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Managing 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*.

Managing a sero-discordant relationship was rarely portrayed as simple or problem-free, particularly in its early stages. Participants described HIV as impacting on many aspects of the relationship, including how partners felt about one another and how happy they felt in their relationship. This paper discusses the HIV-related worries and problems that participants had and the ways they tried to overcome them. It also highlights the range of other issues that they had to contend with and the desire expressed by some for HIV not to dominate their relationship or become the focus of their lives.

FACING UNCERTAINTY

Uncertainty, in many different forms, dominated their stories and was a significant issue for participants, particularly in the early stages of a relationship. Ongoing fears of HIV transmission were very common among those who had been recently diagnosed or had only been with their partner for a short time. Several people, both with diagnosed HIV and without, described how fears of acquiring or transmitting HIV had made their relationship with their partner very difficult.

Living with a person who has got HIV there is a part of you which is like you sort of become a spy of your own life, you spy on your own life because you're not sure what, you're always looking like, "Shall I get it, do I have it, when?" You're always thinking of a day, at the back of my mind I think sometimes, "One day I'll catch it" [...] It's a question that never goes away. [woman whose last test was negative]

For about a third of the negative or untested partners we interviewed, this concern regarding transmission was manifested in rigorous, and perhaps obsessive, cleaning of both their person and the environment they shared with their partner. Worries about sharing toothbrushes, bath water, clothing, toilets or cups were reported by a few partners,

especially around the time they first became aware of their partner's HIV infection.

Maybe she can leave something which has got HIV, then I get, all the time it is in your head. So all the time you strict clean everywhere, in the toilet, everywhere you clean. [man whose last test was negative]

Negative or untested partners expressing such fear clearly lacked a sufficient understanding of HIV and how it can be transmitted (a situation also faced by some of those with HIV when they were first diagnosed). Continuing uncertainty was also evident in the concern that a significant proportion of participants had regarding conception. Over half of those we interviewed questioned whether it was possible to have HIV-free children if one parent had HIV, while a few still held concerns about whether sex (even protected) could ever be safe enough to prevent them from acquiring HIV. Such feelings had a significant impact on how participants perceived the sustainability of their sero-discordant relationship.

Participants with diagnosed HIV, particularly those who had been diagnosed while already in a relationship with their current partner, also expressed uncertainty about whether their partner would remain with them in the longer term. Even where partners had provided support and encouragement, around a quarter of participants with diagnosed HIV expressed beliefs that their partner would soon leave them for someone who did not have HIV. This fear of abandonment was, not surprisingly, heightened in relationships where the partner without HIV had reacted very badly to disclosure or where the relationship was at breaking point. In a manner that suggested very low self-confidence following diagnosis, a few participants with diagnosed HIV simply felt that their partner deserved someone without HIV.

I felt like my partner, since I was positive, felt like she should have someone else who was not positive, not me who is

positive. I was feeling that, OK, how is, I did not see it being possible for us to live together, one being positive and one negative [...] I did not see it as putting our heads together and agreeing on anything because it was always fighting and fighting. So I was saying to myself, I think it's better for her just to leave me alone instead of going to find somebody else. [man with diagnosed HIV]

Several of the participants without HIV described how hard it was for them to manage their own fears while also acknowledging their partner's concerns. Those who had made a decision to try and maintain or develop the relationship found continuing fears of transmission very draining.

The cause of uncertainty was generally a lack of understanding: either about the nature, prognosis or infectiousness of HIV; or about how the other partner felt about the future of the relationship. Nearly all felt that such uncertainty could best be overcome by talking through worries and concerns with their partner, and by accessing information or services that could inform them about HIV. Around half of all participants described how talking openly and honestly about their feelings regarding HIV, and their feelings for one another, had helped them to sustain and improve their relationship.

I think it build trust between the two of us. There is trust now, she can trust me now. But, I think it has made me more confident as a person and she's so much more well informed now. It's, I think it has made us closer in our relationship. Made us so much closer because the trust is good. [man with diagnosed HIV]

However, for others, communication about HIV and discussion of their worries or fears was rare. There was a perception held by some that discussion only served to make things worse by highlighting their sero-discordance and this made people even less inclined to talk about their feelings.

You get fed up because we have been having so many arguments quite often and it is all about my medical condition so I get fed up and I tell him it's ok for him to go and find someone because I get fed up with these things, you know and I'm like... [Long pause] I am better off on my own you understand... [Starts crying]. He just gets fed up of talking about it... [woman with diagnosed HIV]

Some of the participants with diagnosed HIV, especially women, struggled to engage their partners in discussion about HIV or their worries regarding their relationship. A small number described how their negative or untested partner refused to discuss the issue at all, leaving them facing even greater uncertainty regarding their partner's intentions and the future of their relationship.

