



Research Article

HIV and Sexuality: Perceptions and Experiences of Sexuality among Women Who Live with HIV in Sweden

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Abstract

The aim of this study has been to investigate the potential effects on women's experiences of their sexuality and their sexual relations after being diagnosed with HIV. The result of the qualitative interviews with seven women living with HIV, the result of the interviews shows that the fear of transmission is great and constant. The sexual practices adjust in the purpose to reduce the risk of transmission. The fear of rejection and peoples negative reactions was strong if their status would come to attention, which affected their experiences of well established and have relationships.

Keywords: Gender; HIV/AIDS; Sexuality; Stigma; Women

Introduction

The development of ever more efficient antiretroviral medicines has entailed huge changes for persons living with HIV. Mortality has decreased considerably and HIV-positive persons who are on effective Antiretroviral Therapy (ART) live long lives without serious medical complications, despite certain side effects and limitations. The medication has also been shown to strongly reduce the transmission of the virus and today the risk for transmission is considered virtually non-existent when the person with HIV is on effective ART [1-4]. In line with this development, most people with HIV living in Sweden regard their quality of life as good and in a study by the Public Health Agency of Sweden, it emerged that they are satisfied with their physical and mental health as well as with their relations to friends, partners and family [5]. In contrast, 70% of the persons who took part in the study stated that they were dissatisfied with their sex life and that it had been negatively affected by the HIV diagnosis. This dissatisfaction was above all due to their worry that they would be sexually rejected

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and that they would be reported to the police by a sex partner. Other studies have also shown that women with HIV more often experience hindrances regarding their sexuality than men with the same diagnosis [6].

The reasons for this have not been clarified. However, when the persons selected for a study are women, the focus is often, according to Dowsett, on vulnerability and risks [7]. In studies dealing with the same issues concerning men, the focus is on agency or on sexual interests and culture. Women with HIV live with diagnosis related stigma to a much larger extent than men do and that is why the preventive work for this group, regarding HIV, needs a new perspective on sexuality, a perspective that includes more than just reproduction [8]. Instead of including pleasure and health, sexuality is often, in the preventive programs, reduced to being simply a means of getting pregnant or seen as constituting a risk for the transmission of virus. An alternative way of viewing sexuality is that it is a structure of ideas, discourses and sensations resulting in individual patterns for being turned on, individual possibilities of experiencing pleasure and individual sexuality-related choices. Seeing the global HIV epidemic as something that concerns people that have sex and not just people who may get reproduction problems or people who are victims of sexual abuse, which is what women are sometimes reduced in discussions of HIV, might make it easier to cut down the number of new transmissions of the virus [7]. Viewing sexuality the way Dowsett does is very similar to Week's description of a development of sexuality where sexuality acquires meaning in social relations [7,9]. This gives it a value in social, cultural and political contexts, a different value depending on how the sexuality is expressed, when it is enacted and where and by whom. Traditionally, sexuality has long been characterized by two other positions, where the first one describes sexual expressions as dangerous and accepted only within the context of marriage and the other, which has, for different sociocultural reasons, been repressed, describes sexuality as wholesome and good. Thus, Week's third position can be seen as a development in relation to the two original positions [9].

HIV in Sweden

The aim of the Swedish Communicable Diseases Act (2004:168) is to cater to the population's need of protection against the spread of a number of different infectious diseases. The so-called public health hazards, where, among others, salmonella, smallpox, rabies, chlamydia and HIV are listed, are defined as infectious and potentially fatal diseases that may result in a long period of ill health, or have other serious consequences. It should also be possible to work preventively to reduce the number of individuals affected by those diseases. The duty to inform is part of the Communicable Diseases Act (2004:168) and it means that if a person tests positive for any of the diseases listed in that act, he or she is obliged to inform all persons concerned of the infection, if there is a risk of transmission. Today, there is a great deal of discussion of the duty to inform. The background is that the medicines that are used to treat HIV today, so-called antiretroviral treatment, not only radically reduce morbidity and mortality but also strongly reduce the infectiousness in connection with sexual contacts, in fact reduces it to a minimal risk [10].

