

Serostatus, risk and responsibility

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Rises in new HIV infections and the return of the hyper-epidemics of sexually transmissible infections have occurred among gay men in North America, Western Europe, Australia and New Zealand. If you look beneath the surface, discourses of failed responsibility and blame are a common reaction among gay men, educators, doctors and governments.

When HIV first spread among gay communities in the late 1970s and early 1980s we were 'innocent' because we didn't know it was happening. Underpinning health promotion responses to HIV was the belief that gay men would act responsibly (to themselves) and rationally in order to protect themselves and their health. Over 20 years later, with the rising incidence of HIV infection, we 'know'. Therefore, if we examine our common health-promotion belief, gay men must be 'irrational and irresponsible'—not a comfortable proposition for gay men. Another response to rises in HIV infections is to substitute discourses about 'self-responsibility' with discourses about the 'responsibility' of positive men to the 'other'; if self-responsibility is obviously not always working then let's make positive men 'responsible'. While not denying our partial responsibility, 'sole' responsibility places positive men in a very vulnerable position.

I think there are four useful discourses that are familiar in HIV education and worth examining. They are the discourses of:

i) **self-interest or 'self-responsibility'** This is the dominant responsibility discourse, based on the belief that people will act rationally and responsibly in their perceived self-interest to be healthy. Health, however, may be only one of many competing 'self-interests'. Desire, intimacy and pleasure may be listed among the many 'self-interests' associated with sex. 'I don't live to be healthy; I'm healthy to live,' said a person with HIV about the competing self-interests. Further, risk-taking and transgression can be fun:

'guilty' does indeed make me wet after all. In HIV education, self-responsibility or self-interest has been used as the primary motivation for HIV-negative men to stay that way. It has also been used to target positive men. There has been recent firm evidence of the reality of superinfection and of its potentially detrimental impact on the health of a person with HIV. Thus, encouraging HIV-positive men to avoid superinfection was sometimes positioned as 'the way' to motivate them to respond to rises in HIV infection. It overlooked the fact that unprotected sex between positive men results in no new HIV infections.

ii) **altruism or 'responsibility for the other'**

In HIV education, this discourse describes the responsibility of a person with HIV to avoid transmitting the virus. Historically, community organisations having resisted targeting the sexual behaviour of positive men, and their particular responsibilities to prevent transmission of HIV, for fear of increasing stigmatisation and discrimination—also because of a belief that it was too problematic to talk openly about the possibility of people with HIV having unsafe sex. Yet it was people with HIV in Australia who challenged 'self-responsibility' as the sole behavioural motivator. In arguing for inclusion in prevention education, we were actually arguing that our responsibility and involvement be part of the picture—but I think we wanted the question framed in terms of mutual or shared responsibilities. Internationally, people with HIV attempted to open a dialogue about 'sexual fulfilment' as a way to be inclusive and promote mutual understanding. Locating sole responsibility with positive people where the motivation is altruistic, at a time when 'individualisation' and 'self-interest' are such dominant discourses, seems paradoxical. There is a veiled threat behind any failure to adhere to this altruism—and that is the invocation of public health law and old-

fashioned public health responses—and the accompanying stigmatisation and vilification of the HIV-positive.

iii) **mutual interest or 'shared responsibility'**

The person I remember reconceptualising social relations between HIV-negative and HIV-positive gay men in terms of mutual or shared interest was Paul Kinder, an openly HIV-negative gay man, in a speech to the 2nd National Gay Educators Conference in 1995. This notion was immediately attractive to me because it located an ethic of responsibility in the public or social domain. As a notion, however, shared responsibility did not seem to have a lot of saliency with gay men. Maybe that was because it was an imposed idea. As a positive man, it didn't work for me because there was no mutuality. There were two sets of responsibilities: positive men's responsibility not to transmit HIV and the responsibility of HIV-negative men to respond sensitively and appropriately to the disclosure of HIV-positive status. HIV-negative friends tell me they had a similarly unsatisfactory experience of 'shared responsibility'—so perhaps the problem was the lack of an open public process and dialogue that circulated beyond the small circles of HIV education and social research.

