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Sex and risk within the relationship

Plus One is a qualitative research study that explores the experiences and needs of black African people in relationships where one person has diagnosed HIV and the other does not (ie. sero-discordant). For further information about the study methods and sample please see Report 1 – *Executive summary*.

This report provides an overview of how participants described their management of sexual HIV transmission risk within their sero-discordant relationship. After a brief exploration of the early impact that diagnosis and disclosure had within a sexual relationship, the report considers participants' management of sexual risk over the longer term. Attention is also drawn to the difficulties of negotiation and maintaining harm reduction with a partner who is resistant to risk reduction. This report concludes with a discussion of participants' descriptions of their happiness with the sex that they have within their sero-discordant relationship.

IMMEDIATE IMPACT ON SEX

Many participants described the ways in which an HIV diagnosis immediately impacted on their sex life and there was only a small minority who said that the presence of HIV had not affected their sexual relationships at all. Well over a third of participants talked about a period after diagnosis and disclosure where sexual contact stopped altogether. In some cases this abstinence lasted for a matter of weeks or months, whereas for others it went on for years, sometimes until the end of a relationship. For most of these participants, sex returned once the psychological impact of the diagnosis had been addressed, along with increased comfort with the practical aspects of reducing HIV transmission risk.

Other changes included the introduction of condoms for the first time in a relationship, increased and ongoing anxiety about HIV transmission which can hamper sexual enjoyment, and experiencing a time when intimate relationships were avoided for fear of stigma and rejection.

RISK MANAGEMENT

More than two-thirds of all participants described using male condoms as their means of managing the risk of HIV

transmission. Most of those who used male condoms for penetrative sex said that they did so on every occasion. Many condom users expressed surprise when asked about any additional forms of risk reduction, as they were not aware of any other options.

Fewer than a quarter described using male condoms in combination with some other tactics such as, post-exposure prophylaxis (PEP), considering the viral load of the partner with diagnosed HIV, reducing frequency of penetrative sex, considering whether male partners are circumcised, and washing the genitals before or after sex (the last of which is not a recommended means of reducing HIV transmission risk). However, this group were in the minority of condom users, as most people felt that condoms alone were sufficient to prevent transmission.

Where condom use was not consistent, this was either due to a desire to conceive, or more frequently because of the male partner's difficulties using them. More than one third of all participants described their own or their partner's difficulty with condom use, either because they found them uncomfortable, they felt that condoms reduced intimacy and closeness, or they contributed to erectile dysfunction.

I think it will be the whole process of using it but more to do with the penetrating with a condom. I do feel some pain and yet I don't know why, when I'm using a condom. And it's something that I, I don't know, I really don't know what to do about it and what would help that kind of situation. [man whose last test was negative]

There were a few cases where participants continued with condom use despite these difficulties, either because they got used to them, or because their (usually female) partner had declared that protected sex was non-negotiable. However, one third of all those taking part described ongoing difficulties with condom use.

I am still dying to have proper sex, sex with condoms for me is not proper sex. I am not being evil but at one point I will probably be fed up and tell her that I cannot continue. I don't think that there is anyone who wants to spend his life not having natural sex. [man whose last test was negative]

Sometimes ending the relationship was seen as the only way of overcoming difficulties with male condom use.

There was a small group of condom users (four men and one woman) who had found different condom sizes and thicknesses that alleviated some of these difficulties. Such individuals made it clear that they often needed to move away from free condoms distributed through the clinic or community organisations in order to find a male condom that was acceptable.

When she was, when we were beginning, she used to bring condoms, but I didn't like the type of condom she was bringing. She was bringing these types which are given free, which are almost as thick as hand washing gloves. But I didn't like that. [man whose last test was negative]

This small group of people who sought out condom types that they liked stands out against those who continue to have difficulties while also regarding all condoms as being the same. There were only three current Femidom users in the entire study, with two further women who had tried the female condom, did not like it and no longer used it. When asked, a few had never even heard of it.

