

Abstract

The ability to decide if, when, and how often to reproduce is a human right and a biomedical and sociopolitical goal. Infertility impinges upon this right by restricting the ability of individuals and couples to meet their reproductive desires. While biomedical interventions to address infertility have proliferated in recent years, their distribution has been inequitable; inequalities in rates of infertility, infertility-specific distress, and access to reproductive healthcare to address infertility abound. By examining the collection and utilization of the National Survey of Family Growth Series data, the inception and provisions of Title X, and the structural limitations of the private healthcare system, we identify systematic and linked exclusions of marginalized groups from reproductive health surveillance and the public and private provision of reproductive healthcare, including older, non-white, working class, LGBTQ, geographically remote, less educated, HIV-positive, institutionalized, and disabled individuals. Individuals who are excluded from infertility tracking, services, and treatment—the invisible infertile—are limited in their ability to realize their human right to reproductive health. Utilizing existing resources in public and private clinical spaces may be a useful starting point for addressing these disparities, but a broader commitment to equitable and inclusive surveillance and healthcare provision is also needed.

Keywords: Infertility; human rights; reproductive health; stratification; family planning; healthcare access; marginalization; disability; incarceration; Title X

Introduction

The concept of reproductive health (RH) represents both a field of biomedical attention and a sociopolitical goal. RH refers to the physical, mental, and social well-being of individuals in all matters related to the processes and functions of the reproductive system over the life course, as well as proper fetal and infant development. The World Health Organization, United Nations, the Center for Reproductive Rights, and Ethics Committee of the American Society for Reproductive Medicine recognize RH as a basic human right (Center for Reproductive Rights, n.d.; Ethics Committee of ASRM, 2015; UNFPA, n.d.; World Health Organization, 2013). In the United States, a primary aim of the U.S. Department of Health and Human Services (HHS) is to promote and achieve RH across the population through disease prevention and family planning (OPA, 2019). The Centers for Disease Control and Prevention (CDC) Division of Reproductive Health and the Office of Family Planning (OFP) under the Office of Population Affairs (OPA) are tasked with ensuring RH through surveillance -- gathering data and tracking RH statistics -- and overseeing delivery of public health services. The consensus among health and human rights agencies is that RH entails the ability to decide if, when, and how often to reproduce (World Health Organization, 2013). While this is often interpreted in family planning (FP) policies as providing the means to control the number and timing of pregnancies through contraception, by definition it must also include the means to achieve pregnancy when desired.

RH is also a site of inquiry for sociologists, anthropologists, economists, and public health and policy researchers. Social scientists have long argued that human reproduction is a highly stratified and stratifying social process (Borrero, Schwarz, Creinin, & Ibrahim, 2009; Bridges, 2011; Dehlendorf, Rodriguez, Levy, Borrero, & Steinauer, 2010; Mann, 2013; E. Martin, 1987; Reiter, 1999; Roberts, 1997; Stevens, 2015; Waggoner, 2013). Critical examinations of sex education, family planning, social services, and healthcare settings have demonstrated that how individuals experience reproduction and parenthood is determined by their social location and identity, including age, race, socioeconomic class, gender, sexual orientation, legal status, and dis/abilities. In this paper, we apply sociological observations to a diverse range of social science and public health literature and data in order to understand the links between and consequences of RH surveillance, the structuring of the healthcare system, and the *reproductive imaginary*—a set of collective sociocultural beliefs regarding who can and should reproduce (Inhorn, Tjørnhøj, Goldberg, & la Cour Mosegaard, 2009). Our review suggests that because the primary focus of state-run RH initiatives, including surveillance, family planning, and healthcare access, is to control reproduction through pregnancy prevention, the needs of the infertile are often ignored, perpetuating the invisibility of infertility among marginalized groups and undermining RH as a broader population goal. We argue that state initiatives aimed at ensuring RH actually perpetuate the stratification of human reproduction by focusing on pregnancy prevention rather than RH broadly defined. We focus here on the extent to which the current system meets the needs of the infertile in the US, but recognize that similar processes operate globally to stratify

reproduction worldwide. We call on social scientists, public health researchers, and policymakers to emphasize the ability to bear children as a central component of researching and safeguarding RH.

