Reimagining infertility:
A critical examination of fertility norms, geopolitics, and survey bias

Running title: Reimagining infertility

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Key Messages:

- Survey instruments are shaped by sociocultural and geopolitical forces
- Surveys used to track infertility have the potential to compound the marginalization of under-sampled groups
- The infertility of some groups has been rendered invisible by their exclusion from common tracking methods

Keywords: Survey data; infertility; population policy; invisibilization; reproductive imaginary

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Abstract

While it is estimated that 15% of couples worldwide are infertile, this figure hinges critically on the quality, inclusiveness, and availability of infertility data sources. Current infertility data and statistics fail to account for the infertility experiences of some social groups. We identify these people as the *invisible infertile,* and refer to their omission from infertility data and statistics – whether intentional or unintentional – as the process of *invisibilization*. We identify two processes through which invisibilization in survey data is produced: sampling, with focus on exclusionary definitions of the population at-risk, and survey instrument design, with focus on skip patterns and question wording. Illustrative examples of these processes are drawn from the Integrated Fertility Survey Series and the Demographic and Health Surveys.

Empirical research is not designed in an objective vacuum. Rather, survey instruments and sampling techniques are shaped and influenced by the sociocultural norms and geopolitical context of the time and place in which they are created and conducted, reflecting broader social beliefs about family building and reproduction. Furthermore, population policy singularly aimed at curbing overpopulation in high fertility parts of the world limits the type of reproduction data collected, effectively rendering the infertility of some groups epidemiologically unfathomable. In light of these sociocultural and geopolitical forces, many marginalized groups are missing from RH statistics. The omission of entire groups from the scientific discourse casts doubt on the quality of research questions, validity of the analytic tools, and accuracy of scientific findings. Invisibility may also misguide evidence-based RH and family planning policies and deter equitable access to reproductive healthcare for some social groups, perpetuating social inequalities.

Introduction

Infertility—an inability to conceive or maintain a pregnancy to a live birth—affects 15% of adults of reproductive age worldwide (WHO, 2015). Around the globe, infertility is associated with elevated levels of depression, anxiety, grief, stigmatization, domestic violence, marital discord, poverty, low self-esteem, and increased risk of STIs (Adamson et al., 2011; Barnes, 2014; Bayley, Slade, & Lashen, 2009; Becker, 2000; Boerma & Urassa, 2001; Chachamovich et al., 2010; Donkor & Sandall, 2007; Dyer, 2007; Fledderjohann, 2012, 2017; Lechner, Bolman, & Van Dalen, 2007; Pasi, Hanchate, & Pasha, 2011; Thoma et al., 2013). The accuracy of research on infertility hinges critically on the way infertility is conceptualized and measured. The 15% figure cited masks considerable variation in the distribution of infertility within and between countries. Inadequate evidence exists on how reproductive health (RH) survey datasets include or exclude different social groups within and across populations.

Many cultural factors complicate efforts to track infertility across populations: infertility is defined and medicine practiced differently across cultures; access to healthcare varies widely by e.g. sociodemographics and geographic locale, and infertility research is often conducted in healthcare settings; infertility is a taboo subject in some cultures; and the effects of infertility-related stigma range from mild embarrassment to ostracism and diminished life chances (Bell, 2014; Greil, McQuillan, Shreffler, Johnson, & Slauson-Blevins, 2011a; Inhorn & van Balen, 2002). Furthermore, longstanding global efforts to curb overpopulation have deprioritized the needs of infertile people in the Global South (Frank, 1983; Nachtigall, 2006). We argue that 'reproductive imaginaries' – prevailing social beliefs about who can and should reproduce – shape the design and conclusions of infertility research. Consequently, some marginalized social groups or populations fall under the radar of infertility tracking practices, rendering their infertility and RH needs invisible. We identify these people as the *invisible infertile,* and refer to their omission from infertility data and statistics – whether intentional or unintentional – as the process of *invisibilization*.

Invisibilization, by definition an exclusionary process, is problematic within a broader global development agenda, set forth in the UN 2030 Agenda for Sustainable Development (UNGA, 2015). This agenda includes the promotion of inclusive societies, access to justice for all, and creation of inclusive institutions (SDG 16) in its core aims, and includes a pledge that "no one will be left behind" (p. 1). In their call for "A just, equitable, tolerant, open and socially inclusive world in which the needs of the most vulnerable are met", the UNGA points specifically to the vital role of quality, inclusive data for supporting just and equitable decision-making by policymakers.