Given the uncertainty that many participants faced, it is interesting to note how rare it was for participants to have encountered other people who were in sero-discordant relationships. This lack of visible role-models meant not only that there was a profound lack of advice or information offered by peers, but also led many participants to question whether a sero-discordant relationship could ever be viable in the long

term. Participants described a common perception within black African communities that individuals in such relationships could never be happy and that the uninfected partner could not remain that way indefinitely. However, around a quarter of participants had, with great effort and mutual discussion, discovered that sero-discordant relationships could indeed be happy, healthy and successful.

I think when you are HIV positive you only think you can only go with a person who is HIV positive but because you haven't, your mindset is telling you the only person you can go out with is HIV positive. But it's not true. It's not true. [woman with diagnosed HIV]

POWER AND DISEMPOWERMENT

A theme of power and disempowerment was common within many of the sero-discordant relationships described by participants. Many of those with diagnosed HIV, particularly women, struggled to achieve happiness in their sexual and intimate lives. The section above described how some participants with diagnosed HIV lived in fear that their partner would leave them for someone who did not have HIV. As well as being very unsettling, it was also disempowering. Men and women who found themselves in this position were so gripped by this fear of abandonment that they often accepted their problems within the relationship without question or complaint.

I think more the person living with HIV because we often tend to take responsibility and carry the burden around with the relationship, I think we tend to try a lot more and maybe stay in bad relationships because you think at least it is acceptable, he has accepted my status. I think a lot of times people maybe tend to tolerate a lot more than they would do normally if they didn't have the HIV. [woman with diagnosed HIV]

Participants with diagnosed HIV sometimes described how attempts to question or disagree with their partner were met with cold reminders of their status and an implicit suggestion that they had no right or power to change their current situation.

Whenever we have a slight argument, whenever there's a slight problem and then there's this shouting and this and this, that, hey, you've got the disease, this and that, you know, all these things. [man with diagnosed HIV]

Concerns about the effect of unequal power positions were also raised by around a fifth of partners without diagnosed HIV. A few such individuals described how they were not comfortable with their partner's tentativeness and gratitude, and they were keen to return to a 'normal' relationship where both partners could freely articulate their thoughts and feelings.

You just need, you need to feel when he's not happy, you need to know he's not happy, but it doesn't seem like I will see much of that. So, and then I just don't want to be like controlling in the relationship. I like a bit of a challenge, so I like someone to challenge me. [man whose last test was negative]

Unfortunately this perspective was not evident in the majority

of cases and some troubling accounts of partners taking advantage of their seemingly more powerful position were described. Descriptions of physical assault directed at participants with diagnosed HIV were extremely rare, but frequent emotional or psychological abuse, coupled with threats of disclosure to significant others or withdrawal of financial or practical support were reported by around a quarter of participants with diagnosed HIV.

DEALING WITH DIFFERENCE

Some of the people we interviewed had been in sero-discordant relationships for only a few months, whereas others had been together for many years. Eight participants had been in sero-discordant relationships until relatively recently but, for a variety of reasons, that relationship had ended. Although a third of the participants reported that they were coping well and felt there were no underlying problems in their relationship relating to HIV sero-discordance, many others faced ongoing and complex issues.

Participants, both diagnosed with HIV and not, reported feeling differently about their partners following their diagnosis or disclosure, despite trying their best to deal with the news and accept the situation.

We do love each other still but there's a distance between us, there's now a distance between us because I see sometimes he's like, he's not sure about my feelings about him. [woman whose last test was negative]

Problems with sex and utilising condoms often served to emphasise this distance. Sex is generally perceived as an integral part of any relationship and sexual problems had a significant impact on happiness with the relationship more broadly. Dissatisfaction with sex, and the problems associated with managing the risk of transmission (explored further in Report 4: *Sex and risk*) were the main reasons cited for engagement in sex outside of the relationship, and this was true for both partners in the sero-discordant relationship.

Several participants with diagnosed HIV felt that their partners simply did not understand how difficult life was for them, an issue exacerbated by the fact that some of their partners were very uncomfortable talking about HIV. A few of those undiagnosed partners (mainly women) also felt that their partner with HIV did not understand the problems that they faced.

My husband, I just make like him happy, I never think about anything, because I feel, I feel for him. Like, I know the situation, you know, it's not easy thing to be diagnosed HIV. So I don't want, like, to show him that I have real difficulties, that I'm stressed. I just make like everything is fine to me, that I'm happy about everything. [woman whose last test was negative]

Dealing with the reality of their situation was made worse by a difficulty talking to people outside of their relationship about HIV. Male participants, in particular, were sometimes so concerned about how their news of HIV might be received in their community that they forbade their partners from talking

about it with anyone else. In such circumstances the partner was forced to seek out support in secret and therefore their access to individuals or professional services was severely limited.

In some instances, the pressures of trying to manage the relationship had proved too great and participants had either separated from their sero-discordant partners, or were very close to doing so.

