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The Path to Pregnancy: Fertility Services and Assisted Reproductive Technologies

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Abstract

The emergence of reproductive assistance like fertility treatments and assisted reproductive technologies (ART) in recent decades have provided new paths to pregnancy for many individuals. However, certain demographics in the US like low-income women and women of color are often excluded from utilizing these services on the basis of race, geography, and socioeconomic status. This in turn leads to significant disparities in access to and usage rates of such services. This research points out the perceived shortcomings in the current academic discussion surrounding fertility service disparities with the ultimate goal of expanding access to fertility assistance services for those who need it the most. Discussions about barriers to receiving fertility assistance services for marginalized demographics have been discussed at length in public health publications from governmental entities like the Centers for Disease Control and Prevention. Unfortunately, such discourse has become stagnant due to a lack of novel ideas and repetition of the same recommendations for eliminating access and usage disparities that have been proven ineffective by the fieldwork of social scientists. For example, many public health publications continually call for expansion of state insurance mandates to offer or cover fertility treatments and ART services in order to eliminate treatment disparities despite numerous publications revealing that these disparities persist even in states with comprehensive fertility assistance insurance mandates. To call attention to this pattern and to add nuance and depth to the current academic discussion, this research incorporates perspectives and findings from the fieldwork of social scientists studying fertility assistance services. The main conclusion made by this interdisciplinary research is that our nation's current fertility service disparities and biases effectively encourage the reproduction of those that fit ideological notions of motherhood and discourage the reproduction of those that do not. By addressing fertility treatment disparities from the integrated perspectives of both public health and social science, this research aims to both help lead to novel and effective solutions for eliminating such disparities and to encourage interdisciplinary endeavors across the fields of medicine, public health, and sociology in the future. Lastly, this paper calls for the inclusion of cancer-related infertility and the sub-discipline of oncofertility in future nationwide discussions about fertility treatment access and usage.

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Most people have probably heard at least one story about a baby being a surprise, an accident, or a "honeymoon baby." Hearing many iterations of these stories about abundant fertility may lead people to consider difficulties becoming pregnant a rare occurrence that afflicts only an unfortunate few. Contrary to stories of conception that result in the birth of a child, stories of infertility are a mostly hidden struggle. Yet this struggle is perhaps far more common than one might imagine. From 2011-2015 alone, 7.3 million women in the United States reported utilization of any type of fertility assistance service according to the comprehensive National Survey of Family Growth from the United States Center for Disease Control (CDC) (National Survey of Family Growth, "Infertility services", 2016). Fertility assistance services and the disparities that exist in accessing and utilizing such services have been well-documented in the literature of recent decades, which will be at discussed at length throughout the course of this paper.

With that being said, such discussions have become stagnant over the years, leading to regurgitation of the same statistics and vague pleas to eliminate fertility treatment disparities many times over. Moreover, some dialogue surrounding fertility treatment access and usage inequities fails to address a couple key aspects. First, cancer patients and the sub-discipline of oncofertility as a whole are often left out of the conversation. Second, many policy recommendations proposed in the literature focus solely on eliminating fertility-specific health disparities across racial, geographical, and socioeconomical lines, but fail to address the overarching disparities and discrimination in the field of healthcare that largely contribute to the existence of fertility-specific inequalities in the first place.

This paper will point out the perceived shortcomings in the current academic discussion surrounding fertility service disparities by analyzing demographical data through the lens of

social science literature. For example, the topic of state-mandated fertility service coverage and its effect on fertility treatment usage rates across racial and socioeconomic lines will be analyzed using this interdisciplinary approach. Doing so will hopefully add nuance and depth to the current discussion and encourage future interdisciplinary endeavors across the fields of medicine, public health, and sociology. To accomplish these goals, this paper will first address some common causes of infertility that necessitate the use of reproductive assistance services. Then, general information about different types of fertility treatments will be outlined, followed by barriers to accessing said services across racial, geographical, and socioeconomical lines for both the general population and the oncofertility population. Lastly, barriers to access will be explained and analyzed through social science perspectives in the hopes of encouraging dialogue that is geared toward making tangible strides to decrease both fertility-specific health inequities and societal-level inequities.

A more bottom-up, interdisciplinary approach to understanding and addressing the factors that limit access to and use of fertility services must be employed in the future to decrease the chances of individuals from marginalized minority groups slipping through the cracks and failing to receive the fertility services they seek. To do so, perspectives from the realm of social science that address the everyday realities of women experiencing limited access to fertility services must be incorporated into official nationwide discussions about infertility treatment disparities for both the general and cancer-afflicted populations. Whether intentional or not, our society's current disparities and biases effectively *encourage* the reproduction of women that fit ideological notions of motherhood and *discourage* the reproduction of women that do not (Bell, 2010). In order to more definitively tackle disparities in access to reproduction assistance, our country's deeply rooted biases and overarching health inequities must also be addressed.

PART I: INTRODUCTION & BACKGROUND

Infertility and Impaired Fecundity

Before delving into the specifics of fertility, infertility, and everything in between, it is useful to define some key terms. While there is no standard definition for infertility that is consistent across all relevant organizations and academic disciplines, infertility is often described as the inability of married couples to conceive a clinical pregnancy after one year or more of trying, as described in the CDC's National Public Health Action Plan for the Detection, Prevention, and Management of Infertility. A term adjacent to infertility is impaired fecundity, which refers to individuals of any marital status who are unable to achieve a viable pregnancy after three years of unprotected intercourse ("National Public Health Action Plan", 2014). If infertility and impaired fecundity is the failure to achieve a pregnancy in a timely manner, fertility can be considered the ability to achieve a pregnancy within a 12-month period of attempts to conceive.¹ Although men in addition to women experience fertility struggles, the scope of this paper will focus on women.

Discussions of fertility and infertility have been on the rise in the United States in recent decades, likely due in part to women having their first children later in life than in previous decades. One report summarizing vital birth statistics in the US found that the percentage of women giving birth to their first child who were aged 30 or more years increased 21% in 35 years with percentages rising from only 5% of women in 1975 to 26% of women in 2010 (Hamilton, Martin, & Ventura, 2011). Furthermore, infertility rates increase in both men and women as paternal and maternal age increase due to a reduction in sperm abundance and quality

¹ While the aim of the paper is to discuss fertility issues between couples consisting of cis female and a cis male, it is worth noting that the general nature of these definitions does not account for the wide array of fertility struggles faced by people in communities like the LGBTQ+ community and beyond.

in men and a decrease in oocyte quality and ovulatory function in women. In addition to the aforementioned causes for increased infertility in women as maternal age increases, women's risk of experiencing other fertility complications like endometriosis and tubal factor infertility due to fallopian tube scarring or obstruction also increase (CDC, 2014). Other common causes of fertility issues in women are complications due to autoimmune disorders, abnormal reproductive tract growths such as uterine fibroids, sexually transmitted infections (STIs) like Chlamydia trachomatis and human papillomaviruses, and hormonal conditions like polycystic ovary syndrome ("What are some common causes of female infertility?", 2017). While it is true that some of these common causes of infertility like STIs are preventable in most cases, women from certain demographics in the US like black women are disproportionately affected by particular risk factors like uterine fibroids and chlamydia ("National Public Health Action Plan", 2014). Simply preventing common causes of infertility is not always a feasible solution to eliminating fertility struggles for all populations of women, therefore it remains productive to discuss infertility interventions for those who have already been afflicted with impaired fecundity or infertility or those who will become affected in the future.