Women living with HIV

HIV research and preventive work for a long time had a marked focus on men who have sex with men. One reason for this is the over-representation of this group in the statistics of the number of persons carrying HIV. Knowledge development has also, for a long time, centered on questions regarding sexual risks and so-called risk behaviors. In contrast, there is a considerable lack of research dealing with the connection between sexuality and everyday life and diagnosis, that is, regarding the influence of an HIV diagnosis on the love relationships of everyday life and the view of one's own sexuality. There is, not least, a shortage of research on these issues with regard to other groups than men who have sex with men. Women, for instance, constitute a group that is rarely described in these contexts and that is not seen as a prioritized group within HIV prevention a strange phenomenon, considering that approximately 38% of the number of newly HIV-diagnosed persons in Sweden in 2016 were women [11].

Women who live with HIV may become even more vulnerable in this context due to the current views of female sexuality. Harman and Squire, for example, claim that women who live with HIV are restricted by how media and popular culture present this group [12,13]. The fact that men's sexuality is prioritized in relation to women's sexuality, in a society characterized by patriarchal structures, makes the sexual rights of women dependent on how men's sexuality is expressed [12,14]. Rubin describes how the development of a normative system regarding sexuality has its starting point in contexts to do with sex and gender where men symbolize desire and women symbolize purity [15]. In the same system, good, natural and normal sexuality is represented by heterosexuality and is marital, monogamous, reproductive and non-commercial. The sexual act is also supposed to take place between two persons who are healthy and of the same age and at home, in the couple's own home. The opposite of good sexuality is characterized by being bad, unnatural and abnormal, for instance, due to illness, relations outside of marriage, or relations between persons of the same sex. The legal system has also devoted itself to this division when it has established laws regarding, for example, sexual practices and who is allowed to have sexual relations with whom. This is, furthermore, a clear example of the sexual value hierarchy that Rubin describes and it is sometimes also, in the long run, a stigmatizing process [15].

Women living with HIV and sexual rights

There is very little knowledge today about how the HIV diagnosis affects women's experiences of their sexuality and their sexual relations. How is, for example, their libido affected by an HIV diagnosis? How is the stigma surrounding HIV dealt with in sexual situations? People's sexual rights are part of the human rights and something that in many ways affects people's sexuality [14]. They are formulated by the World Health Organization (WHO), in consultation with, among others, the World Association for Sexual Health (WAS) and they use gender-neutral formulations and deal with, for instance, the right to sexual pleasure, the right to say no to sex and the right to other alternative means of making a living than involuntary sex work (for further information, see the Pan American Health Organization/World Health Organization [2000] "Promotion of Sexual Health: Recommendations for Action"). One problem with the formulations is that they do not bring up how these rights can be expressed and recognized in different ways, depending on what gender persons identify with. The different rights may also clash with one another; for example, one person's right to say no to sex might clash with another person's right

to sexual pleasure. In some contexts, women have, traditionally, had trouble saying no to sexual relations although they have wished to do so. Men, on the other hand, live in a tradition according to which they should always want sex and pleasure, which leads to inequality with regard to the possibility to say no and with regard to the right to pleasure in many situations [14].

The women in Galvao & Steven's study said that in sexual situations where they have to be confronted with their HIV diagnosis, they need to make decisions regarding sexual practice in relation to safer sex, contraception, the risk of being rejected by a partner, maintaining sexual self-confidence and stigmatization [16]. Many women assert that the diagnosis has influenced their sexuality in a number of different ways. Spontaneity is reduced as a result of the risk of transmission of the virus, as well as being related to the access to contraception. This affects their room for sexual maneuver and freedom [8,16]. The aim of this study has been to investigate those questions further. The investigation is a pilot study and will be the basis for a larger and more comprehensive study about women, HIV and sexuality.

Method

The study is based on qualitative research interviews with seven women living with an HIV diagnosis in Sweden. For many people, sex is a sensitive issue and if a person is diagnosed with HIV the issue can become even more sensitive. Those persons who were interviewed were asked if they wanted to participate in the study in connection with a gynecological check-up at one of the larger hospitals in Stockholm and the question were asked under a time period of two months to all patients, in total 14 patients. In order to obtain a broad representation of informants, a voluntary organization was also contacted and that organization displayed notices about the study in their premises. Those who were asked to participate in the study had all lived with their diagnosis for at least one year. The aim of this eligibility criterion was that the persons who took part in the study should have time to process the fact that they had a chronic infection. However, for some patients one year may be a short time, depending on circumstances. In some cases, the staff responsible for recruiting informants for the study made the judgment not to ask a patient if she wanted to participate, due to the patient's general condition or other social hindrances that would have made it difficult to conduct an interview. Those who were asked to participate but did not want to, cited reasons such as not feeling that they had the time, not wishing to account for their sex life to a stranger, or not wanting to talk about things that would make them sad. Seven persons agreed to contribute and in the study they are presented under fictive names in order to maintain their anonymity (Table 1).

