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THE DEVELOPMENT OF A CULTURALLY-INFORMED CERVICAL CANCER
SCREENING AND PREVENTION MHEALTH INTERVENTION FOR AFRICAN
AMERICAN WOMEN

By

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B.S., University of Louisville, 2014
M.S.S.W., University of Louisville, 2018

A Dissertation
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in Social Work

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A Dissertation approved on

June 23rd, 2020

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DEDICATION

I dedicate this dissertation to my grandparents, Ira and Ruby Washington, James and Velma Foster, who have supported me beyond words. They have laid the foundation of my life from Hahira, Ga to Kittrell, NC with their dedication to family and education. I can only hope to have enough tenacity and resolve to live up to their examples.

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ABSTRACT

THE DEVELOPMENT OF A CULTURALLY-INFORMED CERVICAL CANCER SCREENING AND PREVENTION MHEALTH INTERVENTION FOR AFRICAN AMERICAN WOMEN

Ariel Washington

June 23, 2020

Background: Significant strides have been made in reducing the burden of cervical cancer and HPV. Between pap smear screenings and HPV vaccinations, there has been a reduction in cervical cancer incidence in the United States. Unfortunately, those reductions have not been experienced by all ethnic groups. Cervical cancer disparities are a threat to the health of African American women, and innovation in education and the healthcare experience is needed to eliminate this threat. This study aimed to develop and evaluate a culturally tailored intervention using mHealth services to improve cervical cancer and HPV knowledge.

Methods: The development and evaluation of this mHealth intervention involved two phases. The first phase included the culturally tailoring of health messages using a community advisory board of African American women. By meeting in person and virtually, the women were able to tailor twenty-four messages to be disseminated using mHealth. The second phase of this study involved testing of the intervention and evaluation. African American women were recruited and then assessed on their baseline

knowledge of cervical cancer and their experiences of discrimination in medical settings. Participants were then assigned to either the control or intervention group. Those in the intervention group received health messages three times a week for four weeks on their mobile phones. After four weeks had passed, both the control and intervention group were reassessed on their cervical cancer knowledge. mHealth was evaluated for its acceptability, appropriateness, and feasibility using three evaluation measures and qualitative interviews.

Results: Forty-eight women were recruited for this study, with non-random assignment of twenty-five to the intervention group and twenty-three to the control. The baseline scores on the cervical cancer awareness measure indicated a need for education in both groups. Additionally, all participants expressed having experienced some form of discrimination in medical settings. Using a paired-samples t-test the complete-case analysis shows an improvement in cervical cancer knowledge for women in the intervention group.

Conclusions: mHealth intervention shows potential in educating African American women about cervical cancer and HPV. Using mobile phone technology allowed the women to be educated at their convenience and to return to the material later. Future research and practice should consider using the mHealth intervention with hard-to-reach populations or as educational material along with appointment reminders.

TABLE OF CONTENTS

DEDICATION	iii
ACKNOWLEDGEMENTS.....	iv
ABSTRACT.....	vi
LIST OF FIGURES	xiv
LIST OF TABLES	xv
CHAPTER I: INTRODUCTION.....	1
History of Cervical Cancer Prevention.....	3
Background of the Problem	5
Overview of Cervical Cancer and HPV	5
Statement of the Problem.....	9
Background: Previous Work	13
Purpose of the Study	15
Significance and Scope of the Study	17
CHAPTER II: LITERATURE REVIEW.....	19
Social Work as an organizing framework	19
Studies on Cervical Cancer Prevention among African American women	22
Faith-Based Approaches	23

Patient Navigation or Case Management Interventions.....	24
Community-Enhancement Approaches	28
Tailored Messages.....	30
Interventions to Promote HPV Vaccinations	30
Technology-Based Interventions	30
Intention to Vaccinate	32
Message Framing.....	33
Gaps in the Literature.....	34
Theoretical Frameworks for Study	35
Andersen’s Behavioral Health Model.....	35
External Environment	36
Population Characteristics	37
Health Behavior	41
Outcomes	41
Critical Race Theory	42
Integration of Frameworks.....	44
Research Approaches	49
Community-Based Participatory Research.....	49
mHealth Approaches.....	52
Summary	55

CHAPTER III: METHODOLOGY	57
Study Objectives	58
Study Design.....	59
Development of the mHealth Intervention	62
Message Development	63
Message Topic and Delivery.....	67
Study Population.....	68
Recruitment Procedures	69
Measures	71
Demographic Characteristics and Healthcare Behaviors.....	72
Environmental Characteristics	72
Pre-disposing Factors.....	72
Enabling Factors	73
Outcome Variables	73
Cervical Cancer Knowledge	74
Acceptability, Appropriateness, and Feasibility of Intervention.....	74
Qualitative Inquiry	75
Data Analysis	77
Qualitative Analysis	78
CHAPTER IV: RESULTS	80

Sample Characteristics.....	80
Discrimination in Medical Settings	85
Cervical Cancer and HPV knowledge at baseline	86
Aim I: mHealth’s impact.....	94
Missing Data and Multiple Imputation.....	96
Complete Case Analysis	99
Multiple Imputation Analysis	101
Aim II: Evaluating mHealth.....	103
Hypothesis 2.1.....	105
Hypothesis 2.2.....	105
Hypothesis 2.3.....	106
Aim III: Qualitative evaluation of mHealth.....	108
Reflexivity.....	109
Acceptability	111
Appropriateness	113
Feasibility.....	115
Perceived Discrimination.....	118
Mistrust, Trust and Personal Relationships.....	120
CHAPTER V: DISCUSSION AND CONCLUSIONS.....	123
Community-Based Participatory Research Approaches and mHealth.....	124

The continued need for mHealth.....	126
Discrimination in the Health.....	127
Research Aim I: mHealth’s potential	128
Research Aim II: Evaluating mHealth as an intervention strategy	131
Aim III: Qualitative Inquiry into the intervention	134
Limitations	140
Research Implications and Recommendations	143
Social Work Practice Implications	145
Conclusions.....	147
REFERENCES	150
Appendix A: mHealth Demographics.....	163
Appendix B: Discrimination in Medical Settings Scale	166
Appendix C: Cervical Cancer Awareness Measure	167
Appendix D: mHealth Evaluation Measures	169
Appendix E: Interview Guide.....	170
Appendix F: mHealth Message Schedule	171
Appendix G: Coding Matrix	176
Appendix H: Informed Consent.....	184
Appendix I: mHealth Recruitment Material	192
Appendix J: Community Advisory Board Notes	195

Appendix K: IRB Approval Letters	199
Appendix L: Reflexivity Exercise	207
Appendix M: Original Messages	208
CURRICULUM VITAE	216

LIST OF FIGURES

Figure 1 Andersen’s Behavioral Model of Healthcare Utilization.....	35
Figure 2 Andersen’s Behavioral Model + Critical Race Theory Concept Map	44
Figure 3 Study Design Flow of the mHealth Intervention.....	62
Figure 4 Sample mHealth test message	67
Figure 5 Fogg’s Behavioral Model and mHealth.....	68

LIST OF TABLES

Table 1 mHealth message editing by the Community Advisory Board.....	65
Table 2 Variables of interest and their related measures.....	71
Table 3 Research Aims of mHealth study and their measures.....	77
Table 4. 1 Demographic characteristics of the sample by control and intervention groups at baseline.....	81
Table 4. 2 Healthcare characteristics by control and intervention groups at baseline	83
Table 4. 3 Vaccination Status of the Participants' Children.....	84
Table 4. 4 Summary of Differences between the Control and Intervention Group (Mann-Whitney U).....	84
Table 4. 5 Frequency of times experiencing Discrimination in the Medical Settings.....	86
Table 4. 6 Summary of Differences for Risk Factors by the Control and Intervention groups (Mann Whitney-U)	89
Table 4. 7 Risk Factors of Cervical Cancer Responses Agreement	90
Table 4. 8 Warning Signs of Cervical Cancer Responses-Correct and Incorrect...91	
Table 4.9 Participants Beliefs in Time towards Follow-up of Warning Signs	92
Table 4. 10 Participants Confidence in Identifying Cervical Cancer Symptoms ..93	
Table 4.11 Results of an Independent Samples t-Test observing differences between Control and Intervention Groups at baseline.....	94

Table 4. 12 Summary of Differences between Responders and Non-responders (Mann-Whitney U).....	95
Table 4. 13 Questions with the most frequent missing responses.....	97
Table 4. 14 Readability Measures of mHealth Messages	98
Table 4. 15 Readability Measures of Original Messages.....	98
Table 4. 16 Paired Samples t-Test of Mean Differences on cervical cancer awareness, warnings, and risks between Intervention	100
Table 4. 17 Independent Samples t-Test of Mean Differences for Control and Intervention Group 4-week post scores	101
Table 4. 18 Paired Samples t-Test of Mean Differences for the Intervention Group	102
Table 4. 19 Independent Samples t-Test of Mean Differences for Control and Intervention Group.....	103
Table 4. 20 Intervention Group Means of mHealth Evaluation.....	104
Table 4. 21 Acceptability of Intervention Measure- mHealth measured by AIM	105
Table 4. 22 Intervention Appropriateness Measure- mHealth measured by IAM	106
Table 4. 23 Feasibility of Intervention Measure- mHealth measured by FIM.....	107

CHAPTER I: INTRODUCTION

As the American Cancer Society notes, cancer-related mortality has dramatically decreased over the last year and several incidence rates have stabilized (Siegel et al., 2020). Between 1950 to 2009, the overall mortality rate decreased by 11.4% for all primary cancer sites (Howlader et al., 2019). From 2007 to 2017, the mortality trend fell by an additional 15%; while the number of new cases may have increased over the years due to population growth, the incidence rates have stabilized for most populations (Weir et al., 2015). Due to medical advancements within the last fifty years, there have been tremendous strides made in screening, prevention, and treatment. Over time, new research, treatments, and guidelines allowed for a decrease in mortality and a stabilization in incidence rates. Survivorship increases with the improvement of screening and prevention, as individuals are now able to be diagnosed earlier and receive better treatment plans. Advancements such as mammograms and pap smears heavily contributed to the reduction in breast cancer and cervical cancer-related deaths (Bleyer et al., 2016; Landy et al., 2016). Although these medical advancements benefited the general populace, not every group reaped the same benefits equally, resulting in pervasive cancer health disparities.

African Americans find themselves either first or within the top three groups for many mortality and incidence rates of the major cancers (Siegel et al., 2018), a testament to said disparities in cancer health experience. From prevention to survivorship, health

disparities are found in all aspects of the cancer experience for African Americans. They consistently have remained first in cancer-related deaths for all major cancer sites, incidence, and prevalence (Siegel et al., 2020). The five-year survivorship rate for African Americans is lower in most cancer types than their counterparts (American Cancer Society, 2019). These disparities have existed consistently for several decades, even after the passages of the Affordable Care Act, a piece of legislation that decreased the number of uninsured. For the general populace, incidence and mortality have declined or stabilized by percentages larger than that for African Americans (Siegel et al., 2020). However, the improvements in rates seem marginal when comparing the sheer number of African Americans who have difficulty accessing treatment, prevention, or screening. The uninsured rate for this group is 11% in 2015 (Tolbert et al., 2019), a rate that may increase as unemployment rises due to the recent medical pandemic. Because of the current iteration of the health system and systemic conditions, African Americans suffer from an unequal burden from cancer, a burden that has persisted over the years and is in need of innovative culturally driven interventions and policy work to overcome.

In addition to African Americans experiencing health disparities in general, gender differences also impact the ways the health system is navigated and disparities are experienced. Kimberly Crenshaw introduced the topic of intersectionality in terms of oppressive systems that African American women experience during domestic violence (Crenshaw, 1991), the concept can also be applied to the health plight of African American women. African American women, when navigating the health system, will often encounter two different forms of oppression: racism and sexism. Perceived racial discrimination has had an impact on willingness to engage in preventative screening

behavior (Mouton et al., 2010). The same is found for gender discrimination and its impact on engaging in healthcare services (Jacobs et al., 2014). Although there are several ways in which to tackle the cancer experience for African American women, cervical cancer offers one way to make immediate and lasting changes due to the medical ability to greatly reduce, if not eliminate, the disease.

Cervical cancer is regarded as one of the more easily preventable and treatable diseases when detected early enough. It is possible to not only protect African American women from cervical cancer through screening and prevention efforts, but to also protect African American children from HPV related cancers through similar prevention efforts. High-risk HPV strains have been linked to causing cervical, oropharyngeal, anal, penile, vaginal, and vulvar cancers (Chaturvedi, 2010). By focusing prevention efforts on African American women, it is possible to protect two generations from HPV related cancers through prevention efforts.

History of Cervical Cancer Prevention

With the advancements in medical technology and concentrated efforts to increase screening and prevention, a disease that was once the second leading cause of death for women in the 1940s has seen a significant reduction. The steep decline in the mortality rate of cervical cancer has been attributed to the development of the pap smear test (Safaeian & Solomon, 2007). Dr. Papanicolaou developed the test during the 1940s which involves the scraping of the cervix for observation of abnormal cell changes within the cervix. The decrease in mortality and increase in survivorship is credited to the ability of the test to detect precancerous cells early. The revolutionary nature of the test is

evident when considering its tremendous impact on the mortality rate; from 1973 to 2007, the cervical cancer mortality rate has been halved (Adegoke et al., 2012) The reason why cervical cancer is considered an easily preventable and treatable disease when caught early enough is due to the inclusion of the pap smear test as a part of routine medical procedure. Researchers believe that the future rates of cervical cancer will experience a further decline based on the relationship between the human papillomavirus (HPV) and cervical cancer, along with the HPV vaccine (Lowy & Schiller, 2012).

As important as the pap smear test has become to improving the rate of survivorship, increasing early detection, and decreasing mortality, the pap smear remains a point of contention for women. Most women view the test as an uncomfortable experience, one in which they are not fully educated on the reasoning behind the test or why it is occurring. Previous work has found that although women may understand the importance of screening, often the test is negatively perceived as something to be endured, with time and effort devoted to getting through the invasive procedure.

Despite the advancements made and the decreasing rates in incidence and mortality, not all groups have benefited equally from cervical cancer screening and prevention methods. Although the technology, medical procedures, and vaccines to reduce cervical cancer exist and have been used in the general population, the reduction in the disease burden has, unfortunately, not been equal across all racial and ethnic groups. Aspects missing from the current screening and prevention procedures have prevented it from both fully connecting with minority populations and overcoming systemic barriers. To reduce the burden among minority populations, in this case African Americans, developing new intervention strategies is important and imperative to help

close the gap between the adoption of current technology and minorities. The purpose of this study is to develop an intervention using appropriate theories and the cultural context to reduce cervical cancer disparities.

Background of the Problem

Overview of Cervical Cancer and HPV

This year, the American Cancer Society projects there to be 13,800 new cases of cervical cancer in the United States, and 4,290 new deaths (Siegel et al., 2020). Of those projected new cases, African Americans comprise a 9.1 per 100,000 incidence rate and 3.1 per 100,000 rate in mortality rate. Although intervention, medical technology, and research have been devoted to decreasing cervical cancer incidence and mortality, it remains an issue for minority women. The previous rates were underestimated due to the inclusion of women who have undergone a hysterectomy. When corrected for hysterectomies, African American women were found to have an even worse rate of mortality than previously thought with a 10.1 per 100,000, a rate that is 44% higher than their Caucasian counterparts (Beavis et al., 2017). The current mainstay interventions are not reducing the burden in African American women.

Typical interventions for cervical cancer prevention focus on increasing the number of women who routinely undergo screening, either through psychosocial education (Musa et al., 2017) or enhancing access and reducing barriers (Sabatino et al., 2012). Barriers to cervical cancer screening range from perceived costs (Brown et al., 2011), to fear of finding cancer and lack of knowledge (Nardi et al., 2016). Late

screening or having never been screened can often lead to a late-stage diagnosis, which adds to the financial burden of treatment and decreases the chances for survival. Pelletier (2016) shows that there is a higher risk for late-stage diagnosis in older women, women who are uninsured, and women who are on Medicaid. Benard et al. (2017) demonstrated that there is a higher proportion of African American women presenting with a later stage cancer diagnosis than white women. Consistent and regimented screening is one of the best tools for preventing cervical cancer and treating the early spread.

While participating in consistent screening behavior is encouraged and the main intervention, a disconnect occurs between self-reported screening and actual health behavior. Nationwide, the current self-reported screening hovers around 81% for women of all races between the ages of 21 to 65 (Watson et al., 2017), while specifically for African American women, the self-reported screening rate is 85.3%. Based on the screening rate, one would assume that African American women would be diagnosed at early stages and the mortality rate would be low. However, the reality is that African American women regardless of socioeconomic status have remained at the top for mortality rate. One possible explanation for why the screening rate does not seem to have an effect on the mortality rate is because of the difference between self-reported data and actual medical records review. For example, MacLaughlin et al. (2019) found that in the state of Minnesota there was a discrepancy from what the National Health Interview Study data had indicated of self-reported screening for their state and what they found through investigation. When looking at claims data their study found a significant decline in pap smear testing for all age groups over time along with disparities in women who were screened. A similar effect may be found in other states in the US and the self-

reported rates may not coincide with the claims data. This discrepancy may be due to patients misremembering or even wanting to appear up to date in their screening habits. More nuance is needed when discussing increasing cervical cancer screening as the sole way to reduce cervical cancer disparities in minorities.

Due to the relationship between cervical cancer and human papillomavirus (HPV), vaccinating against HPV has become a more recent intervention strategy against cervical cancer. Studies have shown that when the HPV infection is not treated early enough, it can transform into cervical cancer (Bosch et al., 2008; Bosch et al., 2002; Kjaer et al., 2001); furthermore, not only can HPV transform into cervical cancer, certain strands of HPV can later mutate into the head and neck (Liu et al., 2016; Spence et al., 2016), penile, and anus. A common refrain amongst interventionists is that an increased uptake in HPV vaccination can lead to the eradication of cervical cancer. Because of this, HPV vaccination has become a popular intervention avenue.

When introduced in 2006, the health promotion campaign for HPV focused mainly on vaccinating girls between the ages of 9 to 12. At the time, vaccine uptake was slow for a variety of reasons, including concerns expressed by parents over the safety of this vaccine- a concern that is still echoed in 2020. Several studies have found that some parents are still not entirely convinced about the safety of the vaccine for their children. African American adolescents are more likely than white adolescents to initiate the vaccination process but are less likely to follow through with the vaccination cycle (Spencer et al., 2019). There are several reasons why African American parents may not be able to complete the vaccination cycle for their children. Although the initiation rate may be high, a concern persists among African American parents of even initiating the

process, let alone completing (Sanders Thompson et al., 2012). Medical mistrust, vaccination concerns, and lack of knowledge can be found among the African American community, fears that are well-founded when considering the medical history of African Americans as a collective and their treatment from the healthcare field. Health promotion has begun encouraging boys between the ages of 11-12 to be vaccinated as well. Currently, the literature among African American boys is minimal with room for growth. Regardless of gender, there is a concern among African Americans about the HPV vaccination and hesitation about engaging or completing the HPV vaccination cycle. With the creation of the HPV vaccination, vaccinating both genders has become a newer intervention method for preventing HPV related cancers.

Depending on the age of the individual and their immune system, the dosage for HPV vaccination ranges from two to three dosages. However, race, ethnicity, and income impact the rates of HPV vaccination for some adolescents, who are less likely to receive the vaccine (Jeudin et al., 2014). Nationally in 2016, 60.4% of adolescent girls had initiated the process of vaccination, with 43.4% considered finished or up to date on their dosage (Walker et al., 2017). The age at first initiation of the vaccine, geographic region, urban-rural residence, and health insurance are all factors that influence the completion of the vaccination process (Liu et al., 2016). Some of the most common reasons for low completion rates include forgetting to follow through with sequence, lack of insurance, and access to transportation (Holman et al., 2014).

As an intervention method, the HPV vaccination is normally focused on getting younger generations vaccinated against the infection, often making the target population parents of adolescents. However, college-age interventions do exist for individuals

between the ages of 18 to 26 years old; this group is known as the catch-up population. These individuals, for some reason or another, did not receive the vaccination during the recommended ages and are now becoming vaccinated. In general, parents are a significant influence for vaccine uptake in the college age population (LaJoie et al., 2018). Okafor et al. (2015) study found that African American women were less likely to initiate or complete the vaccination process. Gelman et al. (2013) found similar conclusions even when controlling for socioeconomic status and healthcare access. If African American adolescents are less likely to complete the vaccination cycle, and college-aged women are less likely to initiate and complete the vaccination process, then there is a significant potential for harm.

Statement of the Problem

For African American women, cervical cancer is a burdensome disease that disproportionately affects them when compared to the general populace. The rate of incidence and mortality for African American women has remained a problem for this population for the past decade, an issue demonstrated by the high incidence rate - 41% higher than white women - along with a lower five-year survival rate (DeSantis et al., 2016). According to Markt et al. (2018), excess cancer mortality was mediated by both insurance, 18.6%, and treatment by 47.2%. The magnitude and scope of this issue may not be as large as other diseases; however, it does affect a significant portion of women, and the HPV-related illness poses a risk for both African American adolescents and women.

Identifying a singular issue as the cause of cervical cancer disparities is difficult. There is no individual factor that acts as the sole or main contributor. Rather, the interaction between several causes and contributors creates the conditions for disparities and exacerbates the issue. Both individual and structural barriers serve as overall causes of disparities as they create unfavorable conditions and limit the access to quality care. Socioeconomic status, racism (both institutional and interpersonal), and decreased access to care all contribute to overall health disparities in cancer prevention and care.

In discussing contributors to health disparities, it is important to consider how they impact health behaviors and health-seeking behaviors in African American women. Health-seeking behavior influences how, when, and if women will seek care when experiencing a negative health consequence, as well as if actions are taken to prevent it. For African American women, this means that, depending on the contributor to health disparities and the way it impacts their health behavior, they may be reluctant to participate in cervical cancer screening or prevention. Several of the contributors to health disparities have also been shown to impact health-seeking behavior. A negative interpersonal relationship with a health provider (Peterson et al., 2016), socioeconomic status, and a lack of access to care (Chan & So, 2017)- each has the potential to dissuade African American women from seeking needed care.

Socioeconomic status, defined as a person's education and income, is a contributing factor to cervical cancer disparities because it dictates the resources available to women to access services. Along with SES dictating the availability of resources, it also affects their ability to advocate for themselves and their health status when advocacy is a critical step in the health navigation process. Yin et al. (2010) found

that African American women with low socioeconomic status are at higher risk of being diagnosed with cervical cancer than women of other economic means. In addition to a higher risk of diagnosis, those who had public insurance, or no insurance, were diagnosed at later stages than those with private insurance (Davis et al., 2018). In other words, African American women who have a lower SES do not have the necessary resources to seek timely preventative care, which can result in a later stage diagnosis. For African American women of all SES, a constant refrain in delaying care is the fear of diagnosis, concern over costs of the screening, and the inability to find enough time off to seek care (Brown et al., 2011). Women who are of lower SES status often find it even more difficult to take time to seek care due to their caregiving duties and economic constraints. As mentioned before, routine pap smears have helped to not only decrease cervical cancer incidence and mortality but have also allowed for the disease to be caught at earlier stages. Socioeconomic status can determine whether women are able to access or afford preventative services such as pap smears.

Both access to healthcare and socioeconomic status affect the ability of women to utilize preventative services. Affordability, availability, accessibility, accommodation, and acceptability are all related to accessing healthcare (Penchansky & Thomas, 1981). All five concepts are critical to an individual's ability to seek healthcare and change health behaviors. Access barriers to healthcare influence inequities in cancer disparities by causing difficulties for marginalized populations with regards to receiving much needed preventive and treatment care. The lack of culturally sensitive information and knowledge about where to access such information are two barriers towards screening and follow-up, in addition to lack of insurance and reliable transportation (Nolan et al.,

2014). Affordability of such preventative measures as pap smear tests (Akinlotan et al., 2017) and HPV vaccinations (Joseph et al., 2014) acts as another barrier to participating in health-seeking behavior for women without insurance.

In addition to a woman being able to have access to healthcare services, their actual interactions within the healthcare system play an important role in their healthcare experience. A woman's relationship with her healthcare provider is an important contributor to both health-seeking behavior and disparities. The quality of the relationship with the healthcare provider holds important implications for both the health-seeking behavior (van Loenen et al., 2015) and the quality of care received, along with health outcomes. In fact, the quality of the relationship between patient and provider has been linked to clinical decision making and seen as a potential cause of health disparities (Chapman et al., 2013). While causal links have yet to be drawn between cervical cancer disparities and the patient-provider relationship, inferences can be made when considering how the relationship influences other cancer health outcomes. Unfortunately, for African Americans, the relationship between patient and provider has not always been positive, often influenced by unconscious bias. Penner et al. (2016) demonstrates how a provider's implicit bias affects the quality of communication between patient and provider, along with information retained and perceptions of recommended treatment by the patient.

Patients' experiences, both negative and positive, influence their future health-seeking behavior. Having a previous negative health experience affects the likelihood of undergoing routine cervical screening (Chorley et al., 2017). An assumption can be made that African American women who have had negative health experiences with the

medical field would be less likely to engage in routine cervical screening, especially when trust has been broken. Trust is needed for a quality patient-provider relationship to lead to quality care (Birkhäuser et al., 2017). The patient-provider relationship is important for not only a woman's health, but for their children as well. A good relationship with a health provider influences the decisions women make for their children's health. Women are more likely to have their children vaccinated against HPV after having spent time with their provider discussing the issue (Galbraith et al., 2016).

Background: Previous Work

In 2017-18, I participated in a community-based study with African American women in West Louisville to determine the factors that facilitate or prevent women from accessing cervical cancer screening services. Using a community-based participatory research (CBPR) framework, we began assessing the needs of the community for cervical cancer screening and HPV vaccination services. Partnering with the Portland Family Health Center, Shawnee Christian Healthcare and Volunteers of America, we recruited 45 participants for a series of focus groups. We questioned women about what they currently knew about cervical cancer and HPV, also what facilitators and barriers they experienced in trying to participate in cervical cancer screening and prevention services. In addition to being asked about their own personal experiences, we also asked them about their assumptions regarding women in their community and what did they view as their community needs for overcoming these barriers. Seven focus groups were facilitated at four locations in West Louisville including two federally qualified health centers and two social service agencies. A takeaway from the needs assessment was the eagerness for

further participation and the desire for knowledge which the women displayed in all groups. Several of the women offered to participate in the next stage of the research and anticipated the next steps after completion of the groups. Their enthusiasm coupled with the various health clinics and programs in the area illustrated the fact that there was a wellspring of community capacity. Although the women demonstrated a lack of understanding regarding cervical cancer and HPV, their enthusiasm influenced the concept for this study.

The analysis from the focus group study revealed the barriers that the women experienced, such as misconceptions about the screening process, along with their own personal lack of knowledge about cervical cancer and HPV. During analysis, knowledge displayed by the women were assigned categories based on correctness, ranging from complete understanding to total lack of understanding. An example of incorrect knowledge is one of the participants referring to talcum powder as a cause for cervical cancer. Because the women were unsure of cervical cancer and its relationship to HPV, the participants often asked questions of the facilitators and sought validation for information that they had previously heard from outside sources. The questions that the women asked, or instances in which they sought further clarification about information, were recorded and were used for further development of educational material for a health promotion intervention. This emerged organically during the process of coding the data, as the researchers noticed the volume of questions asked by the participants. To reflect their concerns and needs, the researchers developed a code specifically for questions or need for clarification.

After completion of the focus group needs assessment, the research team formed a community advisory board (CAB) and developed a plan to meet the needs discussed by the community and to reduce cervical cancer screening barriers. Board members were recruited from the Kent School of Social Work, UofL School of Public Health and Information Sciences, American Cancer Society, Kentucky Cancer Program, Kentucky Women's Cancer Program and Screening, local church along with several residents of the West Louisville. The board has met since fall 2018 until the present. After meetings in which the focus group data were discussed, at the recommendation of the community members, the community board planned a Women's Wellness event. In addition, to educating women about cervical cancer and HPV, the event offered resources and opportunities to participate in research activities. The event was an opportunity to elicit interest in future projects (including mHealth) to promote cervical cancer prevention among the women who attended.

Purpose of the Study

The purpose of the study was to develop and evaluate an innovative, culturally-appropriate, and scalable mHealth intervention to promote knowledge and behaviors related to cervical cancer screening and the HPV vaccination among African American women.

The study had three specific aims:

Aim 1: To determine if mHealth intervention can improve the cervical cancer and HPV knowledge of African American women.

Hypothesis 1: Women who participate in the mHealth intervention and receive culturally tailored messages will demonstrate an increase from their baseline to their post- intervention Cervical Cancer Awareness Measure (CCAM) scores.

Aim 2: To assess if the mHealth intervention is a feasible, acceptable, and effective strategy for promoting cervical cancer screening and prevention among African American women

Hypothesis 2.1: Women who participate in the mHealth intervention will report high levels of acceptability based on the Acceptability of Intervention Measure (AIM) scores

Hypothesis 2.2: Women who participate in the mHealth intervention will rate the mHealth intervention with high levels of appropriateness based on the Intervention Appropriateness Measure (IAM) scores

Hypothesis 2.3: Women who participate in the mHealth intervention will rate the mHealth intervention with high levels of feasibility of the intervention in their Feasibility of Intervention Measure (FIM) scores.

Aim 3: To obtain information from participants about 1) aspects of the intervention worked, 2) how the intervention could be improved with open-ended questions and 3) how the COVID-19 pandemic impacted the participants' ability to engage with the intervention.

Significance and Scope of the Study

This study has the potential to not only increase cervical cancer and HPV knowledge, but influence screening and prevention behaviors. African American women have an increased risk of testing positive for high-risk HPV (Banister et al., 2015) and have lower series completion rates for vaccination (Reagan-Steiner et al., 2015). It is important to work toward reducing the risk of HPV infection and toward a more consistent and aggressive strategy for prevention and treatment. Because the symptoms of cervical cancer are difficult to recognize, and individuals may be unaware of symptoms, there can be a delay in seeking medical care (Williams et al., 2019). This study offers an opportunity to help African American women follow the recommended guidelines for routine screening and vaccination. Detection and treatment of cancer at early stages can translate to better survival rates.

Along with increasing adherence to the ACS screening guidelines, this study also focuses on increasing HPV vaccination rates. It is important to encourage women to either have their children complete the vaccination process or to catch up on the vaccination themselves if they are eligible. Since 2009, the HPV vaccination has become a viable and important cancer prevention strategy, giving women the opportunity to protect themselves and their children from over six different types of HPV-related cancer. This study has the potential to increase the HPV vaccination rate through education about HPV, the vaccination, and resources available to complete the vaccination process.

While the scope of this study does not encompass eliminating cervical cancer from the United States, it does work toward improving knowledge about cervical cancer and HPV. The study also works towards the reduction of the African American and white

woman cervical cancer disparity gap. This study uses mHealth technology and culturally tailored text messages to educate African American women about cervical health and HPV while also encouraging them to adopt screening and preventive behavior. In this new age of social distancing and concerns about face to face interactions, having a mobile based intervention is important to reach audiences under any circumstances. This study's significance lies in its ability to reach the target population beyond a singular face-to-face interaction and allows for the ability to disseminate knowledge beyond a singular source.

CHAPTER II: LITERATURE REVIEW

The following chapter focuses on the current literature surrounding cervical cancer, HPV, and African American women to gain a better perspective of intervention efforts to decrease cervical cancer burden. Discussions in the beginning section of this chapter focus on interventions in health research that aim to increase cervical cancer screening in African American women using faith-based approaches, patient navigation, community-enhancement, and tailored messages. Because of the relationship between HPV and cervical cancer, it is also important to consider interventions that address HPV vaccination. Interventions that promote HPV vaccination by either increasing behavior or screening using technology, educational material, and message framing are next examined. In addition to considering the current intervention strategies, this chapter next looks at the theoretical frameworks that can examine the problems of cervical cancer disparities and ways to address the problem. The final section of this chapter centers on research approaches that have been used and can be used when attempting to work with marginalized populations.

Social Work as an organizing framework

In order to understand the causes of disparities and offer pathways to overcoming barriers researchers must consider past studies and their theoretical frameworks. Doing so

will offer insight into the causes of cervical cancer disparities and aid in the creation of impactful solutions. This chapter is organized around the following literature: social work intervention studies with a target population of minority women focusing on cervical cancer and HPV prevention; gaps in social work that highlight the need for this study; Andersen's Behavioral Model and Critical Race Theory to explain and offer solutions; and the ability of community-based participatory and mobile health research approaches to offer culturally-derived innovation.

In 2012, the National Association of Social Workers issued twelve grand challenges as part of a social agenda to foster change and improve the social environment. One of these grand challenges concentrates on working to close the health gap and to achieve health equity. Achieving health equity or, in other words, attainment of the highest level of health for all people (Braveman, 2006), stands as a critical goal for reducing health disparities. For health equity to be attained, the barriers to care associated with health disparities need to be reduced or removed. The relationship between disparities and health equity jeopardizes the health of the most vulnerable (Braveman, 2014), as health disparities often pose a direct threat to individuals achieving their highest level of health attainment. The health gap in cancer experience continues to prevail, even as medical advancements improve the overall health of the United States. Smedley et al. (2003) once described cancer as an unequal burden that predominantly impacts minorities. This remains true, as the ever-present health gap continues for another generation and has, in some cases, widened.

The social work presence, found in the practice setting of cancer centers across America, has not yet permeated the literature. Few studies conducted by social workers

focus on the development of interventions for cervical cancer disparities for African American women. This dearth in the literature creates a gap in addressing cervical cancer disparities and HPV vaccine uptake. Of the few social work studies found about HPV vaccination, none include a focus on African American women as their target intervention group. African American women are at high risk for cervical cancer, and an increase in HPV vaccination is one way to alter the risk for younger individuals. This offers an avenue in which social workers have the potential to address cervical cancer disparities and to encourage the increase in HPV vaccination.

