

**Perceptions of Long-Acting Reversible Contraceptives Among Black Women:
Barriers to Reproductive Health and Wellness**

by

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Abstract

Over 45% of pregnancies in the United States are unintended and there is a large disparity in unintended pregnancies between black and white women in the United States. Long-acting reversible contraceptives are over 99% effective and provide a unique set of characteristics that could help reduce the disparity in unintended pregnancies. However, black women in the United States use long-acting reversible contraceptives at lower rates than white women. Understanding the perceptions and attitudes that black women hold regarding LARCs will help give insight into how public health initiatives can be developed so providers can better counsel women on their birth control options. Eight in-depth qualitative interviews were conducted with women at the Mt. Oliver Magee Women's Community Health clinic in Pittsburgh, PA. The results showed that there are still many negative associations and fears regarding LARCs among black women. Also, the participants expressed wanting direct control over their reproductive behaviors and LARCs would not allow for that. This study suggests that there is a need for patient-centered contraceptive counseling for black women, and more research needs to be done to determine how to combat the misinformation still present among women.

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Preface

This research was inspired by casual conversations with my good friends Bria and Whynter and other family members who expressed many negative feelings about long-acting reversible contraceptives. While discussing contraceptive options with my friends and family members some stated that they would never let a doctor or clinician insert a device into them. Through my studies at the University of Pittsburgh Graduate School of Public Health I knew of the benefits that these devices could offer to women in protecting against adverse birth outcomes such as preterm birth and low birth weight infants. Moreover, I was becoming increasingly aware of the health disparities that exist between black and white women in the United States in regard to pregnancy and childbirth.

Black Americans in the United States also have a complicated relationship with the healthcare system due to a long history of mistreatment. In conceptualizing a framework to understand why black women preferred to not use long-acting reversible contraceptives I wanted to understand the historical context of black American's relationship with the medical system and this relationships' impact on reproductive practices in black women.

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1.0 Introduction

In the United States (U.S.) about 45% of pregnancies are unintended [1, 2]. Since 2008, the unintended pregnancy (UIP) rate has declined from 54 per 1,000 to 45 per 1,000. A majority of unintended pregnancies are due to the incorrect use of contraceptive methods [1, 2]. There is an existing disparity in unintended pregnancy rates between black and white women in the United States. The unintended pregnancy rate for black women is three times that of their white counterparts [3]. Unintended pregnancies have negative effects on the health of the mom and the baby [4]. If a woman experiences an unintended pregnancy, she is more likely to have a baby who is born prematurely or experiences low or very low birth weight [3]. Black women in the United States are twice as likely to have an infant who experiences low or very low birth weight compared to their white counterparts [5]. Unintended pregnancies can largely be prevented by the use of long-acting reversible contraceptives (LARCs) [6].

There are two main types of long-acting reversible contraceptives – intrauterine devices (IUDs) and implants. These contraceptives are placed once by a trained clinician and are effective at preventing pregnancy for three to five years with little to no maintenance required by the user. If the woman desires to become pregnant, a trained physician can remove the device and within a few days the woman would return to typical fertility patterns. These devices are helpful in preventing unintended pregnancies because they are over 99% effective, 20 times more effective than oral contraceptive pills, transdermal patches or vaginal rings [6]. However, LARC uptake in the United States is relatively low as only 10% of women use an IUD and 1% of women use an implant as their primary form of contraception [6]. For black women, the rates of LARC use are even lower than the general population of U.S. women [7].

An existing body of literature documents women's overall negative perception and discomfort with LARC devices [8-14]. In qualitative studies, many women have noted that when providers counsel them on their contraceptive options they feel that the provider does not present all of the options without bias [8, 11]. The women mentioned that providers talk about the negative aspects of contraceptive methods like oral contraceptive pills, transdermal patches and condoms and give IUDs and implants glowing reviews while downplaying the risk of complications and the potential side effects [11].

The Dalkon Shield IUD, an IUD released mid-20th century, saw initial success in the United States [15]. However, the device was quickly removed from the market as it was connected with complications such as sepsis, infertility and death. Many of the women who lived through this experience are still alive today and have children and grandchildren. In recent studies many women cited hearing negative stories from their family members or friends as a major contributor in their decision to not use an IUD [14].

For black women, the negative perceptions of LARCs are amplified. Studies document what black women feel as they are discriminated against while they are being counseled on their contraceptive options. Some black women have noted that when providers discuss their birth control options, the providers "packaged" the information regarding contraceptives in order to get the woman to choose an IUD or LARC device. Packaging refers to presenting incomplete information to the women to solicit a medical decision providers felt was appropriate instead of what best suits the woman's medical needs [16]. If a woman was not currently using a LARC method, the doctor would initiate a conversation about the devices regardless of the woman's satisfaction with her current method [11, 12, 17].

Black Americans have suffered many injustices within the evolving medical system of the United States. There are many examples of experimentation and maltreatment of black Americans in history that have caused a legacy of distrust in the medical system. This distrust may have an impact on black women's use of LARC devices. In order to reduce unintended pregnancy rates and adverse birth outcomes in black women, there is a need to understand how historical injustices have impacts on decisions about medical care today.

This paper will begin by examining the history of long-acting reversible contraceptives, the advancements of LARC devices in the 21st century, legacy of medical distrust among black Americans and reproductive coercion and the eugenics movement in the 20th century. This will review how the history of LARCs has left women today with negative impressions of the devices and how this is further complicated for black women by the historical abuses they faced within the medical system. Current attitudes and perceptions of the LARC devices and their relation to the disparity in the unintended pregnancy rates will also be discussed in the second chapter. The third chapter of this thesis is a stand-alone journal article which has not been submitted for publication. Following the journal article are the thesis conclusions.

2.0 Background and Literature Review

2.1 Background

2.1.1 History of Long-Acting Reversible Contraceptives

Loop and coil intrauterine devices were the predecessor to our modern day T-shaped IUD that date back to early 20th century Europe [15]. Over the course of the 20th century, the device went through many iterations by German and Japanese scientists. The U.S. Food and Drug Administration (FDA) approved the use of IUDs in 1968, which made the Lippes Loop, Tatum-T, Saf-T-Coil, Gynekoil and Copper 7 available to consumers [15]. Researchers used plastic to form these new devices to make them more flexible upon insertion and removal [15, 18]. By the early 1970s, three million women in the United States had the Lippes Loop inserted [18].

The Dalkon Shield is one of the most infamous IUDs in U.S. history. Once the device was available in 1971, it became popular among reproductive age women. By 1974, the pharmaceutical company A.H. Robins had sold 2.2 million devices across the country. Initial studies conducted by the pharmaceutical company found that the pregnancy rate was 1.1% and the expulsion rate of the device was 2.3%; however, independent research studies found these claims to be false and that the rates were higher than reported by the pharmaceutical company [15, 18].

In the early 1970s, users of the Dalkon Shield saw high rates of pelvic inflammatory disease (PID) and septic miscarriages when the device failed to prevent pregnancy. PID is especially dangerous because if the disease is not treated correctly or is left untreated, it can result in infertility and death [15, 18]. During this time, the Centers for Disease Control and Prevention (CDC) also

began conducting a study to understand more about the complications associated with this intrauterine device. Over 3,500 case reports of emergency hospitalizations were identified to have occurred in only the first six months of 1973. Five deaths associated with complications from IUDs were also reported [18]. Eventually, the CDC discovered that women who used the Dalkon Shield were more likely to experience complicated pregnancies and that death via miscarriage was three times more likely in users of this device compared to other IUDs [15, 18]. Scientists designed the Dalkon Shield with a distinctive multifilament tail rather than a monofilament tail, which became the source of many issues [15, 18]. The multifilament tail strings deteriorated and therefore bacteria could contaminate the underlying multifilaments of the device [15]. Bacterial contamination of the Dalkon Shield is most likely the cause of the infections seen in women who utilized this device [15, 18]. Concern surrounding the Dalkon Shield became serious and eventually prompted the United States government to get involved by having physicians testify about the dangers of the Dalkon Shield in Congressional hearings [18].

The manufacturer of the Dalkon Shield terminated sales of the device in 1974 [18]. Until the mid-1970s the U.S. FDA did not have much oversight of medical devices that were available to consumers as pharmaceutical companies were not required to provide proof of the safety and efficacy of the devices they were creating. However, in 1976 Congress passed the Medical Device Amendments that required pharmaceutical and other companies that develop medical devices to register with the FDA and follow quality control measures. But to this day, the requirements for medical device approval are much less rigorous compared to drugs [15, 18].

There were thousands of lawsuits against the A.H. Robbins Company and the company was forced to file for bankruptcy in 1985. However, the controversy surrounding the Dalkon Shield all but eliminated the U.S. market for IUDs. Sales for the other manufacturers that produced

IUDs plummeted and by the end of the 20th century less than 1% of contraceptive users had an intrauterine device [15, 18, 19]. Today, IUDs are a very safe option for birth control [18]. However, many women who remember the introduction of the Dalkon Shield IUD are still alive today and have had children. The negative perceptions about the safety of IUDs still persist. Over the past two decades, public health officials and physicians have worked hard to mitigate the negative history of IUDs in the United States [15, 18].