This paper focuses on survey data and its potential to compound inequities. We augment extant literature by homing in on two critical invisibilizing processes in generating infertility data: 1) sampling (defining the population at-risk) and 2) instrument design (question wording, skip patterns). We posit that invisibilization has a reciprocal effect: the inherent biases of reproductive imaginaries shape infertility tracking practices, generating incomplete infertility data, which, in turn, reinforce the limits of reproductive imaginaries. This downward spiral of invisibility may thwart initiatives intended to address the RH, mental health, social, and economic needs of the invisible infertile (Bell, 2014; Inhorn & van Balen, 2002). While many obstacles to studying infertility (e.g. accessibility of healthcare, stigma) are beyond the control of researchers, research can be improved by exploring the limits of our reproductive imaginaries and considering how sampling and instrument design invisibilize infertility. We provide two illustrative examples, the Integrated Fertility Survey Series (IFSS) and the Demographic and Health Surveys (DHS), to demonstrate how surveys can render some social groups and populations invisible.

Reproductive Imaginaries

The 'reproductive imaginary' is a set of shared sociocultural beliefs, influenced by geopolitical forces, regarding who can and should reproduce (Inhorn, 2012; Inhorn, Tjørnhøj, Goldberg, & la Cour Mosegaard, 2009). Because much of the demographic and public health discourse has been strongly influenced by Westerners, the 'reproductive imaginaries' of countries, communities, and social groups has had a notably Western bias (Greene & Biddlecom, 2000). Thus, infertility is commonly perceived to be a condition that primarily impacts white, Western, heterosexual, middle- and upper-class women (Bell, 2014; Inhorn, Ceballo, & Nachtigall, 2009). In reality, infertility affects women and men of all races, ethnicities, nationalities, religions, (dis)abilities, socioeconomic classes, and sexual orientations and identities (Mascarenhas, Flaxman, Boerma, Vanderpoel, & Stevens, 2012; World Health

Organization, 2010). The infertility experiences of underprivileged, non-white, non-Western, and/or non-heterosexual women and men do not fit within the reproductive imaginary; they are unimaginable, their infertility "epidemiologically unfathomable" (Dworkin, 2005). These marginalized sociodemographic groups -- the invisible infertile -- have difficulty obtaining assessment, medical treatment, and social support for their infertility (Barnes, 2014; Bell, 2014; Feldman-Savelsberg, 2002; Fledderjohann, 2012; Greil, McQuillan, Shreffler, Johnson, & Slauson-Blevins, 2011b).

Following World War II, a key aim of geopolitically motivated population policies was to redistribute fertility to alleviate concerns about imbalanced population density globally and unsustainable population growth in low- and middle-income countries (LMICs; Bashford, 2008; Robinson & Ross, 2007). State policies and services aimed at managing population growth and medical resources often overlooked the needs of the infertile (Feldman-Savelsberg, 2002; Greil et al., 2011b; Parrott, 2014; Sundby, 2002). Such policies contributed to stratified reproduction on a global scale by failing to meet the needs of individuals in LMICs whose fertility goals exceeded policy targets (Dixon-Mueller, 1993; Mosher, 2008).

The stratification of reproduction was compounded by public health emergencies—perhaps most notably, the HIV pandemic. As alarm grew, serodiscordant couples were discouraged from having unprotected intercourse; fragmentation of RH and HIV programs grew; and HIV took precedent over other RH issues in many contexts, with only comparatively recent efforts to integrate these policy strands (Brady, 2003; Desgrees du Lou, 1999; Kennedy et al., 2010; Smit, Church, Milford, Harrison, & Beksinska, 2012; Thornton, 2008).

Addressing the needs of infertile people can be expensive and (erroneously) presumed to undermine state-led population control efforts. Thirty years ago, Frank (1983) warned that while treating infertility in sub-Saharan Africa (SSA) might initially result in an estimated 15% increase in total fertility, inattention to infertility would prolong high fertility. Where infertility is recognized as common, childbearing is both early and frequent, as couples seek to meet their fertility goals before they encounter a problem. Where infertility is less threatening, later childbearing and more widely spaced birth intervals are preferred, resulting in lower lifetime fertility (Frank, 1983; Sundby, 2002).