Several studies offer a solution or perspective on cervical cancer disparities, but few delve as deeply into the social context as social work-oriented studies. Social work's commitment to understanding the broader social context and working in the realms of social justice encourages researchers and practitioners to work with communities to create sustainable change. The National Association of Social Workers (NASW) lists in our code of conduct the principles of service; social justice; dignity and worth of persons. These principles and standards, such as cultural awareness and social diversity, compel social workers to design, implement, and evaluate culturally appropriate practice and centering person in environment. While other fields may focus on the individual or the population, social work realizes that the person-in-environment operates as an essential aspect of understanding the deeper context of a social problem and building an informed intervention strategy. By following this perspective, community-based participatory research becomes an optimal choice when dealing with the social justice issue of cervical cancer disparities.

Studies on Cervical Cancer Prevention among African American women

Over the past decade, several studies have attempted to address cervical cancer disparities in an African American population, ranging in approach from psychosocial education, to faith-based orientations, to case management, to text-based services. Featured below are a few of the studies that meet the criteria of interventions targeting African American women with the goal of changing screening and prevention behavior. Two literature reviews were conducted to understand social work's contribution to the field of cervical cancer disparities and examine what interventions have been used to improve cervical cancer and HPV outcomes in African Americans. One search focused specifically on cervical cancer interventions and African American women with the inclusion criteria of cervical cancer screening or prevention interventions, African American women as the target intervention population, and social work as the primary author. Another search was conducted focusing on HPV interventions and African American women, parents, or adolescents. The goal for each search was to find social work-specific studies that dealt with these target populations. Due to the limited number of studies found in both searches, the inclusion criteria were widened to include health professionals in general.

Searches were done in EBSCO, Cochrane, PsychoInfo, Google Scholar, and Medline with a time restriction from 2000 to 2020, a total of 38,411 studies were found. In addition to using those specific databases, to ensure that studies were not overlooked, ten social work journals, such as Health and Social Work and the Journal of Psychosocial Oncology, were searched individually for articles relating to cervical cancer and health disparities. A limited number of studies were found with a social worker as a primary

author for cervical cancer screening and prevention interventions that targeted the African American population. Sixteen studies met the inclusion criteria: 3 in social work, 7 in public health, 3 in medicine, 1 in nursing, 1 in clinical psychology, and 1 in health education.

Faith-Based Approaches

Due to the close relationship, many African American women have with faith institutions, faith-based interventions have been employed by researchers as a way to explore and address cervical cancer disparities. Their usage allows for researchers to interact with populations that may be otherwise hard to reach. Matthews et al. (2006) found that participants in their intervention believed church plays an important role in health promotion, that personal relationships with lay health advocates promote screening, that targeted messages are useful for education and awareness, and that social stigma can act as a barrier to cervical cancer screening. The study offered useful insights into the role faith-based organizations can play in facilitating health education, however results would have been more robust if the researchers had collected demographic data. Focus group evaluation are best done with a clear understanding of who is in the room and the impact of their lived experiences on their answers. Without collecting demographic data, it can be challenging to parse the role external factors may have played in participants answers.

Haynes et al. (2014) adapted the Con Amor Aprendemos (CAA), an intervention created for the Latino community, to With Love We Learn (WLWL) for African American women. According to the researchers, the WLWL program was well-received

during its pilot, with a few adjustments suggested for content tailoring in order to fit the target population better. In their study, lay health ministers educated couples on anatomy, sexually transmitted infections, cervical health, and HPV through interactive games and educational tools. As a pilot study, the researchers had impressive results but would have benefited from reporting on the change in participants' knowledge and attitudes after engaging in the WLWL program.

Faith-based interventions operate as a useful strategy for engaging with African American women due to the social context and history of the church in the African American community. Although these two studies aimed their intervention specifically toward churches, the present study did not take the same approach. The intention of this study focused on reaching a broad spectrum of African American women, as targeting only the faith-based community can exclude non-churchgoing African American women. This study contains a small similarity between WLWL due to the use of community members to adapt or tailor the curriculum messages, in an effort to ensure that the women successfully connect with the information.

Patient Navigation or Case Management Interventions

Researchers and practitioners utilize patient navigation, developed by Dr. Harold Freeman as an intervention strategy for helping vulnerable populations navigate barriers to timely diagnosis and treatment (Freeman, 2012), to address disparities in cancer care and treatment. This strategy improves the navigation of the cervical cancer screening process and addresses the barriers to screening for minority women. The principles of patient navigation according to Dr. Freeman involved a patient-centered health care

service delivery model; integration of the health care system for an individual; elimination of barriers to care; navigators integrated into healthcare team; delivery of patient navigation services that are cost-effective; clear defined beginning and end of services; skilled workers; and navigation across disconnected systems.

Markossian et al. (2012) measured the effectiveness of patient navigation services for low-income minority women with an abnormal breast or cervical cancer screening. The study was a nonrandomized, controlled design in which both navigated and controlled patients were recruited from a federally qualified health center network or a hospital-based ambulatory care center. Five of the navigation sites were chosen as the intervention group because they treated predominantly African American and Latina women, while fourteen navigation sites served as a medical record-based control. They found that the time between an abnormal screening result and the diagnostic resolution shortened through the aid of patient navigation services. By comparing the five predominantly minority clinics sites versus the fourteen additional sites, there is the possibility that a significant difference could be found between the two-different group. The authors attempted to correct for the differences in navigation and comparison sites demographics by controlling for covariates and clinic sites. After having run a logistic regression analysis, with and without women who were self-identified as white or other, the authors found that there was not a significant difference in results and dropped them from the data analysis. This is one of the few studies to do a survival analysis overtime using Kaplan Meier curves, which is a welcomed change that helps in the evaluation of their intervention.

Boston REACH Coalition developed the Women's Health Demonstration Project to address cervical cancer screening disparities among African American women (Clark et al., 2011). Their approach involved using case management services in a primary care setting to address the various social and medical factors that may dissuade African American women from participating in cervical cancer screening or engaging in a timely follow-up. The researchers found prolonged exposure to case management services led to a greater chance of adhering to screening guidelines and having social support for childcare was associated with greater screening adherence for women out of compliance at baseline. According to this study, insurance acted as the only indicator for whether timely follow-up after an abnormal result occurred. One of their mentioned limitations was a loss in focus group and intervention site due to funding constraints. As the researchers note, control groups are important for increasing the rigor of a study and having the ability to make more persuasive conclusions.

Falk et al. (2018), a study with a social worker as the primary author, responded to the needs of any earlier program in rural Texas, Friend to Friend, and added patient navigation services to the community-based educational program. The objective of this program was to build an infrastructure of services and educational programs that would improve screening amongst underserved, uninsured or underinsured, and older, women. Although they were a smaller percent of the sample, there was some promise to be found in having African American women in the Friend to Friend program engaging in patient navigation services. There was not a significant difference between African American women and non-Hispanic white women in this sample for breast or cervical screening. According to the authors this means that African American women were just as likely as

non-Hispanic white women to engage in services. Results may differ across implementation sites, as the protocol varied depending on the region.

Rodriguez et al. (2020) adapted and modernized the National Witness Project model, a faith and community-based model used at multiple sites across the US, to educate and empower women about breast and cervical cancer. Their goal was to not only update the curriculum of this older program but to also determine its effectiveness and feasibility. The updated curriculum featured information about breast and cervical cancer screening, and the addition of information about HPV vaccination. By using a combination of community-based participatory approaches and patient navigation services they were able to improve participants' knowledge using both the original and updated curriculum. Unfortunately, they were not able to collect education level, which may impact the navigation of patients in both the health system and their intervention. The study also did not feature a control group in their design, so causality is limited, but there is promise when considering that this was a multi-site study in both Arkansas and New York.

Patient navigation and case management are effective and useful strategies for addressing structural and interpersonal barriers. Through the use of patient navigation services, individuals become able to address the context of screening and not just the act itself. Case management allows for a lessening of worry surrounding the ability to be screened, the results of the screening, and whether treatment can even be afforded due to financial constraints. Both intervention avenues have resulted in improved screening behavior for African American women; however, additional intervention avenues address similar contexts of screening behavior, but with a broader community perspective.

Community-Enhancement Approaches

The Screening Older Minority Women Project, a social work study, was a community enhancement intervention developed to increase breast and cervical cancer screening among minority women (Bullock & McGraw, 2006). The primary goal of the project was to enhance the capacity for health behavior change among older women of color using a community enhancement approach. Researchers and community workers educated women on the importance of screening behaviors, rectified barriers, and fostered a sustainable community environment. The study brought in the broader context of community and worked on the intra-racial relationship across generational lines. Community health coworkers recruited the younger women to an educational session, and then depending on whether they were assigned the intervention, the younger women then in turn recommended and helped recruit older women. As an early attempt at community enhancement approaches and cervical cancer education, Bullock and McGraw (2006) offer insightful information about the feasibility and potential to use this approach; especially as one of the few social work led studies on this subject. However, limitations found in the study demonstrate gaps and potential for future research directions. The researchers did not clearly describe their intervention, there was confusion over the recruitment and inclusion of participants and their outcome data resulted in only descriptive statistics.

Staples et al. (2018), another community-based study, attempted to improve cervical cancer and HPV knowledge in female students through a series of lectures at historically black colleges or universities (HBCUs). They developed an educational intervention in the form of a age-appropriate, culturally relevant one-hour interactive

PowerPoint lecture on topics such as cervical anatomy, disease progression, and steps taken during a pap test. After completion of the educational intervention, the cervical cancer and HPV knowledge scores improved for the students and many expressed an interest in getting screened. A highlight of this study was the researchers use of interactive learning and a Bitmoji, in this case a black female character, to relate with the students. Although, the authors used a culturally relevant intervention, there was not much influence from the community in their intervention development. While it is essential to keep the health information accurate and informative, the authors would likely have benefited more from the use of community advisors when interacting with this population of young adult African American women.

Teteh et al. (2019) also used a community lecture format as an educational intervention to increase cervical cancer and HPV knowledge. Panelists from academia, a community advocate, and a pharmaceutical representative were able to have a dialogue with community members about the importance of and the process involved with vaccination, and the relationship between HPV and cervical cancer. After their educational intervention, both perceived knowledge and trust increased in the participants.

Each study focused on the importance of including the community when developing research in marginalized communities. Community enhancement approaches allow for a sense of empowerment and ownership for community members as they aid researchers in developing innovative solutions to social problems. However, there are limitations to each study that reflect a need for a sustainable and nuance approach to continued research.

Tailored Messages

Tailored messages have been used to prompt health behavior changes in various topics, ranging from reducing blood pressure (Hageman et al., 2014), cancer screening (Jensen et al., 2012), and smoking cessation (Hébert et al., 2018). Jibaja-Weiss et al. (2003) investigated if personalized tailored messages created a greater increase in appointment scheduling and cervical cancer screening participation than usual care or generic messages. Their tailored messages contained information about the participant's personal risk for breast or cervical cancer based on their medical records. Surprisingly, women in the tailored messaging group had the lowest rate of scheduling a pap test and actual receipt of screening services. As the authors note in their discussion, a heightened level of personalization not only takes a considerable amount of effort, but also creates anxiety in the participant. Instead of focusing on their risk for breast or cervical cancer, the women possibly became alarmed and distressed seeing their personal medical information reflected back to them in this context.

Interventions to Promote HPV Vaccinations

Technology-Based Interventions

DiClemente et al. (2015) conducted a public health study, called Girls OnGuard, using computer-based interactive multimedia to increase HPV vaccine uptake in a health clinic. They developed the intervention on the Information-Motivation-Behavioral skills model in which individuals are viewed as likely to initiate and maintain positive health behaviors to the extent that they are well informed, motivated to act, and possess the necessary behavioral skills. Intervention conditions for Girls OnGuard featured a twelve-

minute, interactive, computer-delivered media presentation on HPV vaccination designed to enhance initial uptake and compliance of HPV4, in addition to a motivational keychain to store as a vaccine reminder. As a result of this intervention, only a small number of participants received the first dose of the vaccination, and even fewer completed the vaccination course. The inclusion of technology into the health field has allowed for several new intervention strategies to develop. DiClemente, et al remains one of the few studies to incorporate technology into HPV vaccination with African Americans as the target population.

A more recent technology-based study is the CervixCheck developed by Le and Holt (2018). This study was an integration of mobile text messages with a faith-based curriculum that sought to improve cervical cancer screening and prevention in African American women. Using the Theory of Planned Behavior, the researchers worked to encourage promotion of positive health behaviors in church-going African American women between the ages of 21-65. The incorporation of faith-based messages alongside health information made a positive impact on the women in their target population as there was an increase in knowledge about cervical cancer and subjective norms. Unfortunately, their use of a singular pre-post test design over a course of 16 days makes it difficult to draw generalizations on whether this particular intervention can be used across geographical and cultural lines. It is possible that the CervixCheck while effective for church-going women, would not have the same success with African American women who do not regularly attend church services.

Intention to Vaccinate

Tiro et al. (2015) conducted a randomized control trial at four safety-net hospitals using an educational intervention to impact HPV vaccination. This study developed an educational brochure after asking parents what information they wanted besides the standard CDC brochure. The HPV-specific brochure mailed to African American individuals before dose 1 did not increase vaccination initiation. However, for doses 2 and 3, recall phone calls with the parents who had yet to complete the process were conducted and found to be effective at improving vaccination completion. The researchers included randomization of eligible patients, a comparison group, and used electronic health records to observe outcomes. Of its limitations the external threat to generalizability was its use in an urban safety-net clinic. The population of that clinic may not be representative of the target group as a whole and has its own challenges to screening.

Joseph et al. (2016) attempted to see if a brief negotiated interview intervention, focusing on client concerns, could improve HPV vaccine initiation and cervical cancer knowledge. The intervention group did not significantly differ from the control group in vaccine initiation or coverage at any point in the vaccination process. The study observed a significant increase in knowledge about HPV in the intervention group compared to the control group. In their discussion, the authors acknowledge that the increase in knowledge did not often translate to an increase in vaccination initiation. A concern for most studies is a focus only on increasing knowledge, without acknowledge the various factors that make initiation and completion challenging for this population.

In both studies, intention to vaccinate is one of the desired health outcomes for numerous reasons. Researchers often couple improving HPV knowledge and intention to vaccinate together in the hopes the improvement of knowledge will lead to increased vaccination coverage. Because of the length in the time needed to complete the vaccination process, which can be up to a year for vaccination completion, researchers often attempt to influence the parents' intention to vaccinate in order to prompt vaccination initiation or coverage. Concern exists about whether the intention to vaccinate directly translates into the initiation and completion of the vaccination process.

Message Framing

In addition to tailored messaging, message framing becomes important to ensure the intervention thoroughly conveys health behavior information. Lechuga et al. (2011) explored whether the framework of the message, i.e. using a gain or a loss framework, affected the reception of the vaccination message. The study presented educational materials as a choice in which mothers could protect their daughter by getting them vaccinated, a gain framework, or potentially harm them by not getting them vaccinated, a loss framework. Having presented the educational intervention to three different ethnic groups, the authors found that framing the messages using either a gain or loss framework led to a greater intention to vaccinate. For African American mothers, the loss framework displayed higher intentions than the gain framework, meaning the loss framework was the most impactful. For non-Hispanic white mothers, both frames were effective. Lechuga demonstrated the significant effect of the loss framework on whether African American mothers intended to vaccinate their daughters. The limitations of this

study are the same as others, there is a potential for intention to not result in behavior change.

Gaps in the Literature

Interventions that are tailored toward African Americans are crucial for addressing cervical cancer disparities. The health outcome for these interventions are often an increase in cervical cancer screening or an uptake in the HPV vaccination. Both serve as essential strategies in reducing the number of women diagnosed with cervical cancer. Since the creation of the oncology social work profession, social workers are well positioned to intervene at several points in health disparities. Any time point in the cancer care continuum can serve as an intervention point for addressing cervical cancer disparities, whether it is prevention, screening, treatment, or survivorship. Thus, it is surprising to discover so few articles devoted to the topic of cervical cancer disparities in the African American population led by social workers.

Prevention is a gap in the social work literature, and an intervention point in which social workers can and should focus on contributing to the overall knowledge base. Not only is there an opportunity to increase social work's presence in developing and evaluating interventions to address cervical cancer, a similar gap is found within the HPV vaccination literature as well. HPV vaccination is another intervention strategy (primary prevention) for addressing health disparities and social workers, community, medical or otherwise, exist in a unique position to address this issue. Social workers can and do offer valuable insight to the medical field, and social work studies devoted to cervical cancer disparities are needed in this field. The social problem of health disparities is one in

which social workers can respond to and that our code of ethics support compels to help alleviate suffering. Future research by social workers, that use community-based methods can help fill a gap in both practice and literature.

Theoretical Frameworks for Study

Andersen’s Behavioral Health Model

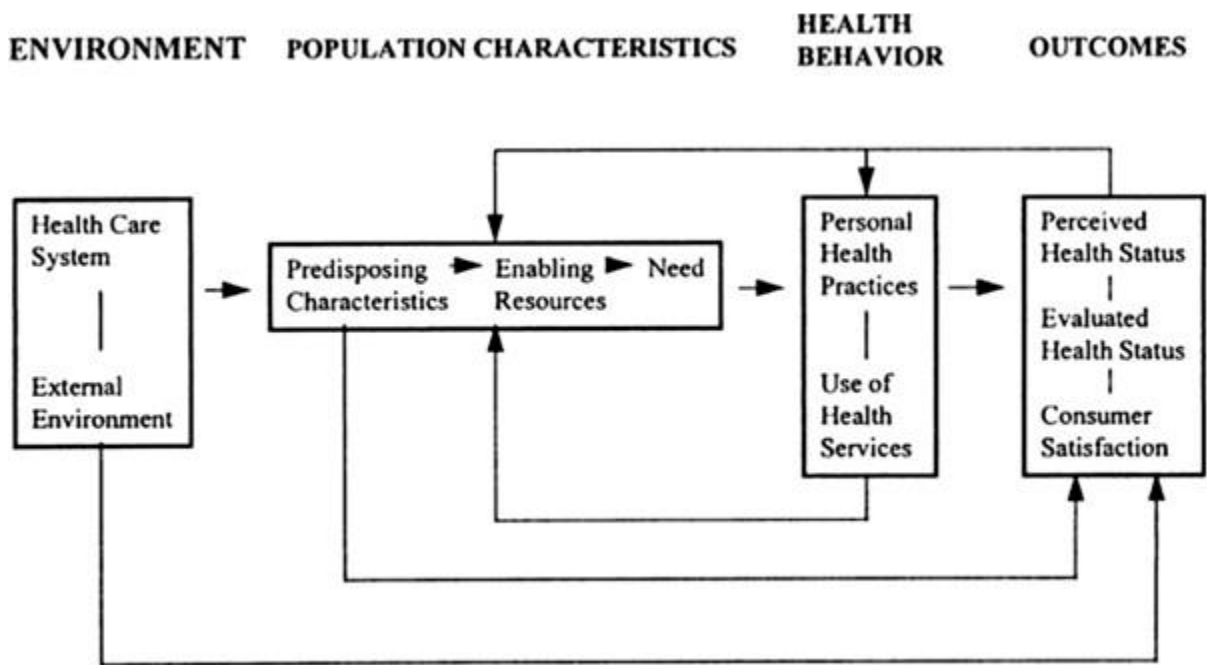


Figure 1 Andersen’s Behavioral Model of Healthcare Utilization

Andersen Behavioral Model of Healthcare Utilization was designed specifically to describe and understand why individuals use healthcare and what factors influence their use. This model explicitly uses health outcomes as the main variable and is useful for analyzing disparities at a micro, mezzo, or macro level. Because cervical cancer health disparities are a mix of healthcare use and prevention, the inclusion of this theory is necessary to better understand healthcare navigation and utilization. Overall,

Andersen's theory and the subsequent expansions allow for an opportunity to examine the relationship between utilization and health disparities. One of Andersen's revisions includes components related to the external environment, health behavior, and health outcome while reclassifying his initial theoretical model underneath the umbrella of population characteristics.

External Environment

In Andersen's revised theoretical model, he added an external environment component, in which the physical environment, politics, economics, and the healthcare system as a whole impact the utilization of healthcare services (Andersen, 1995). The external environment and healthcare system play a vital role in determining an individual's potential need for health services, their ability to access health services, and whether any health services are available. For example, the political environment has impacted healthcare utilization, with the implementation of the Affordable Care Act resulting in a reduction in health access and utilization disparities (Chen et al., 2016). Environmental hazards, the built environment, and access to related services act as factors of the physical environment that impact healthcare utilization (Woolf & Aron, 2013). This impact influences whether an individual finds themselves needing health services and if health services are even available. The external environment dictates and can potentially disrupt the flow of the health care system, as it results in an individual's increased need for usage or the decreased ability to access.

Cervical disparities can be better understood when analyzing the ways in which the environment affects African American women. For consideration, African American

women who live in urban environments can struggle with finding reliable transportation to utilizing health services. The Girls OnGuard study, which was designed to improve HPV vaccination in African American adolescents, demonstrates the impact of the built physical environment on healthcare utilization as the study had low vaccination rates due to a change in the bus schedule which affected participants' ability to continue in the study (DiClemente et al., 2015). Following this model, the external environmental factor of transportation and built environment resulted in a negative impact on overall health outcomes. Transportation barriers negatively impact healthcare access for individuals with lower socioeconomic status and ethnic minorities (Syed et al., 2013). This possible impact can contribute to the negative experience of health differences for African American women in an urban environment.

Population Characteristics

During the 1970s, in the first iteration of Andersen's behavioral model, population characteristics were the sole focus. According to the theoretical model at the time, healthcare utilization could be predicted or was experienced by predisposing characteristics affecting enabling resources, which in turn affected need and then ultimately use of health services (Andersen, 1995). This initial model was absorbed into a larger model that takes into account extenuating circumstances surrounding health utilization.

Predisposing characteristics, according to Andersen (1995), were demographics, social structures, and health beliefs. Factors considered biological imperatives, such as age and gender, were deemed demographics that affected the need for healthcare services.

The reasoning behind this change looked at the ability of age and gender of an individual to determine need and frequency of use. An older individual may find themselves with a litany of health concerns, or a pregnant woman may be in need of consistent checkups. Race, occupation, and educational attainment were captured in social structures, as they were often used to determine the social status an individual has in society.

As the literature has demonstrated, race (Ben et al., 2017), education (Datta et al., 2006), and insurance status (Ward et al., 2008) are population characteristics which have all had an effect on healthcare utilization and availability of services. Population characteristics determine what resources are available to use in seeking services and how the possession of those characteristics themselves impact the overall navigation of the health system. This is demonstrated by the negative impact of perceived discrimination on the screening behavior of African American women (Mouton et al., 2010). The race of the women in the study dictated not only the resources available to them but how the experience of racism affected their willingness and need to seek out health services. With cervical cancer, an emphasis is placed on screening behavior due to the benefits of discovering the disease in its early stages; African American women who are discouraged from getting screened due to the experience of everyday discrimination find themselves at risk for developing cervical cancer.

The original model of the 1970s, useful in examining health utilization and its influences during its time, was considered by some researchers to be an oversimplification of a complex problem. Other researchers have expanded on this model in order to study vulnerable populations (Gelberg et al., 2000), psychosocial factors, and even the experiences of African American women (Bradley et al., 2002). Bradley et al.

(2002) expanded on the initial model by including psychosocial factors in predisposing characteristics that help to deepen health utilization knowledge. They expanded on it by either including or redefining concepts such as attitudes, knowledge, social norms, and perceived control. In their model, they enacted a switch in the order from predisposing characteristics influencing need and enabling factors to need and enabling factors influencing predisposing characteristics. Psychosocial factors are important for explaining why health differences may exist, for example, the lack of cervical cancer knowledge making it less likely for a woman to be screened or have their children vaccinated. Another possible scenario is the lack of perceived control making African American women hesitant to seek out cervical cancer prevention services for their children or themselves.

Andersen later added some aspects initially considered enabling resources to the external environment component in the updated model. Enabling resources are both community and individual level resources that are necessary to be able to receive and be able to afford healthcare services (Andersen, 1995). Within enabling resources, issues such as physician scarcity, transportation, and income can be used as a measurement for predicting whether individuals intend to and will be able to use health services. Enabling resources are essential aspects that let individuals believe that they can both afford and readily find available health services. This can be demonstrated as an individual who does not have insurance or is underinsured being hesitant to utilize any healthcare service for fear of incurring debt. The cost of HPV vaccination (Sanders Thompson et al., 2012) and cervical cancer screening (Brown et al., 2011) has been cited as a barrier to cervical cancer prevention for African Americans. Keeping this in mind, the lack of enabling

resources can be used as both an explanation and a point of intervention for cervical cancer disparities.

The original purpose of Andersen's model was to capture healthcare utilization by individuals, and thus, it often focused more on quantitative data related to the number of visits and diagnoses. In his original definition, need was based on evaluative need, which used a professional judgment about an individual's health status and their need for medical care (Andersen, 1995). Utilization was supposed to be measured in the number of visits or times in which healthcare services were sought. A focus on the biological aspects of health and illness at the time did not account for all the social factors that go into effect around the concept of need. Although useful during its original iteration, evaluative need limits and oversimplifies the actual needs of individuals and how they view said medical needs. Depending upon the patient's view of their biological needs, they may or may not seek services as a result.

In his update of the model, Andersen even agrees with the criticism that evaluative need only tells part of the story of utilization. When considering preventative services and utilization, the original definition of need would make it difficult to capture how an individual's perceived need influences their utilization of the service. A woman could believe or perceive that she is not at risk for cervical cancer and thus does not need screening, when in fact she may be in an early stage of cancer or at high risk. Her perception and not the biological needs of her body would affect her seeking services. Perceived need serves as both a critical intervention point and a possible explanation for cervical cancer disparities. Depending on the attitudes, knowledge, and norms of an individual, they may not perceive themselves as being in need of cervical cancer screening

or prevention services, and thus not use either service. Times in which evaluative need and perceived need may not match lead to frustration on both the healthcare provider and patient, along with dissatisfaction of services. This dissatisfaction and frustration could affect future health-seeking behavior in individuals, potentially placing them at risk.

Health Behavior

To take into account the individual practices of health, Andersen introduced the concept of health behaviors into his most recent model. According to Andersen (1995), health behavior is both personal health practices and the use of health services, in which exists a relationship between health behavior, population characteristics, and health outcomes. With this model, health behavior affects both population characteristics and health outcomes, as all three components are influenced by each other, creating a loop of healthcare utilization. Health behavior has been defined elsewhere as activities undertaken by an individual for the purpose of maintaining or enhancing their health, preventing health problems, or achieving a positive body image (Cockerham, 2014). Cervical cancer health behaviors would be activities such as HPV vaccination or undergoing a pap test, taken in an effort to prevent or screen for early detection of the disease.

Outcomes

The outcome component in Andersen's model is a new adaption and includes perceived health status, evaluated health status, and consumer satisfaction (Andersen, 1995). Problems arise when an individual's perceived and evaluated health status are noncongruent. An individual may perceive their health to be positive and not in need of

additional care when in fact their evaluated health status is poor. Considering that the perceived risk is lower among minorities than their Caucasian counterparts (Orom et al., 2010) and that raising risk appraisal can change an individual's health intentions and behaviors (Sheeran et al., 2014), then this becomes an important intervention avenue. As an intervention method, education would be an essential tool in merging the perceived and evaluated health status, positively influencing the health behavior and use of services.

The updated model views consumer or patient satisfaction as one of the outcomes of healthcare utilization that potentially feeds into population characteristics which in turn drive the use of health care services (Andersen, 1995). The patient's experiences with the healthcare system are believed to have an impact on their future use. Patient satisfaction, patient safety, and clinical effectiveness were all found to have positive associations and an impact on physical, mental, and objective measures of health (Doyle et al., 2013). If the patient is satisfied with the level of care they receive, and the relationship between the patient and provider is positive, then important prevention and screening goals can be met.

Critical Race Theory

According to Graham et al. (2011), several tenets of critical race theory relevant to the public health field include: dominant cultural orientation discrimination; race and ethnic relations approaches; narrative as inquiry; contextual and historicized analysis; and investigator relationship to research and the scholarly voice. Those same tenets of critical race theory also have relevance to social work and can be used in health disparities research. Adopting a critical race theory praxis allows for the centering of race when

discussing health disparities, along with the ability to use historical context to delve deeper into the root causes of health disparities.

Race and ethnic relations approaches Colorblindness and race consciousness

American society approaches race and ethnic social relations in several different ways. Colorblindness, race consciousness, interest convergence, material determinism, and structural determinism are each avenues in which individuals or groups navigate the racial or ethnic landscape (Graham et al., 2011). With colorblindness, race does not factor in the possibility of root causes of health differences; however, with race consciousness, race is specifically and intentionally raised as a possible explanation for those differences (Ford & Airhihenbuwa, 2010). The praxis of claiming to no longer see color, i.e. colorblindness, is utilized as an attempt to address racism, but this makes it difficult to acknowledge the effects of race on health. Race consciousness, a critical race concept, allows for the impact of race to be considered as a potential cause of health differences in society. With this concept, race is not swept under the rug but brought to the forefront of consideration.

For health disparities research, acknowledging and bringing race to the forefront is important to accomplish both effective observation and eventual elimination of racial differences in care and treatment. Research shows racial differences across the cancer care continuum and their continued existence over the span of decades. While the praxis of colorblindness has made it difficult to note these discrepancies, race consciousness points out the glaringly obvious disparities in the cancer experience. Racial health disparities are evident in cervical cancer, due to the high incidence and mortality rate of African American women when compared with their white counterparts (Yoo et al.,

2017). Recent research has even demonstrated that the disparity between the two is larger than previously thought (Beavis et al., 2017). Adopting a critical race approach towards health disparities allows for a focus to be placed on racial cancer disparities instead of assuming disparities result from some yet to be discovered factors.

Integration of Frameworks

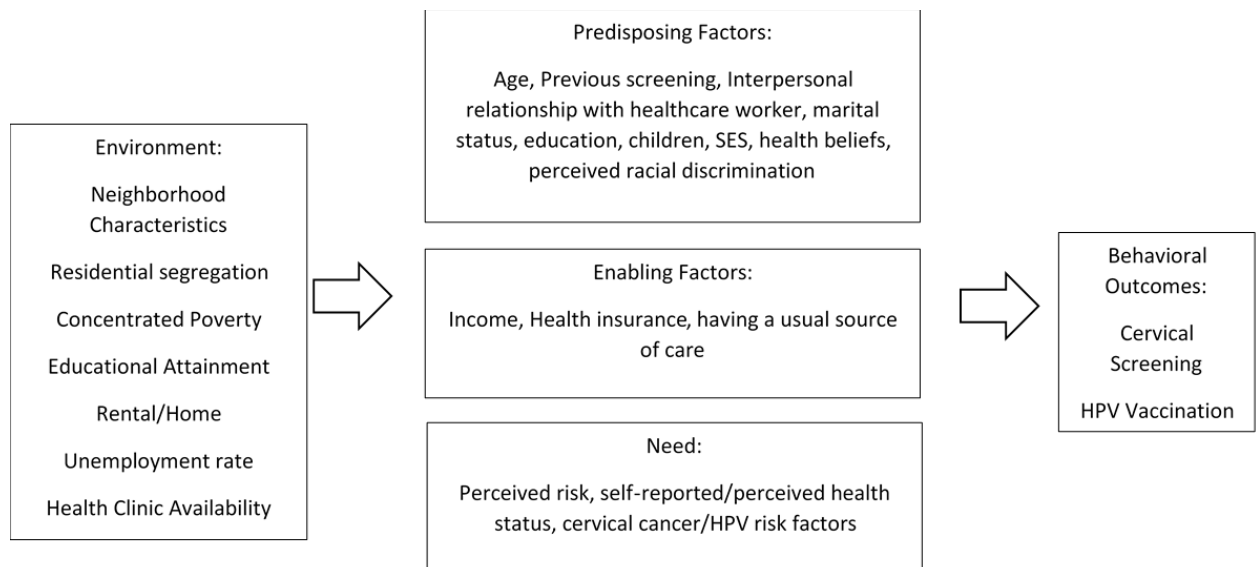


Figure 2 Andersen’s Behavioral Model + Critical Race Theory Concept Map

Ford and Airhihenbuwa (2010) demonstrated the possibility of merging Andersen’s Behavior Model and Critical Race Theory together. From their study, they used Andersen’s Behavior Model as the overall structure of their conceptual model and elements of critical race theory to augment missing pieces and perspectives. Using their approach, race is no longer a manipulable variable, and the focus is less on whether being African American influences behavior and more on how racialized experiences of African Americans affect behavior. A shift occurs in thinking from assuming an individual’s identity will dictate their behavior to operating under the assumption that an individual’s

behavior is the direct response to their experiences in society. With this shift, the screening and prevention behavior of African American women has been impacted by their individual and collective racialized experiences in society. This is a departure from previous assumptions that because the women identified as black, they simply did not engage in preventive behavior. Working with the latter assumption allows for a deeper understanding of why screening and vaccination rates are low and a focus on a root cause of the issue.

The integration between Andersen's Behavior Model and Critical Race Theory allows for the centering of race in explaining healthcare service utilization among African American women. In the context of Andersen alone, race was used as a predisposing character without further background given; before, race and identity were seen almost as a static indicator of future behavior. Because this study includes only women who identify as African American or of African descent, the element of race is no longer manipulable and intra-racial comparisons can be made. The centering of race and intra-racial comparisons allows for the focus to solely be on African American women, which means differences observed within the group are due to variables of interest beyond race. Most often, studies make interracial comparisons that do not delve deeper into what may be significant differences due to racialized experiences. Essentially, instead of comparing the results of this study or behaviors displayed by the participants across racial lines, the centering of race in this context focuses only on the racialized experiences of African American women.

External Environment In this model, the external environment consists of neighborhood characteristics, residential segregation, concentrated poverty, educational

attainment, rental vs home ownership, unemployment rate, and health clinic availability. Residential segregation, such as redlining, a practice in which loans or mortgages are provided to a particular community on a discriminatory basis, confines a large population of African Americans to a set number of zip codes. While not every African American who is a resident of a city lives in redline zip codes, the zip codes that are part of the redline section are often predominately African American, suffering from concentrated poverty, high unemployment rates, and limited access to quality grocery stores. The health effects of redlining can be found in breast cancer (Beyer et al., 2016), cervical cancer (Krieger et al., 2020), pregnancy (Mendez et al., 2014), and self-rated health (McClure et al., 2019). Krieger et al. (2020) in demonstrated the relationship between historical redlining and its health effects. Cervical cancer was more likely to be found in historically redlined areas, in their sample the majority of minority women had cervical cancer.

