The Law of Communicable Diseases Act and disclosure to sexual partners among HIV-positive youth

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In Sweden, human immunodeficiency virus (HIV) is included among the venereal diseases covered by the Law of Communicable Diseases Act. HIV-positive (HIV⁺) people are required to inform their sexual partners about their infection and adopt safe sex behaviours. However, it is unclear how the law is perceived. This study explores how HIV⁺ youth in Sweden perceive the law, handle their sexuality and disclose their HIV diagnosis to sexual partners. Ten HIV⁺ women and men between 17 and 24 years of age were recruited from three different HIV infection clinics. These participants were interviewed in depth. The interviews were tape-recorded, transcribed verbatim and analysed according to a grounded theory approach. The core category—cultured to take responsibility—illuminates the informants' double-edged experiences regarding the law and how they handle disclosure to sexual partners. The legislation implies both support and burden for these HIV⁺ youth; they feel that they have a great deal of responsibility, sometimes more than they can handle. 'Switch off lust', 'balancing lust, fear and obedience' and 'switch off the disease' are strategies that describe how the informants manage sexuality and disclosure. Young HIV⁺ people have a difficult time informing partners of their HIV diagnosis and discussing safe sex strategies. These are challenges that health care providers need to take seriously. HIV⁺ youth need better communication strategies to negotiate safer sex. Staff with extended education on sexuality should be a part of HIV health care.

Keywords: HIV-positive youth; sexual behaviour; legislation; disclosure; qualitative study

Introduction

In the Nordic countries, laws about sexually transmitted infections (STI) were introduced between the First and Second World Wars (Moi, 2001). In Sweden, human immunodeficiency virus (HIV) is covered by the Law of Communicable Diseases Act, 1985, which permits registration of infected people, compulsory partner notification, tracing and isolation of patients who are spreading the infection (www.government.se, 2004, p. 168). This should be distinguished from the Swedish Penal Code: the criminal law that is applied when a person is spreading the infection purposely. Once diagnosed, all HIV-positive (HIV⁺) people are required by law to inform sexual partners about their infection and to adopt safe sex behaviours such as obligatory condom use. The law aims at balancing the interest in protecting the public against contagious diseases and protecting the HIV-infected person's security and integrity.

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Some Europeans appear to resent the Swedish law because they believe sexuality is a private matter and are concerned that an individual's rights will collide with public health interests. Many people believe that the Swedish law marginalizes infected people; often these people are the most vulnerable, such as migrants and less educated people (Danziger, 1999). Advantages and disadvantages have been discussed, but most people in Sweden seem to accept compulsory prevention for the good of society (Fixelid & Ramstedt, 1997).

In Europe, approximately one in three HIV-infected people are unaware that they are HIV⁺ (Editorial, 2006). Research from the United States shows that long-term HIV infection does not prevent people from having sex, and that unprotected sex is common among HIV⁺ youth. This indicates that new cases of HIV will be diagnosed among adolescents and youth (Butler et al., 2003; Diamond & Buskin, 2000; Rotheram-Borus & Miller, 1998; Rotheram-Borus et al., 2001). In the West, infected people can receive anti-HIV treatment (Miles, Edwards, & Clapson, 2004). Although this will optimize adolescence survival into adulthood, it might increase the risk of HIV transmission. Therefore, this qualitative study explores how HIV⁺ youth in Sweden perceive the law and handle their sexuality and disclosure of HIV to sexual partners.

Method

At the time of data collection, figures from Sweden reported less than 50 cases and up to 62 cases in the age category 15–24 years: 42 women and 20 men (Tötterman & Rahman, 2002). The low HIV incidence rate limited the recruitment options. Health care providers from three HIV infection clinics asked young HIV⁺ patients to participate and informed them verbally and in writing about the study. Nine informants were recruited from these clinics and one was recruited from a voluntary HIV organization. Seven other young patients who were asked refused because of emotional motives or time constraints. Patients without a Swedish residence permit, those who were on drugs or those who had severe psychological problems were not asked.