The first contraceptive implant introduced to the United States market was Norplant. Researchers began development of Norplant in 1966, which was approved by the U.S. FDA on December 10, 1990. This device consisted of six plastic rods inserted under the skin of the woman's arm. The plastics rods held 36 milligrams of levonorgestrel that was slowly released into the blood stream over a period of five years [15, 18, 19]. Shortly after release, researchers determined that the cumulative risk of pregnancy for women after five years of use was less than 5% [15]. Wyeth Ayerst, the pharmaceutical company responsible for the implant, saw initial success with the device. After the first year over 100,000 women opted to use the device. By the mid-1990s the number of women who utilized Norplant rose to over 500,000 [18, 19]. Upon its initial release Norplant cost \$350 with additional cost for surgical insertion and removal that had price tags ranging from \$150 to \$650 [20]. Despite the price barrier, the device became so popular that Wyeth Ayerst was unable to produce it quickly enough and women were placed on waiting lists to receive the contraceptive [18].

Enthusiasm surrounded the Norplant device because it was highly effective at preventing pregnancy, and politicians and physicians hoped that it would aid in relieving the high number of unintended pregnancies experienced by women all over the country [19]. After FDA approval of the Norplant, the *Philadelphia Inquirer* published a news story hailing the device as a "foolproof"

method of preventing pregnancy and “reducing the underclass” [19, 21]. The author of the article recommended that all women who utilize welfare benefits be offered financial incentive for Norplant utilization. It was hypothesized that, if all of the underprivileged black women in the United States were to use the Norplant, this would reduce the amount of money needed for public assistance and prevent undesired populations from reproducing [20, 22].

Bills introduced in Kansas, Louisiana, Mississippi, Tennessee and Ohio state legislatures proposed offering incentives for women who utilized public assistance to receive Norplant. Moreover, Washington, South Carolina, Ohio and Kansas all proposed state bills that would require women with substance use disorder who gave birth to infants with neonatal abstinence syndrome to have Norplant inserted upon the birth of the child. Other state legislatures introduced policies that would have mandated Norplant insertion with the receipt of public assistance, upon criminal convictions [22], and for teenagers who had given birth to at least one child [20, 23].

In 1991, Darlene Johnson a 27-year-old woman was convicted of corporal child abuse with past convictions of “check fraud, petty theft, disturbing the peace and burglary” [22, p.60]. For the child abuse crimes, the judge proposed that Johnson serve time on probation. During this time Johnson was to attend therapy and parenting classes, cease use of all drugs and alcohol and agree to get Norplant inserted once she delivered her fifth child [20, 22]. Johnson’s lawyer made the argument that insertion of the Norplant impeded on Johnson’s right to privacy and that Johnson had agreed to the device insertion simply for fear of being sent back to prison. Johnson suffered from high blood pressure and diabetes, which her lawyer argued would have put her at further risk of complications with the Norplant insertion [23]. There were questions about whether or not the judge had fully explained the risks and benefits of the Norplant insertion or if he was even qualified to have such discussion with the defendant [22]. Ultimately, the judge determined that Johnson

gave informed consent to the device and even though the contraceptive would interfere with Johnson's right to reproduction, this was justified in order to prevent future child abuse [22].

Multiple cases similar to Darlene Johnson occurred in the 1990s, all which created unrest and discord among reproductive justice advocates. More questions arose when the U.S. government made the Norplant available to women on Medicaid [19]. Initially, the Norplant was accessible only to women with financial means because the device had a high upfront cost [19, 20]. Soon after lawmakers realized the benefits of the device, it became available with Medicaid benefits. Black women disproportionately use Medicaid benefits and policy makers hoped that this would entice more poor black women to choose the Norplant for contraception [24].

Headlines announced the adverse side effects of the contraceptive device, which included irregular menstrual patterns, headaches, weight gain and strokes [15, 18, 19]. Excessive bleeding was problematic as over 50% of the women who were using Norplant experienced bleeding for over eight days per month [18]. Doctors were trained to insert the device, but training to remove the device was sparse and inconsistent [18, 19]. Inadequate training for medical providers led to many women filing lawsuits due to painful and complex removals [18, 19].

By the mid-1990s, over 50,000 women filed claims against the pharmaceutical company Wyeth Ayerst, stating that they had not been fully informed of the side effects and potential complications of the insertion and removal process. Negative press continued to surround the manufacture of Norplant. In 1999, the company quietly agreed to pay around 36,000 women a cash settlement for failure to adequately inform them about the side effects of the device [18]. Due to public discontent with the contraceptive, Norplant sales plummeted from 800 to 60 Norplant devices per day [19]. Eventually, Norplant sales were halted in 2002 and it would be another four years before another implantable contraceptive option was introduced in the United States [15].

2.1.2 Long-Acting Reversible Contraceptives

The American College of Obstetrics recommends LARCs as the “first-line” method of contraception among reproductive age women [25]. LARCs are over 99.9% effective at preventing pregnancy and are 20 times more effective than oral contraceptive pills (OCPs), transdermal patches or vaginal rings. Examples of LARCs include the intrauterine device or IUD, which can be either hormonal or non-hormonal, and the hormonal subdermal implant [6]. A trained physician inserts the LARC device at a scheduled clinical visit and once the device is inserted there is little to no maintenance needed by the woman for three to five years [6, 25]. If a woman wants to become pregnant, the LARC device can be removed by the clinician at any time and within a few days, most women will regain the ability to conceive [6, 25].

Almost all women can safely use a LARC method to prevent pregnancy. Risk factors such as hypersensitivity to copper and pre-existing conditions such as breast cancer, sexually transmitted infections, and gynecological cancers are assessed prior to insertion of the device as use in women with these conditions may be contraindicated [6, 26]. Long-acting reversible contraceptives are safe to use while breastfeeding and immediately after giving birth, experiencing a miscarriage or having an abortion [6, 25, 26]. LARC devices are also very discreet and do not interfere during sexual intercourse as they are inserted into the uterus or underneath the skin [6].

Hormonal IUDs release a continuous small dose of levonorgestrel over a period of three to five years, which inhibits fertilization of the egg by the sperm by thickening the cervical mucous and preventing ovulation [6]. Hormonal IUDs release a majority of the hormone locally within the uterus and therefore, reduce the chance that a woman may experience symptoms typically associated with hormones such as headaches, nausea, mood changes and/or breast tenderness [25, 27, 28]. Release of the hormone levonorgestrel in the uterus may reduce the thickness of the uterine

lining and reduce or eliminate menstrual bleeding in some women; however, ovulation may continue to occur [6, 25]. Copper intrauterine devices release copper ions that are toxic to sperm cells and kill them upon contact [6]. The most commonly reported side effects of the copper IUD are increased menstrual bleeding and pain. Side effects of the inserted devices are minimal for a large percentage of women [6]. Risk of complication with IUDs is extremely low and may include expulsion of the device, method failure or perforation of the uterus. Expulsion rates can range from 2% to 10% within the first year and roughly 1.4 per 1,000 IUD insertions result in perforation [6].

The hormonal subdermal implant is a single rod that releases progestin and prevents pregnancy by suppressing ovulation, thickening the cervical mucous and thinning the lining of the uterus. Possible side effects of the implant include changes in menstruation patterns such as lower frequency or complete elimination of bleeding, headaches, digestive issues, tenderness of the breasts, weight gain and acne [6, 25]. Risk of complications during the insertion process of the implant is less than 1.0% and includes bleeding, bruising, deep or “unrecognized” placement of the device [6, 25]. Unrecognized placement of the subdermal implant refers to a physician or trained provider mistakenly not placing the implant underneath the woman’s skin [29].

Long-acting reversible contraceptives are highly effective and less than 1% of women who use an IUD or implant will experience an unintended pregnancy if the devices are used perfectly [6, 25]. Perfect use of a contraceptive method means that the method usage was adhered to with the strict criteria of a clinical trial [30]. In reality, no method of contraceptive is used perfectly. However, LARC methods are unique because once the device is inserted by a trained physician it requires little to no user maintenance, dramatically reducing the probability of method failure [26]. After one year post insertion, over 80% of women continued to utilize the copper or hormonal IUD, and 84% of women continued use of the Implanon implant as compared to women who used

only condoms or OCP, which have continuation rates of 53% and 68% percent respectively [26]. These data suggest that women are satisfied with these contraceptive options overall.

The oral contraceptive pill, tubal ligation, and the male condom remain the primary form of contraceptive among women ages 15-44 [31]. LARC use among American women has been historically low compared to the oral contraceptive pill or basic barrier methods such as condoms. From 2002 to 2013 the rate of IUD use increased from 2% to only 10%. Within the same time frame, the rate of implant use among American women rose from 0.4% to a mere 1.0% [6].

According to the Guttmacher Institute, in 2014 roughly 14% of women utilized a long-acting reversible contraceptive as their primary form of birth control [32]. In addition, black women are more likely to inconsistently use, misuse or not use contraceptives at all as compared to white women [7, 33, 34]. Contraceptive non-use is associated with increased risk of unintended pregnancy, preterm birth and low birth weight [3]. Encouraging the use of long-acting reversible contraceptives among black women may help to prevent unintended pregnancy and negative birth outcomes in black women [4].

Social and structural barriers prevent women, particularly black women, from accessing and obtaining LARCs [35]. For example, only half of OB/GYN providers in the United States offer LARC insertion procedures due to lack of training or assumed lack of interest among patients [36]. Only 22% of family medicine practices across the United States consistently offer IUD insertions and only 14% consistently provide implant insertions [37]. The lack of providers who offer the service severely hinders women's access to these services.

The Affordable Care Act of 2010 was revolutionary as private insurance, Planned Parenthood, federally qualified health centers (FQHCs) and OB/GYN offices that received Title X federal funding all began to offer contraceptives for little to no cost. However, many women

still lacked access to private health insurance or clinics in their area that provided these services [36]. It is easier for many women to visit a pharmacy where less effective methods of birth control are readily available.

