



**Sexual and Reproductive Health Needs of
Women and Adolescent Girls living with HIV**

**Research Report on Qualitative Findings
from Brazil, Ethiopia and the Ukraine**

July 2006

EngenderHealth/UNFPA

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Acknowledgements

UNFPA and EngenderHealth would like to acknowledge the invaluable support of those who contributed to this qualitative study and report.

The HIV-positive women and adolescent girls and male partners of HIV-positive women, who so giving of themselves, found the time to generously share their experiences and stories in the name of improving services for other women and their community. The health workers, programme managers, policy makers, and community leaders who agreed to be interviewed for this research and who wholeheartedly spoke about their experiences for the aim of improving services for women in their communities.

The principal investigators for the study, Rasha Dabash and Paul Perchal. The principal writer Rasha Dabash and reviewers Marcia Mayfield, Paul Perchal and Lynn Collins.

The research teams and Ministries of Health in Brazil, Ethiopia, and the Ukraine including Beyeberu Assefa, Silvani Arruda, Oksana Babenko, and Sharone Beatty. The PLWH organizations that assisted with recruiting research subjects for the study including Positive Prevention Group and the National PLWH Network of Brazil (Brazil), Mikdam (Ethiopia), and Club Svitanok (The Ukraine).

UNFPA and EngenderHealth colleagues both at the country level and in New York for their ongoing support and inspiration.

These activities and report were made possible through financial support from UNFPA. The views and opinions expressed in this publication are those of the authors and do not necessarily reflect those of UNFPA, the United Nations Population Fund.

EXECUTIVE SUMMARY

Globally, women represent almost half of the 40 million people worldwide living with HIV and are increasingly becoming a larger proportion. Many women who are HIV positive do not know their HIV status until they become pregnant and are tested as a part of antenatal care. For many HIV positive women, antenatal care and PMTCT are the primary entry points to SRH services as HIV positive women. This presents an opportunity for counselling and access to services to address future SRH needs. For women living with HIV, the challenges of receiving adequate SRH services are often complicated by stigma and discrimination resulting in denial of their rights under the guise of preserving health or preventing perinatal transmission. Limited access to other health services, including care and treatment, also has dire consequences on HIV positive women's ability to protect their health, placing this already vulnerable population at even greater risk of morbidity and mortality.

Between January and July 2005, research teams in Brazil, Ethiopia and the Ukraine carried out a total of 11 focus group discussions and 93 in-depth interviews. In all, the research included 182 respondents, including women and adolescent girls living with HIV, male partners of women living with HIV, providers, and policy influentials¹. The research explored the sexual and reproductive health intentions and needs of individuals and probed issues relating to family planning, sexually transmitted infections, breast and cervical cancer, maternity care services and the prevention of mother-to-child transmission as well as access and quality of care.

Key Findings

This research identified some interesting trends across the three countries and some issues unique to each setting that need to be considered in strategic planning efforts to improve HIV-positive women's and adolescent girl's access and utilization of SRH services. Research findings suggest that women and adolescents living with HIV face many challenges to exercising their rights. Limited access to information, counselling and services, poor quality or insufficient care, stigma and discrimination, gender inequalities, and often faltering community and family support are among the barriers which confront HIV positive women and adolescents.

The provision of effective reproductive health care for HIV positive women should be guided first and foremost by a rights-based approach. Policies and programmes should address identified gaps through advocacy, strategic planning, and collaborative international and local commitment to bridging the reality of existing services and women's desires and rights to fulfilling lives that include making informed choices about their sexual and reproductive

¹ Policy makers and community leaders

health.

This research indicates more advocacy is required, including engagement of policy influentials, to address lack of awareness, and policy and programmatic gaps, regarding the rights and health needs of HIV-positive women and adolescent girls. There is unevenness of health providers' understanding of SRH of women living with HIV and an inability to respond to their rights. It is also essential to ensure that HIV-positive women and adolescent girls are aware of their rights so they can exercise them.