Another cause of infertility for child-bearing individuals is cancer. When a child is 10 years old, he or she possesses a 1.67% chance of receiving a cancer diagnosis in the next 30 years, or by the time they have aged 40 years (White *et al*, 2015). While this may not seem like a large percentage, this means that just under 5.5 million 10-year-olds in the US will receive a cancer diagnosis before their years of childbearing are over. Similarly, over 135,000 people under the age of 45 will be diagnosed with cancer each year, with approximately one-half of these individuals being females (National Cancer Institute, 2018). Fortunately, not all cancers and their treatments result in fertility issues. If a cancer can be treated surgically or with minimal

intervention, a person's fertility should not be affected. Cancers that do involve high-intensity intervention, however, create the possibility of cancer-related infertility.

Generally speaking, the most common causes of cancer-related infertility in women are often caused by cytotoxic chemotherapy and radiotherapy. Depending on the specific type of chemotherapy, cytotoxic chemotherapy can result in gonadal damage (Salama, Isachenko, Rahimi, & Mallmann, 2017). Alkylating agents, a class of chemotherapy drugs that damage the DNA of cancer cells and in turn prevent any further growth, are used as a standard line of therapy against a variety of cancer types. Alkylating agents exhibit dose-dependent germline toxicity or "gonadotoxicity" by also damaging ovarian and fallopian tissues. Even more damaging to the female reproductive tract is radiation therapy or "radiotherapy", which is used in a targeted fashion for the treatment of solid tumor cancers or is delivered to the whole body in the case of total body irradiation used for non-solid tumor hematologic malignancies. Because of its ability to kill over 50% of a female's ovarian follicles with just 2 Gy of radiation, radiotherapy can cause gonadotoxicity, early menopause, and complete ovarian failure. While only 2 Gy of radiation is sufficient to largely decrease a woman's fertility options, some treatment courses require closer to 10 Gy of radiation or more (Lee, 2017). Despite the ability of cancer treatments to destroy female reproductive tracts, cancer-related infertility is often excluded from lists of the most common and damaging medical conditions that can decrease infertility and impaired fecundity for women who later try to conceive.

The aforementioned forms of cancer treatment can greatly decrease a woman's chance of conceiving and giving birth to a healthy infant should she later attempt to become pregnant. One study assessing the long-term effects of these treatments on pregnancy outcomes for cancer survivors found that the pregnancy rate among people who have received treatment for cancer is

around 20% lower than the general population. Both alkylating chemotherapy and radiation can cause generalized gonadotoxicity, but radiotherapy has been shown to also damage the uterus and consequently increase the risk of later experiencing spontaneous abortion, premature birth, and giving birth to infants with a low birth weight (Lee, 2017). As briefly mentioned above, greater than or equal to 10 Gy of radiotherapy is the amount of radiation standardly used in treatment plans for individuals with cancer of the blood or immune system. Unfortunately, pregnancy rates decrease 82% when exposed to this amount of radiation (Green, Kawashima, & Leisenring, 2009). Anti-cancer treatment is most damaging to those that receive treatment at a younger age, with cancer survivors that undergo therapy before the age of 20 experiencing infertility at three times the rate of those who have not undergone cancer treatment (Barton, 2013). For this reason, cancers that disproportionately affect younger individuals who are still of child-bearing potential deserve special attention in nationwide discussions about fertility.

One of the types of cancer that largely affects children and adolescents is blood cancer. Blood cancers, also known as hematological malignancies, are a broad category of cancer that consists of leukemia, lymphoma, and myeloma. While hematological malignancies account for only 7-9% of new cancer cases for women of all ages, specific types of blood cancers like leukemia pose a large threat to females before and during their reproductive years. Leukemia accounts for 31% of all cancer in pre-pubertal girls aged 0-14 and 12% of cancer cases in adolescents aged 15-19 years (Siegel, 2018; Leukemia & Lymphoma Society, 2016). Advances in medical technology, early detection and diagnosis, and high-intensity treatment in the last half a century of hematological cancer treatment has increased 5-year survival rate from 34.1% in the 1970s to 62% for all leukemia patients, with patients younger than 45 years reaching a 75.4% 5year survival rate (National Cancer Institute, 2016). While this increase in survival is an

outstanding feat, the very high-intensity treatment that makes this increased survival possible also simultaneously decimates the reproductive tracts of those that undergo the therapy.

Because blood cancers recur at a high rate compared to solid mass cancers, blood cancer survivors often experience disease that relapses or proves resistant to multiple lines of therapy that often necessitates the use of hematopoietic stem cell transplantation (HSCT) as the most promising line of treatment (Lee, 2017). Unfortunately, those that undergo HSCT experience infertility at 36 times the rate of those that do not undergo an HSCT (Carter et al, 2006). Though sometimes overlooked in discussions of fertility preservation and treatments, cancer survivors whose chances of reproduction have been lessened by treatments like cytotoxic chemotherapy and radiotherapy should be included in future discussions.

Fertility Treatments & ART Services for the General Population

Fertility issues that affect both the regular population and the cancer-afflicted population often cause people to turn to their biomedical providers for assistance in ameliorating their struggles to conceive, carry a pregnancy to term, or both. This reproductive assistance falls into the following two main categories: general fertility treatment and assisted reproductive technologies (ART). General fertility treatments options are the less involved of the two options, consisting mostly of non-invasive and low-tech interventions, which is likely why this category of fertility assistance is most prevalent. Of the women aged 15-44 who participated in the 2015-2017 CDC National Survey of Family Growth, 12.7% reported having ever utilized any type of reproductive assistance including both general fertility treatment and ART. Notably, only 0.6% of women reported utilization of ART services. In the realm of general fertility treatment options, 6.7% of women received general medical fertility advice, 5.8% had themselves or their

partners tested for infertility factors, 5.1% received help preventing miscarriage, 4.3% received ovulation medication, 1.4% underwent artificial insemination, and 0.8% underwent surgery to reverse tubal blockage (National Survey of Family Growth, "Infertility services", 2019) (Fig. 1). Understandably, the least invasive and likely least expensive fertility services like general medical advice and help preventing a miscarriage were most prevalent, whereas highintervention ART services were least prevalent.

