19 Jan. 2017. Web.

¹⁶⁷ Pugh 2017

¹⁶⁸ Rosenbaum 2015

Parenthood is unambiguously ineffective. After Texas's 2011 closure of Planned Parenthood clinics, FQHCs and other providers were faced with increasing women's health service capacity by an average of 81% to compensate for the new influx of patients. In the immediate wake of these closures, Hidalgo County alone faced a 531% increase in service demand. It is also estimated that if Planned Parenthood locations were to close in Midland county, non-Planned Parenthood affiliated clinics would have to increase services by 537% in order to compensate for the decrease in women's healthcare coverage. Considering the already limited Title X funding available, low-income communities simply cannot expect other healthcare providers to be able to take on new patients. Resource allocation within FQHCs must account for the broad range of services that their patients depend on. Though Pap tests are relatively cheap, FQHCs would nonetheless have to expend more money, time, and space to accommodate an increased demand for preventative services.

It is unwise and unjust to claim that FQHCs are an effective alternative in the wake of Planned Parenthood closures. This is especially relevant as Republican efforts to repeal the Medicaid expansion that is covering those clinics and cut Title X spending. If cervical cancer I&M is to be eradicated or reduced at the very least, there must be accessible options for preventative care for low-income, medically underserved women. Increasing awareness of CDC screening guidelines and the benefits of the HPV vaccine can only work if women can feasibly get such care. Therefore, clinics and programs such as Planned Parenthood that actively strive to provide services to the medically underserved are both essential and irreplaceable.

¹⁶⁹ Rosenbaum 2015

¹⁷⁰ Reid: A Vote Against Planned Parenthood is A Vote Against Critical Women's Health Care Services 2015

Symbolic Attacks

Attacks on Planned Parenthood health centers and other family-planning clinics are an affront to women's healthcare and the technological strides made towards cancer prevention and eradication. The U.S. abortion debate that has continually swept the nation ever since 1973's *Roe v. Wade* supreme court ruling ensuring women access to abortion. This debate and anti-choice censuring of women and their healthcare providers has been a notable attack on a women's bodily autonomy. As anti-choice movements persist in their disapprobation of Planned Parenthood, a quiet, more insidious attack on women's bodies has been made; that being an attack on a woman's right to protect herself against cancer. Given the extensive barriers to access of cervical cancer preventative services (see *Chapter 4: Barriers to Access*), the closure of low-cost reproductive health clinics further reduces their ability to preserve if not improve their reproductive health.

In an age of anti-science rhetoric, technological advances such as the Pap test, HPV test, and HPV vaccine are often underappreciated. The value of the Pap test is vastly unappreciated by those outside of the medical community. Cervical cancer was once one of the leading causes of cancer-related deaths of American women¹⁷¹ and as of 2014 the disease did not even make the top ten.¹⁷² By reducing access via defunding Planned Parenthood, the technology behind the Pap test is being inherently devalued—as are the lives of the women that rely on it. Any attempts to reduce access to Pap tests undermine the immense efficacy of the technology. The only way to truly appreciate and utilize the diagnostic advancement is by expanding its use and access.

¹⁷¹ "What is Cervical Cancer?"

¹⁷² "United States Cancer Statistics: 1999-2014 Incidence and Mortality Web-based Report"

Conclusions

In this chapter I have used the attacks on Planned Parenthood as a case study to demonstrate the importance of the organization and its impact on expanding access of cervical cancer prevention methods, particularly to the medically underserved and underinsured. The battle for moralistic control over a woman's right to choose has effectively reduced or even eliminated access to screening for women in affected areas. The ramifications of defunding independent family-planning clinics—particularly Planned Parenthood and its affiliate clinics—are accurately demonstrated in the aftermath of Texas's 2011 defunding decision. Non-healthcare scholars or professionals have made ignorantly erroneous claims that defunding Planned Parenthood will have no effect on women's health based on the presupposition that FQHCs can readily take on new patients. This has proven to be flagrantly incorrect and women's bodies and lives have suffered as a result. As Planned Parenthood continues to be attacked by right-wing and anti-choice groups, the lives of women who depend on the organization for cancer screening are put at risk. The only way to eradicate cervical cancer in the U.S. is to expand access to Pap tests, HPV tests, and HPV vaccines—a method that is undermined by the closures of Planned Parenthood clinics that provide such care.