2.2 Historical Perspectives on Black Americans and the Healthcare System

2.2.1 The Legacy of Medical Distrust Among Black Americans

Disparities in the use of LARCs among black women may be partially explained by the mistrust of medical providers among black Americans. The Tuskegee Syphilis study is often cited as the initial cause of black American distrust of the biomedical field [38-40]. However, there is a long history of medical exploitation and abuse of black bodies in the United States [41]. Since the introduction of slavery into the United States, medical doctors were consulted for black slave health issues to serve the financial interests of the white slave owners [42, 43]. Black bodies were often examined and inspected by physicians to ensure that their bodies were worth the investment of the white plantation option. Even in death, black bodies were often taken from their graves to be utilized as cadavers for teaching white medical students anatomy courses [21, 42].

Four hundred years ago, the first slaves were brought to the Americas from the western coast of Africa [44]. In America, African Americans had no rights or ability to claim to their bodies and effectively no control over the medical care that they received. Slave owners decided the extent to which their injured or sick enslaved workers would receive medical attention. Prior to the mid-1800s, sterile surgeries and anesthesia were non-existent, making any medical procedure extremely risky. Most surgeries ended in painful infections or death. Medicines were tainted with

dangerous chemicals such as mercury or arsenic and other remedies were laced with addictive opiates [45, 46]. Even if a slave was fortunate enough to receive medication, 18th and 19th century medications often caused addiction or killed many black slaves [21]. Moreover, the caustic chemicals in the medications may have triggered lung injuries that accounted for a large number of slave deaths during this time period [21]. Slaves were considered expendable by a vast majority of the slave owners during the antebellum period. If one were to get sick or injured, slave owners would simply replace them by purchasing another slave or forcing enslaved women to reproduce [21, 42].

Medical training prior to the mid-1800s was very scattered and based on unfounded “scientific” rationales. There was a need for a standardized medical curriculum in order to entice students to study medicine and attend newly erected medical institutions. In order for physicians to treat their white patients more effectively, they acquired black bodies on which to practice their newly proposed treatment techniques. At the time, slaves were the perfect medical puppets as they had no authority to object to anything done to them by white authority figures [21].

Members of the white upper class were able to afford physicians to make private home visits for the sick members of their family. Hospitals were reserved for poor whites and blacks in America who could not afford medical care. Seeking medical attention at a hospital was essentially giving one’s consent for unnecessary medical and surgical procedures for the benefit of medical students’ training [47]. Black patients significantly outnumbered whites in these public hospitals. Poor whites and free blacks were charged fees for admission to the hospitals whereas slaves were admitted for free. Upon death, the bodies of these individuals were given to local medical schools for students to dissect and learn human anatomy. It seems ironic that white medical professionals wanted to use black bodies as the basis of scientific discovery when they were considered to be

sub-human. However, white physicians knew that white southerners would never agree to their bodies being used for medical discoveries and black bodies were readily available due to their high mortality rates in the antebellum south [21].

As a result of “academic” hospitals, physicians were encouraged to publish the results in medical journals that were read only by other white, male physicians. In these journals, racist documentation described medical conditions like hydrocephalus, quadruplets or Siamese twins that doctors attributed only to blacks. These reports contained patients’ names and other personal information, and even speculated on their patients’ sexual urges and completely disregarded their privacy. Black Americans had no legal standing to sue these medical journals for releasing identifiable information unlike their white counterparts who could stop the circulation of their private medical information [21]. Misinformation regarding black inferiority spread across the country [21, 42, 48].

In the 19th century, many medical schools had successfully established themselves around the country. One of the most effective way of recruiting white students to the school was to boast about the opportunities for anatomical exploration on actual cadavers. Professors, physicians and medical students needed cadavers to understand disease processes in the body [49]. During this time, the only legal means of obtaining cadavers was getting bodies of those with a criminal sentence of execution and dissection, which was utilized for brutal murderers and very rare. This method of obtaining bodies for medical schools was not effective. Contrary to practices today, in the 19th century family members took very good care of a loved one who passed away by and bathing and grooming the body prior to physically placing it in the ground. Postmortem care of an individual gave them status and signified their importance to the family and the community. If your body was given to medical institutions for anatomical dissection, it gave the opposite

impression. White Americans bodies were respected and left untouched in their gated cemeteries [21]. However, for many years white professors and other staff at medical schools were tasked with acquiring black bodies from their graves [21, 50].

Grave robbing was very common in the antebellum period [41]. In 1788, a group of blacks wrote to the New York City Common Council stating that medical students consistently raided black burial grounds at night, looking for newly deceased persons [21]. Their letter was ignored and for the most part the council officials showed little interest in protecting black grave sites. White officials knew that blacks had very specific traditions surrounding the burial of their loved ones and that the thought of their body being dug up to be used for medical exploitation was deeply disturbing. This fact was used to control the behavior of slaves and free blacks by consistently sending reminders of their inherent inferiority [21].

Again, white people's indifference to grave robbing in black cemeteries was because they knew that if medical institutions did not get bodies from there, they would start using white cemeteries. States solidified the difference between the number of black bodies and white bodies in anatomy labs by introducing legislation that would purposely direct the bodies of black criminals to medical schools. There is a documented case from 1829 of a doctor who paid a graveyard manager on behalf of multiple medical schools in Philadelphia to obtain 50 to 85 cadavers per month during the "dissecting season." Dissecting season occurred from fall to spring in order to ensure peak dissecting potential and prevent the bodies from decaying rapidly. Only bodies that were preserved in whiskey were able to be sustained during other seasons. Black Americans who lived in neighborhoods near medical schools were very well aware of this seasonality and often expressed sentiments like "Please God, I hope when I die, it'll be in the summertime" [21].

Black bodies were preserved, mummified or stuffed and put on display in medical schools [42]. One woman who had Paget's disease, a bone disorder, had an extremely distorted skeleton that was hung on display for years for white medical school students to study. A man named Tom, who committed a crime, was coerced into giving his body to a medical school by being promised gingerbread until his execution. Once executed, a doctor hung his skeleton on the door of his practice where it terrified patients [21].

Disrespect of black bodies is a recurring theme in history. Bodies of lynched black men and women were left swinging from trees and body parts were left around in public areas ensuring that black Americans would see them [21, 51]. Images circulated through newspapers or advertisements showed deceased black bodies dressed up in ridiculous outfits or stripped nude. Medical students often took pictures with body parts of black cadavers as a rite of passage for successfully completing their anatomy classes. All of these experiences of racialized medicine terrified blacks and discouraged them from engaging with the medical system [21].

By the start of the 20th century, grave robbing became socially unacceptable, and scientists and medical professionals needed other methods of making new scientific discoveries. The Tuskegee syphilis study promised 600 black men who were very poor sharecroppers infected with syphilis in rural Alabama free medical care by joining the program [38]. Even after the discovery that penicillin could cure the infection, doctors purposely withheld medication to study the disease course in the human body. Doctors made the claim that sexually transmitted infections had different disease pathology in whites and blacks. For whites, it was thought to cause extreme damage to the neurological system as compared to causing extreme damage of the cardiovascular system of blacks [21].

Syphilis was a major public health problem in the late 19th century and early 20th century. Anyone could acquire the disease through sexual intercourse or from a vaginal birth. In its initial stage, sores develop on the genitalia with flulike systems. Without treatment, the disease can progress into its latent secondary stage before initiation of skin growths, sores, bone decay, and heart damage. In the third phase, neurological damage, blindness, insanity, paralysis and death can occur [21, 52]. Because medical care for blacks after slavery was virtually non-existent, the promise of free medical care to rid themselves of “bad blood” was an offer that many of them could not pass up.

When the Public Health Service (PHS) doctors announced the start of the program, hundreds of individuals lined up in order to get their blood drawn under the pretense of free health assessments and screening tests. PHS doctors shared the sentiment that black Americans in Macon County, Alabama, were not responsible enough to manage their own health [21]. They incorrectly hypothesized that the syphilis infections that ravaged this community were due to the sexual immorality of blacks [21, 53]. It was later discovered that most of the syphilis infections were passed congenitally from mother to child [54]. Doctors gave patients suspected of a syphilis infection “treatment” in the form of vitamins, arsenic and mercury.

PHS doctors were able to identify their select group of patients by taking very detailed medical histories and excruciating spinal taps. Women and men with recent infections were excluded due to hidden sores in women and because they wanted a very sick cohort of men. Eventually, Dr. Raymond Vonderlehr, a doctor intimately involved with the study, added a “control” group that consisted of men who were not infected with syphilis. Twelve of the men initially assigned to the control group contracted the disease and were simply transferred to the

initial observational cohort. At this point in the study, any conclusions or comparisons between groups were invalid due to poor experimental design [21, 40].

In order to ensure that the cohort of selected men was kept in the study, the PHS doctors hired Eunice Rivers, a black nurse, to maintain relationships with the men so that they would show up for their appointments and when they died, that their bodies would be returned to the doctors for autopsy. Because the doctors did not think that Rivers was enough to keep the men engaged, they offered the men free burials upon their predictable demise. Rivers monitored the men so well that virtually the entire cohort received no medical attention between 1932 and 1972. Eunice Rivers was at the service of the doctors until the study was forcibly ended in 1972 [21].