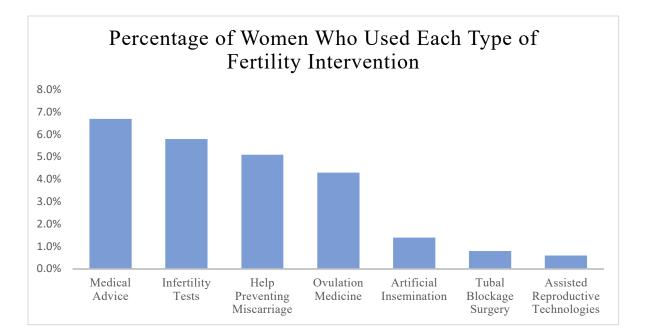


Figure 1. Percentage of women aged 15-44 surveyed in the 2015-2017 CDC National Survey of Family Growth who received each type of reproductive assistance.

Compared to general fertility treatment services, ART services are more involved and more costly. ART for females can be defined as a type of fertility service in which oocytes are surgically extracted from the female and fertilized *ex vivo* in a laboratory setting with the purpose of providing the user with expanded fertility options (Art Success Rates, 2019). Using this definition of ART, intrauterine insemination or "artificial insemination" does not technically

constitute as an ART service because the female's eggs are never extracted and handled *ex vivo*. The vast majority of ART services involve *in vitro* fertilization (IVF) procedures, which consists most routinely of stimulating oocyte production with gonadotropin-based ovulation medication, surgically removing and fertilizing oocytes, and re-implanting the fertilized embryo into a woman's uterus via the cervix (Art Success Rates, 2019). In the most recent national ART summary report released by the CDC in 2016, over 99% of performed ART procedures that year involved the use of IVF. The two other types of ART services for females which place an egg or a zygote directly into a woman's fallopian tube, gamete intrafallopian transfer and zygote intrafallopian transfer, require surgical incisions and general anesthesia and are therefore rarely implemented (2016 ART National Summary Report, 2018).

As previously alluded to, ART procedures like IVF are more costly than general non-ART fertility services because the former often require the labor of and collaboration among multiple physicians and laboratory staff members. Including the ovulation medications, the median out-of-pocket cost of a cycle of IVF in the US is \$19,200. Taking into account that the average number of IVF cycles required to conceive is 2.7, the average total IVF cost is \$51,840 (Ethics Committee of the ASMR). Although it carries a hefty price tag, the development of ART in recent decades has created new pathways to conception that were previously unavailable for those who were unable to conceive or achieve a clinical pregnancy even after exhausting all non-ART modes of fertility treatment.

It is worth noting that the IVF process can be personalized based on each individual's reason for using ART and on her life stage, so a complete IVF cycle does not always take place within a short window of time. For example, a single woman may elect to extract and freeze ("cryopreserve") some of her oocytes in the hopes of maintaining many reproductive options for

the future, such as completion of the IVF process using the sperm of a future partner or sperm donor. This is in fact so common that the ontological category of "anticipated infertility" has emerged in sociological publications to describe "the condition in which one believes one may be infertile in the future" (Martin, 2010). This idea of anticipated infertility is relevant to the general population and is the driving principle behind the use of fertility preservation techniques for female cancer patients. Furthermore, if a person's choice of sperm is known at the start of the IVF process as is often the case with couples undergoing ART services, fertilized embryos that were generated but not implanted during a previous IVF cycle can also be cryopreserved for possible future usage. Lastly, 3% of ART cycles involve the use of a surrogate either by choice or by necessity if the woman is incapable of carrying and delivering a healthy infant (2016 ART National Summary Report, 2018). A flowchart of fertility treatment options spanning both the realms of general infertility treatment and ART can be summarized in Figure 2.²

² Please note that this diagram does not cover all fertility treatment options for males because this paper is focused on female fertility. This is not intended to be an exhaustive list of every single fertility treatment service on the market, but rather to serve as general guideline for a logical order in which to proceed with the most common forms of treatment in the realm of biomedicine. Every individual is unique and should create an appropriate plan of action with their providers.

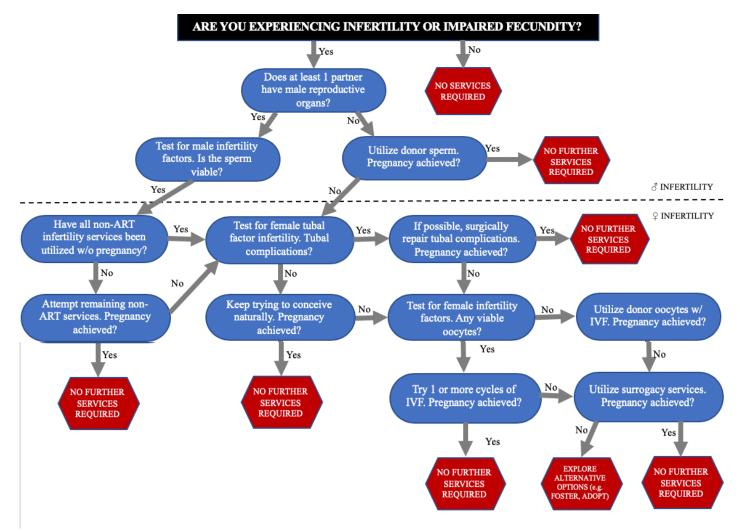


Figure 2. Summary of fertility treatment options including both general fertility treatments and ART services for the female general population.

Before any discrepancies in access to or utilization of ART services can be addressed, accurate ART usage rates must be collected and organized. The National ART Surveillance System (NASS), a standardized data-reporting system led by the CDC, does just this. Using data obtained from US fertility clinics, medical providers can present those pursuing ART services with reasonable estimates of success based on data from previous people who have similar demographics, medical history, and infertility diagnoses (National Art Surveillance, 2019). In 2016 alone, 263,577 ART cycles were performed at the 463 verified ART clinics in the US.

Excluding the 25% of cycles that were initiated with the intention to cryopreserve any resulting oocytes or embryos, the 75% of cycles that were initiated with the intention to proceed to embryo transfer and live birth resulted in the birth of 76, 897 live infants. In terms of general outcomes, women under the age of 40 achieved a pregnancy per ART cycle success rate of 29.0% and a live birth per cycle success rate of 23.5% (2016 ART National Summary Report, 2018). Continued availability of comprehensive ART data plays a key role in future discussions about fertility treatment access.