Many low-income neighborhoods are also considered food deserts, in which it is difficult for quality, healthy food to be sourced and low supermarket availability exists (Walker et al., 2010). The availability and quality of food in neighborhoods affect the healthy eating habits in individuals (Hilmers et al., 2012; Krukowski et al., 2010), which in turn affect overall health. An unhealthy diet resulting from food deserts or oases often places low-income individuals at risk for obesity (Ghosh-Dastidar et al., 2014).

Homeownership versus rental housing has been added to the discussion when considering neighborhood characteristics. Homeownership has traditionally been seen as a positive investment, with indicators of a beneficial contribution to psychological health, physical health, social capital and neighborhood impacts, civic engagement, and

parenting (Rohe & Lindblad, 2013). Although homeownership does offer social benefits, negative consequences may arise, especially after the last housing crisis and the looming Covid-19 pandemic-induced housing instability. Individuals become stressed over mortgage payments and potential foreclosures, leading to negative health outcomes. However, those who experience a worsening economic and housing instability tended to have poorer access to care, no usual source of care, were uninsured, postponed needed medical care, and postponed medication (Reid et al., 2008). Nationally the African American homeownership is 44% , the lowest rate when compared to other demographic groups, while the national average is 65.3% and for white homeowners 73.7% (United States Census Bureau, 2020).

Healthcare availability is another important external environmental indicator to consider when discussing health behaviors. While the availability of health services may not be poorer in lower-income neighborhoods than in higher-income neighborhoods, the type of medical services available differs (Hussein et al., 2016). The availability of health clinics proves to be important for establishing a usual source of care and having options when seeking treatment.

Predisposing factors in this proposed model are age, vaccination status, previous screening, interpersonal relationships with healthcare workers, marital status, education, number of children, socioeconomic status, health beliefs, and perceived racial discrimination. Both age and gender have been associated with health behaviors such as screening and prevention-related activities, as well as with health beliefs such as responsibility and risks (Deeks et al., 2009). Women between the ages of 31 to 40 years old are more likely to participate in pap smear screening than women who are over the

age of 61 years old (Deeks et al., 2009). Since the development and prevalence of the HPV vaccination, a new target population of women has formed in need of consideration when discussing screening and prevention. When compared to unvaccinated women, women who have received at least one dose of the HPV vaccination were more likely to receive a recommendation from their provider for pap smear screening, to obtain a pap smear after a recommendation, and to initiate pap smear screening on their own (Guo et al., 2017).

Enabling factors of the model of this study are income, health insurance status, and having a usual source of healthcare. Reiter and Linnan (2011), in a community-based trial, demonstrated women with an annual household income of at least \$50,000 or more, employed, insured, or self-reported in good health were more likely to have received a pap smear within the last 3 years. Household income and employment have been used as indicators for socioeconomic status; in regards to cancer screening, they indicate that the individual is able to access health resources. Employment, income, and health insurance are often necessary for ensuring that one is able to afford to be screened or is even aware of screening needs.

Need factors for this study's model are: perceived risk of cervical cancer and HPV; self-reported or perceived health status; and cervical cancer or HPV risk factors. Women unaware of the risks associated with cervical cancer and who do not feel as if they are at risk personally are less likely to receive a pap smear test (Ackerson & Gretebeck, 2007). African Americans were more likely to report lack of knowledge as a barrier to cervical cancer screening (Akinlotan et al., 2017). If an individual is unaware of the risks of cervical cancer or HPV, unsure of the screening procedures, and less

knowledgeable about cervical cancer in general, then it is unlikely they will engage in screening and prevention behavior.

Behavioral outcomes in the model of this study focus on cervical cancer screening adherence or HPV vaccination process completed for either the participant or their children. Focusing on outcomes that can help detect and eliminate the disease remains an important aspect of cervical cancer prevention. Cervical cancer screening methods, such as the pap smear, have resulted in a marked decline in reported cases of cervical cancer and a decrease in death associated with the disease. With the inclusion of the HPV vaccination, the possibility to eliminate not only cervical cancer entirely over the course of a decade but at least six other forms of cancer is within reach. For the goals of elimination of cervical cancer and racial health disparities to be achieved, the imperative rests on developing culturally derived health interventions and social justice policy work.

Research Approaches

Community-Based Participatory Research

Participatory action research has been used to develop innovative solutions to social problems in underserved communities by allowing for community perspectives in research. Two main traditions found in participatory action research, as we currently know it today, originally stemmed from two traditions: the Lewin tradition (also known as the northern global tradition), and the southern global tradition. The Lewin tradition, one of the earlier approaches to community-based work, is based on the action work research by Lewin (1946). According to Lewin (1946), social science research should

merge theory and practice together by studying the effects and conditions of the current social problem and working towards social action simultaneously. His commitment towards the idea of merging field theory and practice while interacting within the community itself gave rise to action research and seeded the idea of the Lewin tradition of participatory action research in psychology and beyond. Western academics are more familiar with the Lewin tradition and use it often in their participatory action work.

Started in the global south as a reaction to the colonialist practices, the southern tradition emphasizes an emancipatory framework for research (Wallerstein & Duran, 2017). Paulo Friere, who developed the southern tradition in the 1970s (Ferreira & Gendron, 2011), based it on the belief that communities should no longer be seen as objects of studies, but as agents for knowledge production in their own right. With the southern tradition, communities could produce knowledge while also challenging dominant and oppressive traditions in society. Considering the contentious history that many communities of color have with academia and research, unsurprisingly, their preference for participatory action research often leans more towards the southern tradition rather than Lewin.

Both the northern and southern traditions serve as the historical roots of community-based participatory research, the current iteration of which has not drastically changed. As mentioned by Israel (2013), there are nine components that are associated with the current practice of community-based participatory work: acknowledging community as a unit of identity; building on strengths and resources within the community; facilitating a collaborative, equitable partnership in all phases of research, involving an empowering and power-sharing process that attends to social inequalities;

fostering co-learning and capacity building among all partners; integrating and achieving a balance between knowledge generation and intervention for mutual benefit of all partners; focusing on the local relevance of public health problems and on ecological perspectives that attend to multiple determinants of health; involving systems development using a cyclical and iterative process; disseminating results to all partners and involving them in wider dissemination of results; involving long-term process and commitment to sustainability.

An example of community-based participatory research by a social worker is Gehlert and Coleman (2010), who used a community-based participatory approach to address breast cancer disparities in the South Side of Chicago. After noting the wide disparity among African American women and white women regarding their breast cancer mortality rate, they decided a community-based approach would be the best in working towards reducing said disparity. The researchers first conducted a series of focus groups with African American women to learn of their attitudes, concerns, and beliefs regarding breast cancer and its treatment. From the focus groups, several women were invited to participate in a community advisory board with the researchers and several community organizations. The community advisory board served as a guiding agency to help disseminate knowledge and plan research-education related activity. Through the community-based process, the researchers and community were able to form a 100-organization strong taskforce.

Another example, this time involving cervical cancer in African American women, used members of the faith-based community to adopt and revise a cervical cancer education program (Haynes et al., 2014 Bell, & Flowers, 2014). Members of the

community, faith leaders, and trainers met to review the curriculum, discuss it in a focus group, and work towards training the trainer to accomplish their goal. As the researchers note, community engagement held a critical role ensuring the intervention became culturally appropriate and relevant to the women in the community. Since the community was allowed to participate in tailoring the intervention, they were both empowered and given a sense of ownership over the program. Instead of having an intervention that was difficult to implement and not culturally relevant to the women in the community, they were given a program that made an impact on their community and that they enjoyed.

mHealth Approaches

mHealth has emerged as an innovative and interactive intervention strategy in the medical field due to the proliferation of mobile phones and their capabilities for education, outreach, and dissemination. mHealth encompasses everything mobile technology-related, from health apps to text message interventions delivered on mobile phones. Text messaging interventions have been used for breast, cervical, colorectal, and lung cancers, and have shown to improve cancer screening rates (Uy et al., 2017). Since 95% of adults report owning mobile phones (Pew Research Center, 2017) and 62% of smartphone owners report using their cell phone to look up information about a health condition (Smith, 2015), studies about health behaviors and technology use become more necessary. Technology offers an interesting and new avenue to reach minority populations and help promote health behavior change.

Digital health has allowed for a more equal partnership to form between healthcare professionals and patients, a partnership that differs from the traditional

paternalistic medical model that was once employed (Meskó et al., 2017). This transformation greatly benefits African Americans, who have had difficulties with the interpersonal relationships with their healthcare providers. Unfortunately, for African Americans, the patient-provider relationship can fall victim to negative interpersonal interactions, as evidenced by implicit bias against people of color in treatment decisions, treatment adherence, and health outcomes (Hall et al., 2015). The bias that African American patients experience may lead to them being reluctant to seek out services and hesitant to participate in intervention programs. A more equal partnership between African Americans and their healthcare providers can transform the way in which both parties interact with one another and potentially reduce the risk of health disparities due to interpersonal strife.

The leveling effect of digital and mHealth allows for individuals to become empowered in their health decisions and engage in the decision-making process. Patient empowerment is both a process and outcome in which patients are able to think critically and autonomously; as a consequence, self-efficacy is enhanced in the patient (Anderson & Funnell, 2010). For African Americans, who have experienced perceived discrimination from and poor communication with their healthcare professionals and developed a sense of medical mistrust when their health concerns are dismissed (Cuevas et al., 2016), empowerment remains needed. mHealth and digital health offer a way to empower individuals to feel part of the decision-making process, while also allowing them to be better educated on their health. Previous work and research show that African American women feel as if they lack knowledge about cervical health and HPV. They express familiarity with the terms; however, when pressed for more details, they are

unable to articulate what exactly cervical cancer and HPV are and how both can be prevented. mHealth interventions serve as an opportunity to empower and educate women on cervical cancer screening and prevention practices, as well as teach them how to best safeguard their loved ones from the illness.

A common theme with mHealth interventions is their delivery to a mobile phone, either via mobile apps or text messages. While most mHealth interventions focus on delivering the intervention to smartphones, i.e. phones that are capable of internet use or apps, a race and class differential exists when it comes to owning smartphone technology. Only 77% of African Americans own or have access to smartphones, while 98% own a cellphone of any kind (Pew Research Center, 2017). Sixty-seven percent of individuals who make less than \$30,000 and 69% of those with a high school degree as their highest educational attainment own a smartphone. This means there are African American women who do not own a smartphone and could potentially miss out on the intervention. Those who do not own smartphones still own a mobile phone capable of sending and receiving text messages. To ensure that African American women across the socioeconomic spectrum have an opportunity to participate in the intervention, a text message intervention was proposed rather than an intervention that necessitates the use of apps. Depending on the mobile phone plan the women have, they may not have a data plan that allows for unlimited data usage necessary for app use.

Past mHealth interventions have focused on a wide variety of areas from weight loss tips to vaccination reminders. While there have been studies that looked at the use of mHealth interventions in increasing vaccine uptake, or even cervical cancer screening adherence, not many have focused on African American women or their daughters. One

study did look at increasing the vaccine adherence (Kharbanda et al., 2011) for adolescent girls who have already received one or two doses of the HPV vaccine but did not exclusively focus on African American adolescents. Space exists in literature and the field for a study in which African American women are prompted through mHealth interventions to not only adhere to screening guidelines for themselves but to also encourage African American adolescents to begin vaccination procedures and complete the process. This study differs from previous mHealth interventions in that before the focus centered on either vaccination or education in general or with an urban population, whereas here, the aims resulted in the merger between all aspects to affect health behavior change.

Summary

While several studies attempt to address cervical cancer screening and prevention in African American women, gaps remain to be filled. Filling in the knowledge gap necessitates interventions that focus on the direct delivery of information to African American women about cervical cancer and HPV. Lack of knowledge is a consistent finding across several major studies as a barrier for African American women regarding improved screening and prevention behavior (Akinlotan et al., 2017; Brown et al., 2011; Strohl et al., 2015). Most of the studies presented attempted to address this issue, but a more in-depth and prolonged attempt is needed. None of the studies presented kept contact with participants longer than a week to sixteen days, and in most, follow-up was limited. By delivering educational materials through their mobile phone, this study achieved prolonged contact with participants. Aspects of community-based participatory

research and mobile health technology used in this study addressed the continued disparities in cervical cancer and encouraged prevention behavior.

CHAPTER III: METHODOLOGY

The purpose of the study is to educate and empower African American women to become more knowledgeable about cervical health and HPV while prompting a change in health behavior. This is a quasi-experimental pilot study that focuses on the development of a culturally tailored intervention for African American women. During this study, a mHealth intervention was developed to deliver appropriate health messages to the target audience. The health messages were culturally tailored and delivered three times a week for the period of one month to the mobile phones of participants. At the conclusion of the intervention program, women were invited to participate in an evaluative focus group, individual interview, or provide written feedback to discuss the mHealth intervention and its impact.

While the proposed study will use elements similar to other community-based interventions, such as the use of a community advisory board throughout the project, there are aspects of the study that differ from previous works. Unlike the Screening Older Minority Women project, the proposed study will not use lay health advisors for intervention delivery; instead, intervention delivery will be done via the participants' mobile phones. The study also differs in the development of the educational materials, as the study uses the community advisory board to revise the educational messages to fit the community's needs and perspective

Study Objectives

The purpose of this study is to determine if a community-based mHealth intervention will promote cervical cancer screening and HPV vaccination uptake in African American women in Louisville.

The study has three specific aims:

Aim 1: To determine if mHealth intervention can improve cervical cancer and HPV knowledge of African American women.

Hypothesis 1: Women who participate in the mHealth intervention and receive culturally tailored messages will demonstrate an increase from their baseline to their post-intervention Cervical Cancer Awareness Measure (CCAM) scores.

Aim 2: To assess if the mHealth intervention is a feasible, acceptable, and effective strategy for promoting cervical cancer screening and prevention among African American women.

Hypothesis 2.1: Women who participate in the mHealth intervention will report high levels of acceptability based on the Acceptability of Intervention Measure (AIM) scores

Hypothesis 2.2: Women who participate in the mHealth intervention will rate the mHealth intervention with high levels of appropriateness based on the Intervention Appropriateness Measure (IAM) scores

Hypothesis 2.3: Women who participate in the mHealth intervention will rate the mHealth intervention with high levels of feasibility of the intervention in their Feasibility of Intervention Measure (FIM) scores.

Aim 3: To obtain information from participants about 1) aspects of the intervention worked, 2) how the intervention could be improved with open-ended questions and 3) how the COVID-19 pandemic impacted the participants' ability to engage with the intervention

Hypothesis 3.1: Qualitative data will show that the intervention participants favorably viewed the intervention as acceptable, appropriate, and feasible for intervention use

Study Design

The study included three phases and uses a quasi-experimental design: development of the intervention, implementation of the intervention, and evaluation of the intervention. As mentioned previously, the needs assessment from an earlier focus group study suggested a need for tailoring the health messages to better relate to the target population. During the developmental phase, a community advisory board (CAB) aided in the development of the mHealth intervention. The community advisory board was composed of members of the community and health professionals to help tailor and pilot test the messages based on the content that was generated earlier in the focus groups. In previous studies, CABs have been used to tailor cultural interventions and formalize community partnerships between academic institutions and the local community (Newman et al., 2011).

Next, the intervention was implemented with African American women who had agreed to participate in the study. Before the intervention is implemented, women who have enrolled in the study were administered a baseline questionnaire, using an adapted version of the Cervical Cancer Awareness Measure (CCAM). The CCAM was a test of their knowledge about cervical cancer and HPV and asked questions related to their attitudes about screening behavior (Simon et al., 2012). The score from CCAM was used for evaluation later in the study to determine whether the intervention had contributed to the improvement cervical cancer and HPV knowledge scores. Adherence to the program was measured by asking participants during the evaluative qualitative interviews whether they have opened the messages and if they have clicked the links provided in the text messages.

Finally, the intervention was evaluated in two ways by comparing the baseline scores to the post-intervention scores and with an evaluative qualitative interview. To reassess the women on their knowledge and attitudes, women were reassessed on the warnings signs, risk factors, and peak incidence. The women were assessed on their knowledge of cervical cancer and HPV to determine whether their score improved from the baseline. At the end of the intervention, the women had scores for the baseline and the final score, totaling two unique scores for analysis. Participants in the intervention group were also given an evaluation questionnaire to measure how they view the mHealth intervention; as a result, scores on the acceptability, appropriateness, and feasibility were calculated and included in statistical analysis.

At the conclusion of the one-month program, the participants were invited to an evaluation focus group. With focus groups, researchers can assess the feasibility and

effectiveness of intervention while discussing areas in need of improvement. While every woman who has participated in the program were invited to join the focus group, the goal was to have between 5 to 10 women participate. Due to Covid-19, the in-person focus groups were shifted to an online platform, offered multiple times, and an individual interview was offered as an alternative to participating in the focus group. It was through the qualitative inquiry that the women answered questions focusing on their experience using the intervention, what can be improved in the delivery and content of the messages, and in what ways would they like to receive information in the future.

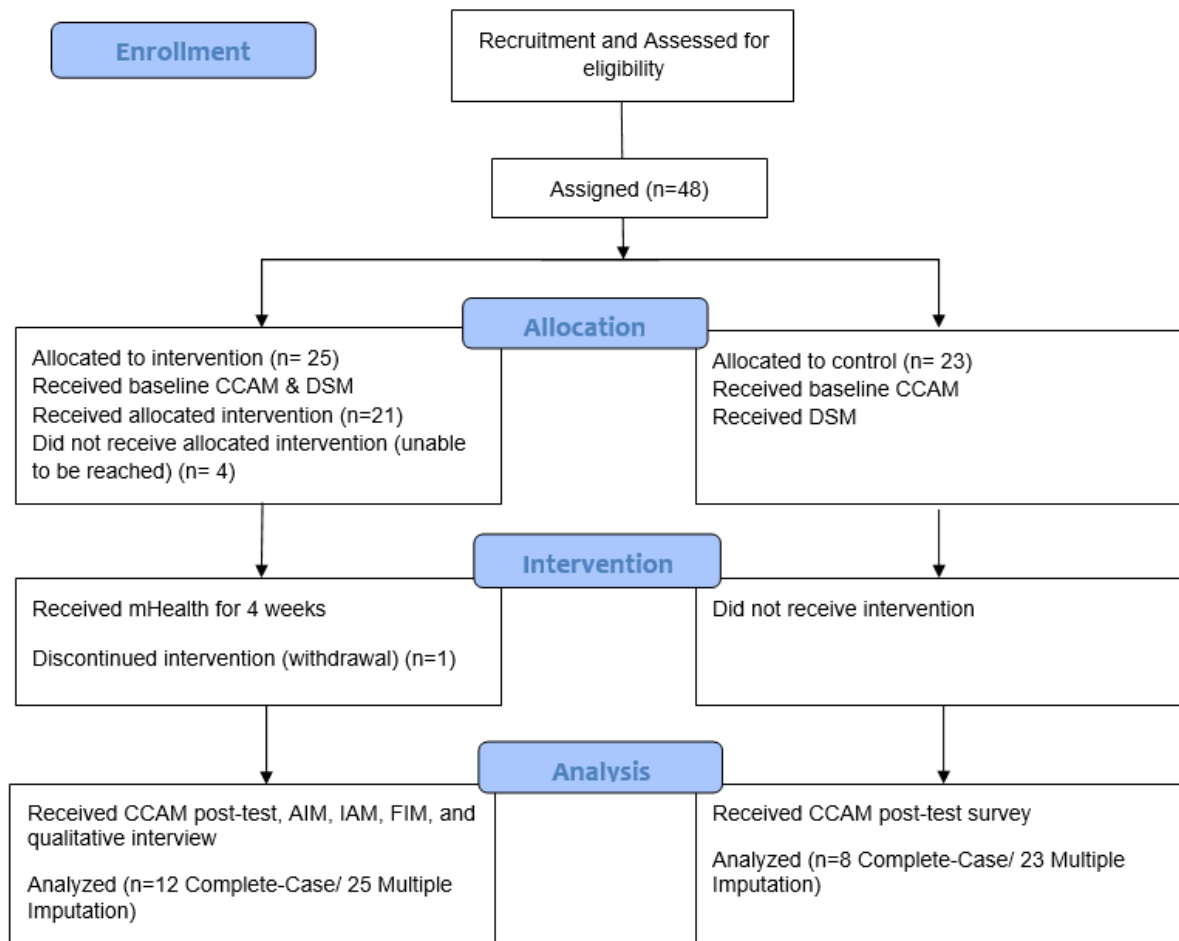


Figure 3 Study Design Flow of the mHealth Intervention

Development of the mHealth Intervention

The intervention was developed with input from two sources: 1) findings from the previous focus group needs assessment on cervical cancer prevention services conducted with women in the West Louisville communities and 2) collaborative work with a community advisory board established for the purpose of designing culturally tailored messages. From the focus group needs assessment transcripts, a list of questions was generated to further explore what information the women needed in order to better understand cervical cancer and HPV. The answers to the generated questions were then researched and developed by an undergraduate research assistant who was assigned to the needs assessment project. This document prompted an initial discussion with the CAB members in developing the educational content for the mHealth intervention.

The intervention is the delivery of culturally tailored text messages to the mobile phone of participants at least three times a week. Although the exact number of text message reminders vary from study to study, Kharbanda et al. (2011) found that text message reminders received at least three times a week help to improve vaccination rates. BulkSMS is a short messaging service (SMS) service provider that has been used by businesses and campaigns to allow focused messaging solutions. Using BulkSMS, the text messages were delivered three times a week for four weeks. The messages were delivered one way, in which the participants only receive information and are not able to respond.

Message Development

As a result of the focus group needs assessment two documents were created using information from the Centers for Disease Control and Prevention and the American Cancer Society. Culturally tailored messages were developed from these original documents with the help of the CAB to ensure that the messages are relevant to the women in the community. Table 1 shows an example of a traditional message and what is needed to transform it into a more appropriate and effective message.

In its current incarnation, the content messages are medical and technical; as noted in Huang and Shen (2016) culturally tailored messages are helpful in the persuasion of cancer communication. To ensure that the content messages are framed in an appropriate cultural context, a community advisory board formed for the express purpose of tailoring the messages for the text messaging program. All CAB members self-identified as African Americans ranging in age from early twenties to late thirties. Of the CAB members, four were in a health profession field, two worked in public health, two were social workers and one woman was a public-school educator. The CAB met several times either in person or through phone conference during December 2019 and January 2020. Meetings were approximately 60 minutes and held during the evenings. Members were later consulted about the mHealth intervention and asked to aid in study recruitment among their network.

During the CAB meetings, members were presented with the original questions, the traditional message response; their opinions were solicited on how best to make the information manageable, the possible format for delivery, and if there was a need for substitution in language. The original document with the health messages was five pages

on questions and answers, the CAB worked through narrowing down which questions that they determined were the most important and how best to present the information to the participants. A brief discussion was had on how much the language should be changed; it was recommended by those in the health field to simplify the messages but not to alter too much that the health information would be lost. The CAB recommended that there should be a health message that relates to the importance of cervical cancer screening and prevention for African American women. It was decided by the CAB to keep the question and answer format of the messages because the flow seemed better succinct at getting the message across. After meeting with the CAB, the messages were edited, written, and organized to reflect their recommendations. Messages were organized into two overall categories: cervical health and cancer, and HPV. CAB members agreed on the importance of including HPV health messages in educating this target population, as some of the women participating were mothers or considering motherhood. The resulting document was then emailed back to the CAB soliciting their comments and opinions, feedback ranged from suggestions of wording to agreement about the content. In addition to emailed feedback, a phone conference was held with two of the CAB members discussing the documents.

The final step in message development involved fitting the health messages to the format of text messages using the BulkSMS platform. There is a character count limit for messages sent on the BulkSMS platform, which is similar to other platforms. This limited the initial plans and detailedness of the message to make sure that the point of the health message was simple and succinct. Because of this, the messages were tailored shortened once again to make sure that the messages 1) fit the character count, or 2) if it exceeded

the character count then the messages were not overly long. BulkSMS had a character count limit of 160, but would allow for additional characters for an increasing fee.

Table 1 demonstrates the revising process from traditional to CAB editing to final message content. Within the CAB editing most medical jargon is either eliminated or simplified, sentences were removed for being ‘too technical’, and the essential meanings of the message are highlighted. When asked if the language was appropriate or needed to change, the CAB recommended that the language is appropriate and did not make any recommendations for change.

Table 1

mHealth message editing by the Community Advisory Board

Traditional Messages	CAB Revised Message	Actual Message
<p>What Is Cervical Cancer?</p> <p>Cervical cancer starts in the cells lining the cervix - the lower part of the uterus (womb). The cervix connects the body of the uterus (the upper part where a fetus grows) to the vagina (birth canal). Cancer starts when cells in the body begin to grow out of control. To learn more about how cancers start and spread, see What Is Cancer?</p>	<ul style="list-style-type: none"> • What is cervical cancer? • https://www.cancer.org/cancer/cervical-cancer/about/what-is-cervical-cancer.html • Cervical cancer starts in the cells lining the cervix - the lower part of the uterus (womb). Cervical cancers start from cells with pre-cancerous changes (pre-cancers), only some of the women with pre-cancers of the cervix will develop cancer. It usually takes 	<p>What is cervical cancer?</p> <p>Cervical cancer starts in the cells lining the cervix -- the lower part of the uterus (womb). Cervical cancers start from cells with pre-cancerous changes (pre-cancers), only some of the women with pre-cancers of the cervix will develop cancer. It usually takes several years for cervical pre-cancer to change to cervical cancer, but it also can happen in less than a year. -These changes can be detected by the Pap test and</p>

The cervix is made of two parts and is covered with two different types of cells.

The endocervix is the opening of the cervix that leads into the uterus. It is covered with glandular cells.

The exocervix (or ectocervix) is the outer part of the cervix that can be seen by the doctor during a speculum exam. It is covered in squamous cells.

The place where these two cell types meet in the cervix is called the transformation zone. The exact location of the transformation zone changes as you get older and if you give birth.

Most cervical cancers begin in the cells in the transformation zone.

several years for cervical pre-cancer to change to cervical cancer, but it also can happen in less than a year. For most women, pre-cancerous cells will go away without any treatment. Still, in some women pre-cancers turn into true (invasive) cancers.

- These changes can be detected by the Pap test and treated to prevent cancer from developing.

treated to prevent cancer from developing.
<http://bit.ly/2THqHvc>

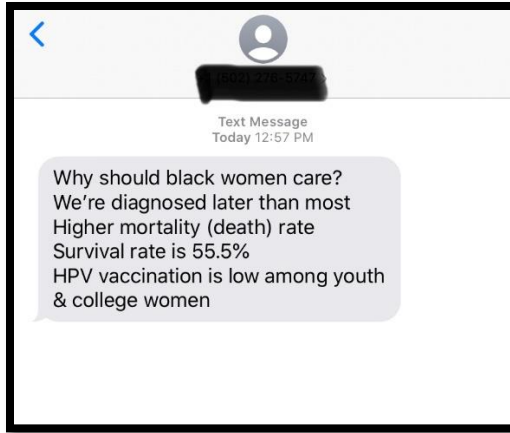


Figure 4 Sample mHealth test message

Message Topic and Delivery

While the community advisory board was used to tailor the content of the messages, Fogg's Behavior Model guided the refinement of the messages and helped to create the dissemination strategy. Fogg (2009) discussed how the relationship between motivation, ability, and prompts triggers desired behavior in individuals by using technology. The majority of adult Americans have access to a mobile phone with text message capabilities, making text message education a valid strategy for reaching individuals easily and quickly. According to Fogg's model, change is only accomplished when motivation and ability are sufficiently high enough to trigger the desired action. A participant may have high motivation to get screened or have their children vaccinated; however, they may have the low ability and in need of a prompt to raise their ability from thought to the desired action. Using Fogg's model, messages were shortened to not overwhelm the recipient with information, and shortened links were provided so that the recipient could research additional information on their own.

Messages were delivered via the BulkSMS platform which allows for a longer character count (compared to most of the other platforms) and has a feature that schedules messages. Scheduled messages were delivered three times a week at noon to the participants in the intervention group.

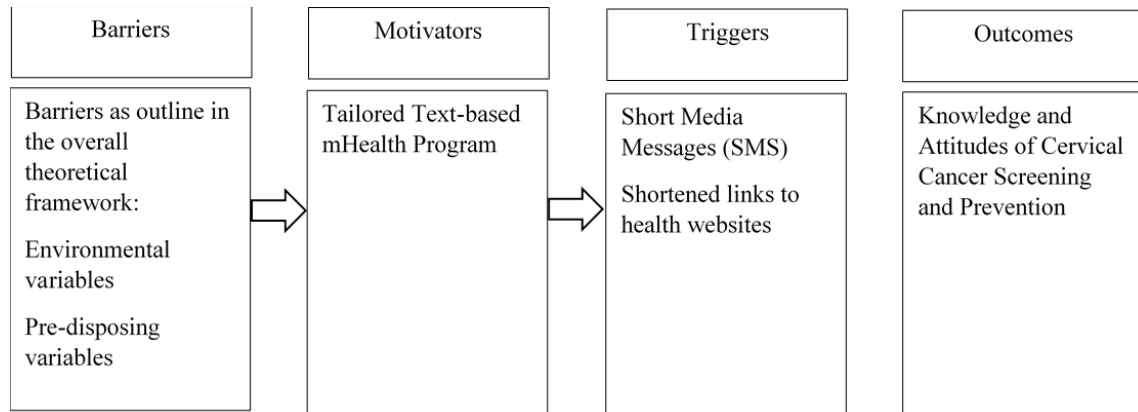


Figure 5 Fogg's Behavioral Model and mHealth

Study Population

Participants

Women who self-identify as African American or African descent over the age of 18 met the inclusion criteria to participate in this study. The American Cancer Society guidelines state that women should receive their first pap smears at or before the age of 21. Although the HPV vaccination has been available since 2009, there are individuals who have yet to complete the vaccination process or receive a single dose. According to the CDC Control and Prevention (2018), in 2016 there was an increase of women who have received at least one dose; however racial disparities in vaccination coverage exist. African American women had a lower coverage of vaccines in comparison to white women, a rate that increased from 2015 to 2016.

Sample Size Justification

Power analysis was conducted using GPower, a statistical software program allowing for the calculation of power, effect size, and sample size (Faul et al., 2007). Running a power analysis on paired samples t-test, a power of 0.8, an alpha level of 0.05, an effect size of 0.5 using Cohen's d, at least 35 women are needed to avoid committing a type one error. Because of the intention to use a sample from a specific population for this intervention a purposive sampling design was used.

Inclusion Criteria. The inclusion criteria for women to participate in this study, was to self-identify as African American or African descent, over the age of 18, and to have access to a mobile phone

Exclusion Criteria. Exclusion criteria are who do not fit the inclusion criteria or who have had cervical cancer.

Recruitment Procedures

Enrollment. Participants were recruited via IRB approved health flyers, personal conversations, forwarded announcements and social media posts from health clinics, churches, social service programs, community spaces, a local university, and email listservs provided by trusted sources and CAB members. CAB members helped in recruitment efforts, as ambassadors for the program. After Covid-19 prevented in-person recruitment, online recruitment was used to increase in enrollment in the study. The University of Louisville IRB approved social media posts (see Appendix J) featured an introductory message appealing to women to join the study, a link for the study and the IRB approved flyer. CAB members and their networks shared the social media posts on Facebook from the researcher, and a few posted on the researcher's behalf within their

own networks. The Facebook post was also shared within social media groups such as a doctoral student support group.

IRB Approval

The intervention study and qualitative inquiry received approval from the University of Louisville's Institutional Review Board (IRB number: 19.1008).

Data Collection Plan

The data were collected through the use of questionnaires administered online. Using Qualtrics, the participants were sent a questionnaire that included the Cervical Cancer Awareness Measure (CCAM), demographic questions, screening and vaccination history, and a question about their experience with discrimination in a medical setting (See Appendix C).

After completing the 4-week program, a questionnaire containing the previous CCAM scale and AIM, IAM, and FIM scales were administered to better understand if the women in the intervention group found the intervention to be appropriate, acceptable, and feasible. In addition to collecting data on acceptability, appropriateness, and feasibility, data on these constructs were also be collected during an evaluative qualitative inquiry. There were three avenues for the qualitative inquiry; focus group, individual interviews, and written responses. Qualitative questions gather data about what aspects of the intervention have worked for the women, what can be improved on, and what aspects of the intervention do the women assume will be feasible in their community.

Measures

Table 2

Variables of interest and their related measures

Variables/Constructs	Measure	Time
<u>Environment</u>	Neighborhood	Baseline
Neighborhood Characteristics	Demographics collected by the researcher based on participants zip code	
Residential Segregation		
Concentrated Poverty		
Educational Attainment	Zip Code	
Rental/Home		
Unemployment rate		
Health Clinic Availability	Individual Demographics	Baseline
<u>Predisposing Factors</u>		
Age		
Previous Screening		
Marital Status		
Education		
Income		
Health beliefs		
Perceived racial discrimination	Discrimination in Medical Settings (7 items)	
Interpersonal Relationship with healthcare worker		
<u>Enabling Factors</u>	Individual Demographics	Baseline
Health Insurance Status		
Usual Source of Care		
<u>Need for health services</u>	Cervical Cancer Awareness Measure	Baseline
Perceived risk		Post-Intervention
Self-reported/perceived health status		
Cervical Cancer/HPV risk factors		
<u>Outcomes</u>	CCAM	Baseline
Cervical Cancer and HPV Knowledge	Focus Group Evaluation	Post-Intervention
Intention to adhere to ACS guidelines		

Demographic Characteristics and Healthcare Behaviors

Descriptive variables of interest include demographics, such as socioeconomic status, employment, healthcare history, number of children, vaccination status, last doctor's visit, insurance status, and marital status. The demographic questionnaire collected information on these variables.

Environmental Characteristics

Environmental variables included the demographics of the communities that the participants lived in and were measured by the zip codes, they were collected by using the demographic questionnaire. These included rental versus homeownership, health clinic availability, redlining, unemployment rate, etc.

Pre-disposing Factors

Individual demographics were used to measure pre-disposing variables, such as previous screening, marital status, education, income, health beliefs which were all collected on the initial demographic questionnaire.