As World War II approached, the men involved with the study were exempted from the draft so they would not be treated for their infections [55]. The PHS physicians also met with local black doctors in Macon County, Alabama, and ask them to deny treatment to the men in the study. In the late 1990s a physician named Benjamin Roy had been looking into the experimental agenda of the PHS physicians. Roy believed that the scientists were using these men as human incubators for the bacterium so they could create a test and vaccine for the disease [56]. The Tuskegee syphilis study began in 1932, 20 years before scientists were able to culture and grow microorganisms in the laboratory. Roy's theory would explain why the PHS doctors and scientists regularly conducted spinal taps and blood draws on their selected cohort of men in order to have a consistent supply of the syphilis bacterium [21, 56].

In 1943, Thomas Parran, the Surgeon General of the United States, had the opportunity to terminate the study after discovery that penicillin could cure syphilis. However, he opted to continue the study because this was considered to be a unique opportunity for scientific discovery [57]. In 1972, a journalist with the Associated Press broke the story of the Tuskegee study to the

public. The United States public expressed shock, horror and disgust that the U.S. government would participate in this atrocity [39]. The Tuskegee syphilis study was terminated in 1972 [21, 39]. A Macon County attorney filed an almost \$2 billion class-action lawsuit for the remaining individuals who had suffered directly from the exploitation of the PHS doctors [21]. However, out of court in 1973 a \$10 million settlement was reached . This settlement yielded only a meager \$37,500 for each living participant. The legacy of this study has had a huge impact on blacks' relationship with the medical system in the U.S. However, it is incorrect to attribute this mistrust to only the Tuskegee Syphilis Study. This relationship has been established from hundreds of years of discriminatory, exploitative, racialized medical practices [21, 52].

2.2.2 Gynecological Experimentation and Reproductive Coercion

James Marion Sims is often hailed as the “father of modern gynecology” for his contributions to the field of gynecology between the years of 1844 and 1849 [48, 58]. He attended Charleston Medical College in South Carolina and Jefferson Medical College in Philadelphia and decided that he would pursue a specialty in gynecology despite his family’s opposition. Sims is given credit for the first successful surgical cure for a vaginal fistula. However, for black women Sims’ contributions to medicine are overshadowed by his experimentation on enslaved black women [48].

A vaginal fistula is the result of a “crush” injury to the pelvis during the birth of a child when the fetus will not fit through the vaginal canal [59]. The development of a fistula during childbirth causes an abnormal opening between the vaginal canal and either the bladder, rectum or colon. This causes fecal matter or urine to pass through the vaginal canal [60]. During labor, uterine contractions continue to force the fetus through the vaginal birth canal until the fetus becomes

stuck. At this point in the birthing process, the woman's bladder, cervix and vaginal tissues are forcibly wedged between the child's skull and the mother's pelvic bone. Eventually the blood supply to these tissues is cut off and they become necrotic. During this time the fetus can die due to asphyxiation and a couple of days later, the fetus tissue becomes malleable enough to simply slide out of the birthing canal. Sometimes, the mother may experience uterine rupture, sepsis or hemorrhage, which in the 19th century almost always ended in death. If the mother survived this experience, she would be left without any control of her urinary or fecal processes and left feeling socially and physically isolated [59]. Enslaved women who suffered from this condition were often considered less valuable to their owners than their reproductively capable counterparts and this made them especially vulnerable in the world of slavery because they essentially had no economic value.

Sims utilized the "sick houses," or living quarters for women who could not to be cared for by their loved ones, to obtain enslaved women for his experimentation. The women on whom Sims operated were forced to live separately from their families and raise their children within the confines of these medical institutions. Sims tried for five years to cure vaginal fistulas, often rendering women useless to their former slave masters. However, he eventually cured an enslaved woman named "Anarcha" by closing the opening permanently with silver stitches. In 1852, Sims published his success in the *American Journal of Medical Sciences* [48].

The United States and Great Britain banned the trans-Atlantic slave trade at the beginning of the 1800s [42]. This eliminated the continuous supply of slaves from the western coast of Africa. After this, it was apparent to the white plantation owners that the reproductive health of black women was a necessary investment [48]. During the antebellum period, it is estimated that the 50% of infants born to enslaved women were stillborn or died within the first year of life [42, 61,

62]. The safer and easier it was for enslaved women to have children meant that they could have more children and therefore, create more economic wealth for the slave owners. There are numerous accounts of surgical interventions conducted on slave women during the 18th and early 19th century, despite surgery being a rare occurrence even for white men and women during this time period [63].

After some black women gave birth they were chosen by their owners to learn midwifery and nursing to foster reproductive health on the plantations. The urgency for increased birth rates among enslaved black women is related to the sexual abuse experienced by these women in the times of slavery as slave masters often violated them as a means of reproductive control. In some accounts, black slave women described being forced into sexual relationships in order to procreate. Throughout American history, black women's right to reproductive autonomy has often been denied due to the interests of white Americans [48].

2.2.3 Family Planning in the 20th Century

Eugenics is defined as selective breeding of the human population to improve the population's genetic composition [64]. In the 20th century eugenics was characterized by selective breeding by those deemed to have acceptable characteristics. This pseudo-science was popularized by Adolf Hitler in the early 20th century as his justification for mass genocide in the Jewish population. However, while the United States publicly denounced Hitler's radical idea of creating a master Aryan race through mass genocide, U.S. policymakers and women's rights activists tried to find legitimacy in the principle of eugenics to prove that individuals with black skin, individuals who suffered from mental illness or disability and criminals were genetically inferior and should be prevented from reproducing [65]. The sentiment of the early 20th century was that if criminality,

poverty, mental illness and disability could be “bred out” of the U.S. population then the country would rid itself of the social ills that tainted American society [21, 65]. These principles and ideas became popular among American researchers and scientists.

Due to historical institutional racism and the efforts of the scientific community to prove black biological inferiority, black women fell victim to the eugenics movement and were labeled as unfit to bear socially responsible or productive offspring [21]. Black women were hypersexualized and thought to be reproductively irresponsible by having lots of children and depending on governmental assistance. These thoughts led to stereotypes brought forth by Ronald Reagan in the 1980s such as “the Welfare Queen,” which some white Americans used to criminalize low-income black women [24]. The Welfare Queen was a narrative based on a woman named Linda Taylor, who was accused of welfare fraud in the late 1900s. In Reagan’s famous 1976 speech, he outlined how women like Taylor were abusing taxpayer dollars by committing welfare fraud to live lavish lives [66]. This stereotype has evolved to become synonymous with single mothers, living in an inner-city poverty stricken neighborhood, teenage pregnancy and black women [67]. According to U.S. policymakers, it was in their best interest to discourage reproduction among this specific demographic. This change in narrative from encouragement of black reproduction during the times of slavery to deeming the black population in the United States worthy of eradication was fueled by racist stereotypes of the 20th century.

Margaret Sanger is known for her work in pioneering women’s right to access contraceptives. However, her advocacy for birth control access shifted to problematic rhetoric by imposing eugenics policies and ideas on black women across the country [68]. In 1939 Margaret Sanger founded “The Negro Project,” which was created to help control black reproduction [21]. Sanger even sought and gained the support for this project from prominent black figures of the

time such as W.E.B. Du Bois, the founder of the NAACP, and Charles S. Johnson, the first black president of Fisk University. Black leaders like Du Bois supported the Negro Project because they felt the social ills faced by black Americans could be solved with “responsible” reproduction [69]. Family planning clinics staffed with black doctors and nurses were purposely placed in black neighborhoods in order to encourage the use of these medical facilities and to gain the trust of the community. However, the black doctors and nurses who practiced in these facilities had little to no authority over the treatment of their patients. The black doctors and nurses were given instructions by white doctors and health care professionals who funded the project. Moreover, at the advice of Du Bois, Sanger succeeded in targeting predominately black churches across the country to further her agenda in controlling the reproduction of black populations in the United States [21].

In 1960, the U.S. FDA approved the first birth control pill, Enovid-10, which became popular among American women [70]. Towards the end of her lifetime, Sanger became a supporter of the development of the OCP [21]. Sanger’s closest collaborator, Katherine McCormick, personally donated over \$2 million to further the research and development of the pill [70, 71]. Eventually, the OCP was made available to impoverished black women for free or subsidized rates at federally funded Planned Parenthood facilities. Many of these in predominately black communities were the direct descendants of the clinics Sanger initiated with her Negro Project. Shortly after the OCP was placed on the market, black communities became suspicious of the intentions of the medical community, as concerns of racial genocide began to spread. In the 1960s, many local NAACP chapters rescinded their support of birth control. At the Black Power Conference in Newark, New Jersey, in 1967, the members passed a resolution equating

contraception with “black genocide” [72]. These members even organized to burn down a clinic that provided contraception to black women in Cleveland, Ohio [21].

2.3 Unintended Pregnancy

Preventing unintended pregnancy is an important reproductive health goal for families in the United States [73]. Unintended pregnancy is defined as a pregnancy that is “unplanned, mistimed or unwanted” [1, 73]. No contraception is 100% effective at preventing pregnancy; however, unintended pregnancies can largely be prevented by use of highly effective forms of birth control such as IUDs and implants [73]. Since 2008, the UIP rate has declined significantly from 54 per 1,000 to 45 per 1,000 women age 15-44 [2]. In 2011, around 45% of all pregnancies in the United States were unintended [1, 2]. Unintended pregnancies can occur in women of all social-economic levels, racial, educational levels and age categories [73]. However, UIP rates among non-Hispanic black women is three times that of their white counterparts [2, 74]. A majority of UIPs occur due to the improper use of contraceptives [75].