Fertility Treatments & ART Services for the Oncofertility Population

Though Figure 2 serves as a general guideline that can apply to *most* individuals, certain groups of people experience unique medical circumstances that necessitate especially individualized general fertility and ART treatment plans. Individuals who are about to receive or have already received fertility-compromising cancer treatment are an example of such a group. If a female patient who is about to undergo anti-cancer therapy is post-pubertal, in most cases the individual can undergo ovarian stimulation and oocyte retrieval followed by cryopreservation like any person unafflicted by cancer can do (Salama *et al*, 2017).³ Because of recent novel innovations like emergency IVF or "random start" protocols that allow for oocyte stimulation and retrieval at any point in a female's menstrual cycle, oocytes can be stimulated and retrieved in an average of only two weeks opposed to the 2-6 week time frame for conventional oocyte retrieval (Cakmak & Rosen, 2015). This shortening of the egg-retrieval process timeline

³ The process of gonadal stimulation and subsequent oocyte retrieval is usually the same process for individuals from both the general and oncofertility populations. That being said, data from CDC's NASS suggests that success rates for pregnancy and live birth are higher when fresh eggs opposed to frozen eggs are used. Because oncofertility patients' only option is cryopreservation of samples, their chances of reproduction using IVF is slightly less than that of the general population (National Art Surveillance, 2019).

decreases the likelihood that a woman will opt out of fertility preserving options to avoid a significant delay in receiving chemotherapy or radiation, as is often the case when dealing with blood cancers that require immediate anti-cancer therapy intervention (Salama *et al*, 2017). While the random start method has expanded fertility preservation options for many post-pubertal females with cancer, certain high-risk cases require immediate therapeutic interventions and thus cannot wait even two weeks for an oocyte harvest. Furthermore, traditional IVF processes involving ovarian stimulation are not applicable to all individuals.

Prepubescent girls cannot undergo ovarian stimulation and subsequent oocyte retrieval due to their inactive hypothalamic-pituitary-ovarian axes (Salama et al, 2017). Consequently, the only current fertility option that exists for prepubescent girls is a type of assisted reproductive technology called ovarian tissue cryopreservation. This process consists of collecting immature oocytes from the ovaries to later mature outside the body in preparation for fertilization and eventual transfer into the uterus (Dillon & Gracia, 2012). Finally, women diagnosed with hematological malignancies like lymphoma and leukemia are faced with uniquely difficult fertility preservation prospects. In some cases, oocvtes or ovarian tissue extracted from prepubescent or postpubescent females with blood cancer can be contaminated with malignant cells and therefore cannot be transplanted back into the woman's bodies after remission has been achieved. In attempts to restore fertility for this population, scientists are in the process of developing an artificial human ovary method in which ovarian tissue is extracted, stripped of any cells to eliminate any possibility of malignant cell contamination, new ovarian follicles are matured *ex vivo* in the artificial ovary, and the ovary is transplanted back into the woman after their disease is in remission (Amorim & Shikanov, 2016). Benefits of this method include its applicability to both prepubescent and postpubescent women and its possibility of fertility

restoration capabilities without the use of ovarian stimulation and IVF to become pregnant. This is especially useful in cases where people are unwilling or unable to undergo the IVF process. A summary of all the aforementioned information, can be found below (Fig. 3).

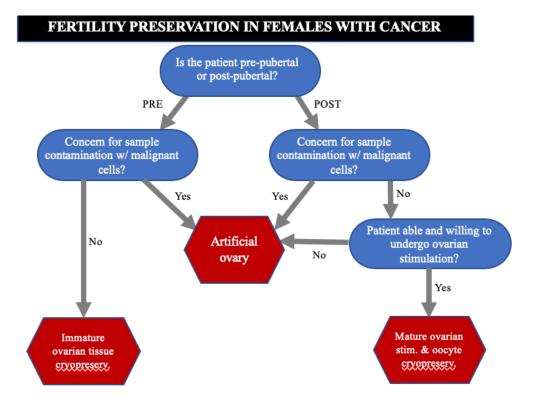


Figure 3. Summary of fertility treatment options for general fertility treatments and ART services for the female oncofertility population. Adapted from Dillon & Gracia, 2012.

In attempts to distribute a consolidated and updated message to oncologists all over the US, the American Society of Clinical Oncology (ASCO) has published clinical practice guidelines on fertility preservation in patients with cancer. In addition to upholding the information found in Figure 3, oncofertility experts emphasize some other important recommendations. First, oncology providers should discuss any possibility of impaired fecundity or infertility with patients and their guardians if applicable as soon as possible. Second, providers should be prepared to refer all at-risk patients to reproductive endocrinologists in a timely

manner even if they are only focused on what they can do as an oncologist, which is to create an anti-cancer treatment plan (Oktay *et al*, 2018). Because impaired fecundity and infertility continue to persist in the US due to both health disparities and illnesses like cancer, understanding the common causes of these fertility issues and the ways both general fertility services and ART services can help ameliorate the problem remain a key part of the discussion surrounding fertility services.

The ASCO guidelines on fertility preservation for cancer patients gain additional legitimacy when considered alongside the fact that unsatisfactory percentages of oncologists were providing childbearing-aged patients with fertility referrals, despite the literature outlining a need for such services. One review of the psychosocial issues faced by adolescents and young adult cancer-survivors found that matters of fertility deeply affected a person's identity, well-being, and future life plans regardless of gender (Crawshaw, 2010). Another study, which assessed the experiences of young women with breast cancer, even more strongly substantiates the need for fertility referrals for cancer patients. Of the surveyed individuals, 29% of the women stated that they would sacrifice some of the efficacy of their anti-cancer therapy by choosing a less effective lower intensity treatment if it decreased their chance of sterility (Partridge *et al*, 2004). While these sources demonstrate the importance of fertility preservation to young cancer patients, other sources show that some oncologists do not consider fertility a priority relative to the cancer, among other reasons for not providing patients with referrals.

As of 2008, only 47% of surveyed oncologists stated *routine referral* of childbearingaged cancer patients to reproductive endocrinologists. Things like hesitance to initiate intimate conversations about fertility, a lack of allocated appointment time to discuss non-cancer related matters, and perceptions that the patient does not have time to address fertility concerns before

receiving cancer treatment were cited as reasons for not providing referrals (Quinn *et al*, 2008). Some oncologists were also not sufficiently educated in matters of oncofertility, so they did not know to always refer patients out for fertility consults. Lack of oncofertility knowledge was the main reason stated by oncologists in a 2010 study which found that only 82% of surveyed oncologists had *ever* referred their patients to a reproductive endocrinologist, over 50% admitted to "rarely referring," and 30% of non-gynecological oncologists claimed to "rarely consider" a female patient's desire for fertility (Forman *et al*, 2010). These discoveries illustrate why there needs to be more emphasis placed on making oncology medical providers proficient in the basics of oncofertility.

