

Title: Living with HIV in Sweden – a survey study on living situation and quality of life

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Type of presentation: oral

Background: The aim of the study was to explore quality of life among people living with HIV and it is the first of its kind and size in Sweden.

Methods: In total, 1096 individuals responded to an anonymous survey which included different areas of life regarding self-rated quality of life. The study was performed at 15 health care units in Sweden, representing 75 per cent of the HIV care in the country, as well as two needle and syringe exchange clinics in Stockholm. The respondents are representative of the different sub groups of people living with HIV in Sweden.

Results: The participants reported high rates of general quality of life and 60% rated their general quality of life as 7 or above on the general quality of life scale that ranges from 0-10. However, the satisfaction with one's economic situation was low and 70% of respondents were also displeased with their sex life, mainly due to difficulties to engage in sexual relationships. Twenty-five per cent had stopped having sex with others after being diagnosed, and another 25% of the respondents reported that HIV had had a negative impact on their ability to experience pleasure in relation to intercourse. Two aspects of HIV stigma significantly correlated with lower quality of life; other people's attitudes to their HIV infection (concerns over public attitudes to people living with HIV) and self-stigma (negative self-image because of the HIV infection). No correlation was shown between quality of life and sex/gender, age, country of birth or city of residence. However, the results showed that psychological symptoms, psychiatric side effects from HIV medication, substance abuse and high consumption of alcohol, homelessness and low income correlated with lower quality of life.

Conclusions: Quality of life among people living with HIV in Sweden is generally high however the results show that quality of life is negatively affected by the social aspects of being open with your HIV status, issues of stigma, possibilities for intimate relationships and a sex life, rather than affected by the medical factors of the infection.

Significance for research, policy or practice going forward: Further research on effective measures to reduce stigma and discrimination of people living with HIV is encouraged.

Key words: HIV, quality of life, stigma, wellbeing, people living with HIV

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