In response to difficulty with male condom use, four participants developed alternative means of managing HIV risk by altering their sexual behaviours. A few women stopped having sex completely when their male partner refused to use condoms.

For the last three, four years I just didn't want to have anything to do with sex, no. ...I'm not happy for [him] to have sex with me without a condom. [woman with diagnosed HIV]

In one other case, a couple decided that avoiding penetrative intercourse would mean that they could dispense with condoms altogether.

Right, so you said you did everything else, do you mind just elaborating, what you mean everything else?

Yeah, well to make love without us having full sex. [woman with diagnosed HIV]

Non-penetrative sex (such as oral sex) was mentioned by a number of other participants as a regular part of their sex lives, although some asked the interviewer for assurances that it was a low risk activity.

Many participants talked about condoms as though they were infallible, however others (about a quarter of those who used condoms regularly) were aware of, and concerned about the possibility of condom failure.

My concern is just fear of passing it on, if condoms were to burst. It happened once when the condom burst. [man with diagnosed HIV]

This was often because they had experience of broken or

slipped condoms. One participant with diagnosed HIV described becoming pregnant as a result of a condom failure with her discordant partner. More than half of the HIV negative partners who experienced a condom breakage with their diagnosed partner did seek and obtain post-exposure prophylaxis (PEP).

Among those participants who discussed their concerns about condom failure, about half appeared to be so distressed by the possibility of HIV transmission resulting from a broken condom that it was seriously hampering their sexual enjoyment.

We used to have sex more, mostly daily but now maybe once in two weeks and every time I will be having sex with her I will be thinking has the condom burst or has something gone wrong. I'm not enjoying it in terms of what I used to. [man whose last test was negative]

Once again, for those who described the detrimental effect that concerns about condom failure had on their capacity for sexual enjoyment, there was little sense that this was a situation that they might be able to change.

When asked direct questions about their knowledge of PEP, nearly a third were unaware of it, and a further third were uncertain about how it worked, or how they might access it. Numerous participants articulated a desire for more information about PEP and felt that it could act as a useful back-up in case condom failure occurred.

Recent scientific evidence indicates that under very specific conditions, people with diagnosed HIV who are otherwise in good health and whose viral load is undetectable are very unlikely to sexually transmit HIV. Participants' understanding and acceptance of this notion of treatment as prevention within the relationship was largely reliant on their broader understandings of the science of HIV transmission and treatment. For example, when participants with diagnosed HIV were asked at the outset of the interview if they knew their own CD4 count and viral load, just under half were uncertain in their response. Some were very open in the interview about their difficulty with what was being communicated to them in clinical settings.

You know when you go to the clinic nothing stays in your head. I can say my first eight years I didn't understand a thing... you know when the doctor tells you that's, some of the words they use are too English. So you don't understand what they mean so when you come to the [support] groups you get more explanation, I didn't know which one was CD4 count and which one is viral load, for a long, long time I just didn't understand. [woman with diagnosed HIV]

When asked later in the interview about their understanding of the interaction between an undetectable viral load and infectiousness, nearly one quarter did not have any awareness of such an association. About half said that they were aware of the notion of treatment as prevention and understood it in theory, but that they were reluctant to rely on it personally.

Yeah basically. It's an opinion, it hasn't been proven yet they are still undergoing testing. [man with diagnosed HIV]

Others said that their faith remained in condoms alone, and

that there was little that could shake that conviction, no matter what the evidence.

If your viral load is undetectable it's a low risk for you transmit. But I think if the HIV is in your system it's a risk, and if you have it [sex] unprotected with anybody you're going to get it. [woman with diagnosed HIV]

There was a small group of female participants who resented the intrusion that treatment as prevention had made with regard to their strict condom use policies with male partners. For a diverse set of reasons (STIs, super-infection, pregnancy), such women felt secure in the protection that condom use had afforded them. Once their partner knew about the notion of treatment as prevention, this would threaten their own power to insist on condoms. Two women clearly stated that they had not told their partner about treatment as prevention in order to ensure that sex remained protected by condoms.