Sociologists have long criticized the state, public health programs, and medicine for surveilling and regulating human behavior (Foucault, 1979, 1994; Lupton, 1995; Saguy, 2013). Others recognize that a robust state is essential for protecting the rights of marginalized groups, and commend the field of critical public health ethics for acknowledging the inherent power relations between states, researchers, and populations and promoting individual autonomy and equity (Callahan & Jennings, 2002; Lupton, 2015). Within this debate, we position ourselves as advocates for marginalized social groups, in favor of population research that reduces human suffering and ensures human rights for all. Where surveillance is used inclusively for planning, it can be a powerful tool for meeting the needs of the most disadvantaged and those whose voices are too often neglected. However, we also agree with Epstein (2007) that inclusion in itself does not inherently imply equity and beneficence; these aims must be actively sought alongside inclusion. This review recognizes the exclusionary and stratifying processes at work in surveillance and makes recommendations for improvement.

Surveillance and Infertility

Infertility is defined as the inability to conceive or sustain a pregnancy to the point of a live birth (CDC, 2016a; WHO, 2015). As with health and illness more broadly, infertility is socially constructed through the interaction of our physical bodies with the social norms, human actors, and healthcare systems of the sociocultural systems in which we live (Conrad, 2007; Conrad & Barker, 2010; Greil, Slauson-Blevins, & McQuillan, 2010). While not all people who experience infertility are distressed (Greil, McQuillan, Johnson, Slauson-Blevins, & Shreffler, 2010), infertility can have negative and sometimes severe consequences. For instance, some individuals and couples report feeling extreme social pressure to conceive, and may experience considerable emotional distress as a result (Greil, 1991; Greil, Slauson-Blevins, et al., 2010; Johnson & Fledderjohann, 2012; McQuillan, Greil, White, & Jacob, 2003). Infertility may also negatively impact the quality and longevity of romantic relationships (Gibson, 1980; Monga, Alexandrescu, Katz, Stein, & Ganiats, 2004; Schmidt, 2006).

Many studies of infertility in the U.S. have focused on those who self-identify as infertile and pursue clinical treatment--namely, white middle- and upper-class heterosexual women--in part reflecting broader beliefs regarding who can and should reproduce, and which social groups enjoy the greatest access to medical testing and treatments (Greil, Slauson-Blevins, and McQuillan 2010) (Nordqvist, 2008; Roberts, 2009). Arguably, these early studies were centered on whiteness, privilege, heteronormativity, and womanhood, ignoring the experiences of people of color (POC), the working class, and men. Nordqvist (2008) argued that “heterosexuality is foundational to, and yet invisible within” early ethnographic studies of assisted reproductive technologies (ART) (273). In recent decades, scholars have explored the reproductive pursuits of gay and lesbian couples, POC, and men

(Agigian, 2004; Barnes, 2014a; Bell, 2009a; Mamo, 2007; Nordqvist, 2014). Bell (Bell, 2014) found that, compared to middle-class white women, working-class women and women of color may experience greater stigmatization if they identify as infertile and/or try to seek treatment. Such socioemotional factors may be barriers to seeking treatment. Similarly, infertile men may feel marginalized by the diagnosis and treatment process (Halcomb, 2018), and may further internalize medical intervention as a negative reflection on their masculinity (Barnes, 2014b). Seeking medical treatment for infertility can be an extremely costly process, both in terms of financial and time resources (Wu, Elliott, Katz, & Smith, 2013), and so may be out of reach for many working class individuals who may not have access to premium health insurance plans and/or independent financial means for meeting the high cost of treatment (Bell, 2009b, 2014). Taken together, inequalities in stigma and healthcare access contribute to the stratification of reproduction (Greil, McQuillan, Shreffler, Johnson, & Slauson-Blevins, 2011).

The National Survey of Family Growth Series (NSFG) is the primary data sets used by the CDC for surveilling a range of RH issues (CDC, 2019a). For tracking population-level trends in infertility, nationally representative survey data are the gold standard. Unlike small-scale clinical and primary data, the sampling techniques employed and sample sizes obtained by such sources in theory render the data generalizable, meaning inferences about the population can be drawn based on findings from the sample. However, the extent to which the data are actually representative of the population hinges critically on the sampling and survey techniques employed. The NSFG inclusion criteria and instrument design historically failed to track infertility among many social groups, including men, people of color, single women, and the LGBTQ community (Authors 2018). In 1955¹, the first wave of the NSFG interviewed only white married heterosexual women. Since then, the inclusion criteria have broadened to include women of all races, divorced women, and, by 1982, never married women with no children. Men were not included in the study until 2002 (see Authors 2018 for a full accounting of the NSFG inclusion criteria). And, although the survey has become more inclusive over time, it still explicitly excludes institutionalized populations, such as incarcerated adults (CDC, 2019a).

