

Fertility-related research needs among women at the margins

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Abstract: *Fertility-related research encompasses fertility intentions, preconception care, research amongst pregnant women, and post-partum outcomes of mothers and children. However, some women remain under-represented within this domain of study. Women frequently missing within fertility-related research include those who are already the most vulnerable to health disparities, including female sex workers, lesbian, gay, bisexual, and transgender women, women living with HIV, and women who use drugs. Yet characterization of the needs of these women is important, given their unique fertility-related concerns, including risks and barriers to care emanating from social stigmas and discrimination. This synthesis provides an overview of fertility-related evidence, highlighting where there are clear research gaps among marginalized women and the potential implications of these data shortfalls. Overall, research among marginalized women to date has addressed pregnancy prevention and in some cases fertility intentions, but the majority of studies have focused on post-conception pregnancy safety and the well-being of the child. However, among female sex workers specifically, data on pregnancy safety and the well-being of the child are largely unavailable. Within each marginalized group, preconception care and effectiveness of conception methods are consistently understudied. Ultimately, the absence of epidemiologic, clinical and programmatic evidence limits the availability and quality of reproductive health services for all women and prevents social action to address these gaps. © 2015 Reproductive Health Matters. Published by Elsevier BV. All rights reserved.*

Keywords: fertility, HIV, female sex workers, LGBT, people who use drugs

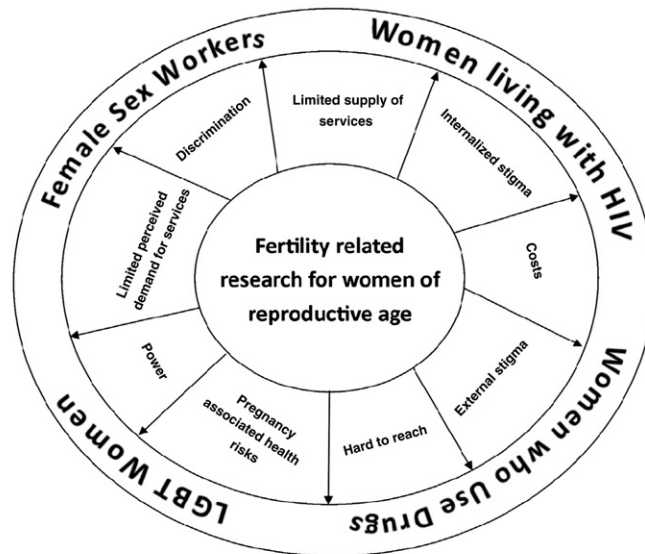
Introduction

Reproductive health and rights are affirmed through guidelines and programmes that are evidence-based and promote informed choices for all women. These informed choices necessitate research to guide understanding of treatment and care options, risks, benefits, potential outcomes, and costs involved. Broadly, pregnant women have long been known to be under-represented in clinical research, generally due to concerns about the safety of interventions or drugs during pregnancy. Under-representation has resulted in limited evidence for how to treat many chronic and infectious conditions among pregnant women.¹ Consequently, the Office of Research on Women's Health within the National Institutes of Health in the United States has concluded that there is a clear need for responsible research in pregnant women to address these gaps.²

Moreover, some women are particularly under-represented within fertility-related research, due

to their occupation, health status, behaviours, or sexual and gender identity.³ Specifically, women often forgotten in fertility-related investigations include female sex workers, women living with or affected by HIV, women who use drugs, and lesbian, gay, bisexual and transgender (LGBT) women (Figure 1).^{*} These underrepresented women are also those who tend to be most vulnerable or have already been pushed to the margins of society. Furthermore, the identified strata of marginalized women are not mutually exclusive and many women, such as female sex workers who are living with HIV, may experience compounded vulnerabilities. Reasons for non-inclusion of certain

^{*}Note that we include gay women in addition to lesbians and bisexual women, as identities within the community vary. It should be noted that many other women who have sex with women may have other identities outside of 'LGBT women' (e.g., gender variant, gender queer, etc.) for which these research gaps may also be relevant.

Figure 1. Women on the margins of fertility-related research and evidence^a

^a Among women of reproductive age, certain sub sets of women remain excluded or not considered within certain aspects of fertility research, including female sex workers, women living HIV, women who use drugs, and lesbians, gay and bisexual (LGBT) women. Underlying reasons are proposed either real reason or those perceived by society, researchers, funders and/or policy makers which contribute to the marginalization or research evidence for all women.

women in research may be explicit and intentional – due to logistics or safety-related concerns, or due to limited awareness of the need to identify and include specific subsets of women in studies. However, the forces pushing some women to the margins of this research also include social determinants such as discrimination and stigma – including HIV-related stigma, homophobia and transphobia – and lack of power due to economic or gender-related inequalities which collectively undermine the reproductive rights of those not conforming to social expectations.^{4,5}

Exclusion or non-representation of marginalized women from the fertility-related research agenda may have negative consequences, particularly because pregnancy-related risks and challenges may be different or amplified among certain subsets of women. Prevention of unwanted pregnancy is important for all women who are not imminently hoping to expand their family. However, depending on a woman's age, relationship status, economic or professional situation, and health status, the impact

of an unintended pregnancy on the health or well-being of mother or child may vary significantly.⁶ Similarly, many women hoping to conceive may be concerned about their health and safety during pregnancy. For women living with HIV, female sex workers and women who use drugs, reducing the exposure to HIV, sexually transmitted infections (STIs), and drug use during pregnancy and the post-partum period are critical considerations specific to the health and well-being of women and their families. For these women and LGBT women hoping to conceive, knowledge and empowerment about effective, affordable methods to assist safer conception is essential. Furthermore, socially marginalized women generally experience greater health disparities, resulting in reduced access and uptake of healthcare services in general,⁷ and potentially negative pregnancy-related outcomes if engagement in care remains insufficient in the perinatal period.⁸

Optimization of reproductive healthcare for all women is important and understanding the

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