I don't want to talk about it [treatment as prevention]...He will want you to take off the condom. [woman with diagnosed HIV]

In contrast to those described above, more than a quarter of those taking part felt that treatment as prevention offered them an increased and improved set of risk reduction options. However, only five individuals actually used their understanding of viral load and infectiousness as a direct means of reducing the risk of transmission within their relationship.

Well she talked me through it and she said, because I trust her implicitly, and she said when it's this, undetectable we're fine to have unprotected sex, yeah. [man whose last test was negative]

In some of these cases, reliance on an undetectable viral load in the absence of condoms was used only for a short space of time while trying to conceive. For others, it offered a welcome relief from the need to always use condoms for the foreseeable future.

The desire to have children was strong among the majority of those taking part, with only a quarter saying that they already had enough children, were too old to consider conception, or had never wanted to be a parent. All participants who had an interest in adding to their family were asked if they were aware of methods of conception that would reduce sexual transmission risk. More than half had a good understanding of sperm-washing, IVF or artificial insemination but only a few mentioned that attending to a partner's viral load can help with safer conception.

I heard that they do this in the hospital. I don't know how it goes that they take the sperm from the man and put it in the woman or something. You get me? I think that's, I will go for that. [woman with diagnosed HIV]

However, several mentioned that the costs of assisted conception were prohibitive. There were also two participants who described conceiving without managing the risk of sexual transmission at all. One quarter of all those taking part in the study had a desire to conceive, but did not have the information that they required to prevent sexual transmission.

Like I said, I am positive and now my husband is negative. If we want to have a baby, can we do it? Is it possible? [woman with diagnosed HIV]

There were only four people taking part in the study who had sought and gained clinical help to safely and successfully conceive.

NEGOTIATING RISK

Responsibility for managing risk was dealt with in highly diverse ways within relationships. A third of those taking part said that they and their partner shared the decisions about dealing with risk. It was almost always the case in these situations that both partners had an equivalent level of concern about the impact that HIV has on the relationship, and they had decided jointly upon solutions.

So we feel we are both responsible for each other's actions because I am HIV positive and he is HIV negative and I do not want to infect him, vice versa as well. So it is up to him to take responsibility and manage his life as well. [woman with diagnosed HIV]

In a few cases, shared responsibility was described as ensuring that a partner took an active role in harm reduction.

I usually have the condoms myself, I have told my partner to take charge so yeah when I am hard enough I ask her to put the condom on, so this way I can say she takes part of the responsibility. [man with diagnosed HIV]

In sharp contrast to these descriptions of shared risk management, were those (accounting for half of the entire sample) who described responsibility for harm reduction as resting entirely with one partner in the relationship. In the vast majority of cases, it was the person with diagnosed HIV who felt that it was their duty to ensure HIV was not transmitted, often in the absence of consistent concern from their partner.

I felt a sense of responsibility actually, and had to bring it [a condom] just in case he didn't and most of the time he didn't so, yeah I just provided it. [woman with diagnosed HIV]

These narratives of sole responsibility connect back to the problems (described above) that many men had using condoms.

I mean I have talked to him, and I have talked to him and I have said well we should because I don't want to pass it on to him, but he is persistent in that he is not willing to use protection.... Because that's not fair really if, if a partner is HIV and they want to use protection and the other one is saying no then really that is a little bit of bullying I think really. [woman with diagnosed HIV]

In relationships where one person described having sole responsibility for managing HIV transmission risk, this was nearly always a role taken on by the partner with diagnosed HIV, as exemplified in the two preceding quotes. There were however, some instances where sole responsibility was taken by a negative partner.