Experiences with medical discrimination was considered a pre-disposing variable and captured by use of the Discrimination in Medical Settings scale. The Discrimination in Medical Settings (DMS) scale was used to capture an individual's perception of racism in the medical setting. Adapted by Peek et al. (2011), the DMS is a result of modifying the Perceived Everyday Discrimination Scale for use specific to health settings and cognitive interviews. Consisting of seven items, the DMS measures whether participants feel as if they have received sub-optimal care and their interpersonal relationship with healthcare professionals. Responses are recorded on a five-point Likert scale, with 1

(never) to 5 (always true). The participant responds to the prompt: “Using the scale indicate if you have ever experienced this scenario.” An example of an item includes: “You feel like a doctor or nurse is not listening to what you were saying.” The complete scale of the DMS can be found in the Appendix C. Scores are averaged, with a higher mean indicating perceived discrimination.

Using factor analysis, the DMS items loaded on a single factor, with one item having a low eigenvalue of 0.5. Peek et al. (2011) tested the scale with a sample of 74 African American patients and retested with 66 African Americans who were also assessed using similar discrimination measures, depression, and social desirability. DMS had a Cronbach alpha of 0.89 in its original test, and a 0.85 on its test-retest reliability.

Enabling Factors

Enabling variables are factors that enable individuals to access healthcare such as health insurance status and having a usual source of care. Two items on the baseline questionnaire measured these variables.

Outcome Variables

The two outcome variables are cervical cancer and HPV knowledge and the intention to adhere to ACS guidelines. These two variables were measured in three ways, by the CCAM, the three measures dedicated to intervention’s effectiveness, and the evaluative qualitative inquiry.

Cervical Cancer Knowledge

An adapted version of the Cervical Cancer Awareness Measure (CCAM) was used to assess pre and post knowledge of cervical cancer and HPV. CCAM consisted of 9 open-ended questions and 31 items which focus on the knowledge and risks of cervical cancer. The internal reliability of this measure is satisfactory with a Cronbach alpha of 0.7 for all components, and test-retest reliability of 0.7 (Simon et al., 2012). Because this measure was originally developed in the U.K., there were two questions that focused on the British National Health Service screening program; they were not relevant to this study therefore excluded.

All items related to the CCAM can be found in the Appendix D. The CCAM is scored by summing the points and then totaled with a range of 0-11 for warning signs (Q2), symptoms of cervical cancer, and 0-11 for risk factors (Q6), scenarios that increase the potential for developing cervical cancer. Higher scores indicate greater knowledge.

Acceptability, Appropriateness, and Feasibility of Intervention

Weiner et al. (2017) developed and psychometrically tested three measures based on the outcomes of acceptability, appropriateness, and feasibility of implementation research. The three outcomes, as defined by Proctor, are useful concepts for determining whether an intervention can be successfully implemented while promoting change. Proctor et al. (2011) defined acceptability as the perception among stakeholders that an intervention is agreeable or satisfactory; appropriateness is the perceived fit of the intervention to the consumer or setting; and feasibility as the extent into which an intervention can be successfully used. For each measure, there are four questions on a 5-

point ordinal scale in which participants are to rate their agreeability to statements relating to the intervention. The measure allows for customization to fit the intervention or program used. An example statement for acceptability would be, ‘mHealth is appealing to me’ and rating it on a 5-point scale to indicate agreeableness. While it does not yet have cutoff scores, in all three measures the scores can be averaged, the higher scores indicate acceptability, appropriateness, and feasibility.

Treatment Integrity

There was no automatic response using the BulkSMS platform that allowed assessing whether the participants in the intervention group opened the message. Messages delivery was reported as either successful or failed. To gain an understanding on whether participants adhered to the program and opened the messages, during the qualitative interviews participants were asked if they opened the messages and read the message contents.

Qualitative Inquiry

After completion of the intervention, women were invited to participate in an evaluative focus group. The purpose of the focus group was to ask the women about the intervention, their healthcare experiences before and after the intervention, and to discuss ways in which the intervention could be improved. A semi-structured interview guide was developed by the researcher focusing on knowledge and attitude regarding cervical cancer, HPV, and vaccination. (see Appendix F). Both open-ended and probing questions were included in the interview guide to assess participants' beliefs, while also keeping the focus group on task. After the completion of each focus group, reflection memos were written by either the facilitator or co-facilitator about the group. Focus group questions

were developed using Andersen's Behavioral Model and Critical Race Theory as sensitizing concepts. Sensitizing concepts draw focus on important aspects of social interaction and help illustrate guidelines for research direction (Bowen, 2006). Questions were developed to gain a deeper understanding of the healthcare experience and knowledge levels before the intervention and to explore whether the women feel as if a value has been added to their overall experience. The focus groups helped explore the feasibility, appropriateness, and acceptability of the mHealth intervention.

Due to the Covid-19 pandemic, plans were made to accommodate public health recommendations for social distancing. The in-person focus group was transformed into an online setting using Microsoft Teams to allow individuals to participate without jeopardizing public health standards. Daily focus groups were offered to participants that allowed them to join groups that were available to them. In addition to offering online focus groups to participants, individuals who could not participate in the online focus group were offered the opportunity to participate in either individual interviews or written responses to the interview guide questions. Focus groups with zero participants were canceled, and groups who only had one participant were then given the option of an individual interview. Individual interviews were similar to the online focus group, they were offered on a secure online platform such as Microsoft Teams and lasted approximately 60 minutes. Individual interviews were offered as a way for participants to engage in the qualitative evaluation who may not have the time or feel comfortable participating in the larger focus group. A third option was offered to individuals who were not available for online interviews. They could provide written responses to the

interview guide on Qualtrics. These three options were submitted and approved by the University’s Institutional Review Board.

Data Analysis

Table 3

Research Aims of mHealth study, timing of measures, and statistical analysis

Research Aims	Measure	Times of Implementation	Data Analysis
To determine if mHealth intervention can improve cervical cancer and HPV knowledge of African American women	CCAM	Baseline, Post-Intervention	Paired Samples t-Tests
Is mHealth and Text Messages a viable intervention strategy?	AIM IAM FIM Focus Groups	Post-Intervention	Calculated Scores Content Analysis
Using an individual interview or focus group, obtain information from participants on which aspects of the intervention worked, how the intervention could be improved, and how the COVID-19 pandemic impacted the participants’ engagement	Qualitative Inquiry	Post Intervention	Content Analysis

Statistical Analysis

Hypothesis 2.1 was tested using a pre-post analysis of the CCAM scores from baseline to post-completion of the intervention. A paired-samples t-test was used to determine if there was a significant increase in knowledge scores for the participants during the intervention.

For hypotheses 2.1, 2.2, and 2.3, participants AIM, IAM, and FIM scores were used to determine whether the women felt as if the intervention was acceptable, appropriate, and feasible for future use. The AIM, IAM, FIM are scored based on the mean amongst participants. While there are no official cutoff scores developed for these measures, best practice says that the higher scores indicate a strong measure of acceptability, appropriateness, and feasibility. Scores for each individual who participates in the study were summed and averaged to assess whether the intervention meets the criteria.

Qualitative Analysis

Qualitative content analysis (Drisko & Maschi, 2015) was utilized on focus group data to extract themes related to acceptability, appropriateness, and feasibility of the mHealth intervention, along with improvements necessary for the intervention. Data collected during the qualitative inquiry illuminated the experiences of the women using the mHealth intervention. Following the completion of the focus groups, the researcher transcribed the responses verbatim. Memos were written after the interviews had been conducted to give further context to the focus group and make note of any standout moments. Transcripts, memos, and completed questionnaires were used to help interpret the coded data and build narrative summaries.

Based on recommendations for deductive content analysis, an unconstrained coding matrix was developed (Assarroudi et al., 2018; Elo & Kyngäs, 2008). Using the advice of Mayring (2014) a categorization matrix and coding scheme were developed, and data were coded towards those categories. The categorization matrix was based on the integrated framework of Andersen's Behavioral Model and Critical Race Theory.

Along with previous work, the matrix was unconstrained to allow for any additional categories to organically emerge. This method was chosen due to the aim of the research project in evaluating the mHealth intervention as a process rather than building theory or exploring the foundation of health education. The categorization matrix used can be found in the Appendix H showing a sample of the categorical definitions, coding rules, and anchor samples.

Dedoose software was utilized to both code and organize the transcripts and to conduct an interrater reliability test based on Cohen's kappa statistic (Dedoose, 2018). After two transcripts were coded, the coders (AW & JA) conducted an inter-rater reliability test and got a 0.89 kappa score indicating excellent agreement. The one area in which the two coders disagreed was discussed in an adjudication process to determine why each coder viewed the code application differently. It was through this process that the coders were able to discuss the possibility of multiple code applications, the relationships between codes, and potential strategies to minimize disagreements. The code definitions remained the same after the process, but the examples and coders interpretation changed. Examples of the code applications can be found in the Appendix G. Further discussion of the relationship between codes can be found in the results section. After discussion, the remaining interviews were coded and discussed between the two coders.

CHAPTER IV: RESULTS

This chapter presents the findings from the hypothesis testing of the mHealth intervention and the qualitative inquiry of the participants' experience with the mHealth intervention. The first section focuses on describing the sample characteristics (demographics, health behaviors related to screening and HPV vaccination) and their perceptions of discrimination in the medical settings. Next, the results of the baseline knowledge of participants on cervical cancer and HPV using the Cervical Cancer Awareness Measure (CCAM) are presented. The third section addresses the hypotheses, on whether the mHealth intervention is associated with increased cervical cancer knowledge from baseline to post-intervention and the acceptability, feasibility and appropriateness of the mHealth intervention. Finally, the qualitative inquiry with intervention participants chronicles the participants' experiences with the intervention and mHealth recommendations.

Sample Characteristics

Demographics. Forty-eight women agreed to participate in the study. All of the 48 women completed the baseline questionnaire. All of the women identified as Black or African American (96%) or Black-multiracial (4%). The majority of women were never married (56%), and just over a quarter were married (27%). This was a highly educated sample, with 77% having obtained a bachelor's, master's, or other professional degree. The majority of the women were employed (86%), and few were either retired or

disabled (13%). The most frequently-reported income level of the participants was between \$40,000-\$59,000 (29%). Demographic data are presented in Table 4.1.

The original sampling frame expanded from encompassing Louisville, KY to the United States due to difficulty in recruiting during the pandemic. Because of this increase participants in this study were from several states across the U.S. Twenty-one participants were from Kentucky with the remaining twenty-seven participants from Illinois, Indiana, Michigan, North Carolina, Ohio and Virginia. Kentucky residents in the sample were highly educated with a reported 67% having a bachelor’s degree or higher; 81% of the Kentucky residents in the sample make \$59,999 or less.

Table 4. 1

Demographic characteristics of the sample by control and intervention groups at baseline

Characteristic	Control		Intervention		Total Sample	
	n	%	n	%	n	%
Marital Status						
Married	9	69	4	31	13	27
Divorced	5	71	2	29	7	15
Separated	1	100	0	0	1	2
Never Married	8	30	19	70	27	56
Education						
HS or GED	1	33	2	67	3	6
Some college	5	100	0	0	5	10
Associate	3	100	0	0	3	6
Bachelor’s	6	33	12	67	18	38
Master’s	6	40	9	60	15	31
Doctoral/ Professional	2	50	2	50	4	8
Employment						

Working (paid employee)	18	47	20	53	38	79
Working (self- employed)	1	25	3	75	4	8
Not working (retired or disabled)	4	67	2	33	6	13
Income						
Less than \$20,000	2	33	4	67	6	13
\$20,000- \$39,999	7	58	5	42	12	25
\$40,000- \$59,000	6	43	8	57	14	29
\$60,000- \$79,000	1	20	4	80	5	10
\$80,000- \$99,000	4	67	2	33	6	13
\$100,000 or more	3	60	2	40	5	10

Healthcare Characteristics There were several questions related to the participant's health history and health status (See Table 4.2). All of the women in the sample had health insurance at baseline, with private being the most frequent response (81%). Approximately 90% of the women reported having seen their doctor within the last year, with only a small percentage (10%) having seen their doctor more than a year earlier. Additionally, just over three-fourths of the women had participated in a pap smear screen within the last year (75%), few of the women had gone longer than a year (13%)

or having never been screened (13%). None of the women had reported being diagnosed with cervical cancer, and two (4%) with a high-risk strain of HPV.

Table 4. 2

Healthcare characteristics by control and intervention groups at baseline

Characteristic	Control		Intervention		Total Sample	
	n	%	n	%	n	%
Insurance Status						
Public	6	67	3	33	9	19
Private	17	44	22	56	39	81
Doctor's Visit						
Within the last 6mos	18	53	16	47	34	71
Within the last year	5	56	4	44	9	19
Longer than a year	0	0	5	100	5	10
Pap Smear Screening						
Never	1	17	5	83	6	13
Within the last year	9	43	12	57	21	44
Within 2-3 years	9	60	6	40	15	31
3+ years	4	67	2	33	6	13
Diagnosed with high-risk strain HPV						
Yes	1	50	1	50	2	4
No	22	48	24	52	46	96

Approximately one-fourth of the sample (n = 12, 25%) had children living at home with them. The ages of the children ranged from 6 months to 21 years old, with a mean

age of 11.3 (SD= 5.4). Of the children in the sample, half of them had been vaccinated against HPV.

Table 4. 3

Vaccination Status of the Participants' Children

	Control		Intervention		Total Sample	
	n	%	n	%	n	%
Children	11	50	11	50	22	100
Number of Children Vaccinated	5	45	6	55	11	50*
Average Age of Children	M	SD	M	SD	M	SD
	12.4	5.8	10.3	5.1	11.3	5.4

*11 out of 22 children vaccinated

Using a Mann-Whitney U test, significant differences between the control and intervention groups were calculated. The groups differed on two variables: marital status and pap smear screening history. The control group had significantly fewer women who were married (Mdn=19.5) than the intervention group (Mdn=29.8) $U=173.0$, $p=.008$, indicating that more women in the control group were married. Women in the control group (Mdn=28.4) significantly rated themselves as having gone longer between pap smear screenings than those in the intervention group (Mdn=20.9) $U=377.5$, $p=.048$.

Table 4. 4

Summary of Differences between the Control and Intervention Group (Mann-Whitney U)

	Control (n=23)	Intervention (n=25)	Z-value
	Mean Rank	Mean Rank	
Marital Status	19.5	29.8	-2.643*

Education	21.7	27.0	-1.37
Employment Status	24.9	24.1	.291
Household Income	25.3	23.7	.401
Insurance Status	26.3	22.9	1.236
Doctor's Visit	22.2	26.6	-1.383
Pap Smear	28.4	20.9	1.977*
Screening ^o			
HPV Vaccination	27.2	22	1.550

*p>.05

^o higher scores indicate the longer length of time in between screenings

Discrimination in Medical Settings

All of the women reported experiencing some form of discrimination in the medical setting (n =48); however, the frequencies of each type of discrimination varied within both the intervention and control groups. There were six items that were used to measure the discrimination in medical settings (see Appendix C for full scale). Participants' scores on the discrimination in medical settings scale include the type of discrimination that was experienced and the frequency in which it occurred. The most frequently chosen items included: 'feeling as if you are being treated with less respect than others,' (100%) and 'feeling as if you are not being listened to,' (100%). The two questions that were not as highly endorsed by the participants (but were still an overwhelming majority) were 'feeling as if the doctor or nurse acts as if you are not smart,' (95.9%) and 'feeling as if you have received poorer service,' (95.8%). All of the participants have affirmed experiencing some form of discrimination across all six items (96%-100%).

The overall baseline mean for all participants of the discrimination in the medical settings scale was 5.88 (SD= .53). Of the individual items, 'being treated with less courtesy,' had the lowest mean at 3.67 (SD= .91). 'Feeling as if you are being less respect

than others,' and 'a doctor or nurse acts as if you are not smart,' had the highest means, 3.85 (SD=.30) and 3.85 (SD=1.11) respectively. The participants were asked to indicate how often they experienced each type of discrimination on a scale from 1 (never) to 5 (always). Table 4.5 shows the frequency with which they experienced each item.

Table 4. 5

Frequency of times experiencing discrimination in the medical setting

	Never	Rarely	Sometimes	Most of the time	Always
Treat with Less Courtesy	1 (2%)	2 (4%)	15 (31%)	23 (48%)	7 (15%)
Respect than others	0 (0%)	1 (2%)	16 (33%)	20 (42%)	11 (23%)
Poorer Service	1 (2%)	2 (4%)	12 (26%)	23 (49%)	9 (19%)
Doctor or nurse acts as if you are not smart	2 (4%)	4 (8%)	9 (19%)	17 (35%)	16 (33%)
Doctor or nurse acts if they're better	1 (2%)	6 (13%)	7 (15%)	20 (42%)	14 (29%)
Not being listened too	0 (0%)	4 (8%)	18 (38%)	16 (33%)	10 (21%)
Total	5	19	77	119	67

Cervical Cancer and HPV knowledge at baseline

Before reporting on the data from hypothesis testing, this section presents the baseline scores of the control and intervention group to gain a better understanding of

their foundational knowledge. There was non-randomization into control and intervention groups, individuals were recruited at different times with the first twenty-five participants assigned to the intervention group, and then twenty-three of participants assigned to the control group. The control group were recruited and assigned four weeks after the intervention group. The scores for the Cervical Cancer Awareness Measure and its subscales, warnings signs, and risk factors are presented overall with significant differences between the two groups noted. Afterward, the data on correct-incorrect answers to the subscales are presented to highlight the items in which the participants' responses were correct.

Missing data analysis. Before statistical analysis can begin, the issue of missing data needs to be addressed. Some of the participants were missing answers to the baseline questions in either the warning signs or risk factors subscale. While every participant addressed at least one of the questions on the subscales, the amount of missing data varied. The missing data could be the result of participants being unsure of the answers and leaving those questions blank and the fact that there was no option for a 'don't know' response.

In order to assess the amount of missing data and investigate whether there is any bias in the missingness of the data, missing data analysis was conducted in SPSS. Missing data on the warning signs subscale ranged from 13% to 34% for the control group, and 4% to 38% for the intervention group. A Little's test (1988) was performed using SPSS to determine if the data met the criterion of missing and the type of missing data. This knowledge aids in the decision making for which method to use for missing data. From Little's test both the control ($\chi = 80.09$, $df=96$, $p =.879$) and intervention group ($\chi =$

69.15, $df = 96$, $p = .472$) were found to be not significant and thus missing data at random (MCAR). The missing data for the risk factors subscale was low, less than 5% of the cases; therefore, a Little's test was not performed. The decision was made to conduct multiple imputations to retain cases for analysis. Multiple imputations are recommended for missing data that are MCAR.

Multiple imputations were conducted in SPSS (26) using linear regression as the model type for scalable variable; ten imputations were created. SPSS was able to generate the missing values based on the constraints of the scales, previously answered items acting as predictors, and with linear regression acting as the model type for scalable variables. Once SPSS was finished calculating the values, a new dataset was automatically created with the ten imputations in one data set. The pooled data from all ten imputations acts as the new dataset, and statistical analysis can be performed without the potential bias of missing data.

Level of cervical cancer awareness. The Cervical Cancer Awareness Measure score was calculated following the instructions of Simon et al. (2012) and summing up the warning signs subscale (20), the risk factors subscale (55), and adding the correct answer of peak incidence of cervical cancer; the highest score possible was 76, indicating high knowledge about cervical cancer. Although the warnings subscale is dichotomous, and the risk factors ordinal, the means were still calculated because the scores were used in the sum total CCAM. The means of both subscales indicated the groups' overall trends when responding to questions about the warning signs and risk factors. To identify which items of risk factors and warnings were correctly or incorrectly answered, frequencies were run for each group— intervention and control (see Table 4.7).

Participants were assessed on risk factors using the subscale of 1 (strongly disagree) to 5 (strongly disagree). All of the presented risk factors are correct, and participants were assessed on whether they could recognize this and how strongly did they agree or disagree. A Mann Whitney U test was performed to determine if there were any differences between the control and intervention group on the risk factors that they correctly answered. There was only one item that was significantly different between the control and intervention groups. The intervention group (Mdn= 28.5) was significantly more likely to rank having been infected with HPV as a risk factor for cervical cancer than the control group (Mdn= 20.2), $U= 188$, $p= .017$.

Table 4. 6

Summary of Differences for Risk Factors by the Control and Intervention groups (Mann Whitney-U)

Risk Factors	Control (n=23)	Intervention (n=25)	Z-value
	Mean Rank	Mean Rank	
HPV Infection	20.2	28.5	-2.395*
Smoking	22.4	25.5	-0.823
Weakened immune system	24.2	24.8	-0.182
Long term use of contraceptive pills	24.8	23.3	.386
Chlamydia Infection	23.5	25.4	-.501
Uncircumcised Sexual Partner	26.0	22.1	1.014
Sex at a young age	24	25	-.274
Many sexual partners	26.5	20.1	1.535
Many children	24.4	23.6	.211
A sexual partner with many sexual partners	24.3	22.7	.418

Not going for pap smear screening	24.4	23.6	.219
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Mean scores were calculated from the items on the risk factors subscale to determine how strongly the participants endorsed their agreement to the correct answers. Every item on the risk subscale is a risk factor for cervical cancer, and participants were awarded points based on how strongly they rated their agreements with the prompted answers. For example, a participant would be awarded four points if they merely agreed that infection with HPV is a risk factor for cervical cancer. Higher scores indicate stronger agreement with the item being a risk factor for cervical cancer, lower scores demonstrate strong disagreement. Only one item was significantly different between the two groups as discussed in table 4.6. Table 4.7 illustrates that both groups disagreed with ‘having an uncircumcised partner’ and ‘having many children’ as risk factors for cervical cancer.

Table 4. 7

Risk Factors of Cervical Cancer Responses Agreement

Risk Factors	Control (n=23)		Intervention (n=25)	
	Mean	SD	Mean	SD
HPV Infection	4.3	.77	4.8	.44
Smoking	4.1	.79	4.1	1.1
Weakened immune system	4.4	.58	4.2	1.1
Long term use of contraceptive pills	3.7	1.1	3.4	1.5
Chlamydia Infection	4.1	.92	4.3	.79
Uncircumcised Sexual Partner	2.8	1.1	2.4	1.5

Sex at young age	3.1	1.3	3.2	1.5
Many sexual partners	4.1	1.1	3.4	1.5
Many Children	2.8	1.1	2.7	1.2
A sexual partner with many sexual partners	3.5	1.3	3.2	1.6
Not going for pap smear screening	4.3	.93	4.1	1.1

After examining risk factors for between group differences and overall trends warning signs were investigated next. A Chi-square test of independence was performed to determine if there was a significant difference between the two groups on warning signs for cervical cancer. This subscale was measured as a categorical variable, all of the warning signs listed are correct and participants were scored on whether they believed the presented symptoms were warning signs with 0 indicating no and 1 indicating yes. The data presented in Table 4.8 shows the percentages of correct and incorrect answers for all participants. Vaginal bleeding after menopause had the highest number of correct response (92%), and blood in stool and urine as the least correctly endorsed item (32%). There were no statistically significant differences between the control and intervention group responses.

Table 4. 8

Warning Signs of Cervical Cancer Responses-Correct and Incorrect

Warning Signs	Correct	Incorrect
Vaginal Bleeding	85%	15%
Lower Back Pain	70%	30%

Unpleasant Vaginal Discharge	75%	25%
Heavier or Longer Menstrual Flow	77%	23%
Persistent Diarrhea	36%	64%
Vaginal Bleeding after Menopause	92%	8%
Persistent Pelvic Pain	88%	12%
Vaginal bleeding during/after sex	72%	28%
Blood in stool or urine	32%	68%
Unexpected weight loss	71%	29%

Both groups were assessed on how long it would take them to seek follow-up care if they were showing signs of cervical cancer; *‘If you had a symptom that you thought might be a sign of cervical cancer how soon would you contact your doctor to make an appointment to discuss it?’* The majority of participants said they would seek immediate care or follow-up with their physician as soon as possible (56%, n=27). (See Table 4.9) Participants who said they would wait longer than a day or as soon as possible listed various reasons for this; for example a few participants mentioned waiting until their next wellness visit, doctor's visit, or when they were sure they had enough money for a co-pay.

Table 4. 9

Table 4.9

Participants’ Beliefs in Time towards Follow-up of Warning Signs

Length of Time	Control		Intervention		Total Sample	
	n	%	n	%	n	%
Immediately	12	44	15	56	27	56
Days to a week	5	71	2	29	7	15

Few weeks to a Month	5	56	4	44	9	19
A few months to a year	1	20	4	80	5	10
Longer than a year	0	0	0	0	-	0

The participants were assessed on how confident they felt that they could identify a symptom of cervical cancer (See Table 4.10). In both groups, very few women felt 'very confident' in their ability to identify a cervical cancer symptom (6%, n=3). Around one-third of the women in the intervention group did not feel confident at all in being able to identify a symptom (33%, n=8). However, 40% of the women in the intervention group felt fairly confident in being able to identify a symptom (n=10). Women in the control group were split on whether they did not feel very confident in identifying a symptom (57%, n=13) or felt fairly to very confident (43%, n=10).

Table 4. 10

Participants Confidence in Identifying Cervical Cancer Symptoms

Confidence	Control		Intervention		Total Sample	
	n	%	n	%	n	%
Not at all	0	0	8	33	8	17
Not very confident	13	57	4	17	17	36
Fairly confident	9	39	10	40	19	40
Very Confident	1	4	2	8	3	6
Total	23		24		47	

For the control group, the average from the CCAM total score was 52.9 (SD = 7.8), with the warning subscale having a mean of 12 (SD = 5.1), and an average of 40.5

(SD = 5.7) risk factors subscale. The intervention group had a group mean of 53.8 (SD =11.6) on the CCAM total score, an average of 14.7 (SD = 5.1) on the warning subscale, and a mean of 39.4 (SD =39.4). An independent-samples t-test was conducted to determine if there were significant differences between the control and intervention group for their overall CCAM score, the warnings signs score, and the risk factors score. Results (see Table 4.11) that there was not a significant difference between the control and intervention groups for their scores on the CCAM, warning, or risk factors.

Table 4.11

Results of an Independent Samples t-Test observing differences between Control and Intervention Groups at baseline

Measures	Control		Intervention		t(46)	p
	M	SD	M	SD		
CCAM	52.91	7.84	53.76	11.63	.293	.771
Warning	12.04	5.13	14.12	5.79	1.31	.197
Risks	40.52	5.69	39.44	8.35	-0.52	.606

In summary, baseline scores did not find a statistically significant difference between the control group for the overall CCAM, the warnings subscale, and the risk factors subscale. The only statistically significant difference that could be found was between the two groups ranking whether HPV is a risk factor for cervical cancer.

Aim I: mHealth’s impact

Hypothesis 1: Women who participate in the mHealth intervention and receive culturally tailored messages will demonstrate an increase from their baseline to their post-intervention Cervical Cancer Awareness Measure (CCAM) scores.

In order to assess whether the mHealth intervention has an impact on cervical cancer and HPV knowledge, CCAM scores at baseline were compared with post-intervention scores using t-tests. Of those allocated to the intervention group, 20 out of 25 participated in the full intervention. One participant withdrew halfway through the intervention, after 2 weeks and four participants who completed the baseline questionnaire did not provide a phone numbers to receive the mHealth messages. After completion of the intervention, over the course of 4 weeks, 20 participants who completed the intervention were sent a posttest survey that included the CCAM. The response rate for completion of the follow-up survey was 65%, prompting a nonresponse bias analysis as guided by the National Center for Education Statistics. A minimal nonresponse bias report was compiled using the Mann-Whitney U test to determine if there was a difference in the frame variables between the responders and non-responders. A Mann-Whitney U test found that there were no significant differences in any of the demographic areas between the respondents and non-responders to the posttest questionnaire.

Table 4. 12

Summary of Differences between Responders and Non-responders (Mann-Whitney U)

	Responders (n=13)	Non-responders (n=7)	Z-value
Marital Status	Mean Rank 9.8	Mean Rank 13	1.66
Education	11.4	10.4	-.35
Employment Status	12.5	8.5	-1.94
Household Income	12.5	8.6	-1.41
Insurance Status	11.1	10.9	-.18
Doctor's Visit	11.3	10.5	-.37

Pap Smear Screening	12.2	9.2	-1.16
HPV Vaccination	10.9	11.3	.167

Missing Data and Multiple Imputation

Because there were no significant differences, further statistical analysis was performed to manage missing data using two approaches: 1) complete case analysis (removing cases with missing data) and 2) Multiple Imputation.

The statistical analysis for both baseline and post-survey intervention scores were tested after the completion of the intervention. Therefore, when the missing data were addressed for the baseline scores, it was also addressed for the post-test scores. Little's test demonstrated that the baseline scores were missing at random. After it was performed on the baseline scores, Little's was then used to assess the missingness type of the post-survey intervention. Little's test for MCAR was performed, which found to be not significant and thus missing data at random ($\chi = 20.75$, $df=51$, $p = 1.00$).

The decision was made to conduct multiple imputations to retain cases for analysis and to perform a sensitivity analysis afterward. Multiple imputations are one method for retaining cases when missing data occurs (Hayati Rezvan et al., 2015; Stavseth et al., 2019; Sterne et al., 2009). It can be used for repeated measures and longitudinal data depending on the type of 'missingness' of the data. Data were imputed in both the intervention and control group using SPSS statistical software and linear regression. Missing values were calculated using previous answers on the subscales as predictors, constraints from the scales' values, and with the aid of linear regression.

Because of the missingness of the data, and the attrition of participants in both the control and intervention group, analysis was done to see which questions had the highest number of missing responses. In Table 4.13 the questions with the highest numbers of missing responses are found. For both groups persistent diarrheas as a warning sign for cervical cancer, and blood in stool or urine were in the top six most frequent missing responses.

Table 4. 13

Questions with the most frequent missing responses

Control	Missing (%)	Intervention	Missing (%)
Do you think persistent diarrhea could be a sign of cervical cancer?	19 (82.6%)	Do you think persistent diarrhea could be a sign of cervical cancer?	16 (64%)
Do you think vaginal bleeding during or after sex could be a sign of cervical cancer?	20 (87%)	Do you think vaginal bleeding after menopause could be a sign of cervical cancer?	15 (60%)
Do you think persistent lower back pain could be a sign of cervical cancer?	17 (73.9%)	Do you think blood in the stool or urine could be a sign of cervical cancer?	15 (60%)
Do you think blood in the stool or urine could be a sign of cervical cancer?	17 (73.9%)	How much do you agree that each of these can increase a woman's chance of developing cancer? - Starting to have sex at a young age (before age 17)	15 (60%)
Do you think unexplained weight loss could be a sign of cervical cancer?	17 (73.9%)		

Message Readability

Both the mHealth messages and the original messages were assessed on readability to determine if the messages could potentially be easy to understand and read. Several measures were used to assess the readability of the mHealth messages including Flesch-Kincaid, Gunning-Fog, Coleman-Liau, Linsear Write, the Automated Readability Index, and SMOG (My Byline Media, 2020). Results for the measures are in Table 4.14. Consensus of mHealth messages demonstrated that the messages were fairly easy to read at a grade level of 7th and a reader's age for the messages could be 11-13 years old.

Table 4. 14

Readability Measures of mHealth Messages

Readability Measure	
Flesch	70.5 (fairly easy to read)
Gunning Fog	9 (9 th Grade)
Flesch-Kincaid	6.5 (7 th Grade)
Coleman-Liau	9 (9 th Grade)
SMOG	6.8 (7 th Grade)
Automated Readability Index	6 (10-11 y/o; 6 th and 7 th Grade)
Linsear Write	6.4 (6 th Grade)

A sampling of the original messages, which were taken from the CDC and American Cancer Society, was also assessed to determine the readability of the text, Table 4.15 features the results. Consensus of mHealth messages demonstrated that the messages were standard to average at a grade level of 9th and a reader's age for the messages could be 13-15 years old.

Table 4. 15

Readability Measures of Original Messages

Readability Measure	
Flesch	60.2 (standard)
Gunning Fog	11.6 (11 th -12 th Grade)
Flesch-Kincaid	8.9 (9 th Grade)
Coleman-Liau	10 (10 th Grade)
SMOG	8.8 (9 th Grade)
Automated Readability Index	8.9 (13-15 y/o; 8 th and 9 th Grade)
Linsear Write	9.4 (9 th Grade)

Complete Case Analysis

In a complete case analysis, statistical analysis was only conducted on cases, respondent questionnaires, that were not missing data (n=12),. A paired-samples t-test was conducted to observe if there were any within group differences between baseline and post-intervention on the Cervical Cancer Awareness Measure for the intervention group. This was done to answer hypothesis 1. There was a significant difference between the baseline (M= 57.2, SD = 11.5) and post-intervention (M= 65.2, SD= 6.4) scores for the overall Cervical Cancer Awareness Measure; $t(10) = -3.4, p = .007$. A significant difference was also found with the risk factors subscale when comparing the baseline (M= 42.6, SD= 6.1) and post-intervention scores (M= 46.7, SD= 5.4); $t(10) = -2.7, p = .022$. However, for the warning signs subscale the difference between the baseline (M= 15.7, SD= 5.8) and post-intervention (M= 18.4, SD= 1.8) were not significant; $t(10) = -1.6, p = .144$.

Table 4. 16

Paired Samples t-Test of Mean Differences on cervical cancer awareness, warnings, and risks between Intervention arms

Measures	Baseline		Post-Intervention		t(10)	p
	M	SD	M	SD		
CCAM	57.2	11.5	65.2	6.4	-3.4	.007*
Warning	15.7	5.8	18.4	1.8	-1.6	.144
Risks	42.6	6.1	46.7	5.4	-2.7	.022*

*p>.05

Using GPower post hoc analysis using Cohen's D and calculated power demonstrated that the CCAM overall score had a large effect size and power ($d=.80$) at 79.6% power, warnings subscale had a medium effect size and power ($d= .525$) at 49% power, and risk factors had large effect size and power ($d= .709$) at 70.6% power.