iv) **mutual obligation or 'contractual responsibility'**

This is similar to shared responsibility but, rather than being between individuals or members of a community at risk, it is about responsibility discourses that circulate in terms of public policy. For example, 'work for the dole' was about 'mutual responsibility', a social contract between the government to provide income support and the recipient to give something in return. There have been implied 'mutual obligation' contracts in HIV social policy. For example, if governments give access to appropriate treatments to people with HIV, then

people with HIV have a return obligation to behave responsibly. Applying 'mutual obligation' in the context of rises in HIV prevention could be to suggest that 'if positive men behave irresponsibly then they should not get access to HIV treatments'. What characterised the early response to HIV in Australia were partnership and an implied mutual obligation. My personal observation would be that in recent years governments are sometimes perceived not to be living up to their part of the mutual obligation of 'partnership' and therefore it is harder for them to invoke 'individual responsibility' discourses when they themselves are not being 'responsible'.

'Responsibility' discourses are being widely invoked in response to rises in new infections. I am not trying to discard them as a notion, although I'd love a wider discussion involving gay men not framed just by 'responsibility' and 'health' and 'HIV' but through other agencies like sex, friendship, and community. Such discussion could include more interesting topics like 'when the carefree becomes careless' and 'why guilt is not wet'.

My problem is which 'responsibility' discourses are invoked, how they are understood historically and how they are perceived to operate. The two most often invoked are 'self-responsibility', which is perceived to have failed because it is not 100 per cent effective, and 'altruism' because it is perceived to have been underused because of political sensitivities or failed because it hasn't been invoked strongly enough. As a reading of history, it's simplistic and inaccurate. As a prescription for what needs to be done, it's woeful.

My major conceptual problem is that the two 'responsibility' discourses used are those that are understood individually rather than publicly. There are very few individually understood and applied behavioural interventions that are effective or are not extremely resource intensive.

Mass behaviour change by both gay men and injecting drug users did happen in the early to mid 1980s. It happened because of what occurred publicly and because of changes in public policy, such as the provision of free needles and syringes through needle exchanges. I'd argue that 'responsibility'—not self-responsibility to be healthy but a broader collective responsibility to gay community about group survival—was indeed part of the story; that is, the public story rather than individual stories.

For me, the question is not about deciding who is individually 'responsible'; it's about the collective responsibility of the partnership response to HIV and locating the debate about responsibility in the 'public' and the 'social' rather than in 'health' and 'the individual'. Our problem is identifying the public arena and the agencies through which to have that discussion.

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SRB 6/001

Bayer, R. (1996). AIDS prevention: Sexual ethics and responsibility. *New England Journal of Medicine*, 334, 1540–1542.

Danziger, R. (1996). An epidemic like any other? Rights and responsibilities in HIV prevention. *British Medical Journal*, 312, 1083–1084.

Signorile, M. (1995). Taking responsibility and seeing why we should. *Reproductive Health Matters*, 3(5), 121–123.

Bayer's article from 1996 examines the debate on sexual ethics in relation to HIV transmission. In the early years of the AIDS epidemic there was resistance to public health policy that focused on the responsibility of people with HIV to protect the uninfected. The reason for this resistance was the belief that such a policy would paradoxically lead to an increased risk of HIV infection because people would fail to protect themselves, and those who engaged in high-risk practices would avoid HIV testing. Therefore 'self-protection', rather than 'self-disclosure', was emphasised and universal condom use was advocated. Politically this was seen as important because it retained a sense of cohesion or solidarity between those who were HIV-positive and those who were HIV-negative.

Bayer argues that the principle of self-protection made it impossible to discuss the responsibility of people with HIV, although by the late 1980s and early 1990s calls for self-disclosure began to be heard. Bayer quotes gay journalist Michelangelo Signorile who in 1995 questioned the messages AIDS organisations were sending through their safer sex education campaigns. He claimed these messages refused to emphasise the particular responsibilities of HIV-positive men and were not attentive to the needs of HIV-negative men, who often felt guilt-ridden because they were still healthy and who still refused to admit their vulnerability.

Danziger, who also quotes Signorile, notes the dramatic changes in the mid-1990s as a result of clinical, epidemiological, and social developments in the AIDS epidemic. It is suggested that these changes, combined with a growing recognition of possible weaknesses inherent in a strictly voluntarist approach to HIV prevention, may herald a new way forward. Danziger suggests that protecting HIV-positive people (from discrimination) and HIV-negative people (from infection) may be achieved by shifting the focus away from individual rights towards an understanding of individual and social responsibilities.