Women's Health

In a heteropatriarchal culture of regulation and politicization of women's bodies, it is essential that efforts be made to protect women's health and bodily autonomy. Outreach programs for cervical cancer screening and clinics that provide affordable and accessible care contribute to such protections by providing women with the power and choice to protect their bodies. All people deserve access to care aimed at preventing cancer and women especially deserve the right to preventative and diagnostic care for cervical cancer. This requires reducing if not removing barriers to access of the Pap test, HPV test, and HPV vaccine as well as improving the implementation of such biotechnologies. The first step in eradicating the disease and enhancing women's health nationwide is by increasing the implementation and utilization of screening and prevention methods for cervical cancer.

Importance of Cervical Cancer Screening

Given the slow progression cervical cancer development—10 to 15 years upon the formation of abnormal cells, or *cervical dysplasia*—the disease is feasibly preventable when abnormal cells are detected in their early stages. Such detections can be effectively diagnosed with regular use of the Pap test. Theoretically, if all women were to follow CDC guidelines for cervical cancer screening, abnormalities would be detected and removed if necessary before the cancer can develop. In recent years, screening and prevention have been made even more effective with the advent of the HPV test—which tests DNA for HPV-induced oncogenetic

changes—and the HPV vaccine. The HPV test in tandem with Pap testing (referred to as cotesting) not only tests for cervical abnormalities but further determines the susceptibility one has to those abnormalities based on whether or not the patient has been infected with high-risk strains of the HPV virus. The HPV vaccine is also intended to stop these strains from infecting their host before any cellular damage or mutation can occur. With this vaccine and the HPV test, the Pap test is then the final defense against the disease.

Cervical cancer can develop from cervical dysplasia if it is not detected and treated preventatively through procedures such as LEEP, cryosurgery, cone biopsy, or hysterectomy. These treatment methods remove the cells before they can become malignant—screening allows healthcare providers to do so. Unscreened and underscreened women are at an undeniably greater risk of developing cervical cancer as undetected abnormal cells may quietly become cancerous without intervention. In order to eradicate cervical cancer in the U.S., it is these inadequately screened women that must be targeted through public health intervention to inform and reduce barriers to access of the Pap test, HPV test, and HPV vaccine. Each time a woman is allowed to go unscreened or underscreened in our healthcare system, efforts to eradicate cervical cancer are inherently undermined. In conclusion, the only way to eradicate the disease to give women in the access to screening and other preventative services.

The Role of Planned Parenthood in Cervical Cancer Prevention

Planned Parenthood is a quintessential example of an effective effort to remove barriers to and expand access of the necessary cervical cancer preventative services for the disease's eradication. For over 100 years the organization has provided affordable access to reproductive

health services in medically underserved areas with the intention of ensuring proper healthcare for *everyone*—regardless of income, gender, orientation, etc. Nearly 75% of the organization and its affiliate health centers' patients are at or below 150% of the federal poverty level¹⁷³ (see *Chapter 4: Barriers to Access* subsection "Health Insurance" for what defines the federal poverty level) and approximately 60% of patients rely on government subsidies through Medicaid and Title X entitlements.¹⁷⁴ Approximately 12% of women that access cancer screening through Planned Parenthood are found to have abnormalities. These 12% are fortunately diagnosed, treated, or externally referred for further analysis and treatment. Planned Parenthood's screening interventions in medically underserved communities break down barriers to access such as income, lack of insurance, stigma, etc. to ensure reproductive healthcare to all.