An independent samples t-test was then conducted to investigate between-group differences in the Cervical Cancer Awareness Measure between the complete cases for the control and intervention groups. The average scores between the two groups were compared to see if there were any differences between the two groups. The intervention group ($M= 65.2$, $SD= 6.4$) had a statistically significant higher mean, $t(17) =2.7$; $p =.015$, on the overall Cervical Cancer Awareness Measure than the control group ($M= 55.3$, $SD= 9.8$).. When comparing the warnings signs subscale scores, there was a statistically significant difference between the control ($M=13.8$, $SD= 4.8$) and intervention group ($M=18.4$, $SD= 1.8$), with the intervention group having a higher mean; $t(17) =2.3$, $p=.048$. However, in comparing the risk factors subscale scores, there was not a statistically significant difference between the control ($M= 41.4$, $SD= 8.8$) and intervention group ($M= 46.7$, $SD=5.4$); $t(17) =1.6$, $p=.119$.

Table 4. 17

Independent Samples t-Test of Mean Differences for Control and Intervention Group 4-week post scores

Measures	Control (n= 8)		Intervention (n=12)		t(17)	p
	M	SD	M	SD		
CCAM	55.3	9.8	65.2	6.4	2.7	.015*
Warning	13.8	4.8	18.4	1.8	2.3	.048*
Risks	41.4	8.8	46.7	5.4	1.6	.119

*p>.05

Using GPower post hoc analysis with Cohen's D and calculated power demonstrated that the CCAM overall score had a large effect size and power ($d=1.2$) at 80.9% power, warnings subscale had a large effect size and power ($d= 1.3$) at 84.8% power, and risk factors had large effect size and power ($d= .73$) at 45.4% power.

Multiple Imputation Analysis

In an effort to retain all 48 cases for analysis, multiple imputations were used to replace missing values. After the missing data were included in the study, further statistical analysis was performed. In a paired samples t-Test, hypothesis 1 was retested to determine if the mHealth intervention improved scores on the Cervical Cancer Awareness Measure. There was not a statistically significant difference, $t(20)= -.17$, $p=.869$, found between baseline (M= 58.8, SD= 9.3) and post-intervention (M= 59.2, SD= 9.2) for the overall measure. No statistically significance was found in the difference between means for the warning signs subscale for the baseline (M= 17.9, SD= 2.8) and

post-intervention (M= 17.8, SD= 1.9); $t(20) = -.21, p = .835$. Finally, there was not a statistically significant difference found between the baseline (M= 40.7, SD= 7.6) and post-intervention (M= 17.9, SD= 7.9) groups for the risk factors; $t(20) = .09, p = .928$.

Table 4. 18

Paired Samples t-Test of Imputed Mean Differences for the Intervention Group

Measures	Baseline		Post-Intervention		t(20)	p
	M	SD	M	SD		
CCAM	58.8	9.3	59.2	9.2	-.17	.869
Warning	17.9	2.8	17.8	1.9	-.21	.835
Risks	40.7	7.6	41.3	7.9	.09	.928

* $p > .05$

Using GPower post hoc analysis with Cohen's D and calculated power demonstrated that the CCAM overall score had a small effect size and power ($d = .04$) at 7.6% power, warnings subscale had a small effect size and power ($d = .04$) at 7.3% power, and risk factors had large effect size and power ($d = .07$) at 10.2% power. The hypothesis was not supported by the test results using multiple imputations.

Next, an independent samples t-test was conducted to determine if there were any statistically significant differences between the control and intervention groups for the measure. There was not a statistically significant difference between the control (M= 54.5, SD= 7.1) and intervention (M= 58.2, SD= 8.8) group for the overall scores; $t(46) = 1.95, p = .15$. No statistically significant difference was found between the control (M= 17.2, SD= 1.4) and intervention (M= 17.7, SD= 1.8) group for warning signs subscale; $t(46) = .76, p = .45$. Lastly, there was not a statistically significant difference found between the control (M= 37.4, SD= 6.6) and intervention (M= 40.4, SD= 7.6) groups for risk factors subscale; $t(46) = 1.66, p = .18$.

Table 4. 19*Independent Samples t-Test of Mean Differences for Control and Intervention Group*

Measures	Control		Intervention		t(46)	p
	M	SD	M	SD		
CCAM	54.5	7.1	58.2	8.8	195	.15
Warning	17.2	1.4	17.7	1.8	.76	.451
Risks	37.4	6.6	40.4	7.6	166	.177

*p>.05

Using GPower post hoc analysis with Cohen's D and calculated power demonstrated that the CCAM overall score had a medium effect size and power ($d=.46$) at 47.3% power, warnings subscale had a relatively small effect size and power ($d= .31$) at 27.8% power, and risk factors had small effect size and power ($d= .42$) at 41.8% power.

The complete case analysis demonstrated a statistically significant improvement for both the overall CCAM and risk factors subscale. There was also a statistically significant difference between the complete cases for the intervention and control group on the CCAM and warnings subscale. However, multiple imputation did not find any statistically significant differences.

Aim II: Evaluating mHealth

This next section focuses on the quantitative evaluation of the mHealth intervention. The Acceptability of the Intervention (AIM), Intervention Appropriateness Measure (IAM), and the Feasibility Measure (FIM) are used to assess the participants opinions of mHealth. Scores on all three measures are calculated by summing the ratings of 4-items from 1 (strongly disagree) to 5 (strongly agree). Higher scores on all the scales

indicate a stronger approval of that intervention theme. Hypothesis 2.1-2.3 assumes that participants will rank the mHealth intervention high, 4 or 5, on all three measures.

Data from the participants who completed both the intervention and post-intervention survey were analyzed for their acceptability, feasibility, and appropriateness of measure scores. This was done to test hypothesis 2.1, 2.2, and 2.3 which were assumptions that mHealth would receive high ratings of acceptability, appropriateness, and feasibility respectively. Scores were calculated by averaging the ratings of a 4-item scale with answers ranging from 1 (strongly disagree) to 5 (strongly agree). The highest possible score that can be achieved on all three scales is 20 points. Table 4.17 presents the mean overall mean scores for all three measures, which were rated highly. The frequencies of participants' opinions about the mHealth intervention and whether they deemed it acceptable, feasible, and appropriateness for educating about cervical cancer and HPV are presented in Table 4.18- 4.20.

Table 4. 20

Intervention Group Means of mHealth Evaluation for acceptability, appropriateness, and feasibility

	N	M	SD
Acceptability of Intervention Measure	13	17.1	4.1
Intervention Appropriateness Measure	13	17.7	2.6
Feasibility of Intervention Measure	13	17.5	2.8

Hypothesis 2.1

Women who participate in the mHealth intervention will report high levels of acceptability based on the Acceptability of Intervention Measure (AIM) scores

Participants who completed the intervention found the overall intervention was acceptable with a mean of 17.1 out of 20 (SD= 4.1) 'm Health meets my approval' had the highest endorsement for somewhat to strongly agree at 92.3%. The other three items had high endorsements as well, approximately around 91.7% having somewhat to strongly agreed on the appealing, likability, and welcome mHealth.

Table 4. 21

Acceptability of Intervention Measure- mHealth measured by AIM

	mHealth meets my approval		mHealth is appealing to me		I like mHealth		I welcome mHealth	
	n	%	n	%	n	%	n	%
Completely disagree	0	0	0	0	0	0	0	0
Somewhat Disagree	0	0	0	0	0	0	0	0
Neither agree nor disagree	1	7.6	1	8.3	1	8.3	1	8.3
Somewhat Agree	4	30.8	4	33.3	4	33.3	3	25
Completely agree	8	61.5	7	58.3	7	58.3	8	66.7
	13		12		12		12	

Hypothesis 2.2

Women who participate in the mHealth intervention will rate the mHealth intervention with high levels of appropriateness based on the Intervention Appropriateness Measure (IAM) scores

Intervention appropriateness was calculated by summing the means for four items on the Intervention Appropriateness Measure (IAM) score. Participants ranked how much they agree with statements asking about whether they view mHealth to be fitting, suitable, applicable, and a good match. The group mean for this subscale was 17.7 out of 20 (SD=2.6). Individual items that were endorsed the highest with statements of agreeing to strongly agree were; 'm Health seems applicable,' and 'm Health seems suitable,' at 92.3% (n=12).

Table 4. 22

Intervention Appropriateness Measure- mHealth measured by IAM

	mHealth seems fitting		mHealth seems suitable		mHealth seems applicable		mHealth seems like a good match	
	n	%	n	%	n	%	n	%
Completely disagree	0	0	0	0	0	0	0	0
Disagree	0	0	0	0	0	0	0	0
Neither agree nor disagree	1	7.7	1	7.7	1	7.7	2	7.7
Agree	4	30.1	5	38.5	5	38.5	6	46.2
Completely agree	8	61.5	7	53.8	7	53.8	5	38.4
Total	13		13		13		13	

Hypothesis 2.3

Women who participate in the mHealth intervention will rate the mHealth intervention with high levels of feasibility of the intervention in their Feasibility of Intervention Measure (FIM) scores.

The feasibility of the intervention was captured by participants' feelings about whether the intervention could be implemented. Participants found that the intervention was feasible with a group mean score of 17.5 out of 20 (SD= 2.8). The highest endorsed item on the scale was 'm Health seems implementable,' with 92.4% (n =12) of the participants somewhat agreeing to strongly agreeing about it. The other three items received high endorsements as well, with more than 90% choosing to somewhat to strongly agree with the statements about mHealth.

Table 4. 23

Feasibility of Intervention Measure- mHealth measured by FIM

	mHealth seems implementable		mHealth seems possible		mHealth seems doable		mHealth seems easy to use	
	n	%	n	%	n	%	n	%
Completely disagree	0	0	0	0	0	0	0	0
Disagree	0	0	0	0	0	0	0	0
Neither agree nor disagree	1	7.7	1	8.3	1	7.7	1	7.7
Agree	6	46.2	4	33.3	5	38.5	5	38.5
Completely agree	6	46.2	7	58.3	7	53.8	7	53.8
Total	13		12		13		13	

Most of the participants who completed the evaluation measures rated mHealth highly for acceptability, appropriateness, and feasibility. mHealth did not receive a low rating of disagree or strongly disagree on any of the evaluation measures.

Aim III: Qualitative evaluation of mHealth

Aim 3: To obtain information from participants about 1) aspects of the intervention worked, 2) how the intervention could be improved with open-ended questions and 3) how the COVID-19 pandemic impacted the participants' ability to engage with the intervention

The final aim of the study was to qualitatively assess the experiences of the women using mHealth and further evaluate the qualities of the intervention. The original study plan was to interview participants who received the intervention within the context of in-person focus groups. However, to accommodate for social distancing and Covid-19, focus groups via Microsoft Teams were offered. In addition, to using the Microsoft Teams platform, individual interviews were offered to all of the intervention participants. Several focus group timeslots were offered to the women so they could 'drop-in' to participate in this second part of the study. Due to time constraints, the women opted for individual interviews. The participants ranged in age from mid-20s to 62 years old, all of the participants had at least a bachelor's degree. All of the women were employed except for one retired individual. Because the women who agreed to participate in the interview were highly educated, several attempts were made to contact and interview women of different socioeconomic status. Unfortunately, I was unable to interview women from a different socioeconomic status. Only one of the women from a different socioeconomic background responded to requests for interviews, and the timing for the interview never worked out.

Using a semi-structured interview guide, the interview focused on the health knowledge and experience of the women before the intervention, while using the

intervention and how do they envision future health visits. Additional topics discussed the potential experiences of women in their community, and whether the mHealth intervention would possibly be useful to them. The interviews with the women included the topic of the intervention itself, the technical aspects of the intervention, perceived discrimination the women themselves have experienced or that their family and friends had, barriers and facilitators to the health education and navigation in the healthcare system. Deductive coding allowed for passages and excerpts from the transcripts to be coded with specific codes based on Andersen's Healthcare Utilization, Critical Race Theory, and my previous research. The codebook was unconstrained, which allowed for additional codes to be added as significant themes organically emerged, such as personal relationships and community.

Reflexivity

I was involved in all stages of the study development, material development, and data analysis. Following Rae and Green's (2016) matrix for reflexivity for health services research, cells 7 and 8 were used to examine my sense of self in the research and its impacts. Questions related to cells 7 and 8 can be found in the Appendix K.

I have spent the past three years immersed in cervical cancer and HPV prevention work. Because of this, I have worked on several studies and boards focused on educating women about cervical cancer and HPV, while promoting efforts in screening and prevention. This perspective may shape the analysis by focusing on the intricate of details related to screening and prevention, rather than looking at the entire data. The hyper focus of this perspective may result in the reduction of overall context and adjacent topics, because I may not view them as currently relevant to the research aims. Because

of the uniqueness of the population and the research aims, I attempted to not dismiss data as being too commonplace. I reasoned that because of the sources of data, and the potential underrepresentation of them in the field, most of the data would be unique in some form or fashion and would not be considered commonplace perspectives.

I consider the analytical authority to shift depending on the goals in place when conducting analysis of the data. If the sole focus of this research had been to fully distill the phenomena of cervical cancer screening and prevention for African American women, then I would consider the analytical authority to rest mainly with the participant. This would call for multiple interactions with the participant and various methods of member checking. However, because the aim of this qualitative inquiry was to understand how the mHealth intervention worked for the participant, the focus was not on the phenomena of the overall experience but on various aspects of the intervention that I found to be more pertinent than the participants. In this case the analytical authority rested mainly with me, although during the interviews I did ask participants about their interpretations of certain phrases or sayings.

The researcher attempted to rely as close to the text as possible when transcribing and analyzing the qualitative data. I do acknowledge that because of the nature of the work and the my current goals it is possible that I may have unconsciously interpreted the data to fit my aims. To prevent grievous oversight, data omissions or fabrication, I worked with a second coder to determine if my interpretations were not bias but closer to universal. This was done by having both coders coding the same interviews, participating in an inter-reliability test, and discussing any discrepancies between the two

interpretations. There were several check-ins between the two as they discussed the codebook, coding, and data interpretations.

As a social work doctoral student, my experience in the field has varied depending on the context. When it comes to health research, I have held various roles from research assistant to now an investigator. In the context of community-based work and work with African American women, as an African American woman myself, my experience in this field is life-long. As a result of this, it is difficult, and I have not always done so, to separate myself from the experience of the women I have interviewed. While I may not have shared their personal experiences, I have shared in having friends, family members, and acquaintances who have faced similar experiences. In an effort to mitigate any potential bias from this, a secondary coder was utilized who was not familiar with the subject material and identified as a white woman. The secondary coder was a fellow doctoral student who has worked in the field of bone marrow transplant, so she is familiar with the oncology world.

Acceptability

Following Weiner's definition of acceptability, excerpts were coded for whether participants viewed mHealth intervention as agreeable, palatable, or satisfactory. The focus in this coding was to note instances in which participants viewed the mHealth intervention as a viable way to gain cervical cancer and HPV knowledge for themselves or members of their community.

Would you recommend the program to your family and friends?

Absolutely. I think that there is a lot of information, but it came in quick tidbits. That is was in laymen's terms. I feel like it was very clear cut and to the point. But also, that I understood. So, I think that would be super helpful especially to people my age and my sister's age.

Acceptability was viewed by many of the participants to be dependent on the age-group demographics of those who encounter the intervention. When asked about whether they would recommend the intervention to others, several of the participants mentioned that it depends on the demographics.

Honestly was oh it is gonna be a different demographic depending on age is how we're gonna have to break that down women between 16 to 25 will receive it part of normal knowledge. 25 to 35 will receive it well. The older we get the more they're gonna say 'I don't need it, I'm not having sex anymore, I don't need, I don't need to know about that. What is this and why do I have?' A little bit of resistance but even so they still need 'cause [they] still have children, grandchildren, neighbors, friends, students. We all know women that have been affected or infected with this disease.

An interesting relationship emerged between the themes of acceptability and appropriateness and their code application. There were a few instances, such as the below quote in which the code application of acceptability and appropriateness could be applied to the same excerpt.

Interviewer: Would you recommend this program to your family and friends? If it was revamped a little bit?

Participant: Most definitely, most definitely. I think every woman needs to be aware of it, and sadly, every man needs to be aware of it too. 'cause if they have a girlfriend, a daughter and niece, a mother and aunt that they are in contact with. They will better understand if she's been diagnosed and what she's going through.

Appropriateness

Across all of the interviews, participants discussed appropriateness in terms of whether they were able to relate to the health messages, felt as if they were understandable, or the mHealth intervention was relevant towards them and their community. Appropriateness was also discussed in terms of whether the messages were 'useful' or not 'useful' depending on the participant. Participants across all interviews felt as if the intervention was appropriate for their needs and relevant to them and their communities.

Interviewer: Did you feel like any information is missing from the intervention? Anything that you feel like women would need to know about cervical cancer, HPV?

Participant: I don't think so. I think you covered it because it is for women it effects women. Geared towards women... The questions that were asked, the impressions it was given you could easily understand it. Symptoms and signs and certain stages of it, an early diagnosis and. I think it was well put together.

As the interviews went on the researcher asked the participants if the language itself was appropriate, this question was asked to assess whether the language in its current iteration of semi-casual language was fine or if the participants would have

preferred a more colloquial approach. As seen in the quote below, participants were fine with the causal language employed and felt as if colloquial language for such a serious topic would be inappropriate.

Interviewer: Most [in general] people text differently than how the messages were presented, right? So, do you think using that same method that same style would be helpful or with hinder getting the messages across?

Participant: Oh, I think the way you had it was good. I don't know because it's a text messages. I I don't know if I wanna see Emojis in my intervention. I mean, I will appreciate if there were pictures, but like the link, If I knew the if I knew earlier on about the link, but has some pictures on those website yet. I mean features would have been nice, but like I don't know, it's text messages there certain text services I don't allow pictures and stuff. Well, I don't know. I think it's good. I don't know that I want emoji thing an intervention

One participant, working as a healthcare professional currently, felt like the health messages in the intervention were appropriate enough to share with others. She even shared the message as an educational tool for a patient.

Interviewer: Did you feel like any of the messages were useful, anything you might have considered passing on to your family members? Your friends? People in your community?

Participant: Let me think of one, that I just recently shared with some girl at my workplace.

Interviewer: Oh, you shared. Did you share one of the messages

Participant: Yeah. I'm trying to remember which one it was. Shoot. I think it was related to fertility. Was it? OH I know. Here it is, recently in the context of a um female patient who is sexually with another female and because of it was making no effort to like protect herself because she couldn't get pregnant. And I think she assumed all STDs that all were transferred from penile insertions into a vagina. Um, I swear I think I read that one exactly that day when I had been "well, actually HPV can be transferred from female to female." And she thought that was interesting. I hope that stuck with her at some point.

Feasibility

While the code definition for feasibility was based on Weiner's as the extent to which an intervention can be successfully used or carried, it was also used to code for instances of technical or mechanical aspects encountered by the participants and the intervention. Participants mentioned ways in which the younger generation may embrace mHealth more and that older generations could potentially struggle with the technology. Interestingly, one of the older participants discussed how, although that is a possibility, she believed that with education and classes, older generations could come on board.

Interviewer: I'm not sure how people who are from an older generation would view text messages.

Participants: Be surprised before that's what I'm saying. I'm 62, that's This is natural for me. That's just something I've had to come on board with in the past for 20 years, 30 year I came on. 20 years at least, But there are some age brackets where they just won't touch it, especially men. I'm not by my I'ma let my wife my touch it. I don't know about that stuff. I don't need to know about that. And then

there's grandmothers like I'll get my grandchild to do that for me and they don't know the grandchildren are sick of you. Learn it because they have things they want to do and they're sitting there while you're telling them will go on this. Can you bring this up for me? Can you send this? Can you look this up for me and their families? [laughter] Ain't this the truth

The topic of message timing was also discussed in the interview. Here is where the overlap between feasibility and experiencing the coronavirus pandemic becomes obvious. Many of the participants mentioned how depending on whether or not their working status during the pandemic impacted or could impact their ability to fully engage with the intervention in real-time. There were two extremes in impacts regarding the effect of the pandemic on their ability to engage with the intervention—either participants were overwhelmed with work related to the virus or they were unemployed with extra time on their hands.

I think that if I hadn't wanted to participate in this maybe some of that information I wouldn't have made an effort to read or look at. Just because right during this pandemic especially in April was hitting, KY was really worried that things were going to get out of control. We were doing a lot of things in quick succession to try to protect nurses that may not have been the safest or the smartest. So, a lot of us were very nervous and scared. I was consistently consumed with coronavirus, so I think that information was what I was strategically looking for. I wanted to know what was going on and because I get several text messages regarding medical history, I was also getting several text messages about new coronavirus-y things. So I think that made it difficult for me to kinda like, 'oh let me read my HPV text,

while I'm also reading my text messages about what's going on in Japan today.' I that it kinda pushed it into the back burner because what was the most important was the information I feel like I needed to get to at that moment was information related to coronavirus.

For some, the pandemic offered time for them to fully take in the intervention; for others, it was a stressor that made it difficult for them to engage with the program in real-time.

Interviewer: So, can you describe for me what your experience of participating in this intervention felt like while the pandemic?

Participant: Yeah, I think for me I don't know about other participant[s], but for me it was helpful because I don't think I would have stopped. Only don't have time to actually sit and check my text messages. I had more time for technology, and I will in my regular life. Like I like connection to the extent that I actually looked at the link said, oh, this is something for CDC. If I wasn't there was no [any] social distancing, I probably would not have had time to do that. So, for me is favored me to have time for to learn something special like with coronavirus. Everyone was like everyone has been encouraging people to like Oh, learning something. You study something, no, something you. Yeah, all of that. So, this one was one of the things I learned. OK. So at least now you can come out again then yeah. [I: Now you can come out of pandemic thing I learned.] Hey, I learned about cervical cancer.

When asked about the timing and frequency of the messages, participants spoke on how the frequency and timing were adequate. A few mentioned how, depending on their schedule, they may not have the time during the middle of the day to read messages; however, they usually reread them later. Others mentioned how if their family members were to engage in the program, some might have been too busy due to household responsibilities for noonday messages.

Interviewer: Do you think they would find the text messages easy to understand?

Participant: They will, I just don't know like the timing of the text messages because I can think about my sister like she has two kids and she's like super busy and she's a working mom but I don't think like at that time I was getting the text message it wasn't at the beginning of a day like I like 6:30 or at the end of the day he was like 10 AM like it was like during work hours so I was wondering if like if it was a working mom or someone who is sleep busy. They may not have had time. To really like you really look at it.

Perceived Discrimination

To center the margins and focus on the experience of the participants who, as African Americans were members of the marginalized community, perceived discrimination was a major code. Earlier results mentioned the quantitative data that looked at the experiences of the participants in medical settings; the qualitative interviews allowed for a more rich understanding of perceived discrimination to manifest. The code definition was a behavioral manifestation of a negative attitude, judgment, or unfair treatment toward members of a group defined as a behavioral manifestation of a negative attitude, judgment, or unfair treatment toward members of a group (Banks, Kohn-Wood,

& Spencer, 2006; D. R. Williams, Spencer, & Jackson, 1999). The second half of this definition was vitally important when coding the health experiences of the women in this program and that of their family and friends.

It's happened to me a couple of times. I'm 62, so once you get a certain age you don't take anything for granted. So once you get your voice and you learn to speak up for yourself, it might have happened once or twice, but not as long as I have a voice it will never happen to me again because I have been conditioned to speak and act, but they're not listen, get up and leave. If you can.

Even if a participant had not experienced perceived discrimination personally themselves, they were still aware of the potential of being treated differently while going through the health experience. This awareness prompts participants to take protective measures to ensure that they are treated with respect.

Um, so far, I've had positive experience actually going to the doctor. I'm not had. And yet you have a negative experience with going to the doctor, but I think it also brought down the fact that when I go to the doctor's office I kinda want to introduce myself and let them know that I'm a public health major and I understand healthcare system. I know all this stuff still that beforehand, whatever implicit bias that the providers, nurses, administrators have they are very well aware of it and will treat me pretty respectfully. Because I know that a lot of providers look down on people of color or black people and females. And especially black woman and feel like we already were stronger than other people, or we don't really feel pain or we just get it. Sometimes we do not, so I have yet to have a negative experience because I go real prepared. I have my questions ready. I'm asking all my questions

and making sure that whatever time I spend there is sufficient enough. Sufficient really. So that I have all my, um, all my questions ready. So far it's been good

Mistrust, Trust and Personal Relationships

Additional themes emerged during the initial data immersion as the primary and secondary coder noticed that participants discussed topics beyond the evaluation measures of the mHealth intervention and in conjunction with perceived discrimination. For example, often when discussing perceived discrimination, participants would mention how perceived discrimination was influenced by mistrust of the healthcare system or providers.

Older black women don't, tend not to trust. Health officials so much because of things that happened in their past or the way they were treated.

This results in hesitance for some black women to either engage in the healthcare system or even adhere to recommended guidelines.

I know a lot of the women in our lives don't do any of their like recommended health screenings and I don't know if because I've, I've read a lot in heard from like my elderly black females in my life that they don't trust doctors a whole lot so I guess if they don't frequently go to the doctor's office and when they do the doctor tell him things and they don't know if it's true and they're off doing their own home remedy and regiments.

Participants' discussions of mistrust often intertwined with conversations about trust and how the role of racial identity plays into. For example, in the below quote, the participant discusses how mistrust of a healthcare provider could potentially lead to harm.

As the participant notes, an individual may be more inclined to believe health information coming from someone they already trust even if that information is wrong.

Interviewer: I was wondering and let me know if I'm putting words into your mouth or if I'm not saying something the way that you envision it. But do you think that them [older black women] not going to the doctor and taking home remedies is them [older black women] trying to have a protective factor for themselves trying to figure out a way to reduce any potential [inaudible] or any potential worry they may have from a medical condition?

Participant: For sure, I think that if you are terrified that your provider and the person that you're supposed to trust is providing you with information that you is gonna hurt you or is inaccurate, if you're doing it yourself [gathering information] from someone that you do trust like your mother or your grandmother and it's information that was given to you from them then I think that you feel safer like you feel like these people are making no efforts to hurt me and I know that like if my mother thinks that I should gargle peroxide in order to fight the coronavirus then it is probably safe for me to do but if my doctor would suggest that I may have questions and concerns.

It is through personal relationships that trust can be established, and mistrust combated. One participant mentioned how her mother would be inclined to use the intervention if someone she knew was behind the messages. Personal relationships, whether between the intervention organizer and participants or participants and their loved ones, play an essential role in establishing engagement with the program.

Interviewer: Just as long as she knew who they were coming from?

Participants: Yeah, I think that would help. Like if she was like, oh this, I save this number as [Interviewer]. [Interviewer], Sent me a text message today like she's definitely going to open it. Read it and see what it's about and I think that like knowing that was from you would make her more likely. Like listen to that information.

Qualitative interviews demonstrated what aspects of mHealth intervention worked for participants and areas that left room for improvement. mHealth was able to continue despite the Covid-19 pandemic, and depending on their responsibilities, participants were able to focus on the intervention.

CHAPTER V: DISCUSSION AND CONCLUSIONS

This quasi-experimental study aimed to develop and evaluate a health education intervention focused on educating African American women about cervical cancer and HPV. With the use of a community advisory board of African American women, relevant theories, and information, health messages were delivered to the women in the intervention group to improve knowledge about cervical cancer and HPV. In addition to developing the mHealth intervention, this study aimed to assess the acceptability, feasibility, and appropriateness of using this intervention with African American women. Results from the mHealth intervention and individual interviews show promise for the intervention, directions for future growth, delve into the experience of using the intervention, and highlight the limitations of the study.

These are the research aims that the results answered:

Aim 1: To determine if mHealth intervention can improve cervical cancer and HPV knowledge of African American women

Aim 2: To assess if the mHealth intervention is a feasible, acceptable and effective strategy for promoting cervical cancer screening and prevention among African American women

Aim 3: To obtain information from participants about 1) aspects of the intervention that worked, 2) how the intervention could be improved with open-ended questions and 3)

how the COVID-19 pandemic impacted the participants' ability to engage with the intervention

Community-Based Participatory Research Approaches and mHealth

Community-based participatory research is rooted in the traditions of social justice and community empowerment. The traditional leaders in both the northern and southern traditions have highlighted CBPR's need and impact when working with marginalized populations (Ferreira & Gendron, 2011; Israel, 2013). The inclusion of a community advisory board in the development of mHealth messages was essential in following this tradition and using a critical race lens. Including African American women from various backgrounds in the development of the messages ensured that this valuable perspective was not lost from the messages and that the messages could relate to women in this community. As mentioned before, this allowed the messages to be less technical and jargon-heavy. Following this approach was one of the most substantial advantages for the mHealth intervention.

Although the board met twice physically, each meeting was productive and enlightening about the needs of African American women and cervical cancer education. The board was essential in helping the researcher edit the messages from their original form to its more palatable version. The board's help gave the researcher confidence in the messages due to having multiple perspectives rather than the researcher's lone experience.

There were a few challenges with using the CBPR approach, mainly in recruitment and continued feedback. The researcher cast a wide net for recruitment, and those who joined the board were the ones most excited about the prospect of health education. As with most projects, it became difficult for the researcher to keep the women

engaged and enthusiastic throughout the entirety of the project. Because of competing responsibilities from the women's lives, enthusiasm, and engagement wavered towards the end of the project, the members helped with the development of the messages and recruitment, they did not participate in the data analysis or qualitative inquiry. This served as a lesson for the researcher in the importance of scheduling time early and being flexible about commitments. In the future, the earlier meetings will focus on the most critical aspects of a project; that way, when engagement wanes, the priority options have already been accomplished. However, these are small challenges that do not take away from the work and helpfulness of the board when initially developing the messages.

The current tailoring of the messages used the perspectives of African American women to assess, evaluate and edit the messages to be more appropriate for the study participants. While, the messages have an easier readability scores than the original messages it can be difficult at first to parse out the cultural tailoring of the message, which is a limitation. A potential source for improvement of the messages is to include more explicit cultural references for African American women in the messages. In the qualitative inquiry, the women interviewed did identify with the messages and were able to relate to them. However, when discussing ways to improve the messages it was suggested the inclusion of personal stories would be an effective way to further connect with the potential participants. Stories from African American women who have been impacted by the disease, those who have undergone routine screening practices, and stories from those who have received the HPV vaccination or parents who have considered vaccinating their children would be powerful in further culturally tailoring the messages. As they currently stand the messages were developed and edited by African

American women whose advice and perspectives were taken into account which fits the basic definition of culturally tailoring. The inclusion of personal narratives will aid in further incorporating the cultural perspective of African American women into the messages, and give the mHealth intervention a deeper cultural perspective.

The continued need for mHealth

mHealth joins a growing body of literature that demonstrates the viability of having a health education delivered via mobile phones. Results from this study demonstrated that mHealth is a promising intervention with the potential to increase cervical cancer and HPV knowledge. Women who participated in the study found the intervention acceptable, appropriate, and feasible for use.

Baseline measures in this study confirmed that there was a need to educate African American women about cervical health and HPV. Scores on the CCAM measure join others in pointing out the need for continued education in this group (Brown et al., 2011; Strohl et al., 2015). Possible reasons for why cervical cancer and HPV knowledge is low could be due to the lack of comprehensive sexual education, short interactions with health providers, or even misinformation about cervical health and HPV. Women, and African American women in particular, are not being educated extensively on their cervical health beyond being told they need to be screened, and their children vaccinated. Therefore, it is not surprising to see low baseline scores for both the intervention and control group. However, there is an indication by the correctly endorsed items on the CCAM measures by the participants, that there is a baseline understanding of cervical cancer. As mentioned in the results, there were certain items that the control and intervention group were able to identify correctly. Those correct answers indicate that

there is still some foundational base from the women and gives a foothold for further education.

Discrimination in the Health

A central theme and consideration when working with marginalized populations is the impact of race on the experience in navigating the health system. Health disparities have existed for decades and continue to manifest in different ways in the cancer experience and general health. African American women often are concerned about their health and those of their loved ones. Because of the existence of health disparities and the need to consciously consider the impact of race on healthcare navigation along with experience, it was essential to include a framework that allowed for the centering of race. The results from the discrimination in medical settings scores validated the inclusion of Critical Race Theory concepts into the problem articulation, theoretical framework, research methods, and health messages. Women who participated in the baseline survey for this study admitted to having experienced some form of discrimination in the medical setting. All forty-eight women marked at least one of the six items as having occurred to them, with several of the women have experienced multiple forms of medical discrimination frequently. It will seem surprising to some that all forty-eight women have admitted to such, but considering what literature currently shows of health disparities, it is not shocking or surprising. The results show which items most frequently experienced, and which items occurred the most. Even items that were not endorsed as frequently as the top two items were only a few points away from being endorsed.

African Americans have experienced perceived discrimination in regard to general health (Benjamins & Middleton, 2019; Hausmann et al., 2011), mental health

(Paradies, 2006), and even health service utilization (Ben et al., 2017), most leading towards a negative health experience or outcome. An implication of these experiences and feelings is the difficulty in maintaining a healthy interpersonal relationship with the healthcare provider, a meaningful relationship that is necessary for fostered trust and patient satisfaction for African Americans. As mentioned in chapters one and two, the interpersonal relationship between patients and providers is vital for tackling the problem of health disparities. Without the trust between patients and providers, it is impossible for African American women to feel comfortable enough for cervical cancer screening and to trust the providers with HPV vaccinations for their children.

Research Aim I: mHealth's potential

mHealth intervention shows promising results in its ability to increase knowledge and confidence about cervical cancer. The results show that there was a statistically significant increase in scores for the overall scale of CCAM, and its subscale risk factors. The aim of hypothesis 1 was to determine if mHealth could accomplish this. The results from the complete case analysis demonstrates that the mHealth intervention likely had an impact on the overall knowledge of HPV for the intervention group participants. However, the multiple imputation data complicates the picture when its results show that there were no significant effects.

The results from the complete case analysis, hypothesis 1.1 was proven valid for the overall measure and the risks subscale. Both scores showed that there was an overall improvement in cervical cancer knowledge and an improvement in the risk factors subscale. The overall scores see substantial improvement by ten points for the participants in the intervention group. An encouraging finding that suggests that

hypothesis 1.1, mHealth does improve the cervical cancer knowledge of the participants, is a possibility. Risk factors improved by five points, demonstrating that it is possible to improve risk factor recognition. However, there was one subscale that was not significant, but there were exciting results for its analysis. Warning signs subscale scores were trending in a positive direction with an improvement in scores as there was a three-point increase with the use of the mHealth program participants in the intervention group improved in their cervical cancer knowledge. The statistical significance reached, the effect size calculated, and the power achieved demonstrate that although the number is small, there is potential in this intervention for achieving knowledge-based outcomes. These results were the preferred outcome and joined others (Le & Holt, 2018; Lee et al., 2015) in suggesting that it is possible to use mHealth to increase cervical cancer knowledge in women.