In-depth interviews and an analysis based on a grounded theory approach were chosen (Glaser, 1978; Strauss & Corbin, 1990). The method is useful when studying areas where little is known or poorly understood, such as sexual behaviour among HIV⁺ youth. Interviews were conducted in Umeå and in Stockholm at a time and place decided upon in collaboration with the informants. Seven informants spoke Swedish and two combined Swedish and English. During one interview a professional interpreter was used. The interviews were open-ended. The broad aim was to explore the experiences of sexual risk-taking. The interview guide included themes concerning the informants' background, sexuality and perceptions of health care. A first study that explored the perceptions of sexual risk-taking and their understanding of why they caught HIV has been published elsewhere (Christianson, Lalos, Westman, & Johansson, 2007). This study is based on the same material where data regarding sexual behaviour after diagnosis, perceptions of health care and the Law of Communicable Diseases Act are analysed. In short, the interviewer posed several open-ended questions such as: 'how are you met by health care providers', 'what is your view about the law?' and 'how does your sexuality work after diagnosis?'. These questions were followed by questions concerning how they handled disclosure to sexual partners. As each interview was scrutinized before the next interview took place, the interviewing researcher was able to check interpretations with the next informant. The interviews lasted for 1.5–2.5 hours and were tape-recorded and transcribed verbatim. There is always a risk that people who are in an emotional transition phase may disclose more than they would otherwise reveal (Kylmä, Vehviläinen-Julkunen, & Lähdevirta, 1999). Therefore, each transcript was sent to the informant for review. Two did not read the transcripts. Follow-up interviews, by

telephone or in person, allowed the informants to clarify or delete parts from their interviews. This additional knowledge can be regarded as another source of data that can give new insights and strengthen the findings.

The researchers read the transcriptions and coded the text independently. Next they compared the open codes and discussed variations. With all interviews in hand, a more thorough analysis began. The interviews were reread in detail and the codes were reorganized and grouped to build categories. Then, together, the researchers evaluated the categorization to achieve consent. The categories, subcategories and core category that emerged during the analytical process will be presented and discussed in this paper. The quotations are given verbatim, and ellipses indicate pauses that occurred during the interviews. The quotations have been selected to illustrate most clearly the informant's experiences and feelings. In some cases, the quotations are shorter than in reality.

Ethical considerations

Much effort was put into carefully informing the participants, both verbally and in writing, about the aim of the study and the voluntary nature of the study. In addition, they were told that their decision to participate, not participate or drop out would not affect their future contact with their clinic in any respect. In reality, the freedom to withdraw can sometimes be problematic (Ringheim, 1995). The term 'free will' is a cultural construct that implies both autonomy and awareness of individual rights that can vary across subgroups within a society. For instance, compared with adults, young people may know less about their rights in research. This was emphasized and discussed with all the informants.

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

Results

The informants (five women and five men) were between 17 and 24 years of age (Table 1). Time from diagnosis to interview varied from 7 months to 5 years (average time of 2 years). All of them underwent medical check-ups. The majority had contact with psychologists/social counsellors. The emerging core category—cultured to take responsibility—means that the informants were educated and required under legislation to govern the transmission of HIV. The first part describes the informant's perceptions regarding the law, and the last part describes their strategies to manage sexuality and disclosure.

Perceptions regarding the law

The informants knew that they had to inform their sexual partners. Some informants accepted this fact, while others worried about the consequences of disobeying the law. Although the law was perceived as a support, most of the time it was viewed as a burden.

Support: health care support

Once diagnosed, they did their best to lower the risk of transmission. Several of them claimed 'at least nobody will get HIV from me now'. Some informants emphasized that a mandatory law for informing sexual partners was a good backup. After the detection of HIV, they were offered free medical check-ups, treatment of HIV and psychological counselling. Because their own family or friends were not always informed, it was important that they received support:

Table 1. Characterization of the informants at the time of the interview.

