

Violations of sexual and reproductive health rights of women living with HIV in clinical settings

in Uganda



This study is part of Link Up. It was conducted by The International Community of Women living with HIV Eastern Africa (ICWEA) with support from STOP AIDS NOW!

ICWEA is a regional advocacy network and membership-based organization for and by women living with HIV.

Link Up aims to improve the SRHR of one million young people affected by HIV across five countries in Africa and Asia. A consortium of partners led by the International HIV/AIDS Alliance is implementing the programme.

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Background of the study

Worldwide there is evidence that women living with HIV experience more stigma and rights violations in health care settings than HIV-negative women. This puts women living with HIV at risk of dropping out of sexual and reproductive health (SRH)/HIV care services. Amongst severe violations are cases of coerced and forced sterilization. In Uganda, the PLHIV Stigma Index Survey Report indicates that 11% of the women were coerced into getting sterilized by health care professionals. Nevertheless, comprehensive information about these violations is still very scanty.

Purpose of the study

The study sought to examine violations of sexual and reproductive health rights (SRHR) of women living with HIV while they were seeking SRH services in clinical settings in Uganda.

Brief methodology

The study took place in 2014, in 9 districts of Uganda: Arua, Gulu, Hoima, Kabale, Kampala, Masaka, Mbale, Mbarara and Soroti. It involved a field survey targeting 744 women living with HIV, 32 focus group discussions with 274 participants (14 male and 18 female groups), 20 interviews with women who experienced coerced or forced sterilization, 63 interviews with key informants (NGO representatives, health workers, government officials). This study enhanced the capacity of young women living with HIV. All research assistants were women living with HIV. They were able to create a confidential setting for the interviewed women living with HIV.

Demographic characteristics respondents

The survey respondents were women living with HIV, aged 15-49 years, who had ever used any form of family planning method. The majority of the women had a partner (58%). Their education level was relatively low; 11% didn't go to school and 54% of the women attended primary school only. The main occupation was farming (34%) and retail business (23%). Most women were selected from rural areas (39%), followed by small towns (32%) and urban areas (29%). The focus group discussions were held with women living with HIV and men living with HIV who were partners/husbands of women who had accessed eMTCT services.



Findings

All participants agreed that women -regardless of their HIV status- have a right to engage in sexual relations, get pregnant, have children, access SRH information, use family planning methods of their choice. But group discussions and key informant interviews revealed that most respondents had limited factual knowledge and awareness about women's SRHR and existing policies and guidelines, which leaves women living with HIV vulnerable and exposed to violations. The study revealed that women living with HIV experience a wide range of SRHR violations, from misinformation and mistreatment or abuse when seeking reproductive health services, to coerced and forced sterilization and forced / coerced abortions.

Further the study established that SRHR violations also occurred in homes and communities in form of restricted mobility to access care; gender-based violence; abandonment; limited decision-making on reproduction (limited choices on when, how and the number of children) and use of family planning; and forced/coerced termination of pregnancy by relatives or spouses.

Counselling

Over 88% of the women received SRH counselling from health workers, mostly after HIV testing. SRH counselling was mainly focused on family planning, according to 71% of the women and 15% of the women had been advised to stop having children. The participants were not aware of the existing guidelines on pre-conception counselling. Over 90% of both men and women respondents felt that women living with HIV should not get pregnant without guidance from health workers. The interview sessions revealed cases in which women encounter mistreatment and negative attitudes behaviour at health facilities. Women and men reported situations in which health workers express their disapproval of HIV positive women who desire to have a child or have become pregnant.

Family Planning

At health facilities the most used family planning methods were: injectables (33%), condoms (25%) and pills (12%). The most popular methods reported in the study were: injectables, implants and sterilization (72 women had been sterilized). The challenges women were facing are in relation to access to Family Planning included refusal of the partner and limited information from health workers.

Attitude and perceived behavioural control towards SRHR services

Half of all responds feels positive to visit a SRHR service. Most import reasons not to visit a SRHR service are 'fear of test results' (75%), available free time (73%), transportation (60%), suitable opening hours (59%), not having enough money (55%), church beliefs (52%) and privacy issues (51%). Having skills has strong influence on the behavioural control. Almost 80% report not to be able to visit a hospital to collect condoms or receive contraceptives. Especially girls (77%) think they cannot

convince their teacher to provide them with a referral letter if one needed. For boys this is much lower (56%).

Forced and coerced sterilization

Of 72 reported sterilizations, 20 women had been coerced or forced to undergo this irreversible operation. Most cases occurred in government hospitals during childbirth when the woman got a C-section. The average age at which sterilization took place was 29. Eleven women were forced to undergo sterilization. Health workers had failed to inform them properly about the procedure. They didn't sign a consent form. Some of them only found out years later when they failed to conceive. Nine women were coerced to undergo sterilization. In these cases mothers were misinformed. For example they understood that the procedure would be reversible: 'tied' tubes could be 'untied' later on. Or health workers convinced them that sterilization would be the best option regarding their health.

The most common and significant effects are psycho-social (trauma), loss of female identity, abandonment by spouses and gender-based violence due to the inability to conceive children. A number of the women reported social isolation - inability to fit in the community and family. The demands from husbands for more children greatly impacted on their social wellbeing.

Support

Although the majority of respondents were aware of the legal implications of forced sterilization, most of them didn't know where they could go for legal support. Actually none of the women, who experienced forced and coerced sterilization, had looked for legal support. In focus group discussions, participants repeatedly shared complaints about legal processes being difficult, tricky, too long, corrupt and expensive. Furthermore they indicated that reproductive health services are generalized and do not address forced sterilization issues specifically. Women who had undergone forced or coerced sterilization needed psycho-social support services because they experienced exclusion and isolation, while others were abandoned by their spouses.

Recommendations

Respondents recommended reaching out to women living with HIV, communities, health workers and men and educating them about women's rights and offering possibilities for legal support in specific cases, like forced or coerced sterilization. They also recommended integrating SRHR information into current HIV/AIDS programmes and services. Counselling services at the community level are necessary to offer psychosocial support to women experiencing SRHR violations. The tubal ligation protocols need to be developed and should be communicated during antenatal clinic visits. Health workers need to be trained in offering professional care without violating women's rights, ensuring that informed consent processes are of high quality. On a national level the current HIV and SRH policies need to be reviewed, taking into account SRHR violations.