As Planned Parenthood continues to be threatened by anti-choice and right-wing efforts to defund the organization due to its offering of abortion services, the need for low-cost and accessible reproductive healthcare clinics is more evident than ever. For the hundreds of thousands of women that rely on Planned Parenthood for its cancer screening services, this may mean reduced if not eliminated access to such in the absence of the organization's clinics. The NBCCEDP, FQHCs, and free and charitable clinics are nationwide alternatives for cervical cancer screening and prevention. However, as previously discussed, they are effectively incapable of undertaking patients that will lose their care in the wake of Planned Parenthood and its affiliate health centers' closures. Like all organizations and programs, the NBCCEDP, FQHCs, and free and charitable clinics face their own issues in providing care that must not be

¹⁷³ By The Numbers

^{174 &}quot;Defunding' Planned Parenthood Defined"

overlooked when discussing the aftermath of defunding Planned Parenthood. Texas's state-wide defunding of 82 family-planning health centers proved just that.

Planned Parenthood is a crucial safety-net system for reproductive healthcare for those who currently cannot (or choose not to) use other providers and also for those who may depend on their low-cost and accessible services in the future as the U.S. economy invariably fluctuates. The organization and its affiliates have taken strides to improve cervical cancer screening in the U.S. and promise to continue to do so as it fights back against defunding threats. Their affordable access and continuing community education of cervical cancer prevention is an invaluable endeavor for cervical cancer eradication. Rather than politicizing and attacking Planned Parenthood, its services must be preserved to both protect women from cervical cancer and set an example for future associations aiming to reduce barriers to access of preventative care as well.

Eradication Within Reach

In summary, socioeconomic circumstances and inadequate access to information and education are driving the discrepancy between the medical and technological ability to eradicate cervical cancer in the U.S. and the continual prevalence of cervical cancer I&M. The war against cancer will continue until the disease ceases claiming the lives of so many. The trouble is though, the battle against cervical cancer can be feasibly won as soon as screening and preventative services are made accessible to (and used by) *everyone* with a cervix. Approximately 4,000 women will die each year due to lack of screening and resources to prevent and treat the disease. Organizations like Planned Parenthood, community outreach programs, and publicly funded cancer screening services must be both protected and expanded in order save these lives. Access

to services and education regarding women's bodies and the CDC's screening guidelines must be widely available across the U.S.

The sharp decline in cervical cancer I&M since the advent of the Pap test has proven the power of screening and prevention methods. Though rates of cervical cancer I&M took such a drastic turn as the Pap test spread in its usage, it has reached a plateau in recent decades. Given the efficacy of the Pap test, HPV test, and HPV vaccine, this plateau in I&M is both unacceptable and avoidable. It is now the responsibility of healthcare providers, public health programs, and policy makers to once again drive a decline in cervical cancer I&M by making the medical technologies capable of eradicating the disease accessible to all.

Works Cited

- "Accelerating HPV Vaccine Uptake: Urgency for Action to Prevent Cancer: Goal 2: Increase Parents', Caregivers', and Adolescents' Acceptance of HPV Vaccines." *National Institutes of Health*. U.S. Department of Health and Human Services, n.d. Web.
- Ackerman, Todd. "Texas Pregnancy-Related Deaths Double." *Houston Chronicle*, 18 Aug. 2016. Web.
- Allen, Heidi, et al. "The Role of Stigma in Access to Health Care for the Poor." *The Milbank Quarterly*, vol. 92, no. 2, 2014, pp. 289–318. JSTOR, JSTOR, www.jstor.org/stable/24369969.
- "Apply for OHP." *Oregon Health Authority*. Oregon.gov, n.d. Web. 28 Dec. 2017.
- Benard, V. B., et al. "Cervical cancer survival in the United States by race and stage (2001-2009):
 - Findings from the CONCORD-2 study." Cancer 123 (2017): 5119–5137.
- Benard, V. B., et al. "Vital signs: Cervical cancer incidence, mortality, and screening united states,
 - 2007-2012.". Atlanta: U.S. Center for Disease Control (2014).
- Benard, V. B. et al. "The Effectiveness of Targeting Never or Rarely Screened Women in a National Cervical Cancer Screening Program for Underserved Women." *Cancer causes & control*: CCC 26.5 (2015): 713–719. PMC.
- Best, Alicia L, PhD,M.P.H., C.H.E.S., et al. "Examining the Influence of Cost Concern and Awareness of Low-Cost Health Care on Cancer Screening among the Medically Underserved." *Journal of health care for the poor and underserved* 28.1 (2017): 79-87. ProQuest. Web. 21 Dec. 2017.
- Blumenthal, P. D., et al. "Training for Cervical Cancer Prevention Programs in Low-Resource Settings: Focus on Visual Inspection with Acetic Acid and Cryotherapy." *International Journal of Gynecology & Obstetrics* 89: S30–S37(2005). Web.
- Breitkopf, Carmen R., et al. "Poor Knowledge regarding the Pap Test among Low-Income Women Undergoing Routine Screening." *Perspectives on Sexual and Reproductive Health* 37.2 (2005): 78-84. Print.