Almost six million unintended pregnancies occur in the United States every year [1]. Unintended pregnancies have a negative impact on the health of the baby and the mother [76, 77]. With an unintended pregnancy, a woman is more likely to have a baby who is born prematurely or low birth weight [4]. It is very important to ensure that women have the resources they need prior to and between pregnancies in order to create and raise healthy babies. Once a woman is aware that she is pregnant it is often too late to prevent adverse birth outcomes [4]. While it is encouraging that the United States overall has seen decreases in the UIP rate over the past two decades, this same trend is not seen for low-income women of color. In fact, the disparity in rates

of UIP between non-Hispanic black women and non-Hispanic white women has widened over the past two decades [3].

A study conducted in 2010 showed that of women who were at risk for UIP, roughly 90% were using some form of contraception [75]. However, contraceptive failure rates are highest among low-income women under the age of 30, non-Hispanic black women, and unwed women. Black women are also more likely to use less effective methods that require daily maintenance, or natural forms of birth control such as oral contraceptive pills, condoms and the rhythm method [34].

Many barriers prevent women from accessing contraceptives such as location of clinics, lack of trained providers and availability of contraceptives at clinics. For example, FQHCs that primarily serve underserved populations have issues stocking IUDs or implants, being reimbursed for providing these services and training providers on these procedures, all which prevent women from obtaining effective contraceptives to prevent unintended pregnancy [78].

Black women across the United States are more likely to be poor, less educated, lack access to stable primary care services and be underinsured compared to white women [33]. These individual factors alone do not explain the disparity in UIP between black and white American women [3]. The Contraceptive CHOICE Study showed that when barriers such as cost, access, and knowledge gaps were removed, women were more likely to choose a highly effective form of birth control, which reduced the chance of experiencing and unintended pregnancy [74, 75].

If a woman does not intend to become pregnant, the likelihood of experiencing a preterm birth increases [1, 3, 4, 74, 75]. Between the years of 1990 and 2007, preterm birth rates increased 21% [3]. Additionally, black women are twice as likely to have an infant born prematurely as compared to white women. Infants born prematurely are more likely to be low birth weight or very

low birth weight [5]. Low birth weight is problematic because as the babies age, they have a higher chance of experiencing chronic diseases such as hypertension, diabetes, heart disease, obesity and asthma. Other health conditions for babies born LBW or VLBW include respiratory distress syndrome, intraventricular hemorrhage, retinopathy of prematurity (the retina does not fully form prior to birth, and can lead to blindness) and increased risk of serious infections due to the lack of development in the child's immune system [5].

Moreover, black infants born LBW are more likely to die prior to their first birthday compared to their white counterparts. In 2016, the infant mortality rate for black infants was 11.4 per 1,000 as compared to 4.9 per 1,000 for white infants [79]. Infant mortality rates are often an indicator of a population's overall health and these data suggest that overall population health in black Americans is poor compared to their white counterparts [80]. A recent study noted that the largest contributors to the disparity in infant mortality rates between black and white women may be related to insurance type, maternal education level, marital status and high blood pressure [81].

A possible explanation for poor pregnancy outcomes among black women is the higher level of consistent chronic stress they face throughout their lifetimes [82, 83]. Stress for black women also occurs when they interact with medical providers, as many have cited feelings of racial discrimination, condescension and bias from their physicians [84, 85]. Black women have commented on experiences interacting with the medical providers in which they feel that providers "package" information based on their preconceived biases and limited information present in the electronic medical record [16]. Medical providers hold a wealth of information and present an interesting power dynamic when counseling women on pregnancy intention, outcomes and contraceptive options. There is evidence that women can sense when health information is selectively provided to them, which can lead to distrust in the provider [16].

Unintended pregnancies not only have a major impact on the health of black women but also cause extreme stress on our economy. In 2010, Medicaid costs related to births, abortion care and miscarriages for UIP amounted to over \$21 billion in taxpayer expenditures [86]. Increasing the number of contraceptive services that are available to families in the United States could dramatically reduce this number. It is estimated that United States taxpayers would save between \$15 to \$19 billion per year by increasing access to family planning services in order to prevent unintended pregnancies [86, 87].

2.4 Literature Review

2.4.1 Perceptions of Long-Acting Reversible Contraceptives

Despite the effectiveness at preventing pregnancies of long-acting reversible contraceptives (LARCs), many women do not use these methods. Many women cite that the most important feature of birth control is the ability to prevent pregnancy. However, less than 10% of women in the United States choose to use a contraceptive implant or IUD [88]. Researchers have identified numerous factors that affect a woman's eagerness to use a LARC method as her primary form of contraception. These factors include, but are not limited to perception of effectiveness at preventing pregnancy, perceptions of the method from family members and friends, patient-provider relationships, fear of side effects, fear of pain during the insertion and high up-front costs [89, 90].

Black women are more likely to use less effective methods of contraception such as barrier methods or to not use contraception at all. This is particularly concerning because of the disparity in unintended pregnancy that exists in the United States. The literature on the impact of misinformation regarding LARCs is limited; however, it does suggest that this deters many women from using them. In particular, a study by Borrero et al. noted that only 55% of the black women surveyed were aware of the implant as a form of contraception. However, 100% of the black women responded that they were aware of oral contraceptive pills and condoms. Only 18% of the black women knew that the IUD likely does not cause infertility, 49% believed that in order to receive an IUD you had to undergo a medical operation and only 45% of women knew that the IUD was more effective at preventing pregnancy than the OCP [91].

Discussion of IUDs and implants in social settings is extremely important in shaping the way women view these devices. A majority of the conversations surrounding contraception are with other women who have close familial or friendship ties. In a study conducted in 2014 in which women were asked how their opinions about LARCs were shaped, the participants stated that the negative stories were almost always the most memorable. One participant mentioned that women assume that birth control methods are supposed to be highly effective at preventing pregnancy and have few to no side effects and thus negative stories become seemingly noteworthy at shaping one's opinions [14]. When specifically discussing IUDs, women mentioned that most of the negative information they were given was related to uterine perforation, migration, heavy cramping and bleeding and loss of infertility. A couple of patients who participated in the study mentioned hearing stories about the Dalkon Shield IUD and how it was fatal for some women who used them. One patient even described her mother as a Dalkon Shield user who almost lost her life due to complications [14].

Similarly, Anderson et al. discuss television commercials and the impact they have in shaping women's views on LARCs. Ten of the 38 participants stated that they had seen television advertisements of women pursuing lawsuits against pharmaceutical companies regarding the negative effects of the levonorgestrel IUD implant. This caused many of the participants with this experience to look elsewhere for contraception [14].

In addition to the misconceptions and knowledge barriers surrounding long-acting reversible contraceptives, there is some discussion among researchers about "provider bias" and its ability to affect the uptake of LARCs in women and particularly black women. Today, blatant displays of reproductive coercion and racism may not be exhibited by providers, but implicit biases can affect whether a woman chooses to have a LARC device inserted. In a qualitative study conducted by Higgins et al. a majority of the women stated that their providers were a trusted source of information when thinking about contraception. The women who did not view their providers as a trusted source of information were almost all black or women of color. These women believed that providers held a paternalistic view of patient care and wanted the patient do what they felt was best without taking into account the patient's needs, wants or desires. Often times, the women who did not trust their providers turned to other sources such as the internet or family and friends for information [85], which can support the spread of misinformation regarding contraceptive methods. Many women felt that their provider did not fully explain the side effects of the LARC devices prior to insertion and they were left dealing with uncomfortable and inconvenient medical issues and side effects. If they requested that the device be removed, women felt like their pain from the side effects was downplayed by providers and were told to just wait the symptoms out [85].

Gomez et al. conducted a study to explore black and Latina women's general perceptions of their contraceptive counseling. One participant stated that when her doctor discussed her contraception options during the appointment, she noticed that the doctor seemed very "enthusiastic" about LARC devices and talked about them in depth but rushed through talking about all of the other contraceptive options. This particular patient felt that her doctor was a "salesperson" and was making an attempt at "selling her a bar of soap" in trying to persuade her into choosing an IUD. At the end of that appointment the patient scheduled a visit to have the ParaGard inserted, but ultimately cancelled after she read negative commentary on the internet [11].

It is vitally important that providers are counseling patients ethically and keeping their needs at the forefront to ensure that patients are satisfied with their contraceptive choices. The role of primary care providers in contraceptive counseling is important because it may have an effect on patient continuation rates of contraceptive methods [10, 11, 13]. Women have described physicians as using "scare tactics" when trying to help them choose a birth control method [11]. The physicians make negative comments about birth control pills, condoms or other less effective methods of contraception. IUDs and implants are discussed and presented as the patient's best option for contraception regardless of her life circumstances. Women have noted that this behavior feels "pushy" and "aggressive" and leaves them feeling that providers were disengaged in their appointment [11].

Furthermore, if the woman was not using a LARC device, the physician raised their contraceptive options at every visit regardless of when the last conversation took place or sometimes without evidence that the woman was sexually active. This often left women feeling pressured into choosing a LARC device just to get the doctor to stop bringing up the conversation

[8, 11]. Black women have noted discriminatory experiences of “repeated provider-initiated” contraceptive counseling in which they believed that their provider was pushing them to be on a long-acting birth control method because they were poor, black or both [11].