Informant	Ethnicity	Education and occupation	Civil status	Sexual orientation	Detection of HIV/diagnosis	Antiretroviral therapy
Man, 22 years	Immigrant from South America	Studying Swedish	Single	Heterosexual	Immigration/HIV diagnosis 7 months ago	Yes
Man, 17 years	Swedish (Swedish mother, African father)	Senior high school	Girlfriend	Heterosexual	Incarcerated in youth prison/2 years ago	No
Man, 24 years	Swedish	Senior high school, working	Single	Homosexual	Kaposi's sarcoma/2 years ago	Yes
Man, 24 years	Swedish (parents from Asia)	Senior high school, working	Boyfriend	Homosexual	Fever and severe bodily pain/2 years ago	Yes
Man, 24 years	Swedish	Senior high school, on sick-leave	Single	Homosexual	Partner notification/2, 5 years ago	Yes
Woman, 17 years	Immigrant from Africa	Senior high school	Single	Heterosexual	Immigration/1, 5 years ago	Yes
Woman, 24 years	Swedish	Senior high school, on sick-leave	Boyfriend and one child	Heterosexual	Pregnancy/2 years ago	Not at the moment. She quit
Woman, 24 years	Swedish	Senior high school, working	Boyfriend	Heterosexual	Partner notification/2 years ago	No
Woman, 19 years	Immigrant from Africa	Senior high school, working	Single	Heterosexual	Immigration/3 years ago	Yes
Woman, 20 years	Swedish	High school, working	Single	Heterosexual	Induced abortion/5 years ago	No

HIV: human immunodeficiency virus.

If it had been cancer, I would have talked to my relatives and would have got support from them but my psychologist, she has helped me a lot . . . to become more brave . . . stand up for myself and accept the situation . . . take control . . . To be able to tell something like this you must become stronger and have a lot of guts.

Burden: to be blamed

One of the informants stated: 'with or without the law I have my problems concerning HIV'. He thought that the infection limited his life sphere. Hence the law was a burden:

. . . well yes the law does not make it easier for me . . . I haven't checked this much but . . . to be registered . . . [sighs] . . . Your anonymity disappears when you are tested and then . . . you're not . . .

One informant thought it was insulting to undergo partner tracing and reveal the names of sexual partners just because 'the law says so'. According to him the procedure was 'Gestapo-like'. For him, the Swedish policy did not provide support.

It is evident who is to be blamed. The HIV⁺ has the responsibility. You are protected until you get it and from now on you will be looked upon like a potential killer. That's the way the law functions and you stand there with all the responsibility.

Other negative encounters with health care were noted. After a condom-breakage, one informant and his HIV⁻ partner received post-prophylactic treatment. The physician informed him that his antiretroviral therapy lowered the quantity of virus, and that the risk for transmission of HIV to his partner was low; however, an opposing attitude was also expressed:

They scared my boyfriend . . . when he talked to a nurse she said, 'you must be careful and do you really want to run the risk of being together with someone who is HIV⁺'.

Double responsibility

Some women thought that the law was personally harmful because it did not emphasize that condoms were a shared liability. If men did not want to use condoms spontaneously, the power to persuade them was restricted, but the duty to convince them was a female issue. They felt that to 'put it on' was all their responsibility. Two females thought that sex without condoms was not a choice for them even if the partner proposed it. This double responsibility worried one informant because she thought she could not always persuade her partners to use condoms:

If they [the authority] want, they can lock me in. For sure they wouldn't do it, but you never know. If you behave badly several times, then maybe they would.

A need to discuss 'bad behaviour' (such as unsafe sex) was expressed. However, fear of the consequences both for themselves and for the physician hindered them. Worries about punishment and that the doctors would lose their medical legitimacy if they refrained from reporting cases of unprotected sex were revealed.