SRB 6/002

Carballo-Dieguez, A. & Bauermeister, J. (2004). 'Barebacking': Intentional condomless anal sex in HIV-risk contexts. Reasons for and against it. *Journal of Homosexuality*, 47(1), 1–16.

The authors conducted a content analysis of messages posted on an internet message board following the decision at gay.com to close down a bareback chat room. Individuals who posted messages were predominantly white/European gay men residing in the US, with an average age of 35 years. Out of 130 messages, 62 (48%) were pro-barebacking, 55 (42%) were anti-barebacking, and 13 (10%) referred to other topics.

The analysis showed that both those in favour of barebacking and those against it felt well informed about HIV/AIDS and the risks of HIV transmission. Those in favour considered sex without condoms more enjoyable than sex with condoms (both in actual experience and in erotic imagery) and felt that sex without condoms provided a sense of freedom. They also downplayed the risks involved in barebacking (by assuming that all barebackers were already HIV-infected and that the risk of superinfection was small). There was also a strong feeling that barebacking was a personal decision and responsibility. This appeal to individual responsibility was invoked by both HIV-positive and HIV-negative respondents.

Respondents who made statements against barebacking cited the risks and contested the assumption that all barebackers must be HIV-positive. These respondents also advocated condom use as well as personal and social responsibility, invoking notions of protecting the community and gay 'family'. Those who opposed barebacking also felt that barebackers were not sufficiently sensitised to the burdens of HIV disease.

SRB 6/003

Davis, M. (2002). HIV prevention rationalities and serostatus in the risk narratives of gay men. *Sexualities*, 5, 281–299.

Much contemporary HIV prevention discourse is underpinned by the concept of rational action which assumes a thoughtful, calculating subject. Davis identifies three approaches: 'self-protection' (aimed at an HIV-negative subject); 'altruism' (aimed at an HIV-positive subject); and 'egalitarianism' (based on the assumption that there are many people who don't know they are HIV-positive and where responsibility for risk avoidance is shared). The article critiques the assumption that HIV-positive people will act with altruism, that HIV-negative people will act to self-protect, and that these are mutually supporting and create a symbiosis of risk management.

This study was undertaken to examine self-regulation and identity related to rationalistic risk administration among homosexually active men in London. Sixteen men, including five who were HIV-positive, were interviewed. The men were asked to discuss a sexual event that had concerned them with regard to HIV transmission. Davis identified three themes: 1) asymmetry (unequal roles of responsibility for HIV prevention based on HIV status); 2) HIV status knowledge/non-knowledge in risk narratives (the use of the HIV test to enable rational self-knowledge and responsibility, but also to define the dangerous 'other' who acts as if he has 'nothing to lose'); and 3) risk administration and resistance (reflexive engagement with health promotion messages believed to be based on an idealised and risk-averse identity).

Davis claims that HIV prevention has become removed from personal experience in its dependence on rationality. He proposed fewer 'facts' to be directed at the actuarial subject and a shift to prevention based on knowledges, rationalities and meanings that circulate in discourses on sex and risk.

SRB 6/004

Dodds, C. (2002). Messages of responsibility: HIV/AIDS prevention materials in England. *Health: An Interdisciplinary Journal for the Social Study of Health, Illness and Medicine*, 6, 139–171.

In an analysis of HIV prevention materials produced by five HIV/AIDS organisations in the UK, Dodds demonstrates that while some campaigns clearly emphasise the behavioural responsibilities of the individual, others 'include reference to the organisational, governmental and social issues that contribute to the continuing spread of HIV' (p. 143). Messages of responsibility are identified in 200 campaign materials produced before 1999, including brochures, postcards and newspaper advertisements, classified according to whether they predominantly construct HIV prevention as an individual, shared or organisational responsibility. While 80 to 100 per cent of materials produced by all organisations were primarily concerned with individual responsibility, less than 10 per cent addressed organisational responsibilities. A shift over time was also observed, with around 80 per cent of 1980s campaigns interested in shared responsibility, dropping to less than 50 per cent in the 1990s. Dodds argues that, although these organisations actively resist a stigmatising politics of victim blaming, their prevention campaigns nonetheless remain focused on individual behaviour change rather than taking up the far more complex task of influencing structural and social transformations.