Inclusive sampling is a necessary but not sufficient condition for producing accurate and inclusive RH statistics, however. The survey did not ask questions about sexual identities until 2006, before which the needs of queer couples/individuals would not have been discernible from those of cis gendered heterosexual respondents. While the NSFG asks about permanent disability as a potential employment status, there are no questions about respondents' experiences of disability outside of the context of employment (CDC, 2019b). It is therefore likewise impossible to assess what the reproductive needs of people with disabilities might be using the NSFG.

¹ The name 'NSFG' only came into use in 1973; the survey has undergone several name changes prior to this harmonization, but has been in operation since 1955.

Our earlier analysis (Authors 2018) represents an examination of research bias, a study in negative space: Who is missing? How were they excluded? What are the sociological implications of their absence? Building on this approach, we now turn our attention to the FP literature to understand whether and how the needs of infertile people are recognized and addressed by the Title X Family Planning Program. While *RH* is an umbrella term that refers to an array of issues related to fertility and pregnancy, maternal and infant health, menstruation and menopause, depression and postpartum depression, and infertility and assisted reproductive technologies, *FP* refers to the comprehensive services available to help women achieve the desired number and spacing of their children (Secretary of Health, Education and Welfare, 1971). If *RH* is the goal, *FP* includes the practical steps toward that goal.

Surveillance and Family Planning

The CDC gathers data to identify, track, and measure the risk factors that affect *RH*. They disseminate their findings to other agencies and the public, so that people can make informed health choices (CDC, 2018; Gavin et al., 2014). Meanwhile, the OFP oversees the funding and operation of Title X Family Planning Program clinics operated by private agencies, such as Planned Parenthood Federation, or local state, county, or city governments. Clinics provide *FP* and basic preventive health services, including health education, access to birth control, preconception care, pregnancy testing and counseling, basic infertility counseling, sexually transmitted disease services and testing, breast and pelvic examinations, and breast and cervical cancer screenings. As described, the *RH* aims of the CDC and OFP are complementary.

Title X Background

In his 1964 State of the Union address, President Lyndon B. Johnson declared war on poverty, which his administration waged through the creation of Economic Opportunity Act (EOA), the Office of Economic Opportunity, and a variety of social programs designed to address the needs of the poor. Although the EOA did not specify funding for *FP*, small *FP* programs began rolling out across the country under the administration's Community Action program (Bailey, 2012a). By the late 1960s, there was growing awareness that unintended childbearing impacted individuals' ability to gain an education and participate in the workforce--factors that directly correlate with socioeconomic status (Vamos, Daley, Perrin, Mahan, & Buhi, 2011). One solution for fighting poverty was to reduce unintended childbearing.

In 1969, in an oft-cited special address to Congress, Republican President Richard Nixon declared (Nixon, 1971: 528):

It is my view that no American woman should be denied access to family planning assistance because of her economic condition. I believe, therefore, that we should establish as a national

goal the provision of adequate family planning services within the next five years to all those who want them but cannot afford them. This we have the capacity to do.

While this appeal to Congress was a huge step in women's rights, this was not its aim; rather, Nixon was arguing for population control (Bailey, 2012b; Vamos et al., 2011). In 1970, Congress passed the Title X Family Planning Program to fund FP and preventive health services for all (Family Planning Services and Population Research Act, 1970). At its inception, Title X did not include any infertility diagnostic or treatment services. Since 1970, a number of laws related to the administration, appropriation, requirements and restrictions of Title X have been enacted.² One piece of legislation, Public Law 95-613, enacted in 1978, ordered that the phrase "family planning methods and services (including natural family planning methods, infertility services, and services for adolescents)" replace the phrase "family planning methods (including natural family planning methods)" (Public Health Services Act, 1978) This change added infertility services to the FP agenda. Since 1978, no other bills related to infertility or infertility services have been added to Title X. "Infertility services" provided by FP clinics have entailed basic advice for achieving pregnancy, preconception counseling, and testing for sexually transmitted infections (STIs).

Title X Evaluations

Over the past four decades, measures of the impact and effectiveness of Title X have proliferated. We are interested not in comparing the capabilities and validity of various models, but rather in how effectiveness, success, and impact are defined and measured and whether infertility variables are included in these analyses.