PART II: DEMOGRAPHICS

Race/Ethnicity

One factor across which disparities in access to and utilization of fertility assistance services can be found is race/ethnicity. It has been well-documented in the demographical literature of recent decades that non-white women generally have lower rates of fertility assistance usage compared white women, especially for black women and non-white Hispanic women (Chandra *et al*, 2014). Although a logical explanation for this disparity would be that perhaps infertility and impaired fecundity are less prevalent in black and Hispanic populations. In reality, the opposite pattern has been found. According to various studies, black and Hispanic women report higher rates of impaired fecundity and infertility (Wellons *et al*, 2009 & Huddleston *et al*, 2010). This gap in infertility rates was highest between black women and white women, with one study reporting infertility in 10.5% of surveyed black women but in only 6.4% of white women (Huddleston *et al*, 2010). Some demographic articles are quick to indirectly

blame black women for their fertility struggles, citing higher rates of chlamydia and subsequently higher tubal factor infertility rates in this population (Huddleston *et* al, 2010). Other articles, however, show that black women are two times more likely to have experienced infertility than white women even after adjusting for SES and infertility risk factors like STIs and uterine fibroids (Wellons *et al*, 2009). Certain populations like black women are undergoing less fertility assistance despite greater affliction with infertility, signifying that something deeper is going on here that is preventing certain minority groups from receiving the care they seek. This paper argues that the something deeper are the broad, societal-level inequalities that specific disparities like fertility access and usage are mere symptoms of (Douthit *et al*, 2015). Both the small-scale and large-scale issues must be addressed together in order to achieve the best possible chance of creating lasting solutions to pervasive healthcare disparities.

Another specific example of how fertility treatment access and usage differ across racial lines is marital status. One study found that the percentages of women aged 40-44 years who had ever been married differed across racial lines. While 88% of non-Hispanic white women reported at least one marriage, only 63% of surveyed black women had ever been married (Raley, Sweeney, & Wondra, 2016). Interestingly, another study found that one in five medical providers refused to allow unmarried women to participate in ART programs (Gurmankin, Caplan & Braverman, 2005). Considering these two sources together adds another layer in the complicated story that is fertility access barriers for black women.

Lastly, race also has a significant effect on cancer survival rates. According to some sources, cancer can have a disproportionately severe impact on select minority groups (Mohapatra, 2015; Cancer Facts & Figures for African Americans, 2019). From 2016-2018, the cancer death rate for all forms of cancer was 14% higher in black women than in white women

(Cancer Facts & Figures for African Americans, 2019). While these disproportionate cancer rates in black women are largely explained by disproportionate levels of poverty, it is nonetheless troubling. It is especially troubling when considered alongside the fact that discrimination can contribute to cancer disparities by racial and ethnic minorities tending to receive a lower-quality of healthcare than majority populations even when factors like age, state of cancer, and insurance status are adjusted for ("Cancer Facts & Figures, 2019). This further proves that overarching racially motivated healthcare inequalities and biases must be addressed for people in both the general and oncofertility populations because they can ultimately contribute to a person's fertility.

<u>Geography</u>

Several studies and official government reports have outlined the disparities in access to fertility services across geographical lines (Harris *et al*, 2017; 2016 ART National Summary Report, 2018). The results of Harris *et. al*'s population-based cross-sectional study on geographical access to ART in the US revealed that ART centers and specialists are unequally distributed throughout the country, with greater clinic densities in states with mandated insurance coverage and higher per capita incomes. The study also indicated that 39.6% of reproductive-aged US women have limited or nonexistent access to nearby ART services due to maldistribution of clinics that render many rural individuals without a feasible option for reproductive assistance (Harris *et al*, 2017). Similarly, the CDC's 2016 National Summary Report on Assisted Reproductive Technologies included a map showing ART-providing clinic densities across the country, which showed a large number of clinics in major metropolitan areas like Seattle, Los Angeles, San Francisco, Dallas/Fort Worth, Boston, and New York (2016 ART

National Summary Report, 2018). While it is both unfortunate and troubling that ART clinics are maldistributed to favor urban locales over rural locales and states with mandated fertility service coverage over states without, it is important to note that these effects are partly unavoidable. Because the number of highly specialized reproductive endocrinologists in the US are limited, not every community in the US has the luxury of being in close proximity to an ART-providing physician and a laboratory capable of the benchwork required for procedures like IVF. What can be changed and needs to be addressed, however, is the fact that the fertility treatment service inequalities are a symptom of the broader issue of certain regions and populations in the US being medically disenfranchised from most or all types of healthcare, not just specialties like fertility (Douthit *et al*, 2015). If specific fertility-related geographic concerns are not addressed in conjunction with the overarching trend of general medical disenfranchisement, it is likely that individuals in these regions and populations will continue to slip through the cracks and fail to receive the fertility services that they seek.

Another deciding factor that can contribute to fertility treatment access across geographical lines is the state in which an individual resides. Starting in the late 1980s, states in the US began enacting laws about insurance mandates for infertility coverage with the intention of reducing healthcare disparities in the realm of fertility and pregnancy. These infertility coverage laws are on a state-by-state basis and can vary in type of service covered and the extent to which insurance companies have to cover such services. For example, laws in some states like California and Texas only require that insurance companies *offer* certain fertility testing and treatment services, but each employer has the ability to decide if they will offer any or all of the services to their employees. The other 15 of the 17 total states that have enacted fertility service insurance laws, however, have more involved mandates to *cover* particular fertility treatments

like. Interestingly, several of these laws include stipulations that allow religious organizations to be exempt from offering infertility service coverage ("Infertility Coverage by State"). Similarly, traditionally conservative states like Arkansas require that any IVF covered under the state insurance mandate must occur by the woman's egg becoming fertilized only by her spouse's sperm, which is inherently discriminatory against non-married individuals and queer couples ("State Infertility Insurance Laws). Lastly, only 7 out of the 17 states with fertility insurance mandates include sections of the law that provide paths to insurance-covered treatment for cases of medical treatment-induced or "iatrogenic" infertility ("Infertility Coverage by State). Because cancer survivors whose fertility has been compromised by anti-cancer therapy would be considered to have the diagnosis of iatrogenic infertility, those who suffer from cancer-related infertility are left without reasonable paths to insurance-covered treatment in over half of the states with mandates. This unfortunate situation is a good example of why those afflicted with cancer will continue to slip through the healthcare cracks if oncofertility remains excluded from important fertility access reports and academic discussions in the future.

