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''Eyes Wide Shut'' – Sexuality and risk in HIV-positive youth in Sweden: A qualitative study

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Abstract
Aims: This study explores the perception of sexual risk-taking behaviour in young HIV+ women and men in Sweden and their understanding of why they caught HIV. *Method*: In-depth interviews were conducted with 10 HIV+ women and men aged 17–24 years, 7 born in Sweden and 3 immigrants. Interviews were tape-recorded, transcribed verbatim, and analysed according to the stages of grounded theory. *Results*: The core category *varying agency in the gendered sexual arena* illustrated a spectrum of power available to these informants during sexual encounters. Two subcategories contextualized sexual practice: *sociocultural blinds* and *from consensual to forced sex*. Lack of adult supervision as a child, naïve views, being in love, alcohol and drugs, the macho ideal, and cultures of silence surrounding sexuality both individually and structurally all blinded them to the risks, making them vulnerable. Grouping narratives according to degree of consensus in sexual encounters demonstrated that sexual risks happened in a context of gendered power relations. *Conclusion*: This pioneering study reveals mechanisms that contribute to vulnerability and varied agency that may help in understanding why and how young people are at risk of contracting HIV. Public health strategies, which consider the role of gender and social background in the context of risky behaviours, could be developed from these findings.

Key Words: *Agency, gender, HIV-positive youth, public health, qualitative study, risk, sexuality*

Introduction

HIV is a global catastrophe that significantly affects young people. Half of all HIV infections worldwide are diagnosed in people under the age of 25 [1]. The most vulnerable are young people in developing countries where general as well as sexual health is subject to such sociocultural conditions as poverty, migration, war, and uneven access to education, health services, and gender inequalities. The few studies on HIV-positive (HIV+) young people in Western countries show that HIV+ young people differ from non-infected teenagers in several ways: early sexual experiences, incarceration, psychiatric care, dropping out of school, homelessness, and higher drug use [2–6]. In Eastern Europe and Central Asia, the epidemic, especially among the young, is increasing because of drug use [7].

In Scandinavia, HIV is a rare disease. Current figures from Sweden report 62 cases in the age category 15–24: 42 women and 20 men [8]. Little attention has been paid to HIV+ youth, to their sexuality, or to gender issues.

Considering gender means looking at young women and men from a social and cultural perspective, examining life circumstances, positions in society, power relations, and societal expectations about femininity and masculinity [9]. This gendered behaviour is dynamic and can change over time and in different circumstances. Gender influences the global course and impact of the HIV/AIDS epidemic. Women and adolescent girls are often more vulnerable than their male counterparts [10,11]. In an ideal world everyone is equal and free to make informed choices, and can choose to abstain from

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sex or use condoms consistently. In reality, women face many HIV-related risks, embedded in the social relations and economic realities of their societies. This power imbalance is underlined by stereotypical gender constructions, which are widespread in both developing and developed countries.

In Sweden gender equality is an established goal, where sexuality is thought to be openly discussed and contraceptives are available. Nevertheless, there is a rapid rise of Chlamydia infections, which is also an important co-factor for HIV infection [12]. This fact does not stop young people from having unprotected sex. Few studies have examined what happens in sexual relations that place both young women and young men at risk of contracting HIV [13]. This research focuses on young HIV+ people and their sexuality in a Swedish setting. Learning from them could improve public health strategies regarding HIV.

Aim

This study explores how young HIV+ women and men in Sweden perceive sexual risk-taking behaviour and their understanding of why they contracted HIV.

Material and method

Recruitment of informants

The staff at three HIV clinics in Sweden invited a criterion sample of young HIV+ persons to participate in this study. They were informed in writing and verbally. Those with a recent HIV diagnosis and those with severe psychological problems were not asked to participate. Seven of those invited declined because of emotional problems or time constraints. Nine informants were recruited from hospitals, one from a voluntary HIV organization. Recruitment took three years.