Moreover, fear that contraceptives may cause infertility is a commonly cited reason for not using contraceptives in some settings, leading to increased fertility and higher rates of unwanted pregnancy (Koster, 2010). Targeted contraceptive programs that do not adequately meet the full set of RH needs of individuals (i.e. beyond reducing fertility) face limited success (Sundby, 2002). Moreover, inattention to infertility may have a negative impact on a range of social and public health outcomes, including STI risks, mental health, and both financial and human costs of ineffective and sometimes dangerous alternative treatments (ESHRE Task Force on Ethics and Law et al., 2009; Gijsels, Mgalla, & Wambura, 2001; Pool & Washija, 2001; Sharma, Mittal, & Aggarwal, 2009).

The limits of our reproductive imaginaries also bias how we generate infertility estimates. As a simple example, Greil et al. (2010) found that 50% of infertile in the US National Survey of Fertility Barriers are "infertile without intent." Greil et al. coined this term to refer to women who meet the clinical[1] definition for infertility, but do not necessarily self-identify as infertile, and do not seek treatment. Overlooked by most traditional definitions of infertility, they are biomedically infertile, but not included in the reproductive imaginary as such.

In a similar vein, it would be nearly impossible to measure 'secondary infertility' (infertility subsequent to the birth of a child) in China, where post-World War II family planning campaigns and the 1979 One Child Policy suppressed families' reproduction (Greenhalgh, 1994; Kane & Choi, 1999). The infertility of Chinese couples who already have a child is invisibilized from the reproductive imaginary. Given that roughly one-sixth of the world population lives in China (Population Reference Bureau, 2015), what does this potentially drastic underestimation of secondary infertility mean for the accuracy of estimates? Successful population polices require an expanded reproductive imaginary that sees beyond macro-level population growth concerns and recognizes the micro-level RH needs of individuals.

Reproductive Rights

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[1] Failing to become pregnant after 12+ months of regular, unprotected intercourse.

In recent decades, legal analyses of forced sterilizations and research on access to assisted reproductive technologies have broadened the discourse on RH to recognize the ability to reproduce as a human right. The reproductive justice movement has advanced legislation and policy initiatives to ensure women maintain the right to have the children they desire (Luna & Luker, 2013). RH is now recognized as a basic human right by the WHO and the UN. According to the WHO (2013a, italics added), RH "implies that people are able to have a responsible, satisfying and safe sex life and that *they have the capability to reproduce* and the freedom to decide if, when and how often to do so." Several UN initiatives, including the Sustainable Development Goals, recognize (cis) women's rights to RH, including control over the number and spacing of their children (United Nations, 2015, p. 5).

Use of infertility medical services is increasing globally; however, global demand for infertility services exceeds the supply, and services are cost-prohibitive for most of the world's infertile couples (Gerrits, 2012; Mascarenhas et al., 2012). Differential access to resources for infertile people by race, gender, sexual orientation, disability, and nationality generates a system of stratified reproduction within and between state lines (Bridges, 2011; Colen, 1986). Invisibilization exacerbates unequal access to quality RH services (Hammarberg & Kirkman, 2013) and fertility-specific distress and stigmatization for the invisible infertile (Bell, 2014; Fledderjohann, 2012). Lack of infertility data and infertility tracking practices that exclude some groups result in unjust state policies and social systems that ignore the social, economic, and health needs of the invisible infertile.

Illustrative Examples of Invisibilization

Below, we provide two brief examples of how sampling and instrument design have contributed to the exclusion of some groups from society's reproductive imaginary.

Integrated Fertility Survey Series

The IFSS is an historical example of invisibilization through sampling. The IFSS has explicitly tracked the prevalence of infertility in ten waves in the US since 1955 (IFSS, n.d.). The first iteration, the Growth of American Families (GAF) survey asked questions related to basic demographics and reproduction: contraceptive use, attitudes toward contraception, pregnancy histories, fecundity, opinions on childbearing and rearing, and fertility expectations. The survey was arguably the first of its kind and progressive in scope. However, all 2,713 respondents were white heterosexual married women, ages 18-39, currently living with their husbands or whose husbands were temporarily away on military duty. Because the surveys were conducted as in-depth daytime interviews with women in their homes, presumably most respondents did not work outside of the home. Though some questions were designed to detect male infertility, these were secondhand (wives') reports. The data failed to assess the reproductive decisions and attitudes of nonwhite, queer, employed, single, divorced, and cohabiting women, and all men.

Sampling reflected the social mores and prescriptive gender roles of the day: The normative family ideal entailed a husband as breadwinner, wife as homemaker, and children. One might argue that it was unnecessary to include divorced women because divorce was much less common in 1955. Actually, divorce rates spiked in the U.S. in the years immediately following the Second World War (Olson, 2015). Nonetheless, divorce was less socially acceptable than it is today (Coontz, 2016). Social institutions, including the GAF, conformed to the family ideals of that era, invisibilizing divorce.