By The Numbers. Rep. Planned Parenthood Federation of America, 2017. Web.

"Cancer Trends Progress Report." National Cancer Institute. National Cancer Institute, Jan. 2017.

Web

- "Cervical Cancer Screening." National Cancer Institute, National Cancer Institute, 22 Sept. 2017, www.cancer.gov/types/cervical/hp/cervical-screening-pdg#link/ 122 toc.
- "Cervical Cancer: Symptoms and Signs." *Cancer.Net*. American Society of Clinical Oncology, 22 Sept. 2017. Web. 15 Jan. 2018.
- "Cervical Dysplasia." MedlinePlus Medical Encyclopedia, U.S. National Library of Medicine, medlineplus.gov/ency/article/001491.htm.
- Chura, Justin, MD. "FDA Approves HPV DNA Test for Cervical Cancer Screening." Cancer Treatment Centers of America. Cancer Treatment Centers of America, 1 May 2014. Web.
- "Clinics." NAFCC. National Association of Free and Charitable Clinics, 2016. Web.
- "Common Reproductive Health Concerns for Women." Centers for Disease Control and Prevention. *Centers for Disease Control and Prevention*, 08 July 2015. Web. 28 Dec. 2017.
- "Community Health Center Delivery Sites and Patient Visits: Total CHCs, 2015." The Henry J. Kaiser Family Foundation. N.p., n.d. Web.
- Comparison of Free & Charitable Clinics to Federally Funded Clinics. Alexandria, VA: National

Association of Free and Charitable Clinics, n.d. PDF.

- Culp-Ressler, Tara. "Cancer Survivors Who Relied On Planned Parenthood's Treatment Tell Texas Not To Defund It." *ThinkProgress*. ThinkProgress, 30 Mar. 2015. Web.
- "'Defunding' Planned Parenthood Defined." *I Stand With Planned Parenthood*. Planned Parenthood Federation of America Inc. and Planned Parenthood Action Fund, Inc., 2018. Web. 14 Jan. 2018.
- De Alba, Israel, et al. "Impact of U.S. Citizenship Status on Cancer Screening Among Immigrant