Interviews were conducted at a time and place decided on in collaboration with the informants. Four informants preferred to have the interview at the hospital, two at their workplace, two at a hotel, one at home, and one at a youth clinic. Seven of the informants spoke fluent Swedish while two combined Swedish and English. A professional interpreter was used in one interview.

Data collection and analysis

We chose an exploratory research strategy with in-depth interviews and open questions [14], and based our analysis on grounded theory [15,16]. The informants were encouraged to speak about sexual encounters, risk attention, and how they thought they contracted HIV. The first 10 interviews were tape-recorded, lasted 1.5–2.5 hours, and were transcribed verbatim. Each transcript was sent to the informant for review. Two did not read the transcripts. Follow-up interviews, by phone or in person, allowed the informants to comment, explain and correct, or delete parts. Notes were taken during these interviews.

Collection of data, transcription, and preliminary analysis were simultaneous. The authors read each interview separately and constructed open codes, describing an experience, a response, or an episode. Systematic comparisons, discussions, and reflections were introduced into the analysis before the next interview took place. Thus the interviewing researcher was able to check ideas and interpretations with the next informant. After completion of all interviews we made a thorough analysis, considering gender, emergent ideas were tested, and a deeper understanding of the complexity of HIV transmission was sought. The theoretical concept *agency* was used to outline the frame of action for the informants [17]. Agency is the power to act in situations and to monitor others' actions, where the interaction depends on others. Here, agency referred to the options these young people used to reflect and act on in sexual situations. We revised the interviews, organized and grouped the codes to create categories, made a selective coding, asked analytical questions of the data, and developed a core category, subcategories, and dimensions that explained why and how the informants caught HIV. To enhance credibility of the findings, four informants read and commented on the preliminary manuscript and individually met MC.

The Medical Ethics Research Committees of Karolinska Institute and Umeå University approved the study in spring 2000.

Results

The ten informants

The informants were 17–24 years of age, 5 women and 5 men. Six were single, and four were in stable relationships. Five worked full time, two were on sick-leave, and three were studying. Most had finished senior high school; one had dropped out of school but had started senior high school studies. Seven informants were born in Sweden; three were immigrants. Three informants had experimented with illicit drugs but did not inject. All had a place to

live. First sexual intercourse varied from ages 12 to 18 years. All five women and two men were heterosexual; three men were homosexual. Time from HIV diagnosis to interview varied from seven months to five years, with an average of two years. Four females contracted HIV by having sex with men. One immigrant woman was uncertain whether it resulted from sexual intercourse or a blood transfusion. Two men contracted HIV after sex with women, three with men.

Varying agency in the gendered sexual arena

We focused on agency and interaction to contextualize the findings. The informants seldom described themselves as victims, but our analysis disclosed a spectrum of capacity for deciding their line of action as sexual agents in a frame of gender order [9]. The core category; *varying agency in the gendered sexual arena*, elicited their performances on the sexual scene. Two subcategories emerged to structure the sexual practice. In the section *sociocultural blinds* we analysed how the informants perceived sexual risk-taking. The informants were innocent and curious, and exploring their sexuality with ''eyes wide open'', but various circumstances shut their eyes regarding attention to risk. *From consensual to forced sex* described their power to act during sexual encounters. This subcategory reflects the fact that although lust and attraction were involved initially, their power to manage situations varied and depended on interactions with sexual partners.

Sociocultural blinds

The following determinants blinded them to the risks of unprotected sex.

Lack of adult supervision. Eight informants were brought up in broken homes where the childhood and adolescent period was problematic, with parents described as fragile or absent. Consequently, these young people lacked adults to serve as role models or to set reasonable limits for sexuality. They experienced loneliness and little support from parents or other adults. Most of them were venturesome and vulnerable:

> I think that I caught HIV… [Sigh] maybe because things have been complicated (during my childhood). I think about … I think…. Why did I have sex with him? Another girl of my age would not. Why did I not…. It is difficult to say, but the person I am reflects everything that I have gone through.