Overall, there is a lack of knowledge surrounding LARC devices and women still continue to have many negative perceptions associated with LARCs. These views and knowledge gaps are particularly dangerous because they actively contribute to reproductive health disparities and adverse birth outcomes. Gomez et al. also found that many of the negative contraceptive counseling experiences that women had occurred relatively early in their reproductive ages; the average age of the participants was 24 [11]. Studies have shown that younger women of color are more likely to receive “provider-driven” contraceptive counseling [12]. Many women who feel pressured into using a LARC device or did not receive adequate information regarding the method at the appointment and resorted to input from the internet or their friends and family discontinue the method shortly after the insertion process.

3.0 Journal Article

Perceptions of Long-Acting Reversible Contraceptives Among Black Women: Barriers to Health and Wellness

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3.1 Abstract

Over 45% of pregnancies in the United States are unintended and there is a large disparity in unintended pregnancies (UIPs) between black and white women in the United States. Long-acting reversible contraceptives are over 99% effective and provide a unique set of characteristics that can help reduce the disparity in unintended pregnancies. However, black women in the United States use long-acting reversible contraceptives at lower rates than white women. Understanding the perceptions and attitudes that black women hold regarding LARCs can help give insight into how public health initiatives can be developed so providers can better counsel women on their

birth control options. Eight in-depth qualitative interviews were conducted with women at the Mt. Oliver Magee Women's Community Health clinic in Pittsburgh, Pennsylvania. The results showed that women have many negative associations and fears regarding LARCs. The participants want direct control over their reproductive behaviors and LARCs do not allow for that. This study suggests that there is a need for emphasis on patient-centered contraceptive counseling for black women and more research needs to be done to determine how to combat the misinformation present in communities and on the internet.

3.2 Introduction

In the United States about 45% of pregnancies are unintended [1, 2]. Since 2008, the unintended pregnancy rate has declined from 54 per 1,000 to 45 per 1,000. A majority of unintended pregnancies are due to the incorrect use of contraceptive methods [1, 2]. There is a disparity in unintended pregnancy rates between black and white women in the United States, with the unintended pregnancy rate for black women three times higher than that of their white counterparts [3]. Unintended pregnancies have negative effects on the health of the baby [4]. If a woman experiences an unintended pregnancy, she is more likely to have a baby who is born prematurely or who has low birth weight or very low birth weight [3]. Black women in the United States are twice as likely to have an infant who experiences low birth weight or very low birth weight compared to their white counterparts [5]. Unintended pregnancies can largely be prevented by the encouraging the use of LARCs [6].

LARC devices prevent unintended pregnancies because they are over 99% effective, 20 times more effective than oral contraceptive pills, transdermal patches and vaginal rings [6]. LARC

devices offer many benefits such as the promotion of a longer interpregnancy interval and little to no user maintenance once the device is placed by a trained provider [6]. However, LARC uptake in the United States is relatively low as only 10% of women use an IUD and 1% of women use an implant as their primary form of contraception [6]. For black women, the rates of LARC use are even lower [7].

An existing body of literature documents women's overall negative perception and discomfort with LARC devices [8-14]. In qualitative studies, many women have noted that when providers counsel them on their contraceptive options they feel that the provider does not present all of the options without bias [8, 11]. The women mentioned that providers talk about the negative aspects of contraceptive methods such as oral contraceptive pills, transdermal patches and condoms but give IUDs and implants glowing reviews while downplaying the risk of complications and the potential side effects [11]. The Dalkon Shield IUD, an IUD released mid-20th century, saw initial success in the United States [15]. However, the device was quickly removed from the market as it was connected with causing complications such as sepsis, infertility and death [15]. In recent studies many women cited hearing negative stories from their family members or friends as a major contributor in their decision to not use an IUD [14]. Today, LARC devices are very safe and effective and the risk of complications is less than 1% [6].

For black women, the negative perceptions of LARCs are amplified. Studies document that black women feel they are discriminated against while being counseled on their contraceptive options [11, 34]. Some black women have noted that when providers discuss birth control options the providers "packaged" the information regarding contraceptives in order to get the woman to choose an IUD or LARC device. If a woman was not currently using a LARC method, the doctor

initiated a conversation about the devices regardless of the woman's satisfaction with her current method [11, 12, 17].

There are many examples of experimentation and maltreatment of black Americans in history that have caused a legacy of distrust in the medical system [41]. This distrust may impact black women's use of LARC devices. In order to reduce unintended pregnancy rates and adverse birth outcomes in black women, there is a need to understand the attitudes and perceptions towards LARC devices.

3.3 Methods

Semi-structured interviews were conducted with eight women age 18 – 44 who self-identified as black or African American at UPMC Magee Womens Hospital Mt. Oliver Community Health Clinic in Pittsburgh, PA. This clinic was ideal for study recruitment because it serves over 200 black women per week and the current standard of care practice includes routine contraceptive counseling and prenatal care. The University of Pittsburgh institutional review board approved this research protocol (PRO1906003).

Numerous administrative and logistical challenges made it difficult to gain entrée into the UPMC Magee Womens Hospital Mt. Oliver Community Health Clinic. For example, the gatekeeper of the clinic experienced a medical condition that delayed response to requests and the private office in which the interviews were conducted were available for limited hours due to other activities occurring at the clinic. These challenges limited data collection to only September 2019.

3.3.1 Recruitment

Upon arrival at the clinic, the medical assistant(s) at the front desk of the clinic screened patients for eligibility in the study. To be eligible the patient had to be 1) between 18 and 44 years of age, 2) self-identify as a black or African American woman, and 3) willing to participate in a 30-minute interview after the conclusion of her appointment. If the woman met the aforementioned inclusion criteria, then the nursing staff referred the patient to the research team.

Recruitment and data collection took place in September 2019. Prior to initiation of the interview, the research team member explained to the participant that the study would be examining their views on long-acting reversible contraceptives and how they conceptualize their contraceptive choices within the context of their overall reproductive health. Each participant was informed that the interview would be audio-recorded and her responses transcribed and analyzed. Participants were given a unique identifier to ensure anonymity. All participants gave verbal consent and no identifying information was collected. Interviews were conducted in a private office space to maintain confidentiality. Perceptions of long-acting reversible contraceptives were explored using the following questions:

- 1) What is your age?
- 2) Tell me what you know about birth control devices like IUDs and implants.
- 3) Would you choose to use an IUD or implant for birth control? Tell me why or why not.
- 4) Other medical devices are often inserted into people's bodies (insulin pump, pacemakers for the heart and breast implants). What makes an IUD or implant different from these devices?
- 5) Tell me what you have heard about IUDs and implants from your family members and friends.

- 6) Why do you think black women overall are less likely to use IUDs or implants?
- 7) How do you think IUDs and implants compare to other birth control methods like the pill or condoms in preventing pregnancy?
- 8) Do you think that using a birth control method like an IUD or implant will help you have a healthy baby in the future?

At the conclusion of the interview, participants were given a \$20 gift card as compensation for their time.

3.3.2 Analysis

Audio-recorded interviews were transcribed into a Word document and the qualitative coding software Dedoose was used to facilitate analysis of the interviews. Any identifying information disclosed by the participants in the interviews (e.g. names, locations other than Pittsburgh, or dates) was deleted in the transcription process. Interviews were analyzed using a carefully designed thematic approach in which all similar ideas and comments shared by the participants were assigned a theme. Themes were pre-determined based on the questions from the interviews in order to create a codebook. The pre-determined themes included knowledge of LARCs, LARC misconceptions and fears, relationship expectations, traditional child rearing practices and birth control, thoughts LARC use among black women, and LARCs and healthy pregnancies. Prior to coding, the primary author read the interviews to identify any sub-themes. After identification of themes and sub-themes the interviews were coded accordingly. All interviews were coded once by the author and reviewed for consistency by the research assistant. The six major themes and sub-themes were then organized to into overarching categories examined

in the results section. Individual quotes from the semi-structured interviews were selected to highlight the themes that arose from analysis.

3.4 Results

Eight women who self-identified as black or African American whose ages ranged from 23 to 44 participated in this research study. The average age of the eight participants was 31. All women who participated in the study indicated having used some form of contraception either currently or in the past. Each woman who participated in the study had at least one previous pregnancy. The themes identified in the interviews are presented below and are titled knowledge of LARCs, LARC misconceptions and fears, relationship expectations, thoughts on LARC use among black women, traditional child rearing practices and birth control and LARC use and healthy pregnancies.

3.4.1 Knowledge of LARCs

Participant knowledge about the efficacy, safety, side effects and potential complications of LARC devices varied. In discussing knowledge about LARCs a 24-year-old participant expressed that her only knowledge about the LARC devices was that they did not always work. She stated, “well I know sometimes they don’t work. . . I just don’t want to get on it, ‘cause there’s no point.” Some patients described not really knowing much about the devices and seeking information from the internet or close family members and friends. A participant stated, “I don’t know much about them. I’ve just read stories about them.” Some of the women mentioned having

heard information about LARC devices from their physician at the clinic but they were not able to state that information during the interview. One participant mentioned that when the doctor spoke with her about her contraceptive options, she felt that not all of the information regarding side effects or complications of the LARC devices was communicated to her, and if she had not conducted her own research she would not have chosen to use a LARC device.

Some women acknowledged not understanding the devices, and they feared a device being inserted into their body. During an interview, a participant expressed, “How do you maintain it? I think that’s a thought a lot of people have going on. How is it clean for your body?” One woman stated, “but I feel that to me, it’s a little dangerous because it’s like this thing going inside of you ... things can happen with that inside of you.” Two of the eight participants mentioned having knowledge on the IUD devices, specifically the Mirena. A 33-year-old participant expressed that she knew that with the Mirena IUD, “it would slow down my period.” One woman indicated that she contemplated getting the Mirena because she did not know much about the device but also, “heard so many horror stories from older women ... mainly black women.” Ultimately, this participant decided to get the IUD after a couple of months of her own research and counseling from her OB/GYN.