FP assessment models use a variety of data sources to measure effectiveness, including state Medicaid records (Mellor, 1998); clinic records³ (Darney, 1975; Udry, Morris, & Bauman, 1976); the NFS⁴ and NSFG (Forrest & Samara, 1996); and various datasets from the National Center for Health Statistics (Bailey, 2012a; Cutright & Jaffe, 1976) and other federal agencies. Mellor's (1998) model demonstrated that fertility declined in the U.S. after the introduction of FP programs. Other models estimated the number of unintended pregnancies averted and Medicaid cost savings (Forrest, Hermalin, & Henshaw, 1981; Forrest & Samara, 1996; Frost, Sonfield, Zolna, & Finer, 2014). Udry et al. (1976) argued that the introduction of federally funded FP resources did not impact contraceptive

² Between 1970 and 2008, 293 bills related to Title X were proposed; 20 of them were enacted into law (Vamos, Daley, Perrin, Mahan, & Buhi, 2011).

³ While clinical records are an important source of information about the treatments being offered in clinics and the characteristics of service users, clinics are notoriously stratified spaces; service users select into accessing clinics, and therefore their needs, preferences, and treatment choices cannot be taken as representative of the broader public. Surveys like the NSFG are taken to be nationally representative and therefore not plagued by this same issue of selection bias; however, as noted in the preceding section, there is strong reason to question the inclusivity of such sources as well.

⁴ National Fertility Survey, an earlier version of the NSFG.

use or fertility; rather, it simply changed the source from which some women acquired contraceptives. A few studies have measured the effects of FP funding and participation on abortion rates (Meier & McFarlane, 1994; Moore & Caldwell, 1977), while others have opined on Title X abortion policy (Steinauer & Darney, 2018). To summarize, FP evaluations always include measures related to contraception availability, acceptance, and use, and FP programs are proven effective when they reduce fertility. None of these assessments includes any measures related to infertility services or even mentions infertility.

In 2003, the OPA began commissioning annual reports, available to the public, based on uniform data gathered each year from Title X funded clinics. These reports, known as Family Planning Annual Reports (FPAR), present collected data in eight discrete categories: clinic network profile, user demographic profile, user social and economic profile, primary contraceptive method, cervical and breast cancer screening, STI testing, staffing and FP encounters, and revenue (RTI International, 2004-2018). One purpose of FPARs is to “estimate the impact of Title X-funded activities on key RH outcomes, including prevention of unintended pregnancy, **infertility**, and invasive cervical cancer” (RTI International, 2018:2, bold added). Data gathered on contraceptive use and cervical screening helps the OPA and other analysts estimate the impact of services on the prevention of unintended pregnancies and cervical cancer. Notably, the annual reports present no categories, measures, or data related to infertility services, making it difficult to estimate whether, how, or to what extent Title X-funded activities prevent or address infertility. In theory, preconception counseling, which is provided by FP clinics, provides clients with information for preserving healthy fertility, but the FPAR does not include data on preconception counseling services.

In 2005, the U.S. Office of Management and Budget commissioned the Institute of Medicine (IOM) to conduct a full review of the Title X Family Planning Program (Burnett & Gartner, 2011). The final 179-page report, published in 2009, noted that STI screening and prevention services could reduce infertility across the population (35-36), but provided no measures or data on infertility services. Screening for chlamydia and gonorrhea can help identify infected individuals at risk for pelvic inflammatory disease, which can cause infertility, but we are not aware of any models that use STI rates to examine whether or to what extent STI screening reduces infertility. Individual-level longitudinal data would be required to understand whether preconception services or STI screening help preserve fertility and prevent infertility. Notably, the FPARs and the 2009 IOM report use the terms “FP” and contraception interchangeably. For example, the section titled “The Use of Family Planning Services” of the IOM report presents data on contraceptive use rates (45-47). While this may not seem problematic, it is revealing. ‘FP’ is synonymous with pregnancy prevention, not family building. If RH includes the ability and right to bear children, are FP programs really committed to RH?