Managing sexuality and disclosure

The informants were seriously concerned with how to handle the information duty when dating people and wondered when was the time right to tell: should one tell when attraction occurred,

when kissing, or when naked? 'Switch off lust', 'switch off the disease' and 'balancing lust, fear and obedience' are subcategories/strategies that describe how the informants manage sexual relations and disclosure to sexual partners.

Switch off lust

Some informants suppressed their sexual needs because they feared that disclosure would imply risk of rejection. If they refrained from informing others, they were afraid of transmitting HIV. The switch-off mechanism helped to manage those situations.

In the beginning I was very horny and thought about sex the whole time, but I learned to switch it off. Because I knew that I was too scared to tell . . .

In the past, the sexual drive before HIV⁺ had been a positive component compared with nowadays when the fear of contaminating others overshadows the lust for sex:

The sexuality I had before and the one I have today is very different and the problem I have now is that I'm afraid of contaminating others and that's the thing I'm thinking about the whole time. Yes I have switched off totally.

Balancing lust, fear and obedience

During encounters that 'could be' sexual, the lust for sex and fear of disobeying the law and the risk for transmitting the virus were balanced. Where disclosure did not work, the threat of juridical sanction guided their actions. Some informants repressed their sexual emotions and tried to take control:

OK, when I'm about to have sex I think; now girl! You have HIV. Now stop girl! Don't go too far. You have already gone too far. Stop it!

Difficulties concerning disclosure made Internet an easy way to find a sexual partner. Dating over the internet was one arena where anonymous sexual contact facilitated non-disclosure:

I met this guy from the internet chat and I did not tell him that I was HIV⁺. We had safe sex . . . of course . . . One should strive to be open, but it is not that easy. The law is inhuman and it doesn't work always.

For some informants the psychological barriers of reciprocal fear and the fear of condom breakage affected sexuality negatively. For example, one man used medical terminology to describe intercourse: operations, cold, clean and abnormal. This mutual fear could also induce negative emotions of unworthiness and feeling like a second-class sexual partner. To reach balance and enjoy sex, one solution could be to find an HIV⁺ partner. This was especially pronounced among the men:

90% of the people having HIV, the ones I know they don't use protection if they have a HIV⁺ partner . . . a luxury you know to drop . . . to feel . . . it's okay to have sex.

Women also mentioned that it would be less problematic to have an HIV⁺ partner, but they were concerned with their own health and reproduction. To give birth to healthy children made the preference for HIV⁻ men obvious.

Switch off the disease

During the interviews examples of unprotected sex were revealed. To escape from moral obligations of disclosure, two informants suppressed the thought of HIV. They were risk-actors that took chances that they regretted later, as they knew that these side-steps could be harmful. One informant described an event of unsafe sex. Afterwards, she regretted her behaviour, felt anxiety, telephoned the man, but hesitated to tell:

It did not come over my mouth . . . and finally he guessed on HIV and . . . he is crying, 'I don't want to die' . . . I felt awful by giving someone such agony . . . I tried to calm him down; 'it's not that bad . . . you're not going to die'.

To take responsibility or not depended on the contextual milieu. Swedish law does not reach overseas and for one man, going abroad implied a feeling of sexual freedom:

Well I'm driving ugly so to speak . . . when I'm going abroad I have a lot of sex.

Discussion

Most informants did their absolute best to be responsible in the case of protecting others from transmitting HIV. The information duty was a dilemma and they sought solutions to overcome these problems. 'When, where and how to disclose' were questions raised to which health care must respond and address in a supportive way. Hence, the informants were only partly content with the health care support in these difficulties. Many of them indicated that the law hindered confidence and honesty because they feared that the physicians could report 'bad behaviour'. With threats of isolation, there is a risk that these young people do not receive the support that they can obtain within health care, but refer solely to what they perceive to be the negative consequences of having the law. Imprisonment and isolation are seldom set in motion; however, it is interesting to speculate about why some informants discussed the topic so eagerly.

