Sexological needs among older women living with HIV in Sweden:

lessons from a group intervention on empowering sexual confidence.

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Background

Ensuring women's wellbeing, sexual and mental health, ending inequalities and discrimination are included in several global goals of Agenda 2030. These rights is also confirmed in World Health Organization declaration on sexual and reproductive health and rights. Women of all ages, including women living with HIV, have the right to a good sexual health, meaning a state of physical, mental and social well-being in relation to their sexuality. Including the possibility of having pleasurable and safe sexual experiences free of coercion, discrimination, violence and disease.

Knowledge about needs and effective interventions about sexual wellbeing among women over 50 years old living with HIV remains poorly researched. Attitudes about sexuality and sexual rights about women living with HIV remain at large negative and discriminating and the burden of stigma and minority stress lays heavily and unfairly upon their shoulders (Narasimhan et al. 2016). Studies about the sexual health among women living with HIV show conflicting results of both a greater sexual satisfaction (than men living with HIV) but also high prevalence of low sexual self-esteem and a vulnerability to and experience of partner violence (Carlsson-Lalloo et al. 2016, Stanton et al. 2019). During menopause access to sexual health education is crucial if women are to adapt and their sexual expression is to evolve. An intersectional approach to address multiple vulnerabilities and knowledge about the impact of minority stress (Meyer 2003) is needed.

Noaks Ark Stockholm is a NGO providing psycho-social services for people living with HIV based on the PLISSIT-model (Taylor et al. 2016) and runs a program for women living with HIV. Specific sexual health interventions requested by the women led to a start-up of a group intervention to create a safe space for empowering peer and professional support. The intervention was implemented in two closed groups during 2021 and 2022.

Aim

To develop a group intervention to improve and empower sexual confidence and self-esteem among women living with HIV.

Result

The method was based on common group interventions from cognitive behavioural therapy, acceptance and commitment therapy (ACT), sexology theories and methods with an inclusion of peer-support. It was then tailored to fit the scope of the intervention and adjusted to have a HIV sensitivity. Each group intervention had five group sessions with a complementary individual one if requested. Each group had 3-6 members. Each session lasted for about 1.5 hours. Though the inclusion criteria had no age limit, all the participants were over 50 years of age.

At the start participants were given the possibility to suggest topics and explore needs so the leaders could adjust the themes. By addressing various dilemmas, the group were talking about different situations as for example: disclosure, dating strategies, intimacy and sex. Individual home assignments was also handed out to reflect and discuss upon. The group provided encouragement and emotional support, reducing the feeling of being alone with the problem. The increased knowledge about topics and the shared experienced served as a psychoeducational component in the intervention.

The results from the CSQ-8 form that the participants filled out after the intervention shared that everyone graded the quality of the interventions excellent or good and would recommend the intervention to a friend in need of similar help. Everyone graded the intervention as helpful to deal with ones problem but varied to what extent the needs had been met. The Female Genital Self-Image Scale (FGSIS) and Sexual Self-Esteem Inventory in Women (SSEI-W) shared a positive change or no change in most of the areas.

“I didn’t think I was interested in sex anymore but during this course I changed my mind. **I probably** like sex!”

Discussion and lessons learned

In Sweden it used to be a crime to not disclose your positive HIV status. Many of the participants are still affected by this fact which has formed an emotional trauma often unprocessed. Stigmatising experiences from health care were expressed as damaging to the internalised stigma, in line with current research (Kay et al. 2018).

A high number of the groups’ participants could not trust that they cannot transfer HIV even if the doctors declared them as unable to transmit (Undetectable=Untransmittable). The knowledge of U=U among people living with HIV is not enough to breach through internalised HIV stigma has been noted in research as well (Rijneveld 2021). The participants had to re-negotiate this time and time again as they disclosed their HIV status to partners, friends and health care staff which worsened their self-worth and (wrongly) focused on others’ acceptance. Our reflection is that the lack of specific interventions, from the health care and non-governmental organisations alike, are insufficient or non-existing regardless of years living with HIV infection. We conclude that there is an acute need to process, gain resources and tools to decrease stigma, empower and increase quality of life around the impact of U=U in everyday life. Especially from health care and through peer support to process and incorporate the theoretical knowledge of U=U to an emotional and behavioural change through therapeutic interventions.

There is a big obstacle for the women in these groups to dare to date and meet a partner for sex or a relationship. It was not uncommon that the women in these groups had been in unhealthy relationships, experiencing violence and a lot of emotional pain. The fear of rejection due to HIV stigma, despite earlier positive experiences of stigma, was not uncommon. The participants have through psychoeducation around minority stress been able to identify norms about HIV, which gained insight into and put words to their experiences. We worked with narrative elements, mentalizing exercises and affective training to manage different types of stressors that minority stress entails. Some of the women had multiple minority positions and also been exposed to racism.

Through the themes and exercises in the group we presented a sex-positive knowledge about how you can get turned on, possibilities of experiencing pleasure and to boost both genital and sexual self-esteem which are confirmed in our results. The members repeatedly highlighted the importance of peer support, different levels of interventions in a HIV normalising environment (which is provided through PLISSIT model) in structured places of care such as Noaks Ark Stockholm. We aim to continue with these interventions onwards.

Conclusion

Group interventions for women, and especially older women, living with HIV to empower sexual confidence and stigma is accepted and recommended. A methodology of ACT with the inclusion of peer support has a positive impact on sexual and genital self-esteem. A more extensive group intervention program and complementary individual interventions are needed to address extensive needs (for example on stigma and interpersonal trauma) but also to have a larger impact on internalised stigma and sexual confidence. Especially if needs have been unmet for several years living with HIV, for menopausal women living with HIV but also for women at an early stage at diagnosis to prevent internalised stigma.

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