Socioeconomic Status

Some of the state-mandated infertility insurance coverage laws include stipulations that exclude certain groups and allow for employer discretion regarding whether or not they wish to extend coverage options to their employees. While these laws are somewhat exclusionary, it should be recalled that this is all taking place within the context of people who actually *have* insurance and live in states with fertility coverage insurance mandates. This leaves particular groups like the unemployed, the uninsured, and those who do not reside in states with mandated fertility insurance coverage at risk of slipping through the cracks. Those who are wealthy enough

can either purchase their own insurance in times of unemployment or simply pay out of pocket for fertility services. For these reasons, much of the matter ultimately comes down to an individual's socioeconomic status.

It is well understood that people of higher SES have greater utilization rates of infertility services. According to cycles of the NSFG from 1982-2010, the ever-use of infertility services was highest among women with greater annual incomes, which is one of the measures of SES. Twenty-one percent of women with household incomes at least four times the national poverty level had ever used a form of fertility assistance, whereas this number was 13% for women with below-poverty income levels. Other measures of SES like education attainment reveal a similar pattern. For instance, 19% women aged 25 years or older who possessed at least a master's level degree reported using medical advice to become pregnant, compared to the 6.4% rate reported by women who did not graduate from high school (Chandra *et al*, 2014). These data suggest that only individuals who can afford to purchase fertility assistance services and who achieved a level of higher education are effectively aided and encouraged to reproduce by society.

Socioeconomic status is also related to cancer in that those who are of lower SES have poorer cancer-related health outcomes than their higher SES counterparts. First, disparities in incidences of certain cancers across socioeconomic lines do exist. However, this finding is generally explained by environmental and lifestyle factors like greater levels of exposure to mutagens and carcinogens and less healthful behaviors such as cigarette smoking and poor diet (Haynes & Smedley, 1999). Nevertheless, a person's social class can increase one's chances of developing cancer and consequently requiring fertility services for iatrogenic infertility. More significantly, cancer survival rates of low-SES people are 10-15% lower than in Americans who are of middle or higher SES populations regardless of a person's race or ethnicity ("Cancer Facts

& Figures 2019"). This statistic shows that although a person's race and socioeconomic status can often be related, this link between SES and cancer is caused only by socioeconomic status. Although the statistical and demographic information provided in the preceding paragraphs is helpful in understanding and pinpointing gaps in access to fertility services for certain populations in the US, situating these statistics and discussing them in a social science context allows for a more nuanced and complete understanding of why these disparities exist. This deeper understanding of fertility service access and usage disparities increases the chances of these issues being solved once and for all.

PART III: ANALYSIS

While outlining demographical information and statistics is a necessary step in the overall goal of expanding access and utilization of various infertility treatment options, only through contextualizing these findings through more social science-oriented sources and perspectives do we arrive at a more complex and thorough understanding of the problem. Part II of this paper was divided into sections according to race/ethnicity, geography, and socioeconomic status, but the analysis portion will be divided into sections by topic. This is being done because in reality, a person's race and socioeconomic status are not stand-alone categories into which an individual cleanly fits. Rather, they are interrelated entities that interact with and shape each other to uniquely affect the experiences of any given person (Crenshaw, 1989). For this reason, this portion of the paper will first attempt to dismantle the myth of expanding insurance mandates as the "cure-all" for fertility treatment access issues, followed by a discussion of the explicit and implicit ways in which the reproduction of some is encouraged, while the reproduction of others is not.

Insurance Mandates as the "Cure-all": Busting the Myth

Demographic-based articles often include vague calls to action or provide possible solutions that have already been proven ineffective by the literature. The disconnect between demographical public health research and social science research contributes to the unfortunate occurrence of some individuals being left without access to fertility treatment options. It is worth noting that the authors of such texts are generally in the business of proposing policy recommendations and not implementing them, making the broad nature of the recommendations justifiable and valid. What is more difficult to overlook, however, is the repeated recommendation of policy changes that have been proven unsuccessful in yielding the intended result of expanding fertility assistance services to marginalized and previously excluded demographics.

Review articles summarizing the main challenges faced by individuals seeking access to infertility services in the US provide useful statistics and draw attention to important patterns in certain demographics like disparities in access to treatment across racial, socioeconomic, and geographical lines. The authors of these papers also often do so with a spirit of inclusion and social justice, yet the complexities inherent to this topic are not always engaged with. Instead of reiterating the same suboptimal pleas to decrease infertility disparities, this paper aims to urge future policy recommenders to utilize a more interdisciplinary and intersectional approach to tackling these issues. While no specific policy recommendations or measures for reducing health inequities will be offered, this paper instead hopes to emphasize the advantage inherent to this interdisciplinary approach. This will be accomplished through the providing of concrete examples that illustrate the enhanced level of clarity that can be achieved when a fertility treatment access inequity is approached from more than one perspective.

To their credit, the authors of demographic-focused analyses of fertility treatment disparities speak very compassionately about inequalities in fertility treatment access that affect different groups. One paper emphasizes that "it is socially unjust in that the right to build a family in the face of infertility appears to have become a function of economic prowess" (Adashi & Dean, 2017). It is admirable that the authors consider it a "central moral imperative" to improve public underwriting and insurance mandates for infertility and ART service coverage in attempts to expand access to those that otherwise would not be able to afford such services. However, literature that is more social science oriented has proven that inequalities persist even in states with mandated insurance coverage for fertility treatments (Jain & Hornstein, 2005; Bitler & Schmidt, 2006). Likewise, the Ethics Committee of the ASRM stresses that "starting a family is a basic human right" and cite the statistic that state-mandated fertility insurance coverage has resulted in a three-fold increase in utilization of fertility services in states with mandates as a reason why it is also an ethical imperative to increase such mandates (Ethics Committee of the ASRM, 2015). The authors of these review articles mean well when outlining the challenges to this topic and offering possible solutions, but they tend to neglect the realities of everyday life for many of the low-income and marginalized women to which these very papers aim to expand fertility treatment access. For example, the first author of the Adashi et al paper's status as a physician at Brown University makes her qualified to discuss public health concerns like maldistribution of ART clinics across the US. But perhaps this leaves her out of touch with the realities of the people she intends to help—a mistake less frequently made by those trained in the social sciences.

For example, there are several sources pre-dating Adashi & Dean (2017) and other demographic-based publications that emphasize the persistence of infertility treatment access

disparities across socioeconomic and geographical divides even in states with mandated infertility coverage. The state of Massachusetts has had mandated and comprehensive insurance coverage for infertility services including IVF since 1987 ("State Infertility Insurance Laws"). Accordingly, Massachusetts will be used as a case study in the following paragraphs to provide some concrete examples from studies that have suggested the existence of persistent disparities in access to and use of fertility treatment services despite the implementation of insurance mandates.