There are several potential reasons for why mHealth was able to increase knowledge. The intervention actively educated women beyond a one-time pamphlet or 15-min doctor's visit about cervical cancer and HPV. For this mHealth intervention, long-term engagement was achieved by the consistent and continued messaging multiple times a week for one month. While the messages may not have been read in real-time all the time, participants had the opportunity to go back and read the messages at their earliest convenience. This strategy allows for the participants to conveniently and quickly receive the needed health information without having to deviate from their daily activities. Unlike a pamphlet or a brief conversation with a healthcare provider, the health messages presented in the intervention are easily found and recalled. There was little

potential for accidentally losing the material or forgetting the in-person interaction after the meeting, as a record of the messages was contained in a single text thread.

Health education, as the World Health Organization describes, is a combination of learning experiences to help individuals and communities change health behaviors by increasing their knowledge and influencing their attitudes. Another potential reason for these findings is that health education efforts often lead to knowledge increase for cervical cancer; evidence of its impact on cervical cancer screening knowledge is found in the literature (Naz et al., 2018). This study joins others in demonstrating that health education can improve cervical cancer and HPV knowledge for African American women (Staples et al., 2018; Tete et al., 2019). For the women participating in this intervention, just the act of reading and internalizing the messages aid in knowledge production for these women. The women in the study who did not previously have much knowledge about cervical cancer and HPV, the text messages that they received gave them much-needed education; therefore, they were able to use the information that they have learned to answer questions on the CCAM.

It is interesting to note that while the complete case analysis did have statistically significant findings, the multiple imputations data did not have similar findings. Using the multiple imputation data increased the p-value for all three measures of interest, resulting in non-statistically significant results. This analysis approach complicates the picture of whether mHealth was able to increase knowledge about cervical cancer, thus disproving hypothesis 1.1. Multiple imputations allowed for all forty-eight cases to be used in the statistical analysis, but when comparing it with the complete case analysis, a confusing picture emerges. The reason why the results may be different between the two

analytical strategies could be due to multiple imputations mathematical tendency to reduce scores close to the mean. This discrepancy between the two results is an issue that can be explored later and after further study. It is possible that the results of the study might not be statistically significant, but it is hard to believe that it would be at the level that multiple imputations suggest.

Multiple imputation analysis usually results in increased power and statistical efficiency when used for longitudinal data (Ibrahim & Molenberghs, 2009). However, in the case of this study multiple imputation in fact had less statistical power than complete case analysis, which gives pause in examining which results to consider. Mukaka et al. (2016) found that in some cases complete case analysis when the missing data is MAR or MCAR, results from complete case analysis are as accurate or even better than multiple imputation. What these two studies imply for the mHealth study is that there is validity in the complete case analysis, however the multiple imputation analysis is important to occur? in conjunction to create a deeper understanding of the missing data and its impact. With adjustments to the multiple imputation model in the mHealth study, it is possible that the results may reflect more closely the complete-case analysis. For this to occur a sensitivity analysis and possible predictive-mean matching could further refine the model for future research.

Research Aim II: Evaluating mHealth as an intervention strategy

All three measures of acceptability, feasibility, and appropriateness gives further insight into the opinion of the participants about the quality of the mHealth intervention. mHealth intervention received high ratings of approval for all three measures by the women in the intervention group. These results supported the hypothesis 2.1, 2.2, and 2.3

as all three measures showed high ratings amongst the women who finished the intervention. Women viewed the mHealth intervention to be acceptable, appropriate, and feasible for usage and disseminating medical information. These concepts are essential for assessing the implementation of the intervention and ensuring that health information is easy to reach and understand. Similar to Montgomery et al. (2018), which is also a mHealth intervention that focuses on black women, participants found their mHealth to be an acceptable and feasible strategy for addressing HPV with black women.

Acceptability in the contexts of this intervention focused on how the participants viewed the intervention and whether they would recommend it to others—also using Weiner et al. (2017) definition of acceptability as the perception among participants that the intervention is acceptable, palatable, and satisfactory. Quantitative results showed that on average, participants believed that the mHealth intervention was acceptable in four ways: meeting their approval, appealing to them, liking mHealth, and welcoming it as an intervention. The results highlight the potential appeal that mHealth holds for not only the women in the intervention group but African American women in general. It is critical to evaluate whether interventions can be successfully implemented with this population, especially when considering that several of the interventions in the earlier chapters struggled with evaluating the acceptability of their program. Le and Holt (2018) did evaluate their intervention and found that African American women did approve of using a mHealth intervention. A sentiment shared with both this study and Montgomery et al. (2018).

Appropriateness is the perception among intervention participants that the intervention is a relevant fit or compatible for addressing the problem (Weiner et al.,

2017). A primary concern during the development of this intervention was to culturally tailor the health messages so that they would be relevant to African American women. Often, health messages and materials can be dense, difficult to parse out, and filled with medical jargon. Using a community advisory board of African American women ensured that the messages were relevant to the women in the study and that they were not lost underneath medical jargon and uncommon phrases. The appropriateness of the messages tied into the critical race approach by allowing for the principle of centering the margins to be followed, as the experiences and perspective of African American women were centered. Health messages are appropriate when they reach their target audience, and stakeholders internalize them.

Other mHealth studies have also used advisory boards to help tailor health messages for us with marginalized populations (Le & Holt, 2018; Lee et al., 2016; Lee et al., 2015). This study allowed for the inclusion of women between the ages of 18 to 21 years of age, which is a departure from the inclusion criteria of Le and Holt (2018), whose focus was on older church-going African American women. The language used in both studies was different as their study used more colloquial language and text speech, such as informally shortening words. During the culturally tailoring phase of this intervention, it was never suggested to edit the language to fit text speech or to use wholly colloquial phrases. Instead, the women in the community advisory board were focused more on simplifying the messages and removing jargon. Based on both quantitative and qualitative responses, the women in the intervention group approved of the appropriateness of the intervention. During the qualitative interviews, the researcher specifically asked if the language felt appropriate to the women in the intervention group.

As noted in the results section, the language felt not only appropriate but also inclusive as well.

Because the women accepted and deemed the intervention appropriate for addressing the health issue, the next step in the evaluation was focusing on the feasibility of the mHealth intervention. Feasibility is the degree to which the intervention could be used by the individual to address the issue (Weiner et al., 2017). The context of how the individuals used the intervention, in what ways the intervention could improve, and focusing on aspects of the intervention that worked was used to assess the feasibility of mHealth. Mainly, feasibility looked at ways to measure the more technical concerns of the mHealth intervention. As Bowen et al. (2009) notes, feasibility is essential in ensuring that the intervention is not only relevant to the health issue but sustainable as well. As shown in the results of this study, the women viewed the mHealth intervention to be easy to use, implementable, possible, and doable. All four concepts were necessary for making sure that the intervention can reach African American women no matter the stage of readiness.

Aim III: Qualitative Inquiry into the intervention

Qualitatively, the results showed that the women interviewed viewed the intervention acceptable. As mentioned in the qualitative results, the women interviewed genuinely believed that this intervention is vital for themselves and other women in the families and communities. All of the women, when asked if they would recommend this intervention, strongly agreed that mHealth is needed, and it has the ability to improve health knowledge. This is similar to another study that showed that women approve of mHealth interventions (Montgomery et al., 2018). The sentiments expressed in mHealth

participants' interview had a similar theme to previous work, in which the women wanted, believed, and advocated for educational opportunities for women in their community. mHealth proved to be an acceptable intervention both quantitatively and qualitatively, and the results show that the women participating in the study would recommend this to their friends.

As the coders worked on the qualitative data, a connection between acceptability and appropriateness became apparent. As mentioned earlier acceptability is defined as perception among participants that mHealth is pleasing, palatable and satisfactory; appropriateness as is the perceived fit, relevance, or compatibility of mHealth (Weiner et al., 2017). During the coding process it became unavoidable to not find evidence of the intertwining relationship between acceptability and appropriateness. For an aspect of the mHealth intervention to be acceptable in this context, it often had to feel appropriate by the individuals. Often when participants made statements about the acceptability, they also mentioned appropriateness as well. To the participants, acceptability and appropriateness were interconnected because without the intervention being appropriate, they may not have been as accepting of mHealth.

As has been mentioned in the literature before, there is a need for culturally tailored interventions to help address health disparities (Campbell et al., 2007). Culturally tailored interventions, or interventions developed with marginalized populations in mind, can reach individuals at a deeper level. Culturally relevant interventions place the content into a context that can connect with the individual based on their culture. Therefore, for individuals, instead of potentially feeling alienated by the information or believing that it is not relevant to their lives they are able to embrace the culturally relevant intervention.

Although few phrases in the health messages used colloquial language, the overall frame of the intervention and the very first message received by the participants focused on African American women and cervical cancer health disparities. Participants were placed into the frame of mind that the information that would come later in the messages was essential and appropriate for them as African American women to better protect the health of their loved ones and themselves. This interconnectedness of acceptable and appropriate allows for the mHealth intervention to be more than just a pamphlet or platitudes towards the women, as participants are given health information that is highly relevant to them and their experiences as African American women.

The qualitative data shows the areas in which improvement is needed for the mHealth intervention, which focuses mainly on timing. During the development of mHealth the researcher considered the literature surrounding timing and frequency. Schwebel (2018) found that for most interventions, the frequency and time of day for messages fluctuated with no set standard of when messages should be delivered. With no set standards or guidelines to draw upon, mHealth followed successful practices as described in the article. Messages were sent to women in the program around noon, three days a week. As one of the respondents notes, for those who are working or dealing with daily activities, this can be a stressful time to focus on reading the text messages. With competing responsibilities, either with life, household responsibilities, or work-related needs, it can be challenging to focus on the health messages during the middle of the day. In response to this, the researcher considered choosing a later time around after-work hours to accommodate the differing schedule conflicts. Although the solution is not perfect, it does allow for less competition for the attention of the participant.

Concerning the timing of the messages, the women who participated in the qualitative interviews mentioned that they did open the messages and read them, which gives a small sense of the intervention adherence in the group. Although some of the women lead busy lives, and especially during the pandemic, they were still able to engage with the intervention. Treatment adherence is a concern and was difficult to track with the BulkSMS platform as there was no information given to determine whether individuals had read or opened the messages. BulkSMS did give reports on the delivery status of messages so the researcher could see that their messages were delivered during their scheduled times.

One way an mHealth study attempted to measure treatment adherence was by looking at the number of links clicked or self-report (Montgomery et al., 2018). While this current study did include links, and it was possible to observe whether the links were clicked on, not much-reported information could be found using this strategy. Some of the earlier presented links had a relatively steady number of clicks, but as time went on in the intervention, link usage decreased; this same instance occurred in the Montgomery study as well. The low number of clicks and interaction may be due to participants not feeling as if they had enough time to devote to reading the material or clicking on the provided links. The researcher included the links to the Center for Disease Control, American Cancer Society, and HealthyTeenNow in case participants became interested and wanted to follow-up on the information presented in the messages.

After assessing for the evaluation measures, a more in-depth reading of the text revealed additional themes that were relevant not only to the intervention itself but also the overall health experience of African American women. Personal relationships and

trust were additional central themes that arose from the interviews. As noted in the results section, participants were aware that an African American woman was implementing the mHealth program, which fostered for them a sense of trust and safety. The women mentioned that not only themselves but their community feel comfortable with knowing that someone who ‘looks like them’ is disseminating information to them. These results are not surprising when remembering the impact that race and racial concordance has on health communication for African Americans (Shen et al., 2018). As one participant mentioned in the results, women in her community need to trust that the source of information is not trying to hurt them.

For a community who has experienced discrimination either personally or collectively, fostering a sense of safety and trust is crucial for not only participating in the mHealth program but for the information to be internalized and health behavior change to occur. There is mixed evidence about the importance of trust and its connection to health behavior. Jacobs et al. (2014) found that there wasn’t much of a relationship between trust and participating in cervical cancer screening, while (Brown et al., 2011) has listed it as a facilitator to screening, and Sanders Thompson et al. (2012) found trust in a provider was a facilitator for HPV vaccination by African American parents. This study, although did not explicitly measure for health behavior change, does add to the literature by implying the importance of trust to screening and vaccination. As the interviewees mentioned, trust is crucial in ensuring whether or not they or their family would participate in any sort of health behavior or follow health advice.

Interwoven through the qualitative data are the themes of personal relationships, trust, and mistrust. All participants mentioned feelings of mistrust that either they have

personally experienced or have witnessed from their friends and family with the healthcare system or healthcare providers. The reason why centering the margins is so essential and critical race theory offers us a lens to develop, evaluate and observe is that there is no separating the race and ethnic identity from the individual. During the interviews, women often mentioned how they have personally experienced or had heard stories from their family and friends of being mistreated in some manner while trying to navigate the health system. Perceived discrimination was shown both quantitatively with the Discrimination in Medical Settings scores and through questions related to the healthcare experience. As literature extensively demonstrates, medical mistrust is not a foreign concept among the African American community. In the case of a few women interviewed, this manifested as a need to form protective factors against perceived discrimination. It is because of medical mistrust that one of the women learned to speak up about her state of her health, and another felt the need to arm herself with knowledge and present her 'credentials'.

Qualitative data demonstrated the various ways in which perceived discrimination manifests during the healthcare experience for African American women; this was highlighted by the extraordinary measures two of the women took to protect themselves from the effects of perceived discrimination. In chapter four a quote is included about the experience of an older woman, who discussed how she refused to allow herself to be taken advantage of again. Another participant discussed how she gathers as much knowledge as possible to be a protective factor. As mentioned in the results, African American women have difficulty fully trusting the healthcare system with their health either due to a personal experience or the experience of someone close to them. mHealth

offers a way to mitigate the effect of perceived discrimination and to continue health education with this population. Previous work has also demonstrated the importance of maintaining the health of oneself and protecting the health of loved ones. This commitment to health education and ‘need’ was evident in both big and small ways during the interviews as women who participated in the individual interview would express sentiments that boiled down to the belief that this specific intervention or intervention in general, is sorely needed to educate individuals in the African American community. Both the quantitative and qualitative data validated the approach and inclusion of Critical Race Theory into the overall study design. To ignore the racialized experiences of African American women is to put their health and that of their community in constant jeopardy from the negative health consequences of disparities.

Limitations

There were several limitations to this study that could impact its results and generalizability. One of the significant threats to validity for this study was Covid-19. The timeframe of this study, from April 2nd, 2020 to May 1st, 2020, occurred right during the initial height of the American public’s pandemic concerns. During this time, participants and the general public were concerned about the potential impact of Covid-19 on their daily lives, threats of illness, and joblessness. Because of the unique situation of a global pandemic and beginning stages of a potential recession, it is entirely plausible that these events impacted the study results and participants.

Due to this possibility of pandemic’s impact, women from the intervention group were asked about their experiences during the global pandemic. While a few of the

participants were retired or students, they did not feel the effects of the pandemic deeply. Those who were working in essential jobs struggled with engagement in the intervention. It will take time and further research to fully understand the impact of Covid-19 on more than just intervention engagement. Results from the qualitative interviews indicate that there was an impact for those interviewed. Because of study constraints it was not possible to interview every participant, therefore it is difficult to determine how widespread of an issue this became. An assumption can be made though, that individuals who were essential workers, or had strenuous responsibilities may have had a different experience than some. It is possible that similar to the health professional interviewed, those with more strenuous responsibilities during the pandemic had less time to devote to engagement in the intervention. Texts may have gone unread or read later, and links not clicked due to the busy schedules of those more heavily impacted by Covid-19.

Another limitation of this study is the small sample size. Recruitment for this study occurred right before the pandemic became a national concern, and it can be assumed that it impacted recruitment numbers. Before the various shutdowns, one of the recruitment strategies for this study involved in-person attendance of community meetings. With the shutdown of various agencies and the university, that plan had to be revised. Recruitment focused instead on online spaces, and the sampling frame widened to include any African American woman living in the United States, 18 or older. Online recruitment from personal and CAB networks could have resulted in selection bias of research participants.

Along with the concern of recruitment, attrition and incomplete data collection led to the reduction of the final sample size of this study. Several messages were sent to

study participants to remind them to follow-up on the post-intervention survey. Control group surveys may have also been affected by historical threats, as the post-intervention survey invitation was sent on May 29th, a time of civil unrest for African Americans. If these two historical events did not occur during data collection, it is possible that results may look different. As a pilot study, this study gives a general idea for the potential of mHealth.

Finally, this study may not be representative of the larger population of women or African American women. The average educational level of women in this study was high, with the majority having a bachelor's degree or higher. Education level has been shown to impact health literacy, with those who have a higher level of education having higher scores of health literacy (Jansen et al., 2018; van der Heide et al., 2013). The high education level of the women in the sample may have enabled them to easily understand and interpret the mHealth messages. Individuals, with less than a college degree may not find the mHealth messages or intervention as easy to use, therefore this intervention may not be generalizable to populations with lower educational levels. The researcher made several attempts to diversify the sample with recruiting participants with a range of educational levels and to include an individual with a high school degree or GED in the qualitative interviews. In hopes of gaining a better understanding of whether mHealth is easy to understand at all levels, the researchers reached out to two individuals whose socioeconomic status differed from the majority. Unfortunately, a mutual time for both interviewer and participant to meet could not be worked out. Future studies should be intentional in their efforts to recruit women who have a lower educational status to ensure that mHealth interventions are viable across all educational levels.

Research Implications and Recommendations

Although Covid-19 proved to be a disrupting historical event, with far-reaching implications for health, employment, and the need for health information, it has offered insights into the direction of future research and practice. Future research should observe the impact of social distancing guidelines on health education research. In particular, they should explore whether mHealth interventions can continue to improve health knowledge and attitudes when participants are unable to engage in face to face interactions. One of the most significant advantages of this intervention was its ability to continue when social distancing guidelines and State lockdowns were in place. There are additional ways to build on the results of this mHealth study and directions for future research to take; studies should work on adapting interactive activities into mHealth, using the intervention to trigger timely follow-up appointments for women who have had abnormal screening results and educational reminders to parents who have children of vaccinating age.

Several mHealth studies have interwoven interactive activities into their interventions with varying levels of success. Le and Holt (2018); Lee et al. (2015) were able to successfully use interactive approaches to their cervical cancer interventions with quizzes, games, and more; however Montgomery et al. (2018), noted that their attempts of interactive activities videos were not a consistent way for engagement. The current study did not have any interactive options beyond the inclusions of additional links for self-education; however, it would be interesting to observe if it is possible to build on the current mHealth study and adapt interactive activities. Adapting interactive activities would have to be done carefully and thoughtfully as not to overwhelm participants of the program, as one of the selling points of the current intervention was its ease in use.

Further research should be undertaken to develop an interactive mHealth intervention that can be used solely on mobile phones. The interactive mHealth messages were developed with smartphones in mind; as mentioned previously, not everyone has access to a smartphone, nor do they always have the necessary data or expenses for such an activity. With the work of a community advisory board and study, future research can adopt interactive activities for mobile phones.

Additional implications of these findings, especially for research, are they join the continually growing body of evidence that suggests mHealth interventions can improve cervical cancer knowledge. Future research can use these findings and the mHealth intervention to investigate whether similar or better results can be found in additional populations. One such population is women who have received an abnormal result for cervical cancer screening and who have yet to schedule or participate in a follow-up appointment. It is vitally important that women who received abnormal results follow-up with their healthcare provider to determine if and which treatments are necessary. For example, research has demonstrated that knowledge (Hui et al., 2014) and fear (Tejeda et al., 2013) are a few barriers for delaying follow-up visits after the abnormal screening. This intervention could be used to research whether consistent education on cervical cancer can not only increase knowledge about the disease but also reduce the time between initial diagnosis of abnormal results and follow-up visits.

This intervention could be beneficial for parents of children who are of the age to be vaccinated. Although parents were included in this study, as shown in the results, they were not the main focus of the study. It would be enlightening to investigate whether parents who participate in mHealth are more likely to have their children vaccinated, both

boys and girls. Messages were included in the intervention that discussed HPV vaccinations, vaccination myths, and the need to discuss this with their child's physicians in hopes that parents would consider this at their child's next checkup. As mentioned earlier in Chapter Two, African American parents are hesitant to vaccinate their children for a variety of reasons, including lack of knowledge and mistrust. mHealth offers a way to educate parents on HPV vaccinations, acknowledge their concerns about the vaccine, and engage them in disputing vaccination myths. Future studies could take the foundation of this study and include pro-vaccination material to be delivered to African American parents.

Social Work Practice Implications

There are several practical implications of the mHealth study that can be used in health clinics, primary care offices, and institutions that engage with African Americans. mHealth is an educational tool that has increased the knowledge of cervical cancer for African American women in the study. A tool that has received high levels of approval for its acceptability, appropriateness, and feasibility for use as an intervention method in educating women about cervical cancer and HPV. This intervention and current study can impact future practice in a few ways; ease of use for the participants, ability to be delivered without face to face interactions, and the ability to be combined with other health measures.

When discussing with the women their usages of mHealth intervention, many mentioned how straightforward the intervention was to use. This intervention was a low-effort educational tool that did not require much of the participants but gave them several

health messages and links that they could explore at their earliest convenience. The messages arrived on a single message thread, and the participants were able to go back to the thread to read about cervical cancer and HPV. As one participant pointed out, the intervention was also effortless because it did not require additional account setup or login. They were delivered messages straight to their phones, and no additional steps were needed. Health clinics and providers could use mHealth to educate their patients effortlessly and affordably about cervical cancer and HPV without having to take much time out of their busy schedules to orchestrate it. Even a health clinic with a small budget could use BulkSMS or another SMS delivering platform to schedule health messages to their participants.

In a time of social distancing and limited face to face interaction, another advantage of this intervention and a practice implication is the digital experience. There is no need for a participant to have a face-to-face interaction with front office staff, nurse, or healthcare provider to begin receiving mHealth messages. They can easily sign up virtually to engage in the program, and do not need any face to face interactions to continue in their involvement. With the potential for another pandemic, or even social unrest, to make face-to-face interactions complicated, this intervention allows for continued contact.

Finally, this intervention can be used to help enhance current health measures that a clinic or primary care office may have in place. Many health institutions have begun to send appointment reminders to patients to help them track when their next visit should occur. Those same reminders could be coupled with mHealth messages to provide an additional trigger for health behavior change or maintenance. For example, an African

American mother who may be arriving soon for her child's annual checkup could receive both an appointment reminder text and mHealth messages about the HPV vaccination. This will allow the mother not only to learn more about HPV vaccinations but also to have the information on hand when talking with her child's physician. mHealth could still be used in health practice after an appointment has ended as continued education. These messages would act as reinforcement from the visits to help remind the patient about medical issues they may have just spoken about with the healthcare provider.

There are several different ways, and directions both future research and practice can be impacted by this study. Both should continue to have health messages such as the ones in this study but also consider including personal stories from African American women about their experiences with a pap smear, cervical cancer, HPV, and HPV vaccination. Testimonies are a powerful form of education and connection for the African American community, therefore hearing stories from those who have been vaccinated both men and women against HPV could potentially positively impact vaccination and screening rates. Not only testimonies, but discussions of strategies that others have used when navigating the health care experience are essential for helping African Americans to navigate what is sometimes a hostile system.

Conclusions

This study was undertaken to develop a culturally relevant mHealth intervention to deliver cervical cancer and HPV health messages to African American women. The literature has shown the profound and damaging impact of cervical cancer health disparities on this population and the need for interventions to reduce the disparity gap

and improve health. In addition to developing the mHealth intervention, it was also essential to assess whether the intervention would meet the approval of African American women, to ensure that an intervention that was being designed for them and was approved by them and could be implemented successfully. For progress to be achieved, it is paramount to have innovative interventions that are influenced by the perspectives of the populations that they intend to help. This study suggests that not only is it possible to improve cervical cancer knowledge, but that mHealth is an intervention that can be used successfully with African American women.

As mentioned before, future studies should investigate the ability of mHealth interventions to prompt health behavior change. Education is necessary and indispensable because if one does not know the symptoms and signs of the disease, how can one recognize it within themselves. Interventions focused on knowledge, and attitude changes are central for achieving that goal, the next necessary step is to translate knowledge increase into behavior change. With the time constraints of this study, and extraordinary events, it was not possible at the moment to track behavior changes, but future research should attempt to address it. mHealth can easily be integrated into current healthcare practices at clinics and primary care offices, with minimal effort required on the part of patients. This integration could potentially lead to knowledge, attitudes, and behavior changes amongst African Americans concerning cervical cancer and HPV.

This study adds to the research base on the need for and impact of mHealth on cervical cancer, HPV, and African Americans. The existence of cervical cancer disparities prompts a need and commitment to ensuring equitable care and service. It is vital to work towards the reduction and elimination of health disparities in general;

cervical cancer disparities serves as one of the more immediate forms to eliminate. Cervical cancer is one of the few diseases that can experience a steep reduction when appropriate actions, such as HPV vaccination and consistent screening, are taken. Cervical cancer burden experienced by African Americans threatens health justice and demonstrates the need for transformation. mHealth alone cannot lead towards the complete elimination of cervical cancer disparities; however, it can aid and empower African American women in their health and the health of their loved ones.

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Appendix A: mHealth Demographics

Cervical Cancer mHealth Demographics

Thank you for your participation. Please answer the following questions to the best of your ability. Your responses are important to us.

Choose one or more races that you consider yourself to be:

- White (1)
- Black or African American (2)
- American Indian or Alaska Native (3)
- Asian (4)
- Native Hawaiian or Pacific Islander (5)
- Other (6) _____

What is your gender?

- Male (1)
- Female (2)

Are you now married, widowed, divorced, separated or never married?

- Married (1)
- Widowed (2)
- Divorced (3)
- Separated (4)
- Never Married (5)

What is the highest level of school you have completed or the highest degree you have received?

- Less than high school degree (1)
- High school graduate (high school diploma or equivalent including GED) (2)
- Some college but no degree (3)
- Associate degree (2-year) (4)
- Bachelor's degree (4-year) (5)
- Master's degree (6)
- Doctoral degree (7)
- Professional degree (JD, MD) (8)

Which statement best describes your current employment status?

- Working (paid employee) (1)
- Working (self-employed) (2)
- Not working (retired) (5)
- Not working (disabled) (6)
- Not working (other) (9)

Information about income is very important to understand. Would you please give your best guess? Please indicate the answer that includes your entire household income in (previous year) before taxes.

- Less than \$20,000 (1)
- \$20,000 to \$39,999 (2)
- \$40,000 to \$59,999 (3)
- \$60,000 to \$79,999 (4)
- \$80,000 to \$99,999 (5)
- \$100,000 or more (6)

What is the number of people living in your home?

How many children live in your home?

What are the ages of children living in your home?

What is your ZIP code?

What is your insurance status?

- No Insurance (1)
- Private Insurance (2)

- Public Insurance (Medicaid, Medicare, or others) (3)

When was your last doctor's visit?

- Within the last 6 months (1)
- Within the last year (2)
- Longer than a year (3)

When was your last pap smear screening?

- Have never received one (1)
- Within the last year (2)
- Within 2-3 years (3)
- Longer than 3 years (4)

Have you ever been diagnosed with Cervical Cancer?

- Yes (1)
- No (2)

Have you ever been diagnosed with a high-risk strain of HPV?

- Yes (1)
- No (2)

Have you been vaccinated for HPV?

- Yes (1)
- No (2)

If you have a child(ren), please complete the following:

Sex	Age	Has he/she been vaccinated?
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Appendix B: Discrimination in Medical Settings Scale

Please indicate your whether the listed events have happened to you.

Discrimination in Medical Settings Scale

	Never	Rarely	Sometimes	Most of the time	Always
You are treated with less courtesy than other people					
You are treated with less respect than other people					
You receive poorer service than others					
A doctor or nurse acts as if he or she thinks you are not smart					
A doctor or nurse acts as if he or she is better than you					
You feel like a doctor or nurse is not listening to what you were saying					

Appendix C: Cervical Cancer Awareness Measure

1. There are many warning signs and symptoms of cervical cancer. Please name as many as you can think of:
- 2.

The following may or may not be warning signs for cervical cancer. We are interested in your opinion:

	Yes	No	Don't Know
Do you think vaginal bleeding between periods could be a sign of cervical cancer?			
Do you think persistent lower back pain could be a sign of cervical cancer?			
Do you think a persistent vaginal discharge that smells unpleasant could be a sign of cervical cancer?			
Do you think menstrual periods that are heavier or longer than usual could be a sign of cervical cancer?			
Do you think persistent diarrhea could be a sign of cervical cancer?			
Do you think vaginal bleeding after menopause could be a sign of cervical cancer?			
Do you think persistent pelvic pain could be a sign of cervical cancer?			
Do you think vaginal bleeding during or after sex could be a sign of cervical cancer?			
Do you think blood in the stool or urine could be a sign of cervical cancer?			
Do you think unexplained weight loss could be a sign of cervical cancer?			

3. If you had a symptom that you thought might be a sign of cervical cancer how soon would you contact your doctor to make an appointment to discuss it?
4. In the next year, who is most likely to develop cervical cancer in the US?
 - a) A woman aged 20 to 29 years
 - b) A woman aged 30 to 49 years
 - c) A woman aged 50 to 69 years
 - d) A woman aged 70 or over
 - e) Cervical cancer is unrelated to age
5. What things do you think affect a woman's chance of developing cervical cancer?
6. The following may or may not increase a woman's chance of developing cervical cancer. How much do you agree that each of these can increase a woman's chance of developing cancer?

	Strongly disagree	Disagree	Not sure	Agree	Strongly Agree
Infection with HPV (human papillomavirus)					
Smoking any cigarettes at all					

Having a weakened immune system
(e.g because of HIV/AIDS,
immunosuppressant drugs or having a
transplant)
Long term use of the contraceptive pill
Infection with Chlamydia (a sexually
transmitted infection)
Having a sexual partner who is not
circumcised
Starting to have sex at a young age
(before age 17)
Having many sexual partners
Having many children
Having a sexual partner with many
previous partners
Not going for regular smear (Pap) tests

7. How confident are you that you would notice a cervical cancer symptom?
Not at all confident Not very confident Fairly confident Very confident

Appendix D: mHealth Evaluation Measures

Acceptability of Intervention Measure

Questions	Completely disagree	Disagree	Neither agree nor disagree	Agree	Completely agree
mHealth meets my approval mHealth is appealing to me I like mHealth I welcome mHealth					

Intervention Appropriateness Measure

	Completely disagree	Disagree	Neither agree nor disagree	Agree	Completely agree
mHealth seems fitting mHealth seems suitable mHealth seems applicable mHealth seems like a good match					

Feasibility of Intervention Measure

	Completely disagree	Disagree	Neither agree nor disagree	Agree	Completely agree
mHealth seems implementable mHealth seems possible mHealth seems doable mHealth seems easy to use					

Appendix E: Interview Guide

Semi-Structured Interview Guide for Qualitative Inquiry

Thinking about the time before you participated in this study, and used the mHealth intervention:

- Describe how knowledgeable you felt before the study about cervical cancer and HPV?
- Before this study how well did you understand the purpose of a pap smear test? HPV vaccination?
- Thinking about the women in your community, would you feel comfortable talking to them about cervical health?
- For those who have recently seen a physician or healthcare provider, tell me about your typical experience?
- For those who have not recently seen a physician or healthcare provider, tell me about why you may not have seen one? Why do you think women in your community may not have seen a physician recently?

While participating in the study and using the text messaging intervention:

- Describe your overall experience with the mHealth intervention?
- Tell me how often you checked the messages, and did you feel as if you understood what was being said?
- When checking the messages did you feel as if you had learned something?
- Describe which messages you were most useful? Which messages seemed not useful?
- How were you able to relate to the messages being used?
- There anything difficult you found about using the mHealth intervention?
- How do you think women in your community will feel about using this intervention?

Having completed the intervention:

Appendix F: mHealth Message Schedule

Week 1

Day 1

1. Thank you for being a part of the study! Share with other black women who maybe interested in learning about cervical cancer & HPV:
<http://bit.ly/mhealthstudy>
2. Why should black women care? We're diagnosed later than most High mortality (death) rate Survival rate is 55.5% HPV vaccination low among youth & college women

Day 2

3. What is cervical cancer? Cervical cancer starts in the cells lining the cervix -- the lower part of the uterus (womb). Cervical cancers start from cells with pre-cancerous changes (pre-cancers), only some of the women with pre-cancers of the cervix will develop cancer. It usually takes several years for cervical pre-cancer to change to cervical cancer, but it also can happen in less than a year. -These changes can be detected by the Pap test and treated to prevent cancer from developing. <http://bit.ly/2THqHvc>
4. Can cervical cancer be prevented? Yes. Both screening (pap test/smear) and HPV vaccination are recommended for prevention. Screening can find conditions that may lead to pre-cancers and can find pre-cancers before they can turn into cervical cancer. How is cervical cancer found? -Pap test/smear or HPV Test -The Pap test collects cells from the cervix so that they can be looked at under a microscope to find cancer and pre-cancers. Can be done during a pelvic exam, but not all pelvic exams include a Pap test.