The GAF, conducted in 1955 and 1960, was succeeded by two waves of the National Fertility Surveys (NSF; 1965, 1970). The National Surveys for Family Growth (NSFG; 1973, 1976, 1982, 1988, 1995, 2002) replaced the NSF in 1973. Over time, the IFSS in its various incarnations broadened its inclusion criteria to adapt to varying family formations (see Table 1). The second wave of the GAF in 1960 included nonwhite women; divorced women were included in the research sample in 1970; and single women were added in 1973. When single women were finally included, the sample was restricted to those with children in the household. Infertile single women were excluded by the population definition until 1982. Until then, researchers could document neither the prevalence nor sequelae of infertility for single, divorced, and cohabiting women.

Table 1. Inclusion criteria for IFSS samples, 1955-2015

Survey Name	Married Women	Single Women	Men
1955 Growth of American Families Survey	White, 18-39	--	--
1960 GAFS	All races, 18-39	White, 23-44, prev. married	--
1965 National Fertility Survey	All races, <=55	--	--
1970 NFS*	All races, <=45	All races, <=45, prev. married	--
1973 National Survey of Family Growth	All races, 15-44	All races, 15-44, with kids in household	--
1976 NSFG	All races, 15-44	All races, 15-44, with kids in household	--
1982 NSFG	All races, 15-44	All races, 15-44	--
1988 NSFG	All races, 15-44	All races, 15-44	--
1995 NSFG	All races, 15-44	All races, 15-44	--
2002 NSFG	All races, 15-44	All races, 15-44	All races, 15-44
2006-2010 NSFG	All races, 15-44	All races, 15-44	All races, 15-44
2011-2013 NSFG[§]	All races, 15-44	All races, 15-44	All races, 15-44
2013-2015 NSFG[§]	All races, 15-44	All races, 15-44	All races, 15-44

*Longitudinal follow-up using the same sample selection criteria in 1975; §Not yet integrated into the IFSS

The glaring omission of men until the twenty-first century reflects broader social beliefs that women are responsible for all aspects of reproduction (Daniels, 2008). Women often bear the onus of infertility--even male-factor infertility (Inhorn, 2003; Inhorn, Tjørnhøj, et al., 2009). Men's exclusion also underscores the extent to which they are responsible for 'information management,' often unrecognized and taken for granted in the household division of labor (Barnes, 2014). Also missing from these datasets are queer families, possibly because they did not meet inclusion criteria, survey questions wording reflect compulsory heterosexuality (Pascoe, 2007), or they felt inhibited from disclosing their sexual identities in a punishing social climate. The two most recent waves of NSFG (2006-2010, 2011-2015), though not yet been integrated into the IFSS, provide more information on the sexual identities of respondents, possibly reflecting increased legitimation of queer families.

Sociocultural mores regarding family formation in the U.S. shaped the reproductive imaginary and, subsequently, the selective research samples for the IFSS, invisibilizing the infertility experiences of nonwhite women, single and divorced women, men, and queer individuals. This has limited researchers' understandings of the processes of family-building, the prevalence of infertility, and the consequences of involuntary childlessness within these populations and over time, and has perpetuated the notion of infertility as a white, married, middle-class female problem.