- Women." *Journal of General Internal Medicine* 20.3 (2005): 290–296. PMC. Web. 28 Dec. 2017.
- Du, Ping, et al. "The Roles of Social Domains, Behavioral Risk, Health Care Resources, and Chlamydia in Spatial Clusters of US Cervical Cancer Mortality: Not all the Clusters are the Same." Cancer Causes & Control 21.10 (2010): 1669-83. Print.
- Fayed, Lisa. "Does Insurance Cover HPV Vaccine Costs?" Verywell. Verwell, 27 Apr. 2017. Web.
- Fayed, Lisa. "How Much Does a Pap Smear Cost Without Insurance?" *Verywell*, Verywell, June 2017. Web.
- "Federal Poverty Level (FPL)." *HealthCare.gov*. U.S. Centers for Medicare & Medicaid Services, n.d. Web. 09 Jan. 2018.
- "Federally Qualified Health Centers." Health Resources & Services Administration. N.p., 01 Apr. 2017. Web. 21 Dec. 2017.
- Fowler C, et al. Trends in Cervical Cancer Screening in Title X-Funded Health Centers United States, 2005–2015. *MMWR Morb Mortal Wkly* Rep 2017;66:981–985. DOI: http://dx.doi.org/10.15585/mmwr.mm6637a4
- Frances, DiAnna Kinder. "Parental Refusal of the Human Papillomavirus Vaccine." *Journal of Pediatric Health Care* 30.6 (2016): 551 557. Print.
- Gillespie, Patrick. "America's Immigrant Economy: More Work, Less Pay." CNNMoney, Cable News Network, 19 Aug. 2016, money.cnn.com/2016/08/19/news/economy/us-immigrant-economy/index.html.
- "Gynecologic Cancers." Centers for Disease Control and Prevention. Centers for Disease Control and Prevention, 07 June 2017. Web.
- Hachey, Krista J., et al. "Requiring Human Papillomavirus Vaccine for Immigrant Women." Abstract. *Obstetrics & Gynecology* 114.5 (2009): 1135-139. Web.
- Health care for unauthorized immigrants. Committee Opinion No. 627. American College of Obstetricians and Gynecologists. *Obstetrics & Gynecology* 2015;125:755–9.

- "HPV and Cancer." Cancer Research UK. N.p., 08 Nov. 2017. Web. 17 Nov. 2017.
- "Human Papillomavirus (HPV)." Centers for Disease Control and Prevention, Centers for Disease Control and Prevention, 17 July 2017, www.cdc.gov/std/hpv/stdfact-hpv.htm.
- "How Federal Funding Works at Planned Parenthood." *Planned Parenthood Action Fund.* Planned Parenthood Action Fund, Inc., 2018. Web. 13 Jan. 2018.
- Kamimura, A., et al. "Women in free clinics: An assessment of health-related quality of life for prevention and health education." *Journal of Community Health*, 40.4 (2015): 793-801.
- Karliner, Leah, et al. "Reducing Health Care Disparities for Minority Women in the Era of the Affordable Care Act: Opportunities within Primary Care." Journal of health care for the poor and underserved 27.2 (2016): 392-415. ProQuest. Web. 21 Dec. 2017.
- Karjane, Nicole W., MD. "Pap Smear." *Medscape*. Ed. Christine Isaacs. WebMD LLC, 02 Dec. 2016. Web. 19 Jan. 2018.
- Kim, Kyounghae, et al. "Potential Links between Health Literacy and Cervical Cancer Screening Behaviors: A Systematic Review." Psycho-oncology 25.2 (2016): 122-30. Print.
- Kitchener, Henry C., et al. "Developing Role of HPV in Cervical Cancer Prevention." BMJ: British Medical Journal 347.7921 (2013): 26-31. Print.
- Lipton, B. J., & Decker, S. L. (2015). ACA provisions associated with increase in percentage of young adult women initiating and completing the HPV vaccine. Health Affairs, 34(5), 757-764,1-6.
- Levano, Whitney, et al. "Public Education and Targeted Outreach to Underserved Women through
 - the National Breast and Cervical Cancer Early Detection Program." *Cancer* 120.S16 (2014): 2591-596. Web.
- "Making Sense of Cervical Cancer." Association of Reproductive Health Professionals,
 Association of Reproductive Health Professionals,
 www.arhp.org/Publications-and-Resources/Patient-Resources/Fact-Sheets/cervical-cance
 r.
- Mcdonald, James Ted, and Jeremiah Neily. "Race, Immigrant Status, and Cancer among Women