Naivety included unawareness of risk or misconceptions. Many had no worries about catching HIV, thinking ''it wouldn't happen to me'' (a fatalistic imagination), which provided a false sense of security. For example, one woman thought that people moving to Sweden were required to test for HIV, and thus incorrectly believed she was not at risk of contracting HIV from immigrants.

Being in love meant investing trust in intimate relations. In our analysis, being in love also expressed subordinate positions, as experienced by one man in his first homosexual relationship:

> Interviewee: I was so in love with him … but he was also … he did not like condoms.
> Interviewer: Did the thought strike you, what if he has HIV?
> Interviewee: No, one doesn't think that way … no I don't think like that, not with him … of course if you meet someone only once, then it is obvious, but I felt that I could trust him … so if he wanted to have unsafe sex, he knows for sure that he doesn't … because I admired him … really….

Cultures of silence had two dimensions: one concerning sexuality in personal relations and one dealing with the silent, uninformed society. Silence surrounded sexuality in private relations; some women said it was difficult to negotiate safe sex with men. Two of the Swedish women were attracted to black men from Africa, inducing some attentiveness to risk, but it was hard to verbalize and handle. One of them related a discussion with her friend, revealing this ambivalence:

> But think if he has HIV? I do not know why I said that … it was very strange and I talked to my best friend and she said ''no he doesn't have it''. But then what if!

This man was her first sexual partner, but she could not talk to *him* about the risk of HIV infection. He was older, married, and had children – qualities associated with power. Similarly, another woman could not ask about HIV. She was unsure that her partners would answer honestly. Though submissive in the relationship, she tested for HIV after a sexual relation ended, thus acting as a responsible agent.

One informant's experience reflected the attitude of the uninformed society. She never worried about catching HIV although relatives and neighbours had died. In her African country nobody talked about HIV/AIDS:

> Even if they get AIDS, they do not ask about it.… Here [in Sweden] if one gets a fever or something they look at a blood test and they see everything, but in my country one doesn't say anything.…

Alcohol and drugs contributed to risky behaviour. The men noted the link between alcohol, drugs, and unsafe sex. Two informants, who thought they had strict upbringings, usually kept control. However, exploring their sexuality at night-time challenged their ideas. When they were drunk, they often practised unsafe sex. One informant lived in an environment of drugs and criminality. Safe sex was not prioritized. He spent his weekdays getting money to buy drugs, partying with his gang, having sex with any women around, and stealing from them to buy more drugs:

> I never worried about HIV … to some extent because I used drugs, you don't think about those things then. You don't think about protecting yourself and catching diseases and things like that.…

The *macho-ideal* determined the positions for three men. They constructed a masculinity that included multiple sexual partners, sex with prostitutes, or ''conquering'' girls in order to raise their status among friends. The idea of being the dominant partner implied power and less risk. A homosexual man thought that being the inserter during anal sex reduced the risk of catching HIV, and his need for sexual pleasure tended to override any concern for his own health. Although he worked with HIV and gay people around him had died, the diagnosis shocked him:

> I never thought that I had it … it was such a tiny risk because I was the ''donor'' so the odds were on my side.

From consensual to forced sex

Five informants thought they knew the exact moment of contamination. The others felt unsure but mentioned likely encounters. The various narratives were categorized according to how agreement or disagreement during sexual interactions was expressed. The concepts *consensual*, *transitional*, *non-consensual* and *overriding sexual activities* were examples of varying agency in sexual liaisons.

Consensual sexual activity covered voluntary liaisons. For instance one woman portrayed her sexual experiences positively, laughing when she recalled the first time. She was 13 and living in Africa, and had sex with an older neighbouring boy:

> I wanted to see what it was like … only try … a first time … but there was a second time and it ended up with a hundred times.

Another woman had had three sexual partners, lived with an HIV-negative partner and concluded that her first partner, a married man, must have been the transmitter. In this relationship sexual pleasure had overshadowed all thoughts about safe sex.

One woman described a long-term romance with a man who withheld information that he was HIV+. She found him trustworthy as he initially used condoms.

