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EUROSUPPORT V: Improving sexual and reproductive health of persons living with HIV

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Introduction and Background

EUROSUPPORT is a European network of HIV treatment centres, HIV research institutions and patient organisations with the objective to evaluate service provision needs of persons living with HIV (PLWH).
PLWH have been an understudied population with respect to HIV and STI risk reduction. Increases in new HIV-infections and in co-infections with sexually transmitted diseases (STDs) have raised concerns about established prevention strategies that primarily target HIV-negative persons (1) .
As health care providers have a unique opportunity to address these issues to their clients (2), EUROSUPPORT V collects evidence on sexual and reproductive health (SRH)-related problems and the needs of PLWH. The ultimate goal is to contribute to the improvement of service provision in this area.
15 study sites from 12 Western and Central European countries participated in this qualitative research on how to improve SRH of PLWH. Data will be used to develop a self-reported instrument to assess factors that influence SRH in a larger European population of PLWH.

Research Questions

(1) What are the major problems and needs of PLWH related to their sexual and reproductive health?
(2) What are the determinants of the adoption of protective SRH-related behaviours (prevention of HIV and STDs and fertility-related decision-making)?
(3) What are the barriers with respect to adequate service provision to PLWH in the field of SRH?

Methodology

We used the methodology of grounded theory (3). Data were collected using a focus group discussions with health care workers (HCW) and PLWH.
A common topic guide and a manual were developed for use in all countries.
Primary data analysis was done on country level. Qualitative data were provided as second codes (including a definition of categories). These data plus a narrative interpretation were translated into English (back translation for validity check). Meta-ethnography (4) was applied to arrive at a cross-country synthesis. An analytical matrix for cross-country analysis was prepared during a data workshop. Data synthesized were validated by the study group members.

Findings

The findings are based on 35 focus groups (20 with HCW and 15 with PLWH) and 23 additional in-depth interviews. This qualitative study provides insight in the problems of PLWH related to their SRH, as they need to adhere to safer sex on a life-long basis. In addition, fertility-related needs are high on the agenda for all heterosexual PLWH.

Major problems of PLWH relating to sexual health

- Gaps in knowledge on HIV transmission, in particular in relation to undetectable viral loads, and specific sexual practices
- Gaps in information about STDs other than HIV
- Individual sense of responsibility for protective behaviours and safer sex norms
- Lack of communication skills about sexuality
- Difficulties with HIV disclosure
- Lack of intimacy and sexual abstinence (difficulties to find a sexual partner)
- Lack of sexual communication and negotiation skills (gender-differences!)
- Sexual problems (reduced libido, problems in sexual arousal, erectile problems, reduced sexual pleasure, sexual aversion, pain during sex) in relation to duration of HIV-infection and/or medical treatment

Major problems of PLWH relating to reproductive health

- Gaps in knowledge on mother-to-child transmission
- Desire to have children
- Access to assisted reproductive technologies to plan pregnancies while reducing the potential risk of HIV-infection to sexual partners (in case of sero-discordant couples) and to the unborn child
- Contraceptive needs and prevention of unplanned pregnancies
- Contraceptive failures leading to abortion
- Difficult access to family planning services
- Lack of high standard care in obstetrics/gynaecology

Information was perceived as a necessary prerequisite to protective behaviour, and misconceptions and myths ("vernacular knowledge") were identified. However, providing sufficient information did not remove fear and concerns among PLWH about infecting sexual partners.

Instead, taking **responsibility** for protecting a sexual partner and oneself was directly related to adopting safer sex practices, and so was social support (by the partner, a specific peer group, or life-style related community). In addition, constructive coping styles were also associated with protective behaviours.

HIV-disclosure was another determinant of healthy sexual behaviours, as it may enable partner to communicate about prevention. Some FG participants reported deliberate decisions not to disclose, as they placed equal responsibility on the partner. Disclosure seemed to be closely linked to the partner's sero-status.

Gender-specific as well as **cultural determinants** influenced the individuals' ability to negotiate protective behaviours. Whereas for gay men SRH-decisions constituted a choice, it was rather defined as a risk for migrant women, over which they have poor control. In addition, fertility-related desires compromised safer sex choices, particularly when there was insufficient access provided to accurate information and adequate reproductive services.

With respect to barriers in **service provision**, policy issues both on the organisational level as well as on the level of health care policies played a role. While HCW perceived themselves as not sufficiently trained to provide SRH services, PLWH expected them to address these issues as an integrated part of a comprehensive bio-psycho-social care model.

Conclusion

Tailored approaches are needed that assist PLWH in their choices relating to healthy sexual behaviours and fertility related decisions. SRH-needs may vary throughout different stages of HIV-disease, contingent on the progression of the disease (e.g. diagnosis, starting with ARV-therapy, occurrence of periods of illness, etc.) and the psychosexual adaptation to living with HIV. Our data show that there is need for including counseling on SRH in standard HIV care in Europe. While intensified sexual counseling among HIV care providers is considered necessary, HCW working requires training to better understand the SRH-related needs of PLWH. A stronger integration of HIV and reproductive health services should improve care for women and couples living with HIV.

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