“Listen to us, learn from us, work alongside us”

UK findings from a global participatory survey among women living with HIV

BACKGROUND
* Women living with HIV are vulnerable to gender-based violence (GBV) pre- and post-diagnosis, in multiple settings, and experience more mental health (MH) issues also.
* A values and preferences survey of women with HIV explored how GBV and MH issues affect their sexual and reproductive health and human rights (SRH&HR), determined priorities, and then assessed implications for policy-makers.

METHODOLOGY
* A global community-based, participatory, user-led, mixed-methods study was conducted on SRH&HR of women with HIV in 94 countries.
* The study was based on an appreciative enquiry approach.
* The women’s life-cycle experiences were researched by online survey and focus group discussions.
* Simple descriptive frequencies were used for quantitative data.
* Thematic coding of open qualitative responses was performed and validated with key respondents.
* The UK results are analysed separately here.

RESULTS
Of 95 participants from, or now living in, the UK:
* 64 (67.4%) responded to each of two optional sections on GBV and MH.
* 79.6% of those who responded reported having experienced at least one form of violence.
* 83% of UK respondents cited experiences of depression and feelings of rejection, with over three quarters reporting self-blame (78%), anxiety (77%) and insomnia (75%), and 70% or over reporting very low self esteem (74%), body image issues (72%) and loneliness (70%).
* In all categories, HIV diagnosis appears to be a major trigger for MH challenges.
* In comparison with global survey data, UK-based women experience less violence overall (80% vs 89%), but similar levels of mental health issues (such as depression at 83% for the UK and 82% globally).
* Qualitative recommendations from open-ended questions included “Empowerment, counselling and support”, “Support and more support” and, “Be in their shoes”.

CONCLUSIONS
* The complex needs and rights of women living with HIV require a stronger health-sector response.
* HIV diagnosis acts as a trigger for GBV – especially in community and healthcare settings – and for MH issues among women with HIV in the UK.
* Measures of GBV must be sought and monitored, particularly within healthcare settings.
* Respondents offered policymakers a comprehensive range of recommendations to achieve their SRH&HR goals.
* Interventions addressing intersecting stigmas, and any especial impacts of diagnosis during pregnancy, are required to women’s SRH&HR.
* National policy guidelines regarding women with HIV must address mental health and GBV.

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