> We used condoms every time so no problems … and we lived together … and you think that you know each other.… Living together for six months you think that you would have noticed something, but I did not. And I was on the pill and suddenly you stop using condoms and the first question to come up is not ''Hey, what's wrong with you?''

Transition between consensual and non-consensual sexual activity, i.e. where borders between approved and forced sex shift. One African woman, who had had sexual intercourse once, said clearly: ''I've tried it once and didn't like it.'' She regretted having sex, blamed herself for giving in to his demands and held herself responsible:

> Maybe if I had not met this boy, then I wouldn't have it … because I keep saying: why did I meet him … it keeps coming in my head … why did I do this?

One informant knew ''with 99%'' certainty he got HIV: during an unstable relationship with an unfaithful lover. The informant fell ill soon after, with fever and a cold. This partner had persuaded the informant to be the receiver of unprotected anal intercourse, although he disliked it:

> The guy that contaminated me, he was nagging about having unprotected sex … because he did not think it was good otherwise.…

One informant's story illustrated that she was not a free agent. One evening downtown, she was waiting for some friends who never came, when a handsome man spoke to her. She was used to older men flirting with her, but had rejected such invitations. On this occasion, she accepted, went with him to a nearby

pub, and got drunk. Later they took a cab to his apartment. She was 15, sexually inexperienced, but adventurous. Her image of sex was based on sensitivity:

> I can try it now. It felt that way. I do not know whether it was a strong feeling or not, but I was prepared. But it wasn't nice at all. He rode his race…. There was no love … and sex without love is totally worthless, from my point of view … plus that I had anal sex … and one can think afterwards how stupid that was…. It felt very unpleasant and I thought to myself, I don't want to do this, but I couldn't say anything. And it didn't feel nice for me at all…. Yes I almost felt used … I had never had sex before….

Non-consensual sexual activities were encounters where the outcome was neither desired nor intended. Power relations occurred among men who had sex with men. The following experience was based on subjugation:

> I was going out a lot … and I had no inhibitions and mingled with the wrong company … party almost every night … extremely … lots of partying … and I drank a lot and it was parties at their worst and I got into a bad situation and I have always protected myself … but this time there was not any … it was only once and I know who it was … one can say that it was a rape … [silence] what happened … it wasn't that I failed to … it wasn't that I wanted but didn't have a condom … well it wasn't based on my free will so to speak…. I didn't report it or anything…. I felt disgusted, went home and took a shower and I became so worried … so worried.

Overriding sexuality was interpreted as a risk-prone version of masculinity.

Three men stated that their sexuality was a habit based on excitement and desire, before they contracted HIV. One informant had "fun" for one summer; he went to parties, and travelled around Europe:

> Yes I had unprotected anal intercourse five times … there's no one special that I can point to … but I know that it happened around July. I got a sore throat in the beginning of August … and much later I realized that it must have happened at that point.

Sometimes it was impossible to know the source of infection:

> I have been active [sexually] … going out a lot and so on and met a lot of girls. It is impossible to know if it was this girl or that girl…. I only thought about shagging and then stealing from her house and getting lots of money.

One informant came from South America where he worked in a computer company. After work, he and his colleagues would go to bars to drink and meet women. Although he did not visit prostitutes regularly, his colleagues did. Because he did not want them to judge him, he sometimes hired a prostitute:

> You come along with friends and then you'll see them sitting there, so most of the time you know who they are, so you sit down with them, buy them beers and then the night is made….

Discussion

From analysis of interviews with HIV+ young people, the core category *varying agency in the gendered sexual arena* presented a spectrum of power available to these informants during sexual encounters. The subcategories *sociocultural blinds* and *from consensual to forced sex* described context-bound experiences in their sexual practice. Lack of adult supervision, naivety, being in love, alcohol and drugs, the macho ideal, and cultures of silence blinded them to perceptions of sexual risks and made them vulnerable. Furthermore, grouping narratives according to degree of consensus in sexual encounters demonstrated that sexual risk-taking happened in a context of gendered power relations.