Recommendations for Further Research

The findings from this study suggest a number of issues or areas for further research including:

- Operations research to address the various programmatic and policy gaps highlighted in this report, such as testing ways to improve access to and quality of SRH services for HIV-positive women and adolescent girls; approaches for reducing stigma and discrimination; and models of service delivery that link SRH and HIV programmes through integrated approaches.
- Exploring approaches to making PMTCT services more widely available by integrating PMTCT into health services in rural areas and outside of specialty research centres in urban areas.
- Assessing missed opportunities for meeting women's SRH needs within the context of existing services in order to understand the root causes of service gaps, including replication of qualitative studies similar to this one in other settings.
- Conducting research similar to the current study in rural areas may yield different results and raise additional issues since most of the respondents in this study were based in primarily urban regions.
- Additional research is needed to clarify issues around hormonal contraceptive use by HIV-positive women, as current gaps in the science make providers more likely to promote only condoms.
- Investigating ways that providers, social workers, peer educators, and others working with HIV-positive women and adolescent girls can help them develop the necessary skills to negotiate condom use.
- Exploring ways to make the voices of HIV-positive women and adolescent girls, as well as their advocates (e.g. health providers, feminists, PLWH groups), heard on the issue of rights and needs of HIV-positive women.

Conclusions

This qualitative study will contribute to a rights-based framework on policy, health systems, and advocacy guidance on SRH for PLWH, especially women and adolescent girls currently under development with key partners. SRH services for PLWH must be accessible, non-discriminatory, compassionate, of high quality and rights-based.

I. INTRODUCTION

A. Background

Globally, women represent almost half of the 40 million people worldwide living with HIV. Due to women's greater physiological, socio-cultural and economic susceptibility to HIV infection, it is likely that the proportion of female adults and young women living with HIV will continue to rise in many regions of the world as has already been seen in Sub-Saharan Africa and the Caribbean.²

Despite the growing magnitude of the HIV pandemic, health interventions that focus on providing care and treatment for HIV-positive individuals have come at a slow pace. Most women do not know their HIV status until they become pregnant and are tested as a part of antenatal care. Due to antenatal care, more women than ever are accessing voluntary HIV counselling and testing (VCT) and prevention of mother to child transmission (PMTCT) programmes in many developing countries, however the breadth and quality of services provided to HIV-positive women are still inadequate. Often lacking are services linking women to appropriate care and treatment, including anti-retroviral (ARV) treatment and comprehensive sexual and reproductive health (SRH) services that can allow women to maintain control over their lives and exercise their rights.

Through lack of access and stigma and discrimination, HIV-positive women and adolescent girls are often denied their rights. In the absence of informed choice and adequate reproductive health services (including care and treatment for reproductive morbidities that may be exacerbated by their HIV infection) HIV-positive women are at even greater risk of morbidity and mortality. They are a group whose needs are complicated by the enormous social stigma and discrimination associated with living with HIV.

To date, little research has focused on exploring the barriers of care and comprehensive SRH services for this group. To better understand how policies and programmes can best respond to the SRH needs of HIV-positive women and adolescent girls, EngenderHealth carried out qualitative research in Brazil, Ethiopia, and the Ukraine as part of a more comprehensive effort to advocate for rights and their SRH needs. The research aims to understand the knowledge and perception of SRH needs of HIV-positive women and adolescent girls from the perspective of a wide group of stakeholders and to identify areas for further research.

² UNAIDS/WHO: AIDS Epidemic Update 2005.

B. Purpose of the Research

The research is part of a larger collaborative project between EngenderHealth, UNFPA, International Community of Women Living with HIV/AIDS (ICW) and other key partners to develop a policy and programme framework and implementation package to address the SRH needs of HIV-positive women and adolescent girls. The specific objectives of the research are to:

- Identify the perspectives of HIV-positive women and adolescents, male partners of HIV-positive women, providers and policy influentials about SRH needs of HIV-positive women and adolescent girls.
- Determine barriers and facilitating factors to SRH services in different settings for HIV-positive women and adolescent girls.
- Guide the development of the SRH framework that addresses the needs of HIV-positive women and adolescent girls by suggesting potential policy and programmatic actions to consider.

Using qualitative methods, the study sought to identify and understand the needs, gaps and barriers to access and use from the perspectives of stakeholders using qualitative methods. Qualitative methods were selected due to their flexibility and ability to explore newer issues from the vantage point of respondents, while allowing for broad insight into the range of issues involved.

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