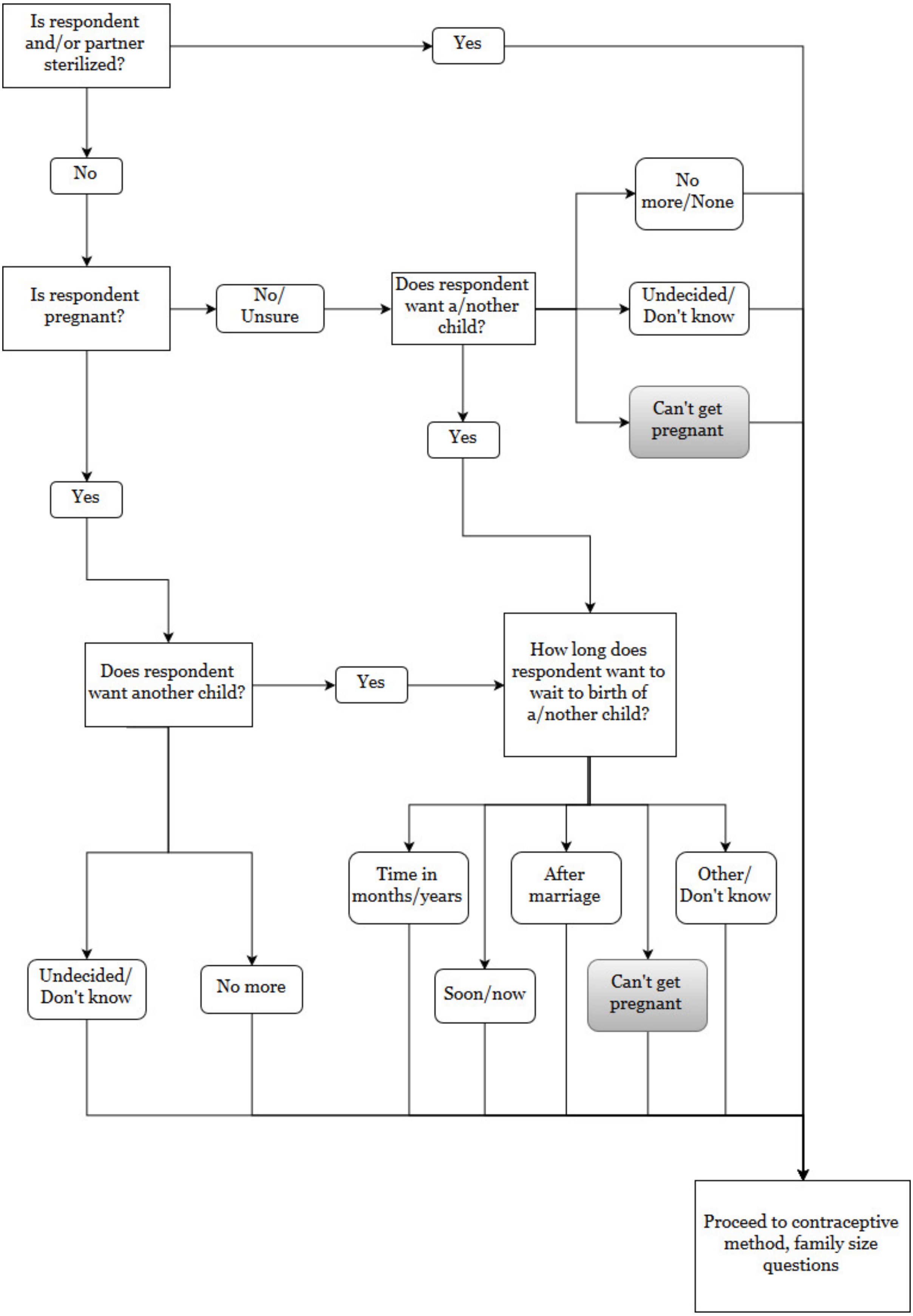
Demographic and Health Surveys

Survey instrument design also potentially invisibilizes, as illustrated by the cross-sectional DHS surveys. The first available DHS is from 1985; data have since been collected in 90 LMICs (USAID, n.d.). In order to be cross-nationally comparable, the DHS questionnaire is a (roughly) standardized instrument, administered by personal interview (USAID, 2017). Since its inception, the core instrument has occasionally undergone revisions, resulting in a new 'Phase' of questionnaires, most recently Phase 7. For brevity, we focus specifically on the Phase 7 women's survey.

The highest rates of infertility are found in LMICs (Mascarenhas et al., 2012) where researchers generate infertility rates from secondary data--most often the DHS. Though infertility is not explicitly a primary focus of the DHS, it is the only reliable population-level data on infertility trends in many settings. Yet data on diagnosis and self-identified (subjective) infertility are not collected. Infertility measures are instead constructed from marital and pregnancy histories (Larsen & Menken, 1991; Larsen & Raggers, 2001). Because these measures are based on a waiting time of 5-7 years since either a) the birth the previous child or b) the start of a relationship (i.e. marriage date), infertility among single women and those in short-term relationships is impossible to measure. This is likely to produce systematic bias: the risk of relationship disruption associated with infertility is greater for unmarried than married women (Fledderjohann, 2017). This is particularly so for self-identified infertility, which may be more salient for a range of sociocultural outcomes (Leonard, 2002).