3.4.2 LARC Misconceptions and Fears

Evidence of misinformation and apprehension regarding contraception, specifically LARCs, was apparent in the interviews. All of the women mentioned hearing “horror” stories about LARC devices from family members or friends and that “some people say it’s like painful, or their body be hurting, or they be sick.” One woman mentioned that a family member had the Nexplanon inserted and it turned her arm “black and blue.” Another mentioned that she had heard

some people had “died from the birth control in their arm” and therefore would never use the device. One of the women revealed that she was apprehensive of a LARC device because, “it was connected to cancer and connected to other things in the body.” A 33-year-old participant stated that LARCs had been “frowned upon” by women in her family because they were scared of “putting in an object and just letting it stay there.” This information was enough to prevent them from using a LARC or continuing with oral contraceptive pills or Depo Provera shots.

Another theme that emerged in the interviews was that no birth control method is 100% effective which potentially makes the use of contraceptives unnecessary. Interestingly, one 24-year-old woman was very adamant about the lack of efficacy of any contraception. She indicated, “Any birth control, you can still get pregnant. It’s not saving nothing.” Even though the doctor informed her that LARCs were over 99% effective, she still would not use that method due to lack of 100% protection from pregnancy. Three of the eight women shared positive feelings about LARC devices, stating that they were anxious about the procedure and side effects prior to the insertion procedure but eventually realized that using a LARC was a good change for them. One participant stated, “I’m happy because I get no scares of pregnancies. I’m good.”

Participants also expressed their concerns with not knowing exactly what the procedure of insertion and removal entailed and were terrified that the doctor would “say one thing and put something else up there.” Lastly, most of the women understood that the hormonal IUD and implant could have negative side effects such as weight gain and acne. The potential for weight gain was a deterrent to choosing a LARC device for contraception. One participant stated that her LARC device “kept bringing my weight up.” Another participant stated, “oh, you just hear the crazy stories ... you’re going to gain a lot of weight.” Overall, perceptions of LARC devices were mostly negative in that they cause a lot of side effects and can be dangerous for women to use.

3.4.3 Relationship Expectations

Many women stated that when they entered into a monogamous heterosexual relationship they wanted to have children with their partner. To do this, they need the flexibility to start and stop taking birth control based on their relationship status. A 39-year old participant stated that she thought black women did not want to use LARCs because of men, “that’s mainly what it is. . . I think I’m in love type thing.” Another woman stated, “they’ll meet somebody and want to get pregnant.” Having LARC devices inserted or removed requires making an appointment with a medical provider, which can take days to weeks whereas use of OCPs, condoms, and rings can be stopped immediately.

A 28-year-old participant expressed, “If I had birth control pills, I could automatically just stop, but with this it is kinda like you can’t really get it out until you actually go to, like, visit a doctor.” The participants’ responses suggested that pregnancy and childbearing were expressions of love for their partner in a relationship. Black women want birth control options that afford some flexibility, allow for more control over their reproduction and give them the ability to get pregnant when they want to.

3.4.4 Traditional Child Rearing Practices and Birth Control

When asked about black women and LARCs some women mentioned that these are not things that parents discuss with you. In fact, a couple of participants mentioned that they were able to obtain information on their contraceptive options only when they were older and had to conduct their own research. Once parents and guardians discovered that their children were sexually active, they would then share information about potential birth control options. A 26-year-old participant

stated, “In the black community, we don’t talk to our kids about birth control unless we find out that they are sexually active.” Some participants said that when they tried to be informed about contraception, family members or friends tried to discourage sexual activity and birth control by sharing traumatic stories about contraceptives’ effect on the body.

3.4.5 Thoughts on LARC Use Among Black Women

Regarding the participants’ thoughts on black women and LARC some women felt that they were explicitly taught not to let any medical professional place foreign objects in their bodies because it could be dangerous. A 44-year-old participant referring to the IUD stated, “actually, I was shocked the older I got, that they had them on the market again.” She continued on to say that black women she knew “had to have hysterectomies” because “I guess [their IUD] got lost in them.” In addition, another woman stated that “oh, my mother said that’s not safe for you, you shouldn’t be getting nothing like that injected in you, leaving that in you for all them years.”

In discussing the implant, another woman stated that “... it could be you know, you’ve been taught not to let people put stuff in you too.” Many women indicated that allowing foreign objects in the body could lead to dangerous repercussions. A 32-year-old woman candidly stated that she thought a lot of black women “have the government in mind when they roll out these things” and they believe that “it’s just a tracking method, they know where you at now.” Some women believed that having a device allows government or some higher authority to track and monitor black women’s reproductive behavior. Another participant mentioned that the non-use of LARC devices “comes from not trusting through history what the doctors, the government, whatever has done to black people.”

3.4.6 LARCs and Healthy Pregnancies

When asked if using a LARC device will aid in having a healthy baby in a future pregnancy, some of the women answered yes and suggested that the devices could help women plan for children better. None of the participants mentioned that LARC devices could be beneficial in promoting the recommended birth spacing and preventing adverse birth outcomes. One participant stated, “I think that it would be better for people that maybe in the long run might just want a child, like for right now, you’re protected.” Other participants were unsure if LARC devices would help with having a future health pregnancy: “I feel like other factors play into having a baby. Mostly your diet and how your lifestyle is ...,” said a 26-year-old participant.

Interestingly, some participants were convinced that using a LARC device would not protect them from pregnancy. One woman stated, “well sometimes they don’t work ... ’cause my friend was on it and is pregnant now.” Some women chose to use less effective forms of birth control or no birth control one participant mentioned that they would just rather use “Plan B,” the over-the-counter emergency contraception in order to prevent an unintended pregnancy.

3.5 Discussion

Based on the eight interviews conducted, it appears there is still a large knowledge gap in relation to long-acting reversible contraceptives among black women. None of the participants was able to clearly articulate safety information, effectiveness or what the insertion and removal procedures of LARCs entailed. Furthermore, a majority of the participants had some hesitation when they were discussing the devices with their doctors. Even though some participants

expressed that their physician had spoken with them about the device they were not able to repeat that information from those consultations during the interview. The participants stated that they turned to family, friends or the internet for information regarding their contraceptive options. It seems as if the women who participated in the interviews trusted the information provided by their family members and friends more than they trusted the information provided by the physicians.

Most women articulated that they have heard negative things about the LARC devices from family members, friends and the internet. This can be particularly dangerous because the internet hosts a number of websites with misinformation that deter women from choosing a contraceptive option that is beneficial for them. Since black women are more likely to not use LARC devices, it is important to ensure that they are receiving proper counseling and are provided with credible resources by their physicians so they can make appropriate decisions for their health.

All of the women mentioned hearing directly personal narratives or second-hand stories from close relatives and other members of their social networks. These stories were overwhelmingly negative in nature and were told to discourage the participant from receiving an IUD or implant. The development of the oral contraceptive pill along with the Dalkon-Shield and Norplant scandals all occurred within recent history. Many of the women who were in their adolescence and early adulthood for those events vividly remember the threats that the devices placed on women's lives and how the methods were used coercively in the black population.

Based on historical manipulation and reproductive coercion of black women, apprehension about contraceptive use is understandable. Unfortunately, systemic racism and biased medical practices result in black women in the United States experiencing preventable health conditions such as preterm birth. Improvements must be made in how physicians and other medical providers counsel black women on LARC devices to improve their health and their children's health.

Moreover, it may be beneficial for public health officials to invest in training and education for peer educators who would be responsible for disseminating information regarding contraceptive options. There seems to be a disconnect between medical providers and patients that continues to reinforce misinformation and negative perceptions. Peer educators could be a potential asset in reducing that gap.

Dynamics of relationships between black men and women were cited as a reason for why black women did not want to use long-acting reversible contraceptives. Women expressed the desire to control their reproductive behavior. IUDs and implants remove this control as they require a visit to a medical provider before conceiving a child. For hundreds of years, black women had little to no control over their reproductive behavior and want the ability to choose when they have children.

Participants mentioned that some members of the black community in the United States have difficulty discussing contraception with their children. This prevented the now adult women from understanding completely what their contraceptive options are and how to prevent pregnancy. Without that information, black women may be less likely to explore all options available to them when they become sexually active. Lastly, participants in the study stated some fears about the U.S. government and physicians. LARC methods were discussed as a means of tracking women's whereabouts. This idea may be related to the legacy of historical practices of forced sterilizations among minority populations in the United States.

LARCs help promote healthy birth spacing in women due to their "long-acting" nature. This is beneficial because it helps to reduce adverse birth outcomes. None of the women who participated in the study were able to conceptually connect a healthy interpregnancy interval with the use of long-acting reversible contraception. It is necessary for women to understand the

importance of healthy birth spacing to have subsequent healthy pregnancies. Focusing on the health of the patient and her future child(ren) is vital to effectively counseling black women on LARCs and other birth control methods.

3.6 Limitations

This study was conducted between September 1 and September 30, 2019, and used clinical staff to recruit women for participation in the study. After having been introduced to the study by the medical assistant(s), an element of self-selection bias may be present among the women who decided to participate in the interview. The women who ultimately decided to participate might have had an underlying interest in the research topic and their responses may not be generalizable. Moreover, when introducing the study to potential participants the staff at the clinic could have introduced an element of bias depending on their feelings about the study topic. Data were collected over a very short period of time, which captured only a select group of women. Moreover, due to time constraints for data collection, recruitment for the study was terminated after eight participants. It is unclear if thematic saturation had been reached within these eight interviews.