Reproductive Healthcare Access

Access to reproductive healthcare in the US, which is essential for monitoring, prevention, and treatment of infertility, can be obtained through public (e.g. Title X) or private (e.g. private health insurance) means. According to the CDC, approximately 7.3 million women in the US -- 12% of women aged 15-44 -- have used infertility services (CDC, 2016b). Infertility help-seeking can be incredibly costly in terms of financial costs, time inputs, and emotional strain (Wu et al., 2013); individuals without economic means, those who experience substantial time poverty, and those without sufficient emotional support resources may therefore be at a considerable disadvantage when seeking help (Missmer, Seifer, & Jain, 2011). Though Title X includes public provision for RH services such as cervical screening and contraceptives, provision for “infertility services” is ambiguous and limited to preconception counseling and STI testing. Title X infertility services, based on Medicaid reimbursement schedules, do not include diagnostics (e.g. hysterosalpingogram, semen analysis) or treatments (e.g. clomid, intrauterine insemination). There are essentially no publicly funded infertility services in the U.S.

Previous research has shown that access to infertility treatment is limited to a small minority of the population (Chandra, Copen, & Stephen, 2014), and has further highlighted a sociodemographic gradient in the utilization of infertility services: older, non-white, working class, geographically remote, less educated, HIV-positive, and disabled individuals access reproductive healthcare for infertility at lower rates (Ceballo, Graham, & Hart, 2015; Chandra & Stephen, 2010; Greil et al., 2011; Inhorn, Ceballo, & Nachtigall, 2009; Inhorn & Fakih, 2006; Kessler, Craig, Plosker, Reed, & Quinn, 2013; Kissil & Davey, 2012; Mehta, Nangia, Dupree, & Smith, 2016). Notably, a gradient in service use/treatment in and of itself is insufficient to conclude that there are inequities in access. Given that some sociodemographic groups have higher *rates*⁵ of infertility (Greil et al., 2011; Huddleston, Cedars, Sohn, Giudice, & Fujimoto, 2010; Quinn & Fujimoto, 2016), differences in healthcare utilization could arguably reflect differences in need rather than barriers to access. However, these differential rates are RH statistics, drawn, for example, from the NSFG, and are therefore subject to the sources of potential bias previously outlined. Additionally, reproductive healthcare is itself an important correlate of infertility prevalence (Huddleston et al., 2010); a sociodemographic gradient in healthcare access may directly contribute to a gradient in infertility prevalence, and then may also drive disparities in accessing treatment and services—a situation of double jeopardy.

There are also other correlates of access that mirror discrepancies in healthcare access, suggesting that sociodemographic gradients are due at least in part to differences in access and not just in prevalence/need. For example, private insurance is a strong predictor of infertility service use

⁵ This could be, for example, due to differences in the timing of fertility, relative risks of STIs, and other sociodemographic differences associated with infertility (Huddleston, Cedars, Sohn, Giudice, & Fujimoto, 2010).

among women (Chandra & Stephen, 2010), suggesting that public provision is inadequate to meet needs. Meanwhile, lack of health insurance has been identified as a critical barrier preventing couples from seeking help (Mehta et al., 2016). Differences in insurance coverage may also be correlated with differences in outcomes, both in terms of success rates for treatment, and in terms of treatment-related risks, such as multiple births (Henne & Bundorf, 2008; J. R. Martin, Bromer, Sakkas, & Patrizio, 2011; Quinn & Fujimoto, 2016); however, evidence on insurance mandates and outcomes is notably mixed (Banks, Norian, Bundorf, & Henne, 2010).

Nor is acquisition of private insurance a guaranteed means of overcoming access barriers even for individuals and couples who are able to obtain private coverage. There are gaps in what is covered and for whom based on the specifics of one's insurance plan (or lack thereof), with important implications for whether individuals and couples seek help/what kind of treatment options they utilize (Crawford et al., 2016; Dupree, Dickey, & Lipshultz, 2016; King & Meyer, 1997). Moreover, groups who access reproductive healthcare less frequently report facing barriers such as time poverty, financial constraints, geographic distance from treatment centers, and emotional strain that are consistent with the idea that gradients in healthcare access are rooted in sociocultural barriers above and beyond differences in need/prevalence (Bell, 2009b; McCarthy-Keith et al., 2010; Mehta et al., 2016; Missmer et al., 2011; Wu et al., 2013). Overall, it is difficult to disentangle the reciprocal nature of the relationship between sociodemographics, healthcare access, and infertility outcomes, but there is ample evidence to suggest a gradient in both access and outcomes (Greil et al., 2011; Huddleston et al., 2010).