Dealing with young HIV⁺ patients and their sexuality is a delicate matter. They might be treated more paternalistically compared to adult patients, who have more power. One informant acted as a responsible agent after a condom-breakage and received post-prophylactic treatment for his boyfriend, but a nurse reacted negatively when the couple sought care; this negative attitude from the staff was sometimes spelt out by the informants. Research from Sweden notes that, generally, both nursing staff and nursing students express empathic attitudes towards HIV-infected patients, but 36% of them still stated that they would refrain from caring for HIV⁺ patients if they could (Röndahl, Innala, & Carlsson, 2003).

Some informants lacked the ability to handle the information duty because they feared others' reactions or rejections. These people avoided sex. Conversely, two informants 'switched off the disease' and occasionally had unsafe sex without disclosure. To disclose one's HIV status to potential sexual partners is a principal concern for young HIV⁺ people (Wiener & Battles, 2006). The internet was described as one arena for sexual contacts where the information duty was ignored and the responsibility for protection was supposed to be shared. Researchers have noted that marginalized people in particular find the internet attractive (Ross, Tikkanen, & Månsson, 2000), and that people who do not disclose their HIV status often take the necessary steps to reduce transmission (Ciccarone, 2002), a result that was also noted in this study.

Generally, women may be less likely to suggest condom use, due to female modesty, gender role constraints or male sexual dominance. To use or not to use a condom is not a choice for HIV⁺ women in Sweden. Here, the females have a double responsibility; they need to persuade men to use condoms and to 'put it on'. This is a double burden both in stable and casual

relations. It can also be trickier for young women to suggest condom use in casual relationships, as society's image of female sexuality gives priority to stable relations with the development of emotional closeness, whereas condoms can be associated more with frivolity (Bajos & Marquet, 2000). Safe sex and condoms must be a shared responsibility, not solely a woman's issue.

Most people need time to come to terms with HIV (Paxton, 2002). To overcome or prevent situations of unsafe sex among HIV⁺ youth, significant effort must be put into giving positive rewards concerning disclosure to diminish the risk for transmission. Disclosure alone does not lead automatically to safer sex, because human behaviour and sexual interaction is complex (Simoni & Pantalone, 2004). However, to speak out can be a way to take control of one's life and to re-establish personal strength. This agrees with one informant: 'to be able to tell something like this you must become stronger and have a lot of guts'. In a study about HIV⁺ people from Africa and Asia it was recognized that negative consequences of disclosure are stigma, rejection by sexual partners and loss of intimacy; however, disclosure can alleviate stress and improve health (Paxton, 2002). To inform clients about these positive effects on well-being is important in order to empower young HIV⁺ to disclose their status. Staff with extended education on sexuality and communication strategies should be a part of routine HIV health care. To disclose can be stressful, but it can be even more disturbing and risky to keep quiet.

Sexual behaviour is embedded in culture, and the specific contextual surrounding these young HIV⁺ people might not produce findings that are universally transferable. The sample did not reflect the diversity and ethnic background we had hoped for. People without permit residence in Sweden, those who were on drugs or those who had severe psychological problems were not even asked; therefore, generalization may be limited. However, the depth of understanding gained can be a rich source of information for further work. 'With or without the law', the conflict concerning sexual needs, disclosing one's HIV status to potential sexual partners and the risk of spreading HIV are major concerns for young HIV⁺ people that give rise to specific sets of actions and interactions not only for these youth, but also for HIV⁺ youth elsewhere.

Conclusion

The Swedish Law of Communicable Diseases Act puts vast responsibility upon these HIV⁺ young people. They describe difficulties regarding disclosure of HIV to sexual partners, which complicates their sexual interactions. HIV⁺ youth should be encouraged and better trained on how to take responsible precautions. This requires assistance from staff with special skills in sexual counselling, assistance that ought to be routine practice at HIV clinics.

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