However, it is important to note that the results of this study are not intended to be generalizable, but rather to begin to explore issues about LARC use and suggest recommendations for future research [16]. The women who participated have a previously established relationship with the health care system and their opinions and comments may not be representative of women who do not regularly receive care from a health care provider. It is also possible that the women who participated in the interviews had a greater working knowledge of their birth control options,

specifically LARCs due to their continuous interactions with the medical care providers at Magee Women's Hospital.

The city of Pittsburgh presents unique circumstances for recruitment into a research study related to health care. Pittsburgh is home to two competitive health care providers, University of Pittsburgh Medical Center (UPMC) and Allegheny Health Network (AHN). It is possible that individuals living in the greater Pittsburgh area have increased access to health care providers due to the sheer number of offices in the area. For example, UPMC has 40 hospitals, over 700 outpatient and doctor's offices and employs roughly 5,000 physicians, most of whom are located within Southwestern Pennsylvania [92]. Allegheny Health Network operates eight hospitals, a number of community health centers and urgent care clinics, and employs about 2,000 physicians [93]. The probability that the women who participated in the study have greater access to health care providers compared to women in areas where medical provisions are not as readily available is likely.

Lastly, this study solely focused on race and how that influences the perceptions of LARCs. Other factors such as education level, insurance status, or socioeconomic status may affect a woman's perception of a particular contraceptive method.

3.7 Conclusion

The eight interviews conducted provided insight into how black women conceptualize and perceive long-acting reversible contraception. From the interviews, it is apparent that LARC counseling is not sufficient and that women often seek advice from outside of the physician's office. Additional information is typically gathered from the internet or family members or friends,

who often gave negative impressions of the LARC devices. Women in the study tended to believe that these devices still were not safe for use in the body although less than 1% of insertions end with a serious complication such as uterine perforation or IUD migration [6, 25]. These data suggest that the idea of LARCs causing harm or being used a form of control is still evident today.

Overall, there were mixed views on whether or not the devices were helpful at preventing pregnancy as some women felt there was no additional benefit provided to them with these devices compared to the pill or the Depo Provera shot as no contraceptive method was 100%. One participant felt that the device was “the greatest thing since sliced bread.” Some participants hinted that they thought the LARC device may help prevent unintended pregnancies because it is inserted once and you do not have to worry about remembering to take a pill every day or going to the store to purchase condoms.

A majority of the participants stated that they were told that using a LARC device was not safe. Specifically, there were statements from the participants noting black women had fears of IUDs because they suffered from major complications or they were specifically taught to not have any devices placed inside them. A major shift in the healthcare system is necessary in order to change the narrative and allow for black Americans to trust the medical system. Providers may benefit from some cultural competency or cultural sensitivity training to help them better counsel women on their reproductive behaviors. Moreover, peer education may be an innovative method of relaying accurate information about LARCs to black women.

This study shows that the perceptions of long-acting reversible contraceptives among black women are mostly negative and associated with misinformation mainly from family, friends and the internet. In order to improve the disparity in unintended pregnancy rates and adverse birth outcomes, it is imperative to understand how these factors work together to produce black

women's views on birth control. LARC devices may not be appropriate for every woman; however, it is possible for rates of their use to increase. The data from this study suggest that there needs to be emphasis placed on patient-centered counseling for black women and more research needs to be done to understand how to break the generational idea that long-acting reversible contraceptives are dangerous and effectively a form of "black genocide."

3.7.1 Implications

The historical examples of mistreatment and exploitation within the healthcare system of black Americans in the United States has left a legacy of health disparities surrounding maternal and infant health. Medical professionals are becoming increasingly aware of the health disparities and their detrimental effects; however, this has had little effect on policies, best practices or standards of care present in healthcare systems.

Unintended pregnancies are largely preventable through the utilization of contraceptive methods such as IUDs or implants [1]. Reducing the number of UIPs among black women would help reduce the disparity in adverse birth outcomes for black infants [33, 94, 95]. However, medical staff are still having a difficult time establishing a trusting relationship with black women patients. Many healthcare organizations do not have the financial resources to support training surrounding implicit biases and racism. Without training and support, well-meaning healthcare employees will continue to unconsciously impose racist stereotypes such as these women are ignorant, untrustworthy, 'welfare queens' and are to blame for their poor maternal health outcomes [42].

Attempting to create an environment in which black women are counseled effectively on their birth control options is going to take audacious, concrete plans put forth by public health

officials. Addressing implicit biases is a public health issue because it affects the health of our communities and contributes to health disparities [96]. When being counseled on their contraceptive options, it is important to ensure that women feel as though they have the agency to make their own medical decisions. Providers should be explaining all of the potential contraceptive options and providing support for whichever option a woman feels best suits her lifestyle.

A few public health initiatives have attempted to ensure that the reproductive health needs of all women are met. For example, the Contraceptive CHOICE study that took place in St. Louis, MO found that when counseled effectively on LARC devices over 75% of women chose to use this form of contraceptive [95]. The researchers found that there was no specific demographic of women that was more likely to choose a LARC device. Another example, in New York City, is Mayor Bill de Blasio's launch of a plan that implements mandatory implicit bias training for private and public health care providers and forms partnerships with community-based organizations to address education surrounding maternal health issues [42].

Reducing health care disparities regarding black maternal health outcomes requires that all medical providers first acknowledge their own biases and work to continually address them. It is up to all public health officials and medical providers to create ways to counsel all patients ethically and effectively on their contraceptive options. Together, we can create a healthy future for all mothers and children.

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4.0 Thesis Conclusions

LARC devices became popular in the United States during the mid-20th century after the FDA approved their use. The first contraceptive implant, Norplant, was introduced to women in the U.S. in 1990. However, many of the women who used the LARC devices of the 20th century like the Dalkon Shield and Norplant experienced severe complications that sometimes resulted in death [15]. Negative perceptions of LARC devices persist in generations after the mid-1900 IUD controversies and may be related to the low uptake rates of long-acting reversible contraceptives today.

The LARC devices of the 21st century are very safe for women to use and over 99% effective at preventing pregnancy. The devices are inserted once and remain effective for three to five years. There are few contraindications for LARC devices and almost all women can use them as their primary form of birth control. Despite the efficacy for preventing pregnancy and simplicity of using the device, LARC uptake in the United States remains very low [6]. For black women in the United States, rates of LARC use are even lower, which may contribute to the high rate of unintended pregnancy among black women [91].

The unintended pregnancy rate in black women is three times higher than that of white women in the United States [1]. Unintended pregnancy increases the risk of having a baby born prematurely or with low birth weight [1, 5]. If a baby is born prematurely or with low birth weight, this can lead to a number of adverse events, future chronic diseases or even death [5]. LARC devices may offer a unique solution to helping women prevent unintended pregnancy and promote the recommended birth spacing of 18 months [9].

There is a legacy of medical distrust among blacks in the United States. Black Americans have experienced a history of experimentation and maltreatment, which has led to a fragile relationship with the healthcare system. Many black Americans do not interact with the healthcare system because they fear being mistreated or discriminated against by the doctor [41]. Black women have also experienced many incidents of reproductive coercion, leaving them to feel as though the government and other entities are trying to control their reproduction [42]. Distrust of the medical system and providers may have implications for the promotion of LARCs as a contraceptive method [21, 48].

Eight women participated in this study. They shared their opinions, perceptions and attitudes about LARC devices. Overall, they lacked knowledge about long-acting reversible contraceptives even though a number of women mentioned that their provider had explicit conversations with them about these methods. Many of the participants relied on close family members, friends and the internet to provide them with information about these contraceptive methods. There was some mention of women wanting to have control over when they wanted to get pregnant. By using a birth control method like the oral contraceptive pill women were able to stop taking the pill, resume normal fertility and get pregnant. If they use a LARC they have to schedule an appointment with their doctor to get the device removed before they were able to get pregnant.

In some of the women's immediate families, contraception was not regularly discussed. Many parents did not have a conversation with the women about contraception until parents discovered that their daughters were sexually active. Parents and guardians shared traumatic stories about birth control to scare the women out of having sex. Lastly, some women felt that by having

a foreign object inserted into their body, the government or higher authority could track and monitor their reproductive behavior.

In-depth qualitative interviews were held with women from September 1 to September 30, 2019. After being informed about the study the women chose to participate and an element of self-selection bias may be present in the sample. Moreover, this study was conducted in Pittsburgh, PA where two competing health systems have numerous facilities all over the area. Women who participated in this study likely have a greater working knowledge of general health care and contraception as they have a previously established relationship with a provider.

Moving forward, it is important that providers explain all of the risks and benefits associated with each contraceptive method so that a woman can make the most informed decision for her individual circumstances. Long-acting reversible contraceptives provide a unique set of protections against pregnancy but this may not be appropriate for every woman. Even after the provider has completed counseling on contraceptive methods at the appointment, the woman should be provided with some materials that she can take home or given credible resources that she can look up online to gather more information. As the results of this study show, family members, friends and the internet seem to impact the contraceptive choices that women make.

Finally, beginning to mend the fractured relationship between the healthcare system in the United States and blacks is going to require systemic changes. Potential solutions to increase trust in the medical system among black Americans include cultural awareness training, revisiting “best practices” policies and acknowledgement of implicit biases.

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