Marginalization of the Invisible Infertile

How research is designed is important, both because it tells us whose reproduction is valuable to the state and society, and because statistics are used to monitor population health, identify reproductive needs, and inform policymaking and healthcare provisions. We can observe this process through an examination of who is missing at each stage in the chain between surveillance and outcomes, and also by examining the subtext in the way that marginalized groups are included when they are present. These processes have important consequences for the RH marginalized individuals.

Who Is Missing

The CDC uses NSFG data to make policy recommendations for FP programs and healthcare services (CDC, 2018; Gavin et al., 2014). Two exclusionary processes in the NSFG have implications for whose reproductive needs are captured by surveillance and met through FP programs and healthcare systems: First, the population at risk, as defined for the sake of sampling, has been conceptualized in a non-inclusive way that reflects a biased reproductive imaginary (Fledderjohann & Barnes, 2018). Second, the design of the survey instrument may marginalize or render entirely invisible the needs and experiences of some groups, even when they are included in the sample. This

may operate through more obvious means, such as exclusion via survey skip patterns, but may also be more subtle. Even question wording may factor into this process. For instance, Greil (1991) found that women experiencing infertility were more inclined to label themselves as ‘not yet pregnant’ than infertile, as the latter label was definitive, while the former allowed for continued hope for a future pregnancy. The language used to assess fertility barriers, then, may strongly influence the data respondents provide, and this process of bias and non-response disproportionately impacts marginalized groups (Fledderjohann & Barnes, 2018; Fledderjohann & Roberts, 2018). Exclusion of the RH needs of disabled people and the incarcerated are examples of this process.

The NSFG does not include a measure of disability (CDC, 2019b) which means that it is not possible to identify the needs of those who identify with a disability using these data. In turn, the RH of disabled people is disregarded by FP policies and healthcare systems. This parallels a broader societal tendency to ignore or even problematize the sexuality and (particularly) reproductive desires of disabled people (Cuskelly & Bryde, 2004; Shakespeare, Gillespie-Sells, & Davies, 1996). Moreover, some women with disabilities seeking to become pregnant report feeling actively discouraged to conceive by healthcare providers (LaPierre, Zimmerman, & Hall, 2017), while others state that medical staff struggle to meet their needs due to inexperience working with disabled women (Tarasoff, 2017). Thus, even where disabled people are able to access healthcare, negative attitudes and lack of knowledge and experience among staff may limit their ability to meet their fertility desires. Drawing on narratives from disabled people, however, Kim (2011) warns that, through compensatory avoidance of the problematic practice of desexualizing disabled people, the real, lived experience of asexuality for some disabled people has been rejected by scholars and activists. Asexual individuals (disabled or otherwise) may struggle to reproduce due to lack of sexual desire, but well-meaning attempts to sexualize disabled people may inadvertently result in a failure to recognize asexuality and its consequences for family building. Thus, both desexualization and asexuality are potential experiences of disabled people that are often stigmatizing and invalidated and, in both cases, there may be (resolvable) implications for their ability to create a family. However, meeting the RH needs of disabled people necessarily requires that those needs be recognized in all their diverse forms.

Similarly, the NSFG explicitly excludes institutionalized populations (CDC, 2019a); exclusion of institutionalized populations could generously be read as a purely pragmatic choice, as these populations may be more difficult to reach using standard survey sampling techniques. On the other hand, these individuals are solely dependent on publicly available RH services due to their restricted freedom to pursue private medical treatment and services; arguably, it is essential that their reproductive needs be identified and included in FP programs. A more cynical reading of the exclusion of institutionalized populations, then, may be that the reproduction of institutionalized populations is less valued by society and, therefore, less carefully monitored and safeguarded. There were nearly 1.5 million adults in prison in the US as of 2016 (Bureau of Justice Statistics, n.d.); this is a considerable minority of the population that is systematically excluded from RH statistics. A rare

study of the RH needs of incarcerated women by Clarke et al. (2006) highlighted the importance of this topic by identifying an increased risk of STIs (a known risk factor for infertility; Trent, Bass, Ness, & Haggerty, 2011). Moreover, the widely-known, well-documented, and staggering elevated risk of incarceration for low-SES individuals and racial and ethnic minorities (Doerner & Demuth, 2010; Lyons & Pettit, 2011; Miller, 2013; Pettit & Western, 2004; Zaw, Hamilton, & Darity, 2016) suggests another avenue through which exclusionary population definitions in survey sampling may serve to reinforce the stratification of reproduction and foster invisibility of infertility among already marginalized groups.