Reflecting on method

In Sweden in 2002, less than 60 known cases of HIV between ages 17 and 24 were documented. This restricted recruitment, which took three years. However, a criterion sample of 10 informants could be regarded as sufficient for theoretical saturation for the purpose of the analysis. Our aim was to explore, understand, and describe sources of variation concerning sexual risk. The informants differed regarding sex, ethnicity, upbringing, and sexual orientation, thus ensuring that varied experiences were examined. The interviews gave us a great deal of knowledge and our analysis was firmly anchored in the data. Despite limitations, we believe that our findings are of value when considering sexual risk-taking in young people, and useful when discussing preventive strategies for HIV.

Approaching a vulnerable group raises ethical considerations. Interviewing HIV+ people might

evoke emotional distress. All informants had the opportunity to see a psychologist after the interviews. The majority, however, said that talking about HIV and sexuality with an interested researcher was a relief, perhaps even a therapeutic experience. In a study such as this the informants might use the researcher as a ''witness'', to their stories, and telling them may change their understanding of their story [18]. Conversely, as researchers, we knew our position was powerful and could influence how informants interpreted their experience, their reality, possibly with negative consequences [19]. To counteract this, prolonged contact with the informants and letting four informants read and comment on the preliminary report was valuable.

The findings

HIV, for the moment, is not a widespread problem for Swedish youth. Three informants caught HIV in their home countries, and the experiences of immigrants from Africa and South America may not reflect Scandinavian circumstances. However, this pioneering study elicits various mechanisms that can help us understand why and how young people are at risk of contracting HIV. We found a consistent pattern of difficulties during childhood: loss or divorce of parents, and foster care. Living with single parents is common in Sweden, and new research describes the health disadvantages for children in such households [20]. This manifold problematic background may have contributed to the informants' vulnerability. Our results agree with research which concludes that an insecure environment can harm the development of independent and responsible behaviour [21]. This is recognized in a qualitative study on African-American HIV+ young women and men who were deep-rooted in a devastating socioeconomic and neglectful psychosocial milieu during their upbringing [22]. The development of gay or bisexual identity may also increase the risk of HIV in young people [6].

Many preventive strategies presuppose that individuals are rational and make logical choices concerning sexuality, but we found that lack of, or restricted, agency put these young people at risk. There are numerous young people in Sweden who live in comparable contexts of social and sexual vulnerability. They might lack the agency necessary to safeguard. This could be further developed as a public health issue.

Typically, adolescence is seen as a stage of identity development intertwined with sexual risk. Adolescents, however, do not see themselves as part of a typical risk group [23,8]. Unsurprisingly, most of the informants did not consider the risk of catching HIV, acting instead with their *eyes wide shut*: their sexuality was a non-reflected action with little if any risk calculation. Although the term *risk* is often associated with negative outcomes, threat, or harm [24], sexual behaviour is multifaceted and risk can be transformed into *chances* worth taking. For example, one woman felt that she was ready to take a chance, and some men found it difficult to think of pleasure and excitement as hazardous. Much behavioural science views sex as harmful behaviour and fails to see sex as pleasure [25]. A recent study on gay HIV+ men and the ways in which they understood their HIV infection showed how they used a discourse of love, pleasure, intimacy, and fatalism in discussions on unsafe sex [26]. In our study, several informants also spoke about love and trust in intimate relations.

Sexual behaviour is embedded in culture. Many young women worldwide have little power to negotiate safe sex [11,27]. The sexual script of femininity often means satisfying men's needs without questioning men's dominance [28] and dominant masculinity traits lead young men into risky or coercive sexual behaviour. In our study, women *and* men had difficulties negotiating safe sex, or discussing HIV risk with their partners. Both women and men experienced involuntary sex. The ideal world where *everyone* is equal and free to make informed choices is still far distant.

Conclusion

The view that HIV is not a problem here has implications for young people living in Sweden. This study reveals mechanisms that contribute to vulnerability and varied agency, which is helpful for understanding why and how young people are at risk of contracting HIV. Public health strategies, which consider the role of gender and social background in the context of risky behaviours, could be developed from these findings.

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