The interviews were semi-structured and the interview guide focused on experiences of sexuality and sexual practices and was constructed after an article search based on the keywords 'sexual expressions', 'women' and 'HIV/AIDS'. Articles not including all of those keywords were excluded. The themes were designed out of the questions that the research haven't treated earlier, primarily sexual practices and attitudes towards the individual sexuality. The interview guide was used as a checklist during the interviews in order not to omit any relevant area. Mainly open questions, such as "How do you define a sexual relation?", were used, in order to obtain individual perceptions of sexuality to as high a degree as possible. In connection with some of the interviews, an area that was not included in the interview guide was sometimes brought up by the informant, which was welcomed, since it helped promote an open conversation around the themes relevant for the study.

Informant	Age	Relational Status	Children	Land of Origin	Number of Years with an HIV Diagnosis
Lotta	48	Married	2 adopted children	Zimbabwe	22
Ulrika	51	Married	1 adopted but related child	Sweden	22
Elisabet	35	Single	1 biological child born after the infection	Sweden	3
Lisa	55	Single	No	Sweden	17
Olivia	46	Married	2 adult biological children born before the infection	Sweden	22
Naima	38	Cohabitant	No	Preferred not to say	13
Barbara	35	Cohabitant	1 biological child born before the infection	Roumania	6

Table 1: Open Conversation with informants

The study has been scrutinized and approved by the Ethics Board of Malmö University (reg.no. HS60-2013-60- 2013/155:8). Parts of the material have been produced with financial support from the appropriations of responding to HIV/AIDS and other infectious diseases (2013/2:5), which were distributed in 2014 by the Public Health Agency to achieve the objectives of the government bill National Strategy on HIV/AIDS and other infectious diseases (2005/06:60).

In the works of the analysis, patterns and distinguishing concepts that characterizes both the individual interviews and the material as a whole, were defined. The process of screening and choose which patterns and concepts that presents in this study, follows a inductive model of analysis and are based on a collaboration between the theoretical reasoning regarding sexuality and the emerging categorizing of the material.

Result

Living with HIV - relations and reactions

Despite the fact that the antiretroviral medication has considerably reduced the risk of transmitting HIV, the informants still believe that there are distinctly negative perceptions of HIV among the public, which, in turn, affects the way they relate to their surroundings. In social contexts, at the workplace, or in everyday social encounters, all informants except one avoid talking about their HIV status, insofar as possible. Similarly, the fear of being rejected in the encounter with a new partner often results in a more wary attitude at the beginning of a relation. However, two of the informants say that they had positive experiences of establishing new relationships and those new partners have not initially reacted negatively on learning about their HIV status. At the beginning of a new, more permanent relationship, the whole group of informants has nevertheless harboured feelings of guilt and shame because of their diagnosis and they have been intent on finding a good way of telling their partner about it. It's about trust and about not raising a barrier to being emotionally involved in another person, simply for fear of not being liked or accepted (Lisa).

All the women describe how, even after having told their partner about their HIV status and established a more permanent relationship, they retain a worry lest their surroundings, for example, the relatives or friends of their partner, should react negatively. In other words, there is a constant feeling that one might be "found out," even if one is very open about one's HIV status with the people one is close to. The worry is also closely linked to a feeling of shame and deficiency, a feeling of being dependent and at a disadvantage in the relationship. Thus, two of the women mention how they experience their diagnosis as an obstacle to leaving a relationship, since they feel that they should be grateful that anyone wants to be in a relationship with them at all. Ulrika, who lives in a relationship where her partner has for a long time entertained a secret, parallel relationship, has chosen to remain

in the relationship: I ought to be glad that he is with me at all, since I am flawed.

The sex life and the fear of transmitting the virus

All the informants describe how they, in connection with learning about their HIV status, thought that they would never again be able to have sex. In the Communicable Diseases Act, it says in chapter 2, section 2, that "anyone who is aware that he or she carries a disease that is dangerous to public health is obliged to inform other people about the infection whenever he or she enters into contacts where a considerable risk for transmitting the infection exists [17]." In other words, the so-called duty to inform others means that a person with an HIV diagnosis must declare his or her HIV status in situations where there is a considerable risk of transmitting the infection to another person.