How Are Marginalized Groups Represented

Not long after Title X was enacted, Cutright and Jaffe (1976) used data from the U.S. Bureau of the Census and the NFS to show that as FP enrollment increased among low SES women, their fertility declined, and that the effect was greater for low- compared to high-SES women. They concluded that the new FP program was “succeeding very well in attaining its objectives” (Cutright & Jaffe, 1976: 110). An analysis by Forrest et al. (Forrest et al., 1981) used data from the Census, the National Center for Health Statistics, and other sources to argue that during the 1970s, FP programs successfully averted 2.6 million unintended adolescent pregnancies, which would have included an estimated 944,000 births, 1,376,000 abortions, and 326,000 miscarriages. For Cutright and Jaffe and Forrest et al, FP programs are effective because they reduce the fertility of low SES women and adolescent girls, respectively.

Three photographs accompany an article titled “The Impact of Family Planning Clinic Programs on Adolescent Pregnancy,” published in 1981 and cited above (Forrest et al, 1981). The first photo shows a young, straight-faced, visibly pregnant African-American woman standing in profile on the steps of a brownstone apartment building. There is no caption. The second photo shows a young white woman, not visibly pregnant, sitting at a table consulting with a white female medical provider. The caption reads, “Teenager gets information about contraception at a family planning clinic.” In the last photo, a seated young African-American woman stares empty-eyed into the camera, holding her pregnant belly. The caption reads, “Family planning clinic programs averted 2.6 million unintended teenage pregnancies in the 1970s,” a fact reiterated in the article as a mark of success (115). The haunting image and its unrelated caption strike a cautionary tone.

Is the reader to understand from the photos that teen pregnancy is a race issue? And that if teen pregnancy is a problem and FP planning clinics are the answer, then FP can reduce the number of African-American babies in the U.S.? The emphasis of FP programs and assessments on pregnancy prevention over family building, including conception, prenatal health, and fetal health, raises a deeper question about RH initiatives: Are they intended to give women reproductive control or control women’s reproduction? Though Title X was hailed as a social, political, and economic boon to

low-income women, a more cynical reading of the situation might be that Title X provided a way to control the reproduction of poor women (see also Stevens, 2015; Ward, 1986).

Consequences of Marginalization

Where reproductive needs are not recognized, discussing and seeking help for RH difficulties can be stigmatizing (Barnes, 2014b; Bell, 2014; Ceballo et al., 2015; Inhorn & Fakih, 2006), which may serve as a barrier to seeking help. Ideas about and monitoring of infertility are a cultural artefact—a product of our particular sociohistorical moment and the resultant reproductive imaginary. How infertility is tracked is a direct consequence of these cultural notions, and there are serious consequences for the way we understand infertility and structure FP programs and healthcare systems that result from this. The ability to choose if, when, and how often to reproduce is a human right, but there are stark inequalities in our understanding of and provision for infertility which serve to stratify reproduction and limit realization of this right.

Although invisibility can create barriers to addressing one's RH needs, not all of the invisible infertile are equally impacted by this process. To the extent that people have the means to seek private services to meet their needs, invisibility may be a barrier to reproduction, but not an insurmountable one. Men's experience of infertility is a good example of this. While cis men are frequently invisible in RH statistics, public rhetoric, and even clinical spaces to some extent (Barnes, 2014b; Halcomb, 2018), their ability to access RH services through the hypervisibility of female partners and through e.g. private insurance means that many infertile men are still able to access healthcare and, ultimately, meet their needs. However, a working-class gay man, whose male privilege but reproductive invisibility intersect with his economic disadvantage and status as a sexual minority, would be far less likely to have his reproductive needs met. This might operate both through limited access to private resources and inadequate provision from the public healthcare system, rooted in part in his invisibility in RH statistics.

In this way, public and private healthcare act as a gatekeeping system that reproduces broader social stratification by limiting the ability of some—particularly those who experience intersecting disadvantages—to meet their reproductive needs and desires. Thus, socially marginalized people who struggle to achieve pregnancy are thrice punished— by social status, infertility stigma and grief, and lack of healthcare access. When reproductive rights are not supported as a public good, they by default become a private issue, and the needs of people who do not have access to private care are made invisible. Equitable reproductive healthcare access and provision of infertility services and treatment as a public good are a necessary prerequisite for ensuring reproductive rights for all.