- in the United States." *Journal of Immigrant and Minority Health* 13.1 (2011): 27-35. ProQuest. Web. 27 Dec. 2017.
- McDougall, Jean A., et al. "Racial and Ethnic Disparities in Cervical Cancer Incidence Rates in the United States, 1992-2003." *Cancer Causes & Control* 18.10 (2007): 1175-86. Print.
- Miceli, Christy. "Miceli: Paul Ryan Needs to Hear My Planned Parenthood Story." *Milwaukee Journal Sentinel*. Milwaukee Journal Sentinel, 08 Apr. 2017. Web.
- Mitchell, Janet B., and Lauren A. McCormack. "Time Trends in Late-Stage Diagnosis of Cervical Cancer: Differences by Race/Ethnicity and Income." *Medical Care* 35.12 (1997): 1220–1224.
- Mone, Amy. "Cervical Dysplasia Treatment." Kimmel Cancer Center. N.p., 17 July 2017. Web. 17 Nov. 2017.
- Montealegre, Jane R., et al. "Nativity Disparities in Late-Stage Diagnosis and Cause-Specific Survival among Hispanic Women with Invasive Cervical Cancer: an Analysis of Surveillance, Epidemiology, and End Results Data." Cancer Causes & Control 24.11 (2013):985–1994. JSTOR.
- "National Breast and Cervical Cancer Early Detection Program (NBCCEDP)." Centers for Disease Control and Prevention. Centers for Disease Control and Prevention, 14 Sept. 2017. Web.
- "National Center for Health Statistics." Centers for Disease Control and Prevention. Centers for Disease Control and Prevention, 03 May 2017. Web. 24 Nov. 2017.
- Olaitan, Adeola. "Gynaecological Cancer: 'Women Are Literally Dying of Embarrassment'." *The Guardian*. Guardian News and Media, 08 Sept. 2015. Web.
- "Pap and HPV Testing." National Cancer Institute, National Cancer Institute, 9 Sept. 2014, www.cancer.gov/types/cervical/pap-hpv-testing-fact-sheet#q6.
- Parekh, Ranna. "What Is Gender Dysphoria?" American Psychiatric Association, American Psychiatric Association, Feb. 2016, www.psychiatry.org/patients-families/gender-dysphoria/what-is-gender-dysphoria.
- Peitzmeier, Sarah M., et al. "Female-to-Male Patients have High Prevalence of Unsatisfactory

- Paps Compared to Non-Transgender Females: Implications for Cervical Cancer Screening." *Journal of General Internal Medicine* 29.5 (2014): 778-84. ProQuest. Web. 28 Dec. 2017.
- Petignat, Patrick, and Roy, Michel. "Diagnosis and Management of Cervical Cancer." BMJ: British Medical Journal 335.7623 (2007): 765. Print.
- Petterson, Stephen M., et al. "Trends in Office-Based Care for Reproductive-Aged Women According to Physician Specialty: A Ten-Year Study." *Journal of Women's Health* 23.12 (2014): 1021-026. Web.
- Planned Parenthood Annual Report 2016-2017. Rep. Planned Parenthood Federation of America, n.d. Web. 14 Jan. 2018.
- Ponce, Ninez A., et al. "Is There a Language Divide in Pap Test Use?" Medical Care, vol. 44, no. 11, 2006, pp. 998–1004. JSTOR, JSTOR, www.jstor.org/stable/41219554.
- Potter, Joseph E., and Kari White. "Defunding Planned Parenthood Was a Disaster in Texas. Congress Shouldn't Do It Nationally." *The Washington Post.* WP Company, 07 Feb. 2017.

 Web. 13 Jan. 2018.
- "Preventive Care Benefits for Women." HealthCare.gov. U.S. Department of Health & Human Services, n.d. Web. 19 Dec. 2017.
- Pugh, Tony. "If GOP Defunds Planned Parenthood Clinics, Health Centers Can't Handle Patient Flood." Miamiherald. *The Miami Herald*, 19 Jan. 2017. Web.
- Ranji, Usha, et al. "Financing Family Planning Services for Low-income Women: The Role of Public Programs." The Henry J. Kaiser Family Foundation. N.p., 31 May 2017. Web.
- Reid: A Vote Against Planned Parenthood is A Vote Against Critical Women's Health Care Services. Washington: Federal Information & News Dispatch, Inc, 2015. ProQuest. Web. 13 Jan. 2018.
- Results Summary: National Survey of Women's Knowledge of Recommended Screenings for Breast and Cervical Cancer. Rep. Planned Parenthood Federation of America, 2017. Web.
- Reyes, Adriana M., and Patricia Y. Miranda. "Trends in Cancer Screening by Citizenship and Health Insurance, 2000-2010." *Journal of Immigrant and Minority Health* 17.3 (2015):