After being diagnosed with HIV, the informants have been very much aware of the obligation to provide information and the law is considered justified. At the same time it is experienced as an obstacle and several informants point out that they experience a marked difference between how they relate to their own sexuality now and how they related to it before they were diagnosed. The worry about transmitting the HIV virus is strong and several informants describe how this worry has affected their libido, despite precautions and despite the fact that the risk is in reality largely non-existent when they are on effective ART. All the informants, however, describe how their libido has returned over time in one way or another, more or less, parallel to their gradual internalization of the knowledge that the risk for transmission of the virus is low when they are on effective ART. Nonetheless, risk reduction is described as an important element of the women's sex lives and as necessary in order for both the women and their partners to feel safe. The informants express uncertainty with regard to risks connected to certain sexual practices, above all oral sex. They abstain from those practices that they are uncertain about, something that Ulrika describes like this: We have to take precautions with regard to oral sex, for example. That is, my husband abstains from giving me oral sex, completely. Doesn't want to risk it.

For all the informants, using contraceptives is considered self-evident when needed to prevent transferring the virus and/or prevent unwanted pregnancies. Which contraceptives work and where to get hold of them, is not quite obvious. However, all of the informants who have vaginal, penetrating intercourse with a partner who was not HIV positive say that this felt good as long as they used a condom. In those cases where the woman's partner was HIV positive too, the scope for activity and playfulness was felt to be larger, since both partners had sex on the same terms. All the informants except one, found a way of dealing with their diagnosis in relation to their sex life: I tell myself that I still have a reasonably normal sex life, or at least as normal as possible under the circumstances, whatever normal means in the present abnormal conditions (Lotta).

However, none of the informants say that they have discussed sexuality, sexual practices and libido in the encounter with different professionals. Instead, all the information has been more geared towards risks around the transmission of the virus.

Discussion and Conclusion

The result of the study shows that the HIV infection has affected the way the informants initiate new relationships and how they practice their sexuality. This is shown in a more wary attitude with regard to starting new (sexual) relationships but also in altered sexual practices. All the informants, with one exception, refrain from receiving oral sex, for example, or choose other practices that are perceived as less likely to transmit the virus.

For all of the informants, the fear of transmitting the virus to one's partner is thus a central issue. They state that they have a good knowledge about the fact that the risk of transmission is very low when they are on effective ART. Yet they are constantly focused on minimizing the risk and on a feeling of being "found out" and of being at a disadvantage in the relationship, that is, the risk of being abandoned because of one's HIV status is perceived to be ever present. In this respect, the informants express a so-called self-stigma, having internalized negative attitudes to HIV of their surroundings, something that also restricts their experiences of sexual pleasure and their libido [18]. They have ended up in a situation where they carry both an external and an internal stigma that are in part exacerbated by a lack of information about sexuality, that is, of information other than about the risks and hazards around the transmission of the virus.

Rubin writes that sexuality can be used as a means of repression, where women often draw a blank with regard to sexual space [15]. According to the results of this study, it seems as if the room for maneuver for women is further restricted in combination with an HIV infection and, as a result, the thought of living in celibacy appears as a matter of course a thought that is often, however, reassessed later, with increased knowledge about the infection. Dowsett states that research and preventive measures need to include sexual practices too, in order to prevent the increase of the number of people who carry the HIV virus and reduce the self-stigma that arises [7]. It is, after all, there, in the sexual encounter, that the concrete transmission of the virus takes place. Squire, on the other hand, proposes more studies on love relationships in this kind of research [13]. These two perspectives represent different theories, where Dowsett requests a new and updated focus on sex in the debate on HIV, whereas Squire promotes an already existing view of women as part of a relation rather than as sexual individuals [7]. Squire's proposal presupposes that women only have sex within a relationship and with one and the same person, which confirms a stereotypical picture of both women and relationships that exists in society today [13].

The results of this study point towards the necessity to adopt a more sexologically oriented approach in working with women, so that women who live with HIV are enabled to exercise their sexual rights, as formulated by the WHO, irrespective of relational status. None of the informants in the study had discussed sexual desire or pleasure with any health care professional after being diagnosed with HIV.

Consequently, an important conclusion of this study is that there is a huge need for the introduction of sexological issues into the encounters between health care professionals and persons living with HIV, in order to reduce the strong stigma that surrounds this diagnosis.

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