SRB 6/005

Flowers, P. (2001). Gay men and HIV/AIDS risk management. *Health: An Interdisciplinary Journal for the Social Study of Health, Illness and Medicine*, 5, 50–75.

HIV risk management among British (and other) gay men has passed through three distinct periods since the start of the epidemic. Each of these has had different implications for the location of risk, processes of 'othering', and the attribution of responsibility and blame.

First, there was a 'confused' period in which the cause of AIDS was poorly understood. Risk was located via a process of 'othering' all gay men vis-à-vis the general public (i.e. socially located risk).

Then, following the identification of the virus HIV, came the second, 'somatic' period. This created the conditions for the construction of different kinds of gay men: those 'posing a risk' (HIV-positive) and those 'being at risk' (HIV-negative). In this period, discourses linking HIV risk with individual bodies became established.

Most recently a third, 'technological' period emerged which is linked to the advent of new HIV treatments and testing technologies related to viral activity (such as viral load and resistance testing). These developments have shifted the location of HIV risks from *between* bodies to *within* the body, 'adding temporal, relational and significantly more *testable* dimensions to the understanding of both HIV and AIDS risks'. With the arrival of each new advance in HIV technologies the locations of risk multiply and the location of risk and responsibility shifts to an ever smaller number of people.

SRB 6/006

Flowers, P. B., Duncan, B., & Frankis, J. (2000). Community, responsibility and culpability: HIV risk-management amongst Scottish gay men. *Journal of Community & Applied Social Psychology*, 10, 285–300.

This paper analyses the impact of HIV testing on Scottish gay men's HIV risk-management and the social construction of gay communities. Eighteen gay men were interviewed and another 19 took part in focus groups.

Two main themes emerged from the data. The first, 'Repositioning the *cordon sanitaire*: gay community perceptions of HIV', illustrates how the advent of HIV testing has not been value-free but has created, in effect, a boundary around men who are HIV-negative in order to protect against HIV. This 'othering' serves to socially exclude HIV-positive men from the gay community.

The other main theme, 'HIV risk management: responsibility, culpability and "negativity"', is concerned with sexual responsibility and behaviour. Several of the HIV-negative men thought that HIV-positive men should bear a greater responsibility for managing HIV risk-reduction during sex. This expectation of disclosure means that there is an assumption of universal negativity and that positive men are responsible for the management of HIV prevention.

These discourses have the effect of locating risk management around 'risky men' rather than 'risky practices'. The findings show how new health technologies can create a framework on which meanings, divisions and identities are built. This contributes to the social exclusion of known or assumed HIV-positive men, thereby fragmenting the gay community. Further, through shifting HIV avoidance mechanisms from their original collective level to that of the individual, such technologies have had the unintended consequence of encouraging gay men to put their faith in lay notions of risk management, which potentially puts them at greater risk of HIV infection.

SRB 6/007

Fraser, S. (2004). 'It's your life!': Injecting drug users, individual responsibility and hepatitis C prevention. *Health: An Interdisciplinary Journal for the Social Study of Health, Illness and Medicine*, 8, 199–221.

Although focused on hepatitis C prevention and injecting drug use, Fraser's analysis of discourses of responsibility has much to offer to the study of HIV prevention and to health promotion more generally. This paper firstly examines hepatitis C prevention campaigns and then considers how these messages about safe-injecting health practices are paralleled in interviews with injecting drug users.

Fraser argues that individual responsibility functions as the primary organising principle of these campaign and interview narratives, and yet individuals cannot always be held responsible for behaviour change. In the case of injecting practices, for example, there may be a mutual obligation to share equipment in order to reduce financial burdens, or the desire to help another person who is suffering and unable to inject themselves. Additionally, health promotion materials rarely acknowledge

that individual behaviour does not entirely eliminate risk, since there are many unresolved medical questions around how 'safe' particular practices are, particularly in the complex environments of sex and drug use.

Importantly, Fraser offers some ideas for how hepatitis C prevention might be done differently to avoid rendering the individual solely responsible for health behaviours. Campaigns could incorporate 'acknowledgement of the location of the individual in networks of power and politics' (p. 217), and some recognition of how difficult it can be to put all of the recommended behaviours into action. Taking this approach, campaign materials would include clear assessments of the possible impediments to behaviour change, and an explanation of the responsibilities of other parties such as governments and advocacy organisations in working towards improved health outcomes.