No because at one time he said maybe if we don't use a condom it will help him with his erection and we tried it but I said to him, you know I can't do this. In my head it cannot happen. We tried it but it couldn't work. [woman whose last test was negative]

In this particular example, the participant described a situation

where her partner with diagnosed HIV felt that she should trust his undetectable viral load to protect them, but she could not contemplate sex without condoms, no matter what his viral load. As a result, she felt isolated in her concern about risk, and unable to have sex with him at all.

SEXUAL SATISFACTION AND PLEASURE

Toward the end of the interview, participants were asked how happy they were with their sex life. Participants answered this question in many different ways, partly depending on how openly they discussed their sex life within the interview. While the majority of participants described some level of dissatisfaction with their sex life, there was a considerable proportion who did not. In the main, those who were satisfied did not elaborate much in their response, but they described sex with their partner as being 'OK'. A small group (about a tenth of all participants) were very happy with their sex lives, describing a sexual relationship with a partner that is fulfilling.

It's the best I've had in my whole life actually. Yeah, no it's very good sex...I suppose it's got a lot to do with also the fact that I'm a lot older now and therefore I'm a bit more bold about what I want and what I don't want...If he finishes before me I'll turn, "No you haven't finished it yet. Can you carry on, please?" And if he's tired I'll say, "Yeah I'll give you an hour and you carry on." [woman with diagnosed HIV]

Among the remainder of participants, the main reason for dissatisfaction with sex related to the limitation that HIV had placed on their sexual freedom. Most often, people would describe how their anxiety about the risk of HIV transmission had decreased their capacity to enjoy sex with their partner. Sometimes this anxiety was linked to a concern about the impact of not having disclosed an HIV diagnosis to a partner.

However, in most cases, where disclosure has occurred, there was a nagging sense that sex could never feel carefree again.

No I'm not really, really happy given all those obstacles which it's not a happy thing, it's not something I wake up and say, I'm looking forward to it, no. [woman whose last test was negative]

Others felt that specific risk-reduction measures (particularly condoms) had intruded on their capacity to enjoy sex. And finally, a tenth of all participants described decreased sexual frequency as contributing to a diminished sexual relationship. In some cases, this decline was attributed to other factors (such as getting older, or having other priorities). It was often the case that decreased sexual activity within the relationship was directly related to concerns about HIV transmission.

SUMMARY

There can be little doubt that having an HIV diagnosis, or being the partner of someone who has diagnosed HIV, has immediate and profound effects on sexual expression, at least in the short-term. In many cases, participants described ways in which they were able to overcome their initially debilitating fears about HIV transmission within the relationship. A number of those taking part were enjoying a happy sex life with their partner; a small group even said that they were having the best sex of their lifetime.

However, enjoyable sex with an acceptable level of risk was no longer experienced by most participants, most of the time. Key issues that prevented this were difficulties with condom use and worries about condom failure, profound lack of awareness of other harm reduction measures that might help to alleviate anxieties about transmission during recreational sex or during sex with the aim of conception, and a lack of self-efficacy to have (or to avoid) certain sexual experiences.

RECOMMENDATIONS

The following recommendations should be considered within the context of *The Knowledge, the Will and the Power (KWP)*: the strategic planning framework for HIV prevention among black African people in England. www.kwp.org.uk provides concise descriptions of aims and related interventions.

1. Promote and provide an array of male and female condoms for both risk reduction and sexual pleasure.
2. Raise the profile of people's difficulties with condom use in community and clinical settings as well as increasing availability of interpersonal counselling and support to address these issues.
3. Provide information, advice and support about harm reduction tactics beyond condom use, including: reducing facilitative factors during sex, having non-penetrative sex, considering viral load and infectiousness, and knowing how and when to access PEP.
4. Provide safer conception advice to all people with diagnosed HIV and their partners while also working to ensure that safer conception options are accessible.
5. Identify people whose sexual negotiation and self-efficacy needs are high and provide sustained therapeutic support.

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