The Phase 7 questionnaire does include a proxy subjective infertility measure. In response to whether/when respondents want a/nother child, interviewers can mark ‘says she can’t get pregnant’ as a possible response. Yet the skip pattern (see Figure 1) to this question selects out several groups of women. If a woman and/*or* her partner are sterilized, women are not asked the relevant question at all—implicitly, a woman’s fecundity is tied to her partner’s. Unsterilized women are then asked if they are pregnant. Women who say either ‘no’ or ‘unsure’ are then asked if they want a/nother child. One possible response is ‘can’t get pregnant’; because only one response is possible, non-pregnant women who both suspect difficulties conceiving and are either a) infertile without intent or b) undecided about childbearing would be invisibilized. Pregnant and non-pregnant women who say (in separate items) that they want another child are asked about timing. Again, one possible response is ‘can’t get pregnant’. Women who, for example, have a specific desired timing in mind but also suspect difficulties conceiving may have their infertility invisibilized by the design of the survey. Moreover, the question wording itself is problematic. Women who suspect difficulties but also hope a future pregnancy is possible may be reluctant to strongly self-label as unable to conceive (Fledderjohann & Johnson, 2015; Greil, 1991).

Figure 1. Flowchart of DHS skip pattern for subjective infertility proxy



Infertility includes not being able to carry a pregnancy to term. The DHS question to capture miscarriages reads as follows: ‘Have you ever had a pregnancy that miscarried, was aborted, or ended in a stillbirth?’ It is impossible to distinguish between spontaneous and induced abortion. The question thereby conflates family planning and fertility problems. Women who have miscarried may be reluctant to answer ‘yes’ to this question due to social desirability bias; abortion stigma can be severe (Kumar, Hessini, & Mitchell, 2009), and conflating abortion with miscarriage may produce a downward bias in estimates of miscarriage and, relatedly, infertility. This is particularly so for currently pregnant women, who would not be identified as infertile through duration-based constructed measures, but may have a history of (invisibilized) miscarriages.

Lack of a detailed infertility module in the DHS arises from the survey’s focus on fertility, and misses the crucial link between fertility and infertility. Through question wording and skip patterns, the instrument design invisibilizes the infertility of e.g. single women, those with sterilized partners, women who have difficulties carrying pregnancies to term, and those reluctant to self-label. This invisibilization likely contributes to the stratification of reproduction in LMICs.

Discussion

Given the centrality of survey data to research and policymaking, it is essential to consider the process through which survey data are collected, and the consequences of this process. Biases in sampling and instrument design invisibilizes some populations and social groups from infertility data. Omission of entire sub-populations from the academic and public health discourse casts doubt on the quality of research questions, the validity of the analytic tools, and the accuracy of the findings. Inaccurate data can derail evidence-based RH and family planning initiatives and impede access to medical treatment and social support for the invisible infertile.

In data-rich countries, surveys extract detailed, explicit information about respondents’ pregnancy intentions, self-identified perceptions of their ability to conceive, frequency of sexual activity, and use of infertility services. Despite this relative wealth of data, infertility among some groups may be overlooked, as exemplified by e.g. the concept of infertility without intent (Greil et al., 2010). In other geographic locales, researchers rely on far less detailed marital and pregnancy histories in secondary data to calculate infertility rates, and rarely have access to data on infertility help-seeking. Yet ensuring universal access to RH is key to safe and measured population growth. For researchers and policymakers interested in monitoring and safeguarding RH, the invisible infertile must be recognized and their needs met.

As the examples provided above illustrate, survey tools are not created in a vacuum, but rather in a cultural milieu which prizes the fertility of some people and discourages the fertility of others. We call on researchers and policymakers to prioritize reproductive justice for the invisible infertile as part of the broader inclusive and equitable global development agenda, which promises to leave no one behind (UNGA, 2015). To that end, we make the following recommendations: First, closely examine current data sets to consider which populations and social groups may be overlooked, ignored, or omitted from the data. Second, design RH research to consider all aspects of reproduction – from high fertility to voluntary childlessness to infertility – and include all social groups and populations. Third, carefully contemplate and communicate the implications of sample selection and survey design for marginalized groups.

We contend that a one-size-fits-all approach to survey design and data collection is not the solution, and may in fact be counterproductive by overlooking within- and between-group nuances and overstating the potential validity of such an approach. We do not advocate for development of a single standardized tool/approach. Instead, we suggest that vigilance and a continuous and open dialogue between demographers, ethnographers, public health researchers, humanitarian workers, social justice advocates and medical professionals is needed to identify and consider the consequences of invisibilization. Survey tools are a cultural artefact, and should be assessed, evaluated, and used cautiously as such.

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