Now I'm old but I'm thinking to separate with him, because it's really hard. He, it must ... him to see that this person which I'm living with, she is helping me, let me try to do good and to help, but he don't think that. So I'm in punishment all the time. [woman whose last test was negative]

However this was not the case for all, and over a third of the sample reported that they were managing to deal with HIV as a part of their relationship and did not feel that it had any long lasting negative impact. They talked openly with their partners about worries and concerns and negotiated their relationship fairly. Partners without diagnosed HIV might assist their partner to adhere to HIV medications or offer practical support during periods of ill-health. Sometimes the need to talk explicitly about fears, hopes and the future helped bring them closer together. This was only the case for a very small number of people, but their voice and experience should be acknowledged.

I was, we were fine about it. Or I was fine about it. It didn't stop or have any, there was never, it was never detrimental to our relationship. In fact it probably brought us together. [man whose last test was negative]

HIV HAS ITS PLACE

HIV had a significant impact on how partners engaged with one another, how they negotiated their relationship and how happy they were. Its presence had changed the nature of nearly all the relationships we explored and changed the way in which individuals perceived their future. However, many of the people we interviewed were keen to emphasise their desire for HIV to not overpower everything else in their lives. Many participants wanted to return to 'normal' and not allow a virus to dominate their relationship.

It was difficult the first days but now he is normal to me. I am just being my normal self. If he say yes, he says yes, if he says no he says no, because I've decided if I put this it will be like a third person in this relationship. [woman whose last test was negative]

This concern to not talk about HIV too often, or give it undue prominence in the relationship, was balanced with a desire to avoid HIV transmission. Some partners wanted to talk about HIV a lot so that they never forgot the very real risk in their immediate environment, while others tried to avoid discussion about it unless absolutely necessary. This latter view was more common among people who had been in sero-discordant relationships for longer periods of time. As their understanding of how HIV can impact on their health and well-being changed

and developed, so too did their perception of HIV within their relationship.

It makes me feel, I am not disgusted about it [HIV], you know it's a way of life, there are a lot of diseases about, not only HIV. It not only HIV you know, not only HIV kills you, cancer kill you. You know blood pressure can kill you, heart attack, you can get knocked down, so to me I got nothing to feel shame about. [man whose last test was negative]

A significant number of participants were also keen to stress that there are many complex reasons why a relationship may not work out and it should not be assumed that HIV is the sole factor in determining success or failure.

We shouldn't always place a huge emphasis on HIV status because you may, you may just not get on with that person, they may have bad character [...] you also need to look at what else makes a good relationship. [woman with diagnosed HIV]

Many other issues or problems caused stress for participants taking part in the study, and these often put a strain on their relationships. High on this list were concerns relating to their immigration status or that of their partner. Unresolved legal status meant that around half of the participants were not able to work legally, which resulted in severe financial hardship. When asked what one thing could help to improve their lives or improve their relationship, nearly half said they wanted their immigration status resolved, giving them the right to work and provide for their family.

The help that will improve my life is that at the moment I cannot make decisions, just if I can get helpers, the most worry

is that not having [immigration] papers and then I can go and start improving my career and then I was going to start learning about HIV and go back home sometimes and go back home and do something about HIV really. [woman with diagnosed HIV]

SUMMARY

At the point of HIV disclosure, some relationships ended immediately, while others found that the challenge helped to bring partners closer together. Some relationships floundered in the early days following disclosure, with one or both partners unable to discuss or resolve their worries or concerns, while others sought advice or support to better understand the consequences of their situation.

Both partners needed time to come to terms with HIV as a part of their lives and what this meant for them on a daily basis, but many also stressed a desire for HIV not to cast a shadow over everything they do. Not knowing any other sero-discordant couples who were content in their relationship meant it was hard for some to conceptualise their own relationship as viable.

There is evidence throughout this report, and in report 4 that follows, of gender-disempowerment. Women, both with diagnosed HIV and without, often struggled to negotiate relationships that they are happy with. Some men with diagnosed HIV also appeared disempowered and this most often related to fears of abandonment by the negative partner. Daily worries and concerns relating to HIV came on top of other everyday stressors, which in many cases included concerns about immigration status.

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. Evidence of the effects of gender inequality among African women was substantial. Interventions to address this will need to be wide-ranging, from policy advocacy and structural change, to micro-financing initiatives and provision of skills training to enable women to better negotiate the sexual relationships they desire. Such interventions need to take account of evidence from, and work in partnership with, other sectors to try and bring about structural level change.
2. Instigate community development initiatives and extend interventions to boost the confidence of people with diagnosed HIV to better negotiate happy and healthy relationships.
3. Devise strategies to highlight people in sero-discordant relationships where both partners are happy, settled and in control, and who are willing to act as role models in their communities.
4. Provide sustained, couple-based therapeutic support enabling shared discussion of concerns and thoughts for the future within the relationship.

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