- 644-51. ProQuest. Web. 27 Dec. 2017.
- Rosenbaum, Sara. J.D. "Planned Parenthood, Community Health Centers, And Women's Health: Getting The Facts Right," *Health Affairs Blog*, September 2, 2015.
- Schleicher, E. (2007). Immigrant Women and Cervical Cancer Prevention in the United States. Baltimore, MD. *Women's and Children's Health Policy Center*. Johns Hopkins Bloomberg School of Public Health.
- SEER Cancer Stat Facts: Cervical Cancer. *National Cancer Institute*. Bethesda, MD, http://seer.cancer.gov/statfacts/html/cervix.html
- "Sex and HIV Education." Guttmacher Institute. Guttmacher Institute, 02 Jan. 2018. Web.
- Shepherd, J., et al. "Cervical Cancer and Sexual Lifestyle: A Systematic Review of Health Education Interventions Targeted at Women." Health Education Research 15.6 (2000): 681-94. Web.
- Singh, G. K. (2012). Rural-urban trends and patterns in cervical cancer mortality, incidence, stage, and survival in the united states, 1950-2008. *Journal of Community Health*, 37(1), 217-23. doi:http://dx.doi.org.libproxy.vassar.edu/10.1007/s10900-011-9439-6
- "Social Ecological Model." *Centers for Disease Control and Prevention*. Centers for Disease Control and Prevention, 27 Oct. 2015. Web.
- Solazzo, Alexa L., et al "Cancer Screening Utilization among U.S. Women: How Mammogram and Pap Test use Varies among Heterosexual, Lesbian, and Bisexual Women."

 Population
- Research and Policy Review 36.3 (2017): 357-77. ProQuest. Web. 28 Dec. 2017.
- "Special Populations." Centers for Disease Control and Prevention. *Centers for Disease Control and Prevention*, 25 Jan. 2017. Web.
- Stevenson, Amanda J., et al. "Effect of Removal of Planned Parenthood from the Texas Women's Health Program." *New England Journal of Medicine* 374.9 (2016): 853-60. Web.
- Strickland, Ashley. "Planned Parenthood: Fast Facts and Revealing Numbers." *CNN*. Cable News Network, 01 Aug. 2017. Web.

- Tan, Siang Yong, and Yvonne Tatsumura. "George Papanicolaou (1883–1962): Discoverer of the
 - Pap Smear." *Singapore Medical Journal* 56.10 (2015): 586–587. PMC. Web. 17 Oct. 2017.
- "The American Cancer Society Guidelines for the Prevention and Early Detection of Cervical Cancer." American Cancer Society, American Cancer Society, 2017. Web.
- "The HPV Vaccine: Access and Use in the U.S." The Henry J. Kaiser Family Foundation. The Henry J. Kaiser Family Foundation, 19 Oct. 2017. Web.
- The Urgent Need for Planned Parenthood Health Centers. Rep. Planned Parenthood Federation of America, 2017. Web.
- Thomson-DeVeaux, Amelia. "How Defunding Planned Parenthood Could Affect Health Care." *FiveThirtyEight*, FiveThirtyEight, 9 Mar. 2017. Web.
- "United States Cancer Statistics: 1999-2014 Incidence and Mortality Web-based Report." Centers for Disease Control and Prevention. U.S. Department of Health and Human Services, 2017. Web. 14 Jan. 2018.
- "What Is Cervical Cancer?" American Cancer Society. American Cancer Society, 2018.