Because overall fertility service usage was found to be greater in states with mandated infertility coverage compared to states without mandated insurance, researchers hoped that those who received fertility treatment in Massachusetts but not in states without mandates were from traditionally under-privileged and medically under-resourced communities (Jain, Harlow & Horsntein, 2002). Instead of extending services to groups like women of color or women of low SES who were previously financially excluded from such services, one Massachusetts study reported that the majority of those accessing fertility services post-mandate were actually white, well-educated women (Jain & Hornstein, 2005). While it is true that the majority of those accessing services were white women, this does not statistically differ from the general population of Massachusetts where 84.5% of women in the state at the time of the study identified as white (γ^2 p-value: 0.057). Hispanic/Latinx women, however, were underrepresented in the number of those who sought infertility services compared to the general Massachusetts population per the 2000 census. Although Hispanic/Latinx women comprised of 6.8% of the general population, they made up only 3.9% of the women accessing fertility services (χ^2 pvalue: 0.011). This study serves as an example for how disparities in fertility treatment access

across racial lines are often not eliminated by the implementation of mandated insurance platforms.

In the same study, the disparities across socioeconomic lines were even more remarkable. Despite 15.1% of the adult Massachusetts population lacking completion of a high-school level education and 45.3% obtaining a high school diploma as their highest education level, not a single person without a high school diploma and only 6.4% of those with only a high school diploma sought infertility treatment (χ^2 p-value: <0.001). Alternatively, nearly half of those that pursued infertility treatment possessed master's or other advanced degrees even though these individuals comprised only 12.4% of the general population of Massachusetts women (χ^2 pvalue: <0.001). Furthermore, 60.4% of women treated earned greater than or equal to \$100,000 per year even though this was the annual income of only 17.7% of the general population (χ^2 pvalue: <0.001) (Jain & Hornstein, 2005). A critical takeaway from this study is that future discussions about eliminating fertility treatment disparities should especially emphasize socioeconomical factors, as they appear to be even more significant than other factors like race in drawing lines between who does seek out and receive fertility treatment and who does not. Nonetheless, all data should be considered and analyzed with the understanding that many of these factors interact in such a multiplicative, complex way (Crenshaw, 1989). It is important to recall that these results are even more surprising and disturbing when considered in conjunction with the fact that African American and Hispanic women have reported infertility not at equal levels with white women, but at *higher* rates (Abma et al, 1997). The very populations that are reporting infertility at the highest rates are receiving the least amount of treatment.

Another paper published one year after Jain & Hornstein's 2005 article emphasizes this finding. Bitler & Schmidt (2006) compiled data from over 30,000 women documented in the

CDC National Survey for Family Growth (NSFG) using data from 1982-2002 who were of childbearing potential (aged 15-44 years). The outcomes of infertility status, impaired fecundity, and ever-use of infertility treatment by women in states with mandated fertility treatment insurance coverage were compared to those of women in states without insurance mandates. The main results of the Bitler & Schmidt study were as follows. While insurance mandates do increase the *overall* infertility service utilization rates in states with mandates, the rate of utilization mainly only increased in communities of older white women who were in possession of advanced degrees—a community of high socioeconomic status that is traditionally overrepresented in fertility clinics (Bitler & Schmidt, 2006; Chandra *et al*, 2014). This study also had more specific findings that revealed the existence of persistent disparities and infertility/impaired fecundity rates even in states with mandated insurance.

According to the NSFG surveys, infertility in Massachusetts was more common for black and Hispanic women than for white women. Both infertility and impaired fecundity were more common for those who did not graduate high school or who possessed a high school diploma as their highest education level compared to women with 4-year college degrees. Lastly, women who were older, white, and received a college education or higher were more likely to have ever received treatment for trouble conceiving (Bitler & Schmidt, 2006). This further exemplifies how disparities in fertility treatment access across both racial lines and socioeconomic lines are often not eradicated by the implementation of state-mandated fertility service coverage. Finally, another paper analyzed these disparities in access to and utilization of fertility treatment across racial lines from the perspective of time. Once again looking at individuals in states with mandated insurance coverage, this paper found that African American women experienced a significantly longer average duration of infertility before seeking treatment of 4.3 years

compared to shorter 3.3 years experienced by white women (p-value: 0.03) (Jain, 2006). Again, it is important to note that the population of interest in the aforementioned studies are insured people residing in states with mandated fertility insurance coverage. This potentially excludes the people residing in the 33 states without insurance coverage mandates and the 11.7% of reproductive aged women (aged 15-44 years) nationwide who were uninsured as of 2017 regardless of state of residence (Guttmacher Institute, 2018). Because insurance mandates only help those who live in applicable states and have insurance, increasing fertility coverage mandates without also addressing more deeply rooted health care inequalities and access to insurance could possibly further exacerbate inequalities on the grounds of race and socioeconomic status.

Explaining the Disparities: Implicit and Explicit Exclusion from Reproduction

In recent decades, social scientists particularly from the realm of sociology have highlighted the experiences and realities of women who are excluded from fertility treatments based on their status as low-SES, non-white, or another medically marginalized identity. These exclusions come down to two categories: explicit exclusion from fertility treatment and implicit exclusion from fertility treatment. While the discrimination and exclusion faced across racial lines was slightly different, low-income women of any race similarly experience exclusion from the realm of fertility treatment both explicitly and implicitly based on the biased notion that poor people are overly fertile and therefore must be controlled by medical professionals.

Explicit Exclusion

Black women are often discouraged from reproducing by doctors and other medical providers in ways that are directly and explicitly exclusionary. One participant from Ann Bell's in-depth interviews with low-SES women was a black woman who many years before had sought medical treatment for a miscarriage. While pursuing medical attention for a miscarriage, the woman cited being "scared" into not having any more kids and was made to feel as though "they just didn't want me to have any kids at all. At all. And that was sad." (Bell, 2010). Especially when considered together with past atrocities committed by medical providers in the United States like the surgical sterilization of ethnic minorities including black women in the 1970s, it becomes increasingly clear why negative physician-provider interactions like the one described have such a directly negative, exclusionary effect (Shreffler et al, 2016). Women in situations like this are taught to trust and be obedient to medical providers based on the clinicians' perceived power and legitimacy granted to them through their association with the powerful cultural institution that is biomedicine (Steinberg, 1997). Thus, when women are being directly discouraged from reproduction based on the views of medical providers or the society that they reflect, doctors and other staff can mask their bias within the guise of concern and medical necessity. After women experience numerous medical encounters in which providers discourage them from getting pregnant, many women find themselves internalizing the notion that they should not reproduce. This example shows how the fieldwork of social scientists like Ann Bell can help us more deeply and therefore more completely understand statistics like that of Tarun Jain's finding that black women endured a significantly longer period of untreated infertility than their white counterparts (Jain, 2006). By analyzing these demographic statistics through the work of social scientists, we gain a better chance of creating actual solutions to the

disparities in fertility treatment access that continue to plague the US despite many calls for change.