SRB 6/008

Janssen, R. S., Holtgrave, D. R., Valdiserri, R. O., Shepherd, M., Gayle, H. D., & De Cock, K. M. (2001). The serostatus approach to fighting the HIV epidemic: Prevention strategies for infected individuals. *American Journal of Public Health*, 91, 1019–1024.

This group of authors from the US Centers for Disease Control and Prevention (CDC) discusses that organisation's new strategy aimed at reducing new HIV infections in the US by 50 per cent in four years. In 2001 the CDC launched a new strategy for HIV prevention called the 'serostatus approach to fighting the epidemic' (SAFE).

The five SAFE objectives are: 1) to increase the number of HIV-infected persons who know their serostatus; 2) to increase the use of health care and preventive services; 3) to increase high-quality care and treatment; 4) to increase adherence to therapy by individuals with HIV; and 5) to increase the number of individuals with HIV who adopt and sustain risk-reduction behaviour. The implications of this final point include making people with HIV a priority for prevention programs, and training service providers to identify ongoing risk behaviour and refer people to appropriate services. Such services include risk-reduction counselling, peer group support, peer-based prevention case management, treatment for sexually transmissible infections, substance abuse treatment and mental health services. The authors state that this move is a 'logical' development and a more strategic use of prevention resources because, although there are millions of people in the US at behavioural risk for HIV infection, 'transmission can only occur from people who are infected with the virus'.

SRB 6/009

Marks, G., Burris, S., & Peterman, T. A. (1999). Reducing sexual transmission of HIV from those who know they are infected: The need for personal and collective responsibility. *AIDS*, 13, 297–306.

The authors review the literature on responsibility for HIV prevention, examining the available research on sexual

risk in positive men and women, and then consider the factors associated with this risk at the individual and social levels.

The authors begin by offering a condensed summary of evidence regarding the prevalence of unsafe sex among positive persons aware of their serostatus. Next, they review the individual-level psychological processes that may impact on sexual behaviour, with an emphasis on how personal responsibility to protect sex partners is negotiated in different contexts. They also examine individualistic approaches to HIV prevention, with particular focus on the potential of clinic-based counselling. They then go on to consider the social aspects of individual choice and suggest that individual-level approaches are necessarily constrained by the social context of people's everyday lives. To this end, the authors identify significant social conditions that have an impact on responsibility in HIV prevention including the hostile political and legal environment in the US regarding homosexuality and drug use. Finally, Marks et al. emphasise the need for issues of collective responsibility to be incorporated within any discussion of HIV prevention. This approach argues that interventions targeting the specific behavioural obligations of positive people must be complemented by 'ecological or population strategies that try to modify the group norms, social practices, and laws that influence a person's attitudes and behaviors' (p. 301).

SRB 6/010

Race, K. (2001). The undetectable crisis: Changing technologies of risk. *Sexualities*, 4, 167–189.

Through the technique of genealogical analysis, Race examines how HIV-positive gay men have been 'responsibilised' through the introduction of medical technologies including HIV-antibody and viral load testing and the availability of highly active antiretroviral treatment (HAART). This article traces a temporal shift in the dynamics of safe sex practice from a time before effective testing methods became available, when gay men were forced to assume that every sexual partner was HIV-positive, to a post-HAART, post-testing environment in which individuals were invested with the technological capacity to be able to judge risk situations for themselves: 'risk management now began to be reconfigured as an individual, self-driven responsibility (and not as a community practice)' (p. 174).

Race argues that reducing the HIV epidemic to the level of the individual implies that positive men must take primary responsibility for containing the sexual transmission of HIV and reducing their viral load to an 'undetectable' level to decrease infectivity. This medical and cultural shift, also characterised by a move away from collective action towards private health-care management, is identified by a 'resurgence of blame discourses' (p. 169) and a 'charged climate that is quick to take on moral tones' (p. 179).

SRB 6/011

Rhodes, T. & Cusick, L. (2002). Accounting for unprotected sex: Stories of agency and acceptability. *Social Science & Medicine*, 55, 211–226.