Day 3

5. How often can you get checked? -Women between ages 21-29 should have a Pap test every 3 years -Women aged 30-65 have an HPV test with their Pap test (co-testing) every 5 years to test for cervical cancer. -Pap test doesn't test for HPV
6. What are the symptoms of cervical cancer? Early on, cervical cancer may not cause signs and symptoms. Advanced cervical cancer may cause bleeding or discharge from the vagina that is not normal for you, such as bleeding after sex. If you have any of these signs, see your doctor. They may be caused by something other than cancer, but the only way to know is to see your doctor.
<http://bit.ly/2wAW2HZ>

Week 2

Day 4

7. What are the risk factors for cervical cancer? -Smoking. -Having HIV (the virus that causes AIDS) or another condition that makes it hard for your body to fight off health problems. -Using birth control pills for a long time (five or more years). -Having given birth to three or more children. -Having several sexual partners.
<http://bit.ly/3cApv51>
8. What are the treatments for cervical cancer? -Cervical cancer is treated in several ways. It depends on the kind of cervical cancer and how far it has spread. Treatments include surgery, chemotherapy, and radiation therapy. -Surgery: Doctors remove cancer tissue in an operation. -Chemotherapy: Using special medicines to shrink or kill the cancer. The drugs can be pills you take or medicines given in your veins, or sometimes both. -Radiation: Using high-energy rays (similar to X-rays) to kill the cancer. <http://bit.ly/2TqBwD0>

Day 5

9. Can you have cervical cancer if you get your tubes tied? Yes. Tubal ligation (also known as having your tubes tied or tubal sterilization) is a type of permanent birth control. The cervix is still intact during this process, thus it is possible to develop cervical cancer. Can you have cervical cancer if you have received a hysterectomy? -Depends. No, If you have had a radical hysterectomy, which involves the complete removal of the cervix. -Yes, If you have had a partial hysterectomy <http://bit.ly/39twWTU>
10. What's the relationship between HPV and Cervical cancer? -HPV itself isn't cancer but it can cause changes in the body that lead to cancer. -Having HPV does not mean you will have cervical cancer. However, when the body can't get rid of a high-risk HPV infection, it can linger over time and turn into cancer.
<http://bit.ly/38uboLD>

Day 6

11. Does HPV cause other cancers?
 - Most cervical cancers
 - Vagina
 - Vulva
 - Penis
 - Anus and/or rectum
 - Head and neck cancers. <http://bit.ly/2TI2FjA>
12. What causes HPV?

-HPV is a viral infection that can be spread through skin to skin contact with someone who already has HPV. Contact includes vaginal, anal, and oral sex.

Is HPV sexually transmitted? Can you get it other ways?

-Yes, it is sexually transmitted and Yes, you can get it other ways.

-You cannot get HPV from toilet seats, hugging or holding hands, swimming pools or hot tubs, sharing food or utensils or from being unclean.

<http://bit.ly/3cyTqLq>

Week 3

Day 7

13. What are the symptoms of HPV? The main symptom of HPV is genital warts (warts on your privates) <https://mayoclinic.in/2xdobFA>
14. What is the test for HPV? For females, the HPV test checks for the virus, not cell changes. The test can be done at the same time as the Pap test, with the same swab or a second swab.

Day 8

15. Can someone without symptoms give HPV to someone else? Yes, HPV can be spread even when an infected person has no visible signs or symptoms. You can get HPV by having sex with someone (regardless of their sex or gender) who is infected with HPV. <https://bit.ly/34UiEjP>
16. What happens to males who get HPV? -Males, just like females who have HPV are at risk of developing genital warts, anal cancer, or head and neck cancer. Males are also at risk of developing penile cancer from HPV. <http://bit.ly/2xdbZEM>

[Day 9](#)

17. Can I treat my HPV with antibiotics? No. Antibiotics are useless against viral infections. <http://bit.ly/2VT8Fcl> There is no treatment for the virus itself. Symptoms, such as warts, and HPV related-cancers can be treated. <http://bit.ly/2PNwkaf>
18. How can HPV be prevented?

The best ways to prevent HPV, or to not spread it to others, is through practicing safe sex and receiving the HPV vaccination. <https://bit.ly/2RW8Gt7>

Week 4

Day 10

19. Who should be vaccinated for HPV?

HPV vaccine is recommended for routine vaccination at age 11 or 12 years for both boys and girls. (Vaccination can be started at age 9.) Two doses of HPV vaccine are recommended for most persons starting the series before their 15th birthday.

Vaccine is also recommended for anyone under 26 who has not been vaccinated already (CDC recommends a three-dose schedule is 0, 1–2 and 6 months)

<https://bit.ly/2VLInXI>

Day 11

20. Are HPV vaccines safe?

Yes. HPV vaccines are very safe. Scientific research shows the benefits of HPV vaccination far outweigh the potential risks. Like all medical interventions, vaccines can have some side effects.

All vaccines used in the United States, including HPV vaccines, are required to go through years of extensive safety testing before they are licensed by the U.S. Food and Drug Administration (FDA). During clinical trials conducted before they were licensed test with over 74,000 males and females <https://bit.ly/2VLInXI>

21. Are the side effects to the vaccine?

Many people who get the HPV vaccine have no side effects at all. Some people report having very mild side effects, like a sore arm from the shot. The most common side effects are usually mild.

On very rare occasions, severe (anaphylactic) allergic reactions may occur after vaccination. People with severe allergies to any component of a vaccine should not receive that vaccine.

<http://bit.ly/38pSgi3>

Day 12

22. Can the vaccine give you HPV?

No. HPV vaccine does not cause HPV infection or cancer.

(<https://www.cdc.gov/hpv/parents/questions-answers.html>)

23. Can I still get HPV if I get the vaccine?

There is a small chance that someone might still get genital warts after having all three HPV vaccine shots. The shot protects against 90% of the HPV strains that cause genital warts. (<https://kidshealth.org/en/teens/3shots.html>)

Appendix G: Coding Matrix

Category Label	Category Definition	Anchor Example
Acceptability	The perception among implementation stakeholders (participants) that a given treatment, service, practice, or innovation is agreeable, palatable, or satisfactory; think content (Weiner et al., 2017)	<p>Would you recommend this program to your family and friends? If it was revamped a little bit?</p> <p>Participant: Most definitely, most definitely. I think every woman needs to be aware of it, and sadly, every man needs to be aware of it too. 'cause if they have a girlfriend, a daughter and niece, a mother and aunt that they are in contact with. They will better understand if she's been diagnosed and what she's going through.</p>
Appropriateness	The perceived fit, relevance, or compatibility of the innovation or evidence-based practice for a given practice setting, provider, or consumer; and/or perceived fit of the innovation to address a particular issue or problem. (Weiner et al., 2017)	<p>Interviewer: Were [you] able to relate to the messages.</p> <p>Participants: Yeah, definitely yeah it was tailored to me and people like me, I don't think it was, uh. Yeah, it looks clear I can understand it. I need something that will be helpful to me. Is that answer your question? [I- Yes] message.</p>

Barriers to health system navigation	Factors that make it difficult for individuals to attend or maintain health appointments, events where individuals find it strenuous to work within the health system	It goes back to that thing about like meeting people where they are because some[times] we don't have time to go to the doctor and sit down there.
Barriers to health knowledge	Factors that make it difficult for women to access care, screening, or vaccination for themselves or their others	And even like the doctors don't spend enough time educating
Community	Instances in which participants mention their community, a larger presence or connection beyond the individual	<p>There's not a lot of education in our communities. Even like from a younger age. Like you don't have to wait till a person is 20 or 18 to know about like yourself and their health and things like that. Early enough making more educated on.</p> <p>It should be like a regular thing like this is something that we should know about ourselves before even were of age to get this test and all in the screen and all that. So that we can even like take into consideration preventive health care 'cause you know that when you're 40 this could happen when you're 25 this could happen you have to start working on it even while you were still 12 or 11 and you</p>

		<p>know. Taking certain precautions beforehand and there's not a lot of education in our community in like the health centers or community centers, churches, local gathering and things like that. Talk about human health in general, which is also an issue. For us</p>
Covid-19	When participants discuss covid-19 and its impact	<p>Has it [Covid-19] affected it [engagement]. No, because I'm in that age bracket where I have time to pay attention. What comes on my phone on my iPad, on my computer or in the mail? I have some, I'm not I don't have a husband to tend to or grandchildren per say or a big family. That's gonna take a lot of my time. So, I have the time to donate too, too, too. Am I saying this right, that might donate to this to this experiment. Yeah I have that I'm. I'm at that leisure stage in my life where I can do this. The faucet will every little bit helps, so I'll I'll throw my hat in the ring and see if I can help.</p>
Effectiveness	Whether an intervention does more good than harm when provided under usual	<p>Oh, I think at the beginning I said I was so three and like,</p>

	circumstances of healthcare practice (“Does it work in practice?”) (Haynes, 1999)	[Now] Uh, an. I think like a 4.5. Out of the five.
Facilitators to health knowledge	Factors that make it easier to access care, screening, or vaccination for themselves or others	A lot of people who may not do that, you know. Because of the experience, the knowledge that I have of clinical practices, that I go prepared. But a lot of women, a lot of black people, or brown people do not go prepared. imagine like just imagining not have any like educational background and once you get a high school diploma they may not know a lot of things.
Facilitators to health system navigation	Factors that positively impact an individual’s ability to navigate the health system	When I go to the doctor’s office I kinda want introduce myself and let them know that I'm a public health major and I understand healthcare system.
Feasibility	Defined as the extent to which a new treatment, or an innovation, can be successfully used or carried out within a given agency or setting; can be used successfully for the individual mainly looking into technical aspects and mechanics. (Weiner et al., 2017)	Um I think the length was appropriate for me it was just difficult and this is not the average person’s issue at all. But for me I work 11-11 and the messages would come after I have been at work for an hour so I was already, like in the middle of something. It was always an inconvenient time for me, but that’s because I literally get to

		work at 11 and 12 is right when I starting to pickup my flow and figuring out what's going on at work
(Health) Knowledge	Instances in which participants discuss their levels of knowledge about cervical cancer or HPV, changes in their knowledge, or even the ways in which they have used the knowledge.	I understand the importance of it. I definitely didn't know as much as I wish I knew about cervical cancer and HPV. I guess I did not know a lot about cervical cancer and HPV like I wish I knew.
Health Seeking Behavior	Actions taken by an individual/community who perceive themselves as having a health problem to remedy the situation; or actions taken by an individual/community to maintain perceived health status	
Healthcare worker relationship	The relationship/interactions between a health professional (doctor, nurse, front office staff) and a patient. Can be positive or negative	Doctors and nurses when I'm talking to people that you think are younger they like dumb things down to the point that I don't think they're giving enough information about what it is that I'm there for you take this medicine you'll get better with no explanation of why they're giving me that medicine or how it's going to get any better

Institutional structures	Formal organizations that participants are required to navigate when seeking or maintaining care; interactions participants have within institutional structures	
Intervention Use	Ways in which participants utilize the intervention for either themselves or others	<p>So, did you ever go back and check the text messages later on?</p> <p>A: Like Oh yeah. Yeah, I sure did. I actually did since I'm learning stuff about my health and stuff, I actually did [go back and check]. On certain days when I'm busy and I don't have time to look at it. When I'm free, I like oh let me see what the mHealth intervention is saying today. Or I'm trying to remember something I just go back to it.</p>
Mistrust	Mistrust often refers to the belief that the entity that is the object of mistrust is acting against one's best interest or well-being (Armstrong, 2008, Grover, 1994); lack of trust in or suspicion of medical organizations Jaiswal, J., & Halkitis, P. N. (2019)	Older black women don't, tend not to trust. Health officials so much because of things that happened in their past or the way they were treated.

Perceived Discrimination	<p>Defined as a behavioral manifestation of a negative attitude, judgment, or unfair treatment toward members of a group (Banks, Kohn-Wood, & Spencer, 2006; D. R. Williams, Spencer, & Jackson, 1999)</p> <p>Perceived everyday discrimination or unfair treatment as a subjectively experienced form of stress that is not randomly distributed in society and is strongly related to race (Banks, 2006)</p>	<p>It's happened to me a couple of times. I'm 62, so once you get a certain age you don't take anything for granted. So once you get your voice and you learn to speak up for yourself, it might have happened once or twice, but not as long as I have a voice it will never happen to me again because I have been conditioned to speak and act, but they're not listen, get up and leave. If you can.</p>
Personal Relationships	<p>Discussions about either intra or interpersonal relationships that participants have and the quality of that relationship. (Side note this may be a little broad)</p>	<p>Interviewer: I was wondering what do you believe is needed to get from the information-knowledge gathering stage to the 'oh I intend to' or 'oh I am taking steps to get myself either screened or vaccinated'?</p> <p>Participant: What do I think? I guess I think its personal experience. I think that if I give you the information and then people that you love and that you trust also firmly believe this information or getting their children vaccinated and you seen</p>

		<p>that those kids are fine. Then I think that is what those two pieces are what you need for oh I guess I'm going to get my child vaccinated or I guess I'm going to go ahead and get pap smears...Personal experience is, that second part, even though I give you the information if you know of or have seen someone have a terrible experience it may make you unlikely to go to get vaccinated or a pap smear or whatever it might be.</p>
Trust	Discussions of trust within the community	<p>Also think them coming from, if they knew that I think my mom would be more open to that situation too because you are a black woman that is sending information to another black woman. And there's definitely more trust in that group.</p>

Appendix H: Informed Consent

UofL Institutional Review Boards
IRB NUMBER: 19.1008
IRB APPROVAL DATE: 05/01/2020

Examining the Acceptability, Appropriateness, and Feasibility of using mHealth for education of Cervical Cancer preventative services with African American women

You are being invited to participate in an online interview answering questions about your previous participation in the intervention portion of this mHealth study. This online interview will ask about your experiences using the mHealth program and your opinions regarding the educational information in the program. The purpose of this study is to understand your experiences using the mHealth program and to evaluate its effectiveness in educating you about cervical cancer and HPV. Completing the interview will take approximately 60 minutes. The interview will be recorded and then transcribed (typed out).

Individuals who agree to participate in this study, will be entered into a drawing to win a \$20 gift card. The winner will be randomly selected.

This study is conducted by Ariel Washington under the direction of Karen Kayser at the University of Louisville. There are no known risks for your participation in this research study. The information collected may not benefit you directly. The information learned in this study may be helpful to others. The information you provide will help us understand how effective was the mHealth program and in what ways can it be improved. Your answers and identity will be kept confidential, and your responses saved on a password protected computer. Identifying information such as your name will not be connected to the transcribed interview responses, nor will any of your identifying data be published in articles written about the study.

Individuals from the Kent School of Social Work, the Institutional Review Board (IRB), the Human Subjects Protection Program Office (HSPPO), and other regulatory agencies may inspect these records. In all other respects, however, the data will be held in confidence to the extent permitted by law. Should the data be published, your identity will not be disclosed.

Taking part in this study is voluntary. By answering questions you agree to take part in this research study. You do not have to answer any questions that make you uncomfortable. You may choose not to take part at all. If you decide to be in this study you may stop taking part at any time. If you decide not to be in this study or if you stop taking part at any time, you will not lose any benefits for which you may qualify.

If you have any questions, concerns, or complaints about the research study, please contact: **Karen Kayser, 502-852-1946**

If you have any questions about your rights as a research subject, you may call the Human Subjects Protection Program Office at (502) 852-5188. You can discuss any questions about your rights as a research subject, in private, with a member of the Institutional Review Board (IRB). You may also call this number if you have other questions about the research, and you cannot reach the research staff, or want to talk to someone else. The IRB is an independent committee made up of people from the University community, staff of the institutions, as well as people from the community not connected with these institutions. The IRB has reviewed this research study.

Version Date: 4.26.20

If you have concerns or complaints about the research or research staff and you do not wish to give your name, you may call 1-877-852-1167. This is a 24 hour hot line answered by people who do not work at the University of Louisville.

Sincerely,

Ariel Washington, MSSW
Doctoral Candidate
Kent School of Social Work, University of Louisville

Karen Kayser, PhD, MSW
Professor and LaRocca Chair of Oncology Social Work
Kent School of Social Work, University of Louisville

Version Date: 4.26.20

Examining the Acceptability, Appropriateness, and Feasibility of using mHealth for education of
Cervical Cancer preventative services with African American women

You are being invited to provide a written response answering questions about your previous participation in the intervention portion of this mHealth study. This written response will ask about your experiences using the mHealth program and your opinions regarding the educational information in the program. The purpose of this study is to understand your experiences using the mHealth program and to evaluate its effectiveness in educating you about cervical cancer and HPV. Completing the written response will take approximately 30 minutes.

Individuals who agree to participate in this study by providing a written response, will be entered into a drawing to win a \$20 gift card. The winner will be randomly selected.

This study is conducted by Ariel Washington under the direction of Karen Kayser at the University of Louisville. There are no known risks for your participation in this research study. The information collected may not benefit you directly. The information learned in this study may be helpful to others. The information you provide will help us understand how effective was the mHealth program and in what ways can it be improved. Your answers and identity will be kept confidential, and your responses saved on a password protected computer. Identifying information such as your name will not be connected to the transcribed written response responses, nor will any of your identifying data be published in articles written about the study.

Individuals from the Kent School of Social Work, the Institutional Review Board (IRB), the Human Subjects Protection Program Office (HSPPPO), and other regulatory agencies may inspect these records. In all other respects, however, the data will be held in confidence to the extent permitted by law. Should the data be published, your identity will not be disclosed.

Taking part in this study is voluntary. By answering questions you agree to take part in this research study. You do not have to answer any questions that make you uncomfortable. You may choose not to take part at all. If you decide to be in this study you may stop taking part at any time. If you decide not to be in this study or if you stop taking part at any time, you will not lose any benefits for which you may qualify.

If you have any questions, concerns, or complaints about the research study, please contact: **Karen Kayser, 502-852-1946**

If you have any questions about your rights as a research subject, you may call the Human Subjects Protection Program Office at (502) 852-5188. You can discuss any questions about your rights as a research subject, in private, with a member of the Institutional Review Board (IRB). You may also call this number if you have other questions about the research, and you cannot reach the research staff, or want to talk to someone else. The IRB is an independent committee made up of people from the University community, staff of the institutions, as well as people from the community not connected with these institutions. The IRB has reviewed this research study.

Version Date: 4.26.20

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Sincerely,

Ariel Washington, MSSW
Doctoral Candidate
Kent School of Social Work, University of Louisville

Karen Kayser, PhD, MSW
Professor and LaRocca Chair of Oncology Social Work
Kent School of Social Work, University of Louisville

Version Date: 4.26.20

Examining the Acceptability, Appropriateness, and Feasibility of using mHealth for education of
Cervical Cancer preventative services with African American women

You are being invited to participate in a research study investigating whether a mobile health (mhealth) program can enhance cervical cancer knowledge and prevention. mHealth program was designed with the purpose of improving cervical cancer knowledge in women using mobile phones. The purpose of the program is to help educate women about cervical cancer, HPV, and how to prevent the disease. We are interested in whether using mobile phones to deliver weekly messages about cervical health and HPV, will help women to better understand the disease and ways to prevent it. Participation in this study would involve answering questions on two questionnaires about cervical cancer prevention, and being assigned to an mHealth program group.

If you agree to participate in the study you will be given 2 questionnaires asking you about cervical cancer, HPV, and your experiences in the medical setting. The first one is linked to this email and the second one will be sent to you 4 weeks later. If you are unable to complete the questionnaires online, then an investigator is willing to meet with you and administer the questionnaires in person. After completion of the attached questionnaire you will be randomly assigned (like flipping a coin) to one of two groups in the mHealth program. Being randomly assigned means that you have an equal chance of being in the group that receives the mHealth intervention or the group that doesn't receive it. If you are assigned to the mHealth intervention group, you will receive weekly text messages about cervical health and HPV for 4 weeks. After completion of the program both groups will be given an additional questionnaire evaluating their knowledge about cervical cancer and how it can be prevented, along with questions evaluating the mHealth program. Also, you will receive another questionnaire following-up about your experiences using the mHealth program and current knowledge about cervical cancer and HPV.

This study is conducted by Ariel Washington under the direction of Karen Kayser at the University of Louisville. There are no known risks for your participation in this research study. The information collected may not benefit you directly. The information learned in this study may be helpful to others. The information you provide will help us to understand if a health program that uses text messaging helps to increase knowledge about cervical cancer and HPV. Your completed survey will be stored on a password protected computer. The questionnaires linked to this form will take approximately 15 to 20 minutes.

Individuals from the Kent School of Social Work, the Institutional Review Board (IRB), the Human Subjects Protection Program Office (HSPPPO), and other regulatory agencies may inspect these records. In all other respects, however, the data will be held in confidence to the extent permitted by law. Should the data be published, your identity will not be disclosed.

Taking part in this study is voluntary. By answering questions on the initial questionnaire you agree to take part in this research study. You do not have to answer any questions that make you uncomfortable. You may choose not to take part at all. If you decide to be in this study you may stop taking part at any time. If you decide not to be in this study or if you stop taking part at any time, you will not lose any benefits for which you may qualify.

If you have any questions, concerns, or complaints about the research study, please contact: **Karen Kayser, 502-852-1946**

Version Date: 10.24.19

If you have any questions about your rights as a research subject, you may call the Human Subjects Protection Program Office at (502) 852-5188. You can discuss any questions about your rights as a research subject, in private, with a member of the Institutional Review Board (IRB). You may also call this number if you have other questions about the research, and you cannot reach the research staff, or want to talk to someone else. The IRB is an independent committee made up of people from the University community, staff of the institutions, as well as people from the community not connected with these institutions. The IRB has reviewed this research study.

If you have concerns or complaints about the research or research staff and you do not wish to give your name, you may call 1-877-852-1167. This is a 24 hour hot line answered by people who do not work at the University of Louisville.

Sincerely,

Ariel Washington, MSSW
Doctoral Candidate
Kent School of Social Work, University of Louisville

Karen Kayser, PhD, MSW
Professor and LaRocca Chair of Oncology Social Work
Kent School of Social Work, University of Louisville

Version Date: 10.24.19

Examining the Acceptability, Appropriateness, and Feasibility of using mHealth for education of
Cervical Cancer preventative services with African American women

You are being invited to participate in a one-time online focus group answering questions about your previous participation in the intervention portion of this mHealth study. This online focus group will ask about your experiences using the mHealth program and your opinions regarding the educational information in the program. The purpose of this study is to understand your experiences using the mHealth program and the evaluate its effectiveness in educating you about cervical cancer and HPV. Completing the focus group will take approximately 60 minutes. The focus group will be recorded and then transcribed (typed out).

Individuals who agree to participate in this study, will be entered into a drawing to win a \$20 gift card. The winner will be randomly selected from the focus group participants.

This study is conducted by Ariel Washington under the direction of Karen Kayser at the University of Louisville. There are no known risks for your participation in this research study. The information collected may not benefit you directly. The information learned in this study may be helpful to others. The information you provide will help us understand how effective was the mHealth program and in what ways can it be improved. Your answers and identity will be kept confidential, and your responses saved on a password protected computer. Identifying information such as your name will not be connected to the transcribed focus group responses, nor will any of your identifying data be published in articles written about the study.

Individuals from the Kent School of Social Work, the Institutional Review Board (IRB), the Human Subjects Protection Program Office (HSPPPO), and other regulatory agencies may inspect these records. In all other respects, however, the data will be held in confidence to the extent permitted by law. Should the data be published, your identity will not be disclosed.

Taking part in this study is voluntary. By answering questions you agree to take part in this research study. You do not have to answer any questions that make you uncomfortable. You may choose not to take part at all. If you decide to be in this study you may stop taking part at any time. If you decide not to be in this study or if you stop taking part at any time, you will not lose any benefits for which you may qualify.

If you have any questions, concerns, or complaints about the research study, please contact: **Karen Kayser, 502-852-1946**

If you have any questions about your rights as a research subject, you may call the Human Subjects Protection Program Office at (502) 852-5188. You can discuss any questions about your rights as a research subject, in private, with a member of the Institutional Review Board (IRB). You may also call this number if you have other questions about the research, and you cannot reach the research staff, or want to talk to someone else. The IRB is an independent committee made up of people from the University community, staff of the institutions, as well as people from the community not connected with these institutions. The IRB has reviewed this research study.

Version Date: 4.26.20

If you have concerns or complaints about the research or research staff and you do not wish to give your name, you may call 1-877-852-1167. This is a 24 hour hot line answered by people who do not work at the University of Louisville.

Sincerely,

Ariel Washington, MSSW
Doctoral Candidate
Kent School of Social Work, University of Louisville

Karen Kayser, PhD, MSW
Professor and LaRocca Chair of Oncology Social Work
Kent School of Social Work, University of Louisville

Version Date: 4.26.20

Appendix I: mHealth Recruitment Material

UofL Institutional Review Boards
IRB NUMBER: 19.1008
IRB APPROVAL DATE: 03/23/2020

Social Media Template:

Text to be included in the body of the post:

Did you know that black women have the second highest rate of contracting cervical cancer and the highest rate of dying from the disease? That there are ways to decrease your chances of developing cervical cancer or a high-risk strain of HPV? Participate in this one-month text-messaging based study that wants to educate black women about screening and prevention from cervical cancer and HPV. All that is required to join the study is to click on this link bit.ly/mhealthstudy and fill out a survey. You'll receive health messages to your cell phone informing you about cervical cancer and HPV. Join today! There's even a chance to win a \$20 gift card.

If interested or would like to know more about this study you can contact:

karen.kayser@louisville.edu (5028521946) or ariel.washington@louisville.edu

Image included with the social media post:

mHealth recruitment Flyer 1.2

Version Date 3.23.20

UofL Institutional Review Boards
IRB NUMBER: 19.1008
IRB APPROVAL DATE: 03/23/2020

UNIVERSITY OF LOUISVILLE
KENT SCHOOL OF SOCIAL WORK



WE NEED YOUR HELP!

WE ARE SEEKING PARTICIPANTS FOR A RESEARCH STUDY THAT SEEKS YOUR KNOWLEDGE AND OPINIONS RELATED TO THE FIGHT AGAINST CERVICAL CANCER

Kentucky is Top 10 for Cervical Cancer Kentucky has one of the highest rates of cervical cancer and cervical cancer death in the nation.	Black Women are at risk Black women have a high rate of developing cervical cancer and dying from the disease.	How can you help? Join us in a project to educate women about the dangers of cervical cancer and HPV.
--	--	---

Signup today by taking a picture of the QR Code or typing in <http://bit.ly/mhealthstudy>



Join for a chance to win a **\$20 gift card!**

If interested or would like to know more about this project, contact karen.kayser@louisville.edu or 502-852-1948 or amwesh02@louisville.edu or 502-278-6747

Version Date 3.23.20

UNIVERSITY OF
LOUISVILLE
KENT SCHOOL OF
SOCIAL WORK



WE NEED YOUR HELP!

**WE ARE SEEKING PARTICIPANTS FOR A RESEARCH STUDY
THAT SEEKS YOUR KNOWLEDGE AND OPINIONS RELATED
TO THE FIGHT AGAINST CERVICAL CANCER**

Kentucky is Top 10 for Cervical Cancer

Kentucky has one of the highest rates of cervical cancer and cervical cancer death in the nation.

Black Women are at risk

Black women have a high rate of developing cervical cancer and dying from the disease.

How can you help?

Join us in a project to educate women about the dangers of cervical cancer and HPV.

Signup today by taking a picture of the QR Code
or typing in <http://bit.ly/mhealthstudy>



Join for a chance to win a **\$20 gift card!**

If interested or would like
to know more about this project, contact karen.kayser@louisville.edu or 502-852-1946
amwash02@louisville.edu or 502-276-5747

Appendix J: Community Advisory Board Notes

Community Advisory Board Notes

12/02/2020

Agenda (In-Person)

Cervical Cancer Focus

- Previous Work- Cervical Cancer Focus Group, Social Justice Project
- Goals for this session
- Appropriateness of health messages
- Need to included disparities information
- Retaining medical information
- Readability of messages
- Recruitment strategy- (Pre Covid 19) churches, UofL RSOs, Health Clinics etc.

12/09/2020 (In- Person)

Agenda

HPV Focus

- Appropriateness of health messages
- Need to included disparities information
- Retaining medical information
- Readability of messages
- Recruitment strategy- (Pre Covid 19) churches, UofL RSOs, Health Clinics etc.

Discussion Topics via Email and Phone

Second Draft of Messages in need of CAB approval

Additional recruitment areas

Include pictures of anatomy

Cervical Cancer Questions:

Can you have cervical cancer if you get your tubes tied?

Yes. Tubal ligation — also known as having your tubes tied or tubal sterilization — is a type of permanent birth control. During tubal ligation, the fallopian tubes are cut, tied or blocked to permanently prevent pregnancy. The cervix is still intact during this process, thus it is possible to develop cervical cancer.

Can you have cervical cancer if you have received a hysterectomy?

Mention the varying degrees

No. A radical hysterectomy, which involves the complete removal of the cervix is actually a treatment option for cervical cancer. It is one of the first treatment options offered for early stage cervical cancer. <https://www.cancer.org/cancer/cervical-cancer/treating/by-stage.html>

#1 Is carcinoma the same as cervical cancer?

Depends

Car how does carcinoma describe it by itself

Cancer that begins in squamous cells. Squamous cells are thin, flat cells that look like fish scales, and are found in the tissue that forms the surface of the skin, the lining of the hollow organs of the body, and the lining of the respiratory and digestive tracts. Most cancers of the anus, cervix, head and neck, and vagina are epidermoid carcinomas. Also called squamous cell carcinoma. <https://www.cancer.gov/publications/dictionaries/cancer-terms/def/epidermoid-carcinoma>

Cervical cancer is a specific type

If the male can get HPV, what kind of cancer could they get? So if they don't get cervical cancer, what do they get? What type of cancers can a male get

HPV can cause cancers of the:

- Cervix, vagina, and vulva in women
- Penis and anal in men
- Anus (external lips) and back of the throat, including the base of the tongue and tonsils (oropharynx), in both women and men

#2 What is cervical cancer? Hyperlink cervix picture or maybe a youtube <https://www.cancer.org/cancer/cervical-cancer/about/what-is-cervical-cancer.html>

[Cervical cancer starts in the cells lining the cervix -- the lower part of the uterus (womb)] This is sometimes called the uterine cervix. The fetus grows in the body of the uterus (the upper part). The cervix connects the body of the uterus to the vagina (birth canal). These two cell types meet at a place called the transformation zone. The exact location of the transformation zone changes as you get older and if you give birth.

cervical cancer is a slow developing

Most cervical cancers begin in the cells in the transformation zone. These cells do not suddenly change into cancer. Instead, the normal cells of the cervix first gradually develop pre-cancerous changes that turn into cancer. Doctors use several terms to describe these pre-cancerous changes, including cervical intraepithelial neoplasia (CIN), squamous intraepithelial lesion (SIL), and

How does my Dr. detect

dysplasia. These changes can be detected by the Pap test and treated to prevent cancer from developing.]

How often should I get tested

Cervical cancers start from cells with pre-cancerous changes (pre-cancers), only some of the women with pre-cancers of the cervix will develop cancer. It usually takes several years for cervical pre-cancer to change to cervical cancer, but it also can happen in less than a year. For most women, pre-cancerous cells will go away without any treatment. Still, in some women pre-cancers turn into true (invasive) cancers.

Can cervical cancer be prevented? *Yes*

The most common form of cervical cancer starts with pre-cancerous changes and there are ways to stop this disease from developing. The first way is to find and treat pre-cancers before they become true cancers, and the second is to prevent the pre-cancers.

Mention HPV vaccine & screening as a prevention not a treatment

How is cervical cancer found? *Willet points*

<https://www.cancer.org/cancer/cervical-cancer/causes-risks-prevention/prevention.html>

Pull out as a separate

A well-proven way to prevent cervical cancer is to have testing (screening). Screening can find conditions that may lead to pre-cancers and can find pre-cancers before they can turn into invasive cancer. The Pap test (or Pap smear) and the human papillomavirus (HPV) test are specific tests used during screenings for cervical cancer. If a pre-cancer is found it can be treated, stopping cervical cancer before it really starts.

The Pap test or smear is a procedure used to collect cells from the cervix so that they can be looked at under a microscope to find cancer and pre-cancers. It's important to know that most invasive cervical cancers are found in women who have not had regular Pap tests. A Pap test can be done during a pelvic exam, but not all pelvic exams include a Pap test.

An HPV test can be done on the same sample of cells collected from the Pap test. The HPV test can help know if there is an HPV infection which is one condition that can lead to pre-cancers.

methods -> if you explicitly worried talk to dr ahead of time.

What are the treatments for cervical cancer?

https://www.cdc.gov/cancer/cervical/basic_info/diagnosis_treatment.htm

Cervical cancer is treated in several ways. It depends on the kind of cervical cancer and how far it has spread. Treatments include surgery, chemotherapy, and radiation therapy.

- range from out of office procedure to OR*
• **Surgery:** Doctors remove cancer tissue in an operation.
- **Chemotherapy:** Using special medicines to shrink or kill the cancer. The drugs can be pills you take or medicines given in your veins, or sometimes both.

Appendix K: IRB Approval Letters



Human Subjects Protection Program Office
 MedCenter One – Suite 200
 501 E. Broadway
 Louisville, KY 40202-1798

DATE: November 08, 2019
TO: Karen Kayser, PhD
FROM: The University of Louisville Institutional Review Board
IRB NUMBER: 19.1008
STUDY TITLE: Examining the Acceptability, Appropriateness, and Feasibility of using mHealth for education of Cervical Cancer preventative services with African American women
REFERENCE #: 694927
IRB STAFF CONTACT: Jackie Powell, CIP 852-4101 jspowe01@louisville.edu

This study was reviewed on 11/08/2019 by the Chair of the Institutional Review Board and approved through Expedited Review Procedure, according to 45 CFR 46.110(b), since this study falls under Category 7: Research on individual or group characteristics or behavior (including, but not limited to, research on perception, cognition, motivation, identity, language, communication, cultural beliefs or practices, and social behavior) or research employing survey, interview, oral history, focus group, program evaluation, human factors evaluation, or quality assurance methodologies

This study now has final IRB approval from 11/08/2019 through 11/07/2022.

This study was also approved through 45 CFR 46.116 (C), which means that an IRB may waive the requirement for the investigator to obtain a signed informed consent form for some or all subjects.

The following items have been approved:

Submission Components				
Form Name	Version	Outcome		
Submit for Initial Review	Version 1.0	Approved as Submitted		
Review Response Submission Form	Version 1.0	Approved as Submitted		
IRB Study Application	Version 1.1	Approved as Submitted		
Study Document				
Title	Version #	Version Date	Outcome	
Cervical Cancer Awareness Measure	Version 1.0	10/24/2019	Approved	
Discrimination in Medical Settings 1.1	Version 1.0	10/24/2019	Approved	
Cervical Cancer Evaluation measures 1.1	Version 1.0	10/24/2019	Approved	
mHealth Demographics survey CLEAN	Version 1.0	10/24/2019	Approved	
mHealth Protocol 1.1 CLEAN	Version 1.0	10/24/2019	Approved	
mHealth Focus Group Questions	Version 1.0	10/14/2019	Approved	
mHealth Recruitment Flyer	Version 1.1	10/24/2019	Approved	
Preamble Unsigned Consent mHealth Focus Group 1.1 CLEAN	Version 1.0	10/24/2019	Approved	

Preamble Unsigned Consent mHealth Final 1.1 CLEAN	Version 1.0	10/24/2019	Approved
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Your study does not require annual continuing review. Your study has been set with a three year expiration date. If your study is still ongoing you will receive iRIS automated reminders to submit a request to continue your study prior to the expiration date above.