Conclusion

In this paper, we have shown that the exclusion of marginalized groups in RH surveillance, FP program services and assessments, and healthcare access creates a reproductive underclass: the

invisible infertile (Authors 2018). This exclusionary process jointly shapes and is shaped by the reproductive imaginary. By examining who is missing from tracking, services, and treatment, we are able to trace the boundaries of the reproductive imaginary and demonstrate which social groups fall within and beyond those boundaries. Our analysis echoes the findings of previous studies: When the reproduction of some groups is prized and safeguarded, while the reproductive needs of others are neglected, social stratification is reproduced and reinforced (Bridges, 2011; Ceballo et al., 2015; Inhorn, Ceballo, et al., 2009; Inhorn & Fakhri, 2006; Roberts, 1997). Importantly, while we have focused on the US as a case study, the processes we have outlined operate within and between countries to create invisible infertility around the globe (Authors 2018).

Sociologists owe a debt of gratitude to scholars and activists in the emerging field of reproductive justice, who have shown that—from contraception to conception, abortion to maternal rights—state apparatuses have the power to turn the reproductive imaginary into stratified reality (Luna & Luker, 2013; Ross & Solinger, 2017). This review provides further evidence of these processes by highlighting the potential psychosocial challenges of infertility and the ways that pregnancy prevention and contraception are prioritized over childbearing and rearing in RH discourse. If RH is framed as a state goal for fighting poverty, curbing population growth, and reducing federal spending on Medicaid, then contraception is the answer. However, if RH is understood in terms of individual well-being and personal rights, then the answers are more complex. Though RH initiatives pay lip service to tracking and addressing infertility and even write “infertility services” into law (Burnett & Gartner, 2011; Vamos et al., 2011), the reality is that the infertility experiences of many social groups were historically and continue to be elided by survey instruments and ignored by FP programs, program assessments, and the healthcare system.

Thanks to the work of pioneering scholars in the areas of reproductive justice and social science, there is a broad, growing recognition that serious inequalities persist in and are even perpetuated by the current system. This is reflected in the Ethics Committee of the American Society for Reproductive Medicine’s (2015) public statement acknowledging disparities in and sociocultural barriers to accessing infertility treatment, and has argued for rectifying this human rights violation by improving insurance coverage, increasing awareness of treatment disparities among healthcare professionals, and aiming to scale up provision for underserved populations. We contend that these recommendations are a starting point, insufficient on their own but a step in the right direction.

RH researchers and FP clinicians, including but not limited to those designing and analyzing the NSFG, can begin by recognizing the breadth of RH, acknowledging that achieving pregnancy is as important to individuals’ lives as avoiding it. RH research should be designed around principles of inclusivity and equity, gathering data on the full reproductive lives of all people of reproductive age, including low-income people, racial minorities, single parents, LGBTQ, people with disabilities and chronic illness, and institutionalized populations. FP program assessments should include data to measure infertility prevented, diagnosed, addressed, and overcome and recognize intended

pregnancies achieved as indicators of program success and effectiveness. This critique applies not only to surveillance, such as through the NSFG, but also to small-scale primary data collection; while such research has often focused on clinical populations for pragmatic reasons, this sampling choice is also highly consequential, perpetuating the hypervisibility of privileged populations in RH discourses (Authors, 2018; Ceballo et al., 2015; Inhorn, Ceballo, et al., 2009). At the very least, peer-reviewed publications and federal reports should acknowledge that their models, which measure effectiveness by contraception use and pregnancies averted, present an incomplete assessment of FP programs and only half the picture of RH.

If RH is indeed a goal of federal agencies, basic infertility services—beyond preconception counseling and cancer and STI screenings—could be added to Medicaid reimbursement schedules and made available at FP clinics. For example, clinics could provide infertility diagnostics, such as hysterosalpingograms for women and semen analyses for men, as they are already equipped with ultrasonography machines and laboratories. Basic infertility treatments, such as hormone therapies for women and men,⁶ could also be provided. We recognize that FP clinics are equipped to provide only basic services, e.g. cervical and breast cancer screenings, not cancer treatments. What we recommend is possible with the resources and expertise available in FP clinics. From surveillance to reproductive healthcare provision, a more inclusive, equitable, and comprehensive approach is needed.

⁶ For example, clomiphene citrate is a popular medication used to stimulate ovulation in women and is prescribed off-label to stimulate sperm production in some cases of male infertility (Barnes 2014). The generic drug is inexpensive and effective. Letrozole has also been proven effective in treating infertility in women with polycystic ovarian syndrome or PCOS.

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