Health promotion discourses cultivate the image of individual risk control and responsibility based on the idea that risks are knowable, calculable and preventable, and that the rational self is averse to risk. Taking Foucault's idea of the presentation of self as a moral enterprise—with the confession a core aspect of self-discipline—Rhodes and Cusick explore self-accounts of unprotected sex in interviews with 73 HIV-positive people and their sexual partners.

Analysis of the data revealed two types of account: stories of agency, and stories of acceptability. Stories of agency tended to conform to orthodox notions of risk acceptability but relied on a lack of agency (and therefore responsibility) for actions to explain unprotected sex. Such accounts appeal to the notion of 'defeasibility' (Scott & Lyman, 1968) and consisted of two dimensions: obstacles to applying risk knowledge and calculus, and lack of power to translate knowledge into risk avoidance behaviour. Stories of agency included: risk calculus and condom accidents (e.g. lack of knowledge about transmission risks and condom breakage), alcohol and drug effects, powerlessness and coercion, and forces of nature (e.g. 'heat of the moment', and the unnaturalness of condoms).

Stories of acceptability challenged the established boundaries around safety and justified unprotected sex in particular contexts. Actions in this grouping did not bring the self into disrepute. Two themes that emerged under acceptability—antibody concordance, and commitment—make use of the notion of shared responsibility. Other accounts position risk as an outcome of individual rather than collective responsibility. The authors call these accounts 'alter responsibility'. They include occasions where serostatus is disclosed (an indication of the potential risk of unprotected sex) and where responsibility for the behaviour of the other is denied (either because they should take care of themselves, or because the act of unprotected sex itself is invoked as a signal of HIV-positive status). The authors suggest that these accounts always result in locating responsibility for unprotected sex with the other. In this way, the responsible self only takes care of itself.

(Reference: Scott, M. B. & Lyman, S. M. (1968) Accounts. *American Sociological Review*, 33, 46–62.)

SRB 6/012

Wolitski, R. J., Bailey, C. J., O'Leary, A., Gómez, C. A., & Parsons, J. T. (2003). Self-perceived responsibility of HIV-seropositive men who have sex with men for preventing HIV transmission. *AIDS & Behavior*, 7, 363–372.

Parsons, J. T., Halkitis, P. N., Wolitski, R. J., & Gómez, C. A. (2003). Correlates of sexual risk behaviors among HIV-positive men who have sex with men. *AIDS Education and Prevention*, 15, 383–400.

Between June and November 1997, Wolitski et al. recruited 250 HIV-positive men who have sex with men (MSM) who had engaged in sex with another man in the past year. The men were recruited from New York City and San Francisco AIDS service organisations, gay community venues and public sex environments to complete a questionnaire and qualitative interview on self-perceived responsibilities to protect others from HIV infection.

Although the interview guide did not contain any specific questions about responsibility, 72 per cent ($n = 180$) of the participants 'spontaneously' described responsibilities in preventing HIV transmission to uninfected partners. The authors organise these discussions according to whether the participants emphasised the responsibility of the positive partner or negative partner, or a mutual sharing of responsibilities. Nearly two-thirds ($n = 114$) spoke about a personal sense of responsibility, often expressed as an altruistic desire to protect sex partners from HIV infection. Around 12 per cent ($n = 22$) believed that, since consenting adults had the right to make their own choices about sexual behaviour, the responsibility lay with the negative partner rather than themselves. And a quarter ($n = 44$) described responsibility in terms of the shared obligation for both partners to take some responsibility.

Some beliefs were firm and unchanging, but others were dependent upon partner characteristics, the setting and the nature of their relationship. So while men with a long-term negative partner felt a significant responsibility to protect their partner, sexual encounters in anonymous or public sex environments were more likely to inspire beliefs about the negative partner's responsibility to protect themselves. [In a second paper describing the expanded quantitative arm to this study, Parsons et al. offer evidence that perceived responsibility to protect partners from HIV infection translates into safer sexual behaviours, either in reporting no unprotected anal intercourse or in choosing to be the receptive rather than the insertive partner.] Other factors influencing perceived responsibility include ethical and religious beliefs, emotional states (depression or loneliness, fear of rejection), sexual arousal, alcohol or drug use, and personal beliefs about levels of risk, as well as the perceived HIV status, age, sexual orientation and sexual experience of partners.

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