Another black woman interviewed by Bell who had experienced fertility struggles for many years explained that she had not yet seen a doctor to address her difficulties becoming pregnant. She was hesitant to see her doctor because she did not believe they had any valuable information for her and expressed that in her experience, all doctors have done is try to "talk you out of getting pregnant" (Bell, 2010). Likely a combination of distrust for the medical establishment after years of mistreatment and internalization of the notion that she was unfit to be a mother, this woman simply accepted her inability to become pregnant as her unalterable fate and did not take action to ameliorate her fertility struggles. This is a vivid example of how society's ideas about what kind of women are unfit to be mothers are exercised through direct doctor-patient interactions, both reflecting our society's notions about motherhood while also continuing to actively shape the landscape of motherhood in a way that encourages the reproduction of only certain women in society.

In addition to being a black woman, the woman in the previous example was neither married nor in a monogamous relationship. Recalling the study that found that one in five medical providers refused inclusion in ART programs to unmarried women, some single women thereby experience direction exclusion from assistance becoming pregnant (Gurmankin, Caplan & Braverman, 2005). This finding takes on another level of significance when considered in conjunction with the demographical information that black women are more likely to be single than white woman (Raley, Sweeney, & Wondra, 2016). Because these data suggest black women are more likely to be single than white women and that single women are more often denied fertility assistance than are married women, black women are faced with an even higher

likelihood of being directly excluded from fertility services because of discrimination on grounds of both racial and marital status.

All of this information considered together illustrates how women who are black, lowincome, unmarried, or any combination of these intersecting identities are effectively discouraged from reproduction. Especially women who are black, low-income, and single are viewed as burdens to both the medical system and to society whose reproduction should be controlled and limited, not encouraged. Such notions are fueled by contrasting stereotypical representations of the infertile, middle to upper-class, married, heterosexual white woman who quietly yearns to fulfill her womanly role of a stay-at-home mom and the poor or working class, unmarried, excessively fertile black "welfare queen" who is indifferent about her role as a mother (Sandelowski & De Lacey, 2002). First, this stereotype has been proven false by findings like the one previously discussed that reveals that black women actually experience infertility more than white women (Wellons *et al*, 2009). This stereotype must persist then, because it can be used by biased individuals and society at large to justify and naturalize women of color's exclusion from "infertility narratives" and subsequent fertility treatment services (Sandelowski & De Lacey, 2002). In this way, medical providers can guard the entrance to the realm of motherhood by directly excluding those that are not deemed by society to be fit mothers and include those that are deemed fit mothers. Until society addresses the deeply ingrained biases that continue to inform these often classist and racist notions of motherhood, it is unlikely that these stereotypes and their negative effects will fully be eliminated.

Low-income white women do not generally experience medical discrimination to the same extent as or in exactly the same manner that low-income black women do. Poor white women are mainly only discriminated against per their low socioeconomic status and not the

"double discrimination" on both socioeconomic and racial grounds (Crenshaw, 1989). Even so, low-income white women are also explicitly excluded from the realm of fertility treatments. Another low-income woman in Bell's sociological analysis was a young, poor white woman who explained that in prior years in exchange for receiving any medical services from a low-income health clinic, she had to agree to go onto a semi-permanent form of birth control called Depo-Provera. Despite the young woman's status as sexually inactive and without any plans to become sexually active, the clinic's social workers forced the woman to take Depo-Provera for six years stating that they were simply enforcing the clinic's "fertility policy" (Bell, 2010). This woman blames the fertility issues she faced at the time of her interview on her prolonged usage of the Depo-Provera. Whether or not this is actually true, encounters like this show how individuals grow to mistrust the medical system especially in matters of fertility. In this particular example, the health clinic's fertility policy explicitly excludes this woman from becoming a mother in the near future should she choose to do so. But perhaps more troubling is the policy's implicit implementation of eugenic logic that low-income women are excessively fertile and unfit mothers, therefore their reproduction must be contained and controlled by the middle and upper classes through the institution of medicine (Steinberg, 1997). These explicit exclusions from reproduction make affected women feel uncomfortable seeking biomedical treatment and often cause them to internalize the notion that they are not fit to be a mother.

Implicit Exclusion

Women who are not deemed to be fit mothers according to society's hegemonic norms of motherhood can experience implicit exclusion from fertility assistance services after many years of directly exclusionary medical interactions, but the implicit exclusion can also be entirely unique. To give an example of the former, one paper argued that some individuals from

medically marginalized populations like women of color have grown to distrust the medical establishment as a whole after repeated exposure to discrimination during medical appointments (White & McQuillan, 2006). After this "medical anxiety" has developed, certain women interviewed reported that they did not trust the medical establishment enough to even seek biomedical treatment when they began to experience infertility (White & McQuillan, 2006). This source serves as another possible explanation for the 2006 finding that black women endured longer durations of infertility before seeking assistance (Jain, 2006). If findings like those of Jain, Wellon *et al*, and others continue to be discussed only by other demographers and not contextualized through the work of social scientists, dialogue surrounding low fertility service access and usage rates among groups like black women will lack the nuanced complexity that is required to make strides toward actually addressing and eliminating these inequalities.

Other social science sources also help to unpack the idea of implicit exclusion from fertility service. For example, a paper by White & Greil (2006) attempts to explain why women of higher SES report higher utilization rates by citing specific sociocultural barriers experienced by people who are non-white and of lower SES. Some of these barriers include language barriers between patients and their providers, communication style differences rooted both in cultural differences and power dynamics, notions of privacy, and biases held by providers (White & Greil, 2006). Bell elaborates on this idea, providing specific instances that though not directly exclusionary, did ultimately prevent low-SES women from following through with the fertility services they sought. For example, the appointment-based nature of medical appointments that take place within the 9 AM-5 PM workday cater to higher SES salaried workers or women who do not work. But to low-income women, however, missing hourly work for these appointments sometimes proved too financially burdensome to continue (Bell, 2010). In this way, low-SES

women experiencing struggles conceiving are effectively forced to choose between having a child and keeping a job in order to earn a living.

Inclusion of social science sources in dialogue about fertility service disparities provide a level of detail, nuance, and truth about the everyday realities of certain populations of women that must be used in future discussions to help generate tangible and effective solutions to eliminating these disparities. Additionally, overarching disparities in the healthcare system must be addressed alongside more fertility-specific disparities to achieve the best possible result. Lastly, this paper has illustrated how interdisciplinary approaches allow for a novel and advantageous way of tackling matters of healthcare inequities and can hopefully be used as a model for future research endeavors.

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