All other IRB requirements are still applicable. You are still required to submit amendments, personnel changes, deviations, etc... to the IRB for review. Please submit a closure amendment to close out your study with the IRB if it ends prior to the three year expiration date.

Human Subjects & HIPAA Research training are required for all study personnel. It is the responsibility of the investigator to ensure that all study personnel maintain current Human Subjects & HIPAA Research training while the study is ongoing.

For guidance on using iRIS, including finding your approved stamped documents, please follow the instructions at <https://louisville.edu/research/humansubjects/IRISSubmissionManual.pdf>

Please note: Consent and assent forms no longer have an expiration date stamped on them. The consent/assents expire if the study lapses in IRB approval. Enrollment cannot take place if a study lapses in approval. For additional information view [Guide 038](#).

Site Approval

If this study will take place at an affiliated research institution, such as UofL Hospital/UofL Health and/or Norton Healthcare, permission to use the site of the affiliated institution is necessary before the research may begin. If this study will take place outside of the University of Louisville Campuses, permission from the organization must be obtained before the research may begin (e.g. Jefferson County Public Schools). Failure to obtain this permission may result in a delay in the start of your research.

Privacy & Encryption Statement

The University of Louisville's Privacy and Encryption Policy requires such information as identifiable medical and health records; credit card, bank account and other personal financial information; social security numbers; proprietary research data; dates of birth (when combined with name, address and/or phone numbers) to be encrypted. For additional information: <http://security.louisville.edu/PolStds/ISO/PS018.htm>.

Implementation of Changes to Previously Approved Research

Prior to the implementation of any changes in the approved research, the investigator will submit any modifications to the IRB and await approval before implementing the changes, unless the change is being made to ensure the safety and welfare of the subjects enrolled in the research. If such occurs, a Protocol Deviation/Violation should be submitted within five days of the occurrence indicating what safety measures were taken, along with an amendment to revise the protocol.

Full Accreditation since June 2005 by the Association for the Accreditation of Human Research Protection Programs, Inc.



Unanticipated Problems Involving Risks to Subjects or Others (UPIRTSOs)

In general, these may include any incident, experience, or outcome, which has been associated with an unexpected event(s), related or possibly related to participation in the research, and suggests that the research places subjects or others at a greater risk of harm than was previously known or suspected. UPIRTSOs may or may not require suspension of the research. Each incident is evaluated on a case by case basis to make this determination. The IRB may require remedial action or education as deemed necessary for the investigator or any other key personnel. The investigator is responsible for reporting UPIRTSOs to the IRB within 5 working days. Use the UPIRTSO form located within the iRIS system to report any UPIRTSOs.

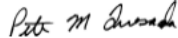
Payments to Subjects

As a reminder, in compliance with University policies and Internal Revenue Service code, all payments (including checks, pre-paid cards, and gift certificates) to research subjects must be reported to the University Controller's Office. For additional information, please contact the Controller's Office at 852-8237 or control@louisville.edu. For additional information:

<http://louisville.edu/research/humansubjects/policies/PayingHumanSubjectsPolicy201412.pdf>

The committee will be advised of this action at a regularly scheduled meeting.

If you have any questions, please contact: Jackie Powell 852-4101 jspowe01@louisville.edu



Peter M. Quesada, Ph.D., Chair
Social/Behavioral/Educational Institutional Review Board
PMQ/jsp

We value your feedback. Please let us know how you think we are doing:

<https://www.surveymonkey.com/r/CCLHXP>

Full Accreditation since June 2005 by the Association for the Accreditation of
Human Research Protection Programs, Inc.



DATE: January 22, 2020
TO: Karen Kayser, PhD
IRB NUMBER: 19.1008
STUDY TITLE: Examining the Acceptability, Appropriateness, and Feasibility of using mHealth for education of Cervical Cancer preventative services with African American women 700157
REFERENCE #: 700157
IRB STAFF CONTACT: Jackie Powell, CIP 852-4101 jspowe01@louisville.edu

The amendment request has been received by the Human Subjects Protection Program Office and approved with changes by the Chair of the Institutional Review Board (IRB) on 01/16/2020. The resubmitted changes were approved administratively. This amendment was approved through the expedited review procedure according to 45 CFR 46.110(B). The following documents have been reviewed and approved:

Submission Components			
Form Name	Version	Outcome	
Request Application, Protocol, or Document Change	Version 1.1	Approved as Submitted	
Review Response Submission Form	Version 1.0	Approved as Submitted	
IRB Study Application	Version 1.2	Approved as Submitted	
Study Document			
Title	Version #	Version Date	Outcome
mHealth Recruitment flyer 1.2	Version 1.0	01/08/2020	Approved
Preamble Unsigned Consent mHealth Focus Group 1.2 CLEAN	Version 1.0	01/08/2020	Approved
Preamble Unsigned Consent mHealth Final 1.2 CLEAN	Version 1.0	01/08/2020	Approved
Cervical Cancer mHealth Protocol Final Version 1.2 CLEAN	Version 1.0	01/08/2020	Approved

The modifications include: Gift card incentives are added to the recruitment strategy to encourage individuals to participate in the study. Gift card recipients will be randomly chosen from those who participate in the study or the post-intervention focus group.

This change does not require subjects to be re-consented.

Please begin using your newly stamped approved documents with any new subjects. The committee will be advised of this action at a regularly scheduled meeting.

For guidance on using iRIS, including finding your approved stamped documents, please follow the instructions at <http://louisville.edu/research/humansubjects/iRISubmissionManual.pdf>.

If you have any questions, please contact: Jackie Powell 852-4101 jspowe01@louisville.edu

Jackie Powell

DATE: March 23, 2020
TO: Karen Kayser, PhD
IRB NUMBER: 19.1008
STUDY TITLE: Examining the Acceptability, Appropriateness, and Feasibility of using mHealth for education of Cervical Cancer preventative services with African American women
REFERENCE #: 704364
IRB STAFF CONTACT: Jackie Powell, CIP 852-4101 jspowe01@louisville.edu

The amendment request has been received by the Human Subjects Protection Program Office and approved by the Chair of the Institutional Review Board (IRB) on 03/23/2020 through the expedited review procedure according to 45 CFR 46.110(B). The following documents have been reviewed and approved:

Submission Components			
Form Name	Version	Outcome	
Request Application, Protocol, or Document Change	Version 2.0	Approved as Submitted	
Review Response Submission Form	Version 1.0	Approved as Submitted	
IRB Study Application	Version 1.3	Approved as Submitted	
Study Document			
Title	Version #	Version Date	Outcome
mHealth Social Media Template 1.1 CLEAN	Version 1.0	03/23/2020	Approved
Cervical Cancer mHealth Protocol Final Version 1.3 CLEAN	Version 1.1	01/08/2020	Approved

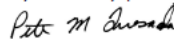
The modifications include: Change in recruitment strategy to include use of social media (i.e Facebook, Twitter, etc) for online recruitment.

This change does not require subjects to be re-consented.

Please begin using your newly stamped approved documents with any new subjects. The committee will be advised of this action at a regularly scheduled meeting.

For guidance on using iRIS, including finding your approved stamped documents, please follow the instructions at <http://louisville.edu/research/humansubjects/iRISSubmissionManual.pdf>.

If you have any questions, please contact: Jackie Powell 852-4101 jspowe01@louisville.edu



Peter M. Quesada, Ph.D., Chair

Social/Behavioral/Educational Institutional Review Board

PMQ/jsp

We value your feedback; let us know how we are doing: <https://www.surveymonkey.com/r/CCLHXRP>

DATE: March 24, 2020
TO: Karen Kayser, PhD
IRB NUMBER: 19.1008
STUDY TITLE: Examining the Acceptability, Appropriateness, and Feasibility of using mHealth for education of Cervical Cancer preventative services with African American women
REFERENCE #: 704649
IRB STAFF CONTACT: Jackie Powell, CIP 852-4101 jspowe01@louisville.edu

The amendment request was received by the Human Subjects Protection Program Office. It was reviewed by the HSPPO staff and found to be complete. The following documents have been approved:

Submission Components			
Form Name	Version	Outcome	
Request Application, Protocol, or Document Change	Version 3.0	Approved as Submitted	
Study Document			
Title	Version #	Version Date	Outcome
mHealth Recruitment flyer 1.2	Version 1.1	03/24/2020	Approved

The modifications include:

Uploaded recruitment flyer to be re-stamped with IRB approval. This flyer was attached to a Social Media Post that was stamped approved on 3/23/20 but the flyer had an older date on it. There are no changes to the flyer but it is being restamped since it is being sent out with the Social Media post.

If you have any questions, please contact: Jackie Powell 852-4101 jspowe01@louisville.edu



Jackie Powell, CIP, Sr. IRB Analyst
 Social/Behavioral/Educational Review Board

DATE: April 30, 2020
TO: Karen Kayser, PhD
FROM: The University of Louisville Institutional Review Board
IRB NUMBER: 19.1008
STUDY TITLE: Examining the Acceptability, Appropriateness, and Feasibility of using mHealth for education of Cervical Cancer preventative services with African American women
REFERENCE #: 706833
DATE OF REVIEW: 04/30/2020
IRB STAFF CONTACT: Jackie Powell, CIP 852-4101 jspowe01@louisville.edu

The Human Subjects Protection Program Office (HSPPPO) has received your personnel change amendment. This information has been reviewed and found to be complete by the Human Subjects Protection Program staff.

The personnel change consists of: The addition of Jill Randall as key study personnel

Submission Components		
Form Name	Version	Outcome
Request Personnel Change Only	Version 1.0	Approved as Submitted

If you have any questions, please contact: Jackie Powell 852-4101 jspowe01@louisville.edu



Jackie Powell, CIP
Senior IRB Analyst

852-4101

Jspowe01@Louisville.edu

We value your feedback; let us know how we are doing: <https://www.surveymonkey.com/r/CCLHXRP>

DATE: May 01, 2020
TO: Karen Kayser, PhD
IRB NUMBER: 19.1008
STUDY TITLE: Examining the Acceptability, Appropriateness, and Feasibility of using mHealth for education of Cervical Cancer preventative services with African American women
REFERENCE #: 706906
IRB STAFF CONTACT: Jackie Powell, CIP 852-4101 jspowe01@louisville.edu

The amendment request has been received by the Human Subjects Protection Program Office and approved with changes by the Chair of the Institutional Review Board (IRB) on 04/30/2020. The resubmitted changes were approved administratively on 05/01/2020. This amendment was approved through the expedited review procedure according to 45 CFR 46.110(B). The following documents have been reviewed and approved:

Submission Components			
Form Name	Version	Outcome	
Request Application, Protocol, or Document Change	Version 5.0	Approved as Submitted	
Review Response Submission Form	Version 1.0	Approved as Submitted	
IRB Study Application	Version 1.5	Approved as Submitted	
Study Document			
Title	Version #	Version Date	Outcome
mHealth Revised Focus Group Questions 1.2 Clean	Version 1.0	05/01/2020	Approved
Cervical Cancer mHealth Protocol Final Version 1.5 CLEAN	Version 1.3	04/26/2020	Approved
Preamble Unsigned Consent mHealth Individual Interview	Version 1.0	04/30/2020	Approved
Preamble Unsigned Consent mHealth Written Response	Version 1.0	04/30/2020	Approved

The modifications include:

- Adding two additional options for participants to provide their qualitative feedback of the mHealth intervention, due to Covid-19. Participants will be offered the chance to participate in an individual interview or provide a written response to the interview guide.
- Revising the interview guide to reflect the potential impact Covid-19 had on participants during the intervention. Adding two additional questions to the interview guide to gauge the impact of Covid-19 on the participants while they were participating in the intervention.

This change does not require subjects to be re-consented.

Please begin using your newly stamped approved documents with any new subjects. The committee will be advised of this action at a regularly scheduled meeting.

Appendix L: Reflexivity Exercise

Rae & Green (2016) Reflexivity Matrix

Data Analysis Phase

Cell 7:

- How does the researcher's experience with the field shape analysis?
- Are some data dismissed as being commonplace, whereas they might not warrant deeper interrogation?
- To what extent does the researcher consider the balance of analytical authority to rest with participant or with the researcher?

Cell 8:

- How does the researcher moderate any drive for the outcomes that might inadvertently lead to data omissions or fabrication?

Appendix M: Original Messages

HPV Q&A

How do I know if I have HPV?

What are the symptoms of HPV?

oThe main symptom of HPV is genital warts (<https://www.mayoclinic.org/diseases-conditions/hpv-infection/symptoms-causes/syc-20351596>)

O Abnormal cell changes in the cervix can be a symptom of HPV that could lead to cervical cancer, however abnormal cell changes are not a guarantee that an individual has HPV. (<https://www.plannedparenthood.org/learn/stds-hiv-safer-sex/hpv/what-are-symptoms-hpv>)

What is the test for HPV? How often can you get tested?

O For females, a Pap test is used to find cell changes or abnormal cells in the cervix. A Pap test does not test for HPV but does test for the abnormal cells which may be caused by HPV.

O The American Cancer Society recommends that women between ages 21 and 29 should have a Pap test every 3 years (at ages 21, 24, and 27) to test for cervical cancer and pre-cancers.

O The American Cancer Society recommends that women aged 30 to 65 have an HPV test with their Pap test (co-testing) every 5 years to test for cervical cancer.

O For females, the HPV test checks for the virus, not cell changes. The test can be done at the same time as the Pap test, with the same swab or a second swab.

O There's no FDA-approved HPV test for men at this time, nor is there an FDA-approved HPV test to find the virus anywhere besides the cervix

O(<https://www.cancer.org/cancer/cancer-causes/infectious-agents/hpv/hpv-and-hpv-testing.html>)

If my partner develops genital warts, does this mean I have HPV?

O Genital warts are spread from sexual skin-to-skin contact with someone who has it — including vaginal, anal, and oral sex.

O <https://www.plannedparenthood.org/learn/stds-hiv-safer-sex/genital-warts>

O Current partners are likely to share HPV, but this may be difficult to prove. Testing options for HPV are limited and most cases are never diagnosed.

O <http://www.nccc-online.org/hpvcervical-cancer/hpv-and-relationships/>

What Causes HPV?

What causes HPV?

O Genital HPV is spread through contact with (touching) the skin of someone who has an HPV infection. Contact includes vaginal, anal, and oral sex.

O Anyone who is sexually active can get HPV and genital warts.

(<https://my.clevelandclinic.org/health/diseases/11901-hpv-human-papilloma-virus>)

Is HPV sexually transmitted? Can you get it other ways?

O The main way HPV is spread is through sexual activity, including vaginal, anal, and oral sex.

O The virus can also be spread by genital contact without sex, although this is not common.

O You cannot get HPV from toilet seats, hugging or holding hands, swimming pools or hot tubs, sharing food or utensils or from being unclean.

o(<https://www.cancer.org/cancer/cancer-causes/infectious-agents/hpv/hpv-and-cancer-info.html>)

Can a boy without symptoms give HPV to a girl? Can a girl give HPV to a boy? What about girl to girl or boy to boy?

O HPV can be spread even when an infected person has no visible signs or symptoms

O You can get HPV by having sex with someone (regardless of their sex or gender) who is infected with HPV. This disease is spread easily during anal or vaginal sex, and it can also be spread through oral sex or other close skin-to-skin touching during sex.

O (<https://www.cdc.gov/std/hpv/stdfact-hpv-and-men.htm>)

What does “viral” mean?

O HPV is a viral infection, meaning that it is caused by a virus, as opposed to bacteria. A virus is a small microorganism that can only reproduce inside a host’s living cell. It is very difficult to kill a virus. That’s why some of the most serious communicable diseases known to medical science are viral in origin.

(<https://www.betterhealth.vic.gov.au/health/conditionsandtreatments/infections-bacterial-and-viral>)

HPV and Cancer

What’s the difference between HPV and Cervical cancer?

O Genital human papillomavirus (HPV) is a sexually transmitted infection. Having HPV does not mean you will undoubtedly have cervical cancer. However, when the body’s immune system can’t get rid of a high-risk HPV infection, it can linger over time and turn

normal cells into abnormal cells and then cancer.

(https://www.cdc.gov/cancer/hpv/basic_info/index.htm)

O HPV itself isn't cancer but it can cause changes in the body that lead to cancer.

Is Cervical Cancer hereditary?

O Cervical cancer may run in some families. If your mother or sister had cervical cancer, your chances of developing the disease are higher than if no one in the family had it. Some researchers suspect that some instances of this familial tendency are caused by an inherited condition that makes some women less able to fight off HPV infection than others. In other instances, women in the same family as a patient already diagnosed could be more likely to have one or more of the other non-genetic risk factors previously described in this section.

O (<https://www.cancer.org/cancer/cervical-cancer/causes-risks-prevention/risk-factors.html>)

How is Cervical Cancer treated? What are the options?

O Depending on the type and stage of your cancer, you may need more than one type of treatment. For the earliest stages of cervical cancer, either surgery or radiation combined with chemo may be used. For later stages, radiation combined with chemo is usually the main treatment. Chemo (by itself) is often used to treat advanced cervical cancer.

O Common types of treatments for cervical cancer include: Surgery, Radiation Therapy, Chemotherapy, Targeted Therapy, or Immunotherapy.

O (<https://www.cancer.org/cancer/cervical-cancer/treating.html>)

What happens to boys who get HPV?

O Males, just like females who have HPV are at risk of developing genital warts, anal cancer, or oropharyngeal cancer. Males are also at risk of developing penile cancer from HPV. (<http://www.ashsexualhealth.org/stdsstis/hpv/what-men-should-know/>)

How does a boy get cervical cancer if he doesn't have a cervix?

O Males are not able to get cervical cancer. However, HPV can cause other forms of cancer such as anal cancer and cancers in the back of the throat, tongue, and tonsils (oropharyngeal cancer) in males and females, and penile cancer in males.

Does HPV cause other cancers?

O Human papillomavirus (HPV) causes most cervical cancers, as well as some cancers of the vagina, vulva, penis, anus, rectum, and oropharynx (cancers of the back of the throat, including the base of the tongue and tonsils).

(<https://www.cdc.gov/cancer/hpv/index.htm>)

HPV and Vaccination

Should boys be vaccinated?

O HPV vaccine is recommended for young men through age 21. HPV vaccine is also recommended for the following people, if they did not get vaccinated when they were younger: young men who have sex with men, including young men who identify as gay or bisexual or who intend to have sex with men through age 26; young adults who are transgender through age 26; and young adults with certain immunocompromising conditions (including HIV) through age 26.

O All kids who are 11 or 12 years old should get two shots of HPV vaccine six to twelve months apart. Adolescents who receive their two shots less than five months apart will require a third dose of HPV vaccine

O <http://www.cdc.gov/hpv/parents/vaccine.html>

At what age should we start asking the doctor to vaccinate our daughter? Our son?

O All girls and boys who are 11 or 12 years old should get the recommended series of HPV vaccine. The vaccination series can be started at age 9 years. Teen boys and girls who did not get vaccinated when they were younger should get it now.

(<https://www.cdc.gov/hpv/parents/questions-answers.html>)

Is there an age limit for the vaccine?

O HPV vaccination is not currently recommended for women over age 26 years. Clinical trials showed that, overall, HPV vaccination offered women limited or no protection against HPV-related diseases. For women over age 26 years, the best way to prevent cervical cancer is to get routine cervical cancer screening, as recommended.

O HPV vaccine is licensed for use in boys and men. It has been found to be safe and effective for males 9 -26 years.

O (<https://www.cdc.gov/std/hpv/stdfact-hpv-vaccine-young-women.htm>)

If your immune system is low (compromised), should you get the vaccine?

O Vaccines are especially critical for people with health conditions such as a weakened immune system. (<https://www.cdc.gov/vaccines/adults/rec-vac/health-conditions/weakened-immune.html>)

O HPV vaccine is recommended for young adults with certain immunocompromising conditions (including HIV) through age 26 if they did not get the vaccine when they were younger. (<https://www.cdc.gov/hpv/parents/questions-answers.html>)

What are the side effects of the vaccine?

O Many people who get the HPV vaccine have no side effects at all. Some people report having very mild side effects, like a sore arm from the shot. The most common side effects are usually mild.

O The most common side effects of HPV vaccine are pain redness or swelling in the arm where the shot was given, fever, headache or feeling tired, nausea, and muscle or joint pain.

O On very rare occasions, severe (anaphylactic) allergic reactions may occur after vaccination. People with severe allergies to any component of a vaccine should not receive that vaccine.

O (<https://www.cdc.gov/vaccinesafety/vaccines/hpv-vaccine.html>)

Can the vaccine give you HPV?

O HPV vaccine does not cause HPV infection or cancer. HPV vaccine is made from one protein from the virus, and is not infectious, meaning that it cannot cause HPV infection or cancer. (<https://www.cdc.gov/hpv/parents/questions-answers.html>)

Can I still get HPV if I get the vaccine?

O There is a small chance that someone might still get genital warts after having all three HPV vaccine shots. The shot protects against 90% of the HPV strains that cause genital warts. But there are lots of different strains (types) of HPV and the vaccine cannot protect against them all. (<https://kidshealth.org/en/teens/3shots.html>)

Treating HPV

Does HPV go away on its own? Will it come back?

O Infection with HPV is very common. In most people, the body is able to clear the infection on its own. But sometimes, the infection doesn't go away. Chronic, or long-lasting infection, especially when it's caused by certain high-risk HPV types, can cause cancer over time.

O (<https://www.cancer.org/cancer/cancer-causes/infectious-agents/hpv/hpv-and-cancer-info.html>)

O Scientists now think that the HPV infection that clears up on its own remains dormant in your body. It can stay dormant or it can come back again. Why it comes back isn't exactly known. But it does seem to be affected by your immune system. A strong immune system may help to keep it dormant.

O (<http://www.foundationforwomenscancer.org/questions-from-readers-hpv-duration/>)

Can I treat my HPV with antibiotics?

O Antibiotics are useless against viral infections.

(<https://www.betterhealth.vic.gov.au/health/conditionsandtreatments/infections-bacterial-and-viral>)

O There is no treatment for the virus itself. Symptoms, such as warts, and HPV related-cancers can be treated. (<https://www.cdc.gov/std/hpv/treatment.htm>)

If you had HPV before, are you immune to it?

O Researchers now think that when the HPV clears up it stays dormant in your body unless your immune system is later compromised in some way, in which case the HPV may become active again. When the HPV is dormant it appears that it is not passed on to a partner. Your best protection is to stay healthy by exercising, eating well, not smoking and seeing your doctor regularly.

(<http://www.foundationforwomenscancer.org/questions-from-readers-hpv-duration/>)

Is HPV curable?

O In most cases, HPV goes away on its own and does not cause any health problems. But when HPV does not go away, it can cause health problems like genital warts and cancer.

(<https://www.cdc.gov/std/hpv/stdfact-hpv.htm>)

O There is no treatment for the virus itself. However, there are treatments for the health problems that HPV can cause. (<https://www.cdc.gov/std/hpv/treatment.htm>)

Cervical Cancer Questions:

1. What is cervical cancer?

<https://www.cancer.org/cancer/cervical-cancer/about/what-is-cervical-cancer.html>

Cervical cancer starts in the cells lining the cervix -- the lower part of the uterus (womb). Cervical cancers start from cells with pre-cancerous changes (pre-cancers), only some of the women with pre-cancers of the cervix will develop cancer. It usually takes several years for cervical pre-cancer to change to cervical cancer, but it also can happen in less than a year. For most women, pre-cancerous cells will go away without any treatment. Still, in some women pre-cancers turn into true (invasive) cancers.

These changes can be detected by the Pap test and treated to prevent cancer from developing.

2. Is carcinoma the same as cervical cancer?

Depends, cervical cancer is a type of carcinoma in which cancerous growths develop in the lining of hollow organs of the body, and the lining of the respiratory and digestive tracts. Most cancers of the anus, cervix, head and neck, and vagina are epidermoid carcinomas. Also called squamous cell carcinoma.

<https://www.cancer.gov/publications/dictionaries/cancer-terms/def/epidermoid-carcinoma>

3. How is cervical cancer found?

- <https://www.cancer.org/cancer/cervical-cancer/causes-risks-prevention/prevention.html>
- The Pap test or smear is a procedure used to collect cells from the cervix so that they can be looked at under a microscope to find cancer and pre-cancers. It's important to know that most invasive cervical cancers are found in women who have not had regular Pap tests. A Pap test can be done during a pelvic exam, but not all pelvic exams include a Pap test.
- An HPV test can be done on the same sample of cells collected from the Pap test. The HPV test can help know if there is an HPV infection which is one condition that can lead to pre-cancers.

Prevention:

- A well-proven way to prevent cervical cancer is to have testing (screening). Screening can find conditions that may lead to pre-cancers and can find pre-cancers before they can turn into invasive cancer. The Pap test (or Pap smear) and the human papillomavirus (HPV) test are specific tests used during screenings for cervical cancer. If a pre-cancer is found it can be treated, stopping cervical cancer before it really starts.

Can cervical cancer be prevented?

The most common form of cervical cancer starts with pre-cancerous changes and there are ways to stop this disease from developing. The first way is to find and treat pre-cancers before they become true cancers, and the second is to prevent the pre-cancers.

What are the treatments for cervical cancer?

https://www.cdc.gov/cancer/cervical/basic_info/diagnosis_treatment.htm

Cervical cancer is treated in several ways. It depends on the kind of cervical cancer and how far it has spread. Treatments include surgery, chemotherapy, and radiation therapy.

- **Surgery:** Doctors remove cancer tissue in an operation.
- **Chemotherapy:** Using special medicines to shrink or kill the cancer. The drugs can be pills you take or medicines given in your veins, or sometimes both.
- **Radiation:** Using high-energy rays (similar to X-rays) to kill the cancer.

Risk factors for cervical cancer?

Other things can increase your risk of cervical cancer—

- [Smoking](#).
- Having [HIV](#) (the virus that causes AIDS) or another condition that makes it hard for your body to fight off health problems.
- Using birth control pills for a long time (five or more years).
- Having given birth to three or more children.
- Having several sexual partners.

https://www.cdc.gov/cancer/cervical/basic_info/risk_factors.htm

What are the symptoms of cervical cancer?

https://www.cdc.gov/cancer/cervical/basic_info/symptoms.htm

Early on, cervical cancer may not cause signs and symptoms. Advanced cervical cancer may cause bleeding or discharge from the vagina that is not normal for you, such as bleeding after sex. If you have any of these signs, see your doctor. They may be caused by something other than cancer, but the only way to know is to see your doctor.

Can you have cervical cancer if you get your tubes tied?

Yes. Tubal ligation — also known as having your tubes tied or tubal sterilization — is a type of permanent birth control. The cervix is still intact during this process, thus it is possible to develop cervical cancer.

Can you have cervical cancer if you have received a hysterectomy?

No. A radical hysterectomy, which involves the complete removal of the cervix is actually a treatment option for cervical cancer. It is one of the first treatment options offered for early stage cervical cancer. <https://www.cancer.org/cancer/cervical-cancer/treating/by-stage.html>

HPV can cause cancers of the:

- [Cervix, vagina, and vulva](#) in women
- [Penisexternal icon](#) in men
- [Anusexternal icon](#) and [back of the throat](#), including the base of the tongue and tonsils (oropharynx), in both women and men

CURRICULUM VITAE

Ariel Michelle Washington

amwash02@louisville.edu

Education:

- 2020 University of Louisville, Louisville, KY, Ph.D. in Social Work, Kent School of Social Work, 2015-2020
- Dissertation Title: The Development of a Culturally Informed Cervical Cancer Screening and Prevention mHealth Intervention for African American women
- Chair: Karen Kayser, Ph.D.
- 2018 University of Louisville, Louisville, KY, Master of Science in Social Work, Kent School of Social Work, 2015-2018
- 2014 University of Louisville, Louisville, KY, Bachelor of Science in Psychology, Department of Psychological and Brain Sciences, 2010-2014

Research Interests: Oncology, Psychosocial Interventions, Health Disparities, African Americans, Community-Based Participatory Research

Research Experience:

Lung Cancer Surveillance: 2014-2015

- Graduate Research Assistant; Dr. Kayser (Supervisor)
- Funded by NIH-supported Cancer Education Program grant (R-25)
- Aided in data collection and analysis of lung cancer patient's preferences for survivorship plans

Lived Experiences Financial Toxicity Study: 2015-2016

- Graduate Research Assistant; Dr. Kayser (Supervisor)
- A qualitative study that explored the financial toxicity that cancer survivors experienced during and after completion of treatment
- Conducted qualitative interviews and aided in analysis

African American Older Adults Living with HIV: 2015-2016

- Graduate Research Assistant; Dr. Harris (Supervisor)
- Funded by Cooperative Consortium for Transdisciplinary Social Justice Research Grant
- The qualitative study focused on learning about the lived experiences of older African Americans living with HIV in Kentucky.
- Conducted qualitative interviews and helped with the analysis

Cervical Cancer Screening and Prevention in Rural America: 2016-Present

- Graduate Research Assistant; Dr. Kayser (Supervisor)
- Combination of a systematic review and using innovative technology such as E.C.H.O to discuss cervical cancer screening and prevention in rural America
- Performed duties associated with the systematic review, maintained database, aided in manuscript preparation, performed the statistical analysis

Cervical Cancer Screening/Vaccination in an Urban Setting: 2017-2018

- Graduate Research Assistant; Dr. Kayser (Supervisor)
- Funded by Cooperative Consortium for Transdisciplinary Social Justice Research Grant
- A qualitative study with the purpose to explore the knowledge, attitudes, and preferences of African American women regarding cervical cancer screening and HPV vaccination.
- Facilitated focus groups, lead the qualitative analysis of the data, and taking the lead in manuscript preparation. Coordinated the community advisory board that was one of several outcomes of this study.

Project SafeSpace: Fall 2018-Spring 2019

- Graduate Research Assistant; Dr. Antle (Supervisor)
- The five-year project focused on reconfiguring infrastructure, and inter- and intra-agency procedures to support an evidence-based continuum of interventions to meet the behavioral needs of children in out-of-home care
- Participated in the program evaluation of the project. Focused on a qualitative analysis of collaboration, implementation, and sustainability.

Health Promotion Campaign Spring 2020-Summer 2020

- Graduate Research Assistant; Dr. Scott LaJoie (Supervisor)
- Funded by Cooperative Consortium for Transdisciplinary Social Justice Research Grant
- Campaign working with a local social service agency in an underserved area. Focusing on teaching teens how to promote health messages and education to their peers using innovation.

Publications:

Washington, A., LaJoie, A.S., Kayser, K., & Anderson, G. (in preparation) Assessing the Access to Cervical Cancer Screening and HPV Vaccination in a High-Risk Urban Community

LaJoie, A.S., Washington, A., Kayser, K., Smith, L., Anderson, G., Randall, J., & Springs, S. (in preparation) Effectiveness of Health Education Programs for Cervical Cancer Prevention in Rural Communities: Implications for Reducing Health Inequity

Smith, L. C., Kayser, K., Washington, A., Harris, L., & Head, B. (in revision) Living with the financial consequences of cancer: A life course perspective

Posters and Presentations:

Washington, A., Kayser, K., Ranjan, Smita., Smith, L., & Kloecker, G. (2014) Is There a Relationship between Patient Worry and Follow-up Care after Curative Treatment for Lung Cancer? Research!Louisville, Sept, 2014, Louisville, KY

Smith, L. C., Kayser, K., Washington, A., Ranjan, S., & Kloecker, G. (2015). A patient-centered approach to address fears of cancer recurrence during surveillance after treatment for lung cancer. IPOS/APOS World Conference, Washington, D.C. (Winner of Student Poster Award)

Washington, A., Kayser, K., & LaJoie, S. (2018) Promoting Cervical Cancer Screening and HPV Vaccination among African American Women, Cervical Cancer Community Advisory Board Meeting, Louisville, KY

Kayser, K.M., Washington, A., Anderson, G., LaJoie, A.S., Harper, D.M., Lee, H., & Harris, L. (2019). Knowledge, attitudes, and behaviors related to accessing cervical cancer prevention services among African American women living in low-income urban communities. Abstract presented at American Psychosocial Oncology Society annual meeting, Mar 1, Atlanta, GA.

Washington, A., LaJoie, A.S., Kayser, K., & Anderson, G. (2019). Knowledge and attitudes related to accessing cervical cancer preventative services among African American women in West Louisville. Poster presented at Research!Louisville, Sept. 11, 2019. 2nd place, Health Disparities Research Award.

LaJoie, A.S., Washington, A., Anderson, G., Randall, J., Smith, L.C. & Kayser, K. (2019). Evaluating the impact of health promotion and health education programs to reduce HPV and cervical cancer burden in rural communities: A systematic review. Paper

presented at the American Public Health Association annual meeting, Nov. 5, 2019.
Abstract #442617

Ballard-Kang, J., Washington, A. (2019) Perceived Safety in the Postsecondary Learning Environment: A Phenomenological Study. Oral paper presented at the Society for Social Work Research Conference, Jan, 19, Washington D.C

Teaching Experience:

SW 204 Introduction to Social Statistics (Spring 2019)

SW 426 Introduction to Social Work Research (Fall 2019)

Relevant Work Experience:

T32 Cancer Care and Delivery Post-Doctoral Fellow, University of Michigan: 2020

Other Experience:

Center for Mental Health Disparities: 2013-2014, Research Assistant

Cancer Education Program: 2014, Student Researcher

Family Health Center Phoenix Medical Respite Program: 2016-2017, Graduate Intern

Gilda's Club: 2017-2018, Graduate Intern

Cervical Cancer Social Justice Project: 2018-19, Research Assistant

Awards and Service:

Journal of Psychosocial Oncology: 2015-17, assistant to the Editor

Journal of Psychosocial Oncology: Reviewer, 2016-2019

Excellence in Health Disparities Research Award 2nd Place Poster (2019)

Graduate Student Council Research Grant (Fall 2019)