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# HIV diagnosis and disclosure

*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*.

For those we interviewed the knowledge that either they or their partner had diagnosed HIV needed to be managed on both an individual and collective level. It impacted on how each partner saw themselves and also how they perceived the future of their relationship. This report begins by exploring how participants with diagnosed HIV became aware of their HIV status, and how they have tried to come to terms with it, before describing their decision making about sharing this status with their partner and their means of doing so. The thoughts and experiences of participants who had not disclosed their status are described. Finally it explores the reactions of the HIV negative or untested partners to disclosure, its impact on a personal level and how they sought to come to terms with this news.

## BECOMING AWARE OF ONE'S HIV STATUS

Each of the 44 participants with diagnosed HIV had considered its impact on their life and future plans. In some instances this diagnosis had occurred relatively recently, whereas for others it had happened many years ago. Most of the participants were diagnosed as part of antenatal screening, or had been tested on medical advice following periods of ill-health. The majority of participants had lost friends, family or previous partners to HIV in their African countries of origin. This experience of HIV as a debilitating and fatal condition had a dramatic impact on their perceptions of their own prognosis here in England.

*Because with my own experiences where I come from in Africa a lot of people have died of this diseases, of HIV and AIDS. I've seen how they suffer and how they really deteriorate until they die and I was imagining all that happening to me. [man with diagnosed HIV]*

Diagnosis was almost always met with shock, fear and uncertainty. It generally left participants with a great sense of

loss: they felt they had lost the life they had before, as well as the chance for a fulfilling future.

*You cannot really plan. You cannot really know what's the future ahead of you; you know it's just like a death sentence. [woman with diagnosed HIV]*

*It just limits my horizon. As much as people say, "The world is still out there for you", which is true, I am sure there was much more out there when I was negative. [man with diagnosed HIV]*

After their diagnosis, some participants were left with low self-confidence or self-esteem and struggled to interact with those around them. Over half were unwell at the time of diagnosis and a few continued to face complex health issues and adverse reactions to HIV medications. A perception of how other people with HIV are treated by fellow black Africans and their understanding of pervasive HIV-related stigma influenced how participants felt about their new HIV positive status and their chances of future happiness. It also influenced whether they felt able to confide in others and seek help or support (a point explored in more detail in Report 5 – *External influences*). Many participants had themselves stigmatised others and becoming that infected 'other' was hard and required a reformulation of how to consider HIV.

*From that moment it has actually changed my views about people because I used to actually discriminate HIV myself. I used to think myself that if you are HIV you brought it on yourself, until I got to the point knowing I was actually positive. From then I changed my views of people. Whatever sickness they have they are still a human being anyway, because the way I am is no different from anyone else who is actually negative. [woman with diagnosed HIV]*

Coming to terms with diagnosis at an individual level was often a long and difficult process, and one that was still continuing

for many of the people we interviewed (a process mirrored in many HIV negative or untested partners). With time, information and, in some cases, support from HIV charities or their health care providers, many of the participants had begun to come to terms with their diagnosis and had found a way of integrating HIV into their everyday lives. Improvements in anti-retroviral therapies in the past decade mean that death is not imminent and people with HIV can still maintain healthy and productive lives. Meeting and talking to other people with HIV often helped those we interviewed to understand that this was possible, as did counselling or advice provided by some of the HIV charities they accessed.

*I look at life with a positive mind now. Or like before now I used to think, oh if you are diagnosed HIV, that is the end for you. I felt as if the world has come to an end for me. I started thinking, 'who will take care of my children?' But now I look forward to the next day. [woman with diagnosed HIV]*

Of course, this was not the case for everyone and many of the participants, particularly those who had been diagnosed with HIV within the past 2 years, were still struggling to come to terms with their status. About a fifth of participants appeared to be really struggling with their status and had not been able to deal with the reality of their situation. While this represents a common stage when coming to terms with significant life events, such as HIV diagnosis, those individuals remain in significant need.

## HIV STATUS DISCLOSURE

All participants with diagnosed HIV had been in relationships and, at one stage or another, faced the decision of whether or not to disclose their status to their partner. The motivations to disclose (or not) were complex and were influenced by a range of personal circumstances and past experiences. Those who had disclosed their status to their current partner most often cited a desire to be 'honest' and expressed a belief that it would be hard to maintain a long-term relationship, and to develop trust and commitment without telling a partner of a positive status. Those with diagnosed HIV were absolutely clear that they did not want to transmit HIV to anyone else, especially someone they cared for in a relationship. As a result it was common for participants to suggest that disclosure was essential to help keep the other person safe: it meant it was possible for them to take any necessary steps, such as seeking post-exposure prophylaxis (PEP), if exposure ever occurred. Some participants with diagnosed HIV wanted their partners to be able to make an informed choice about whether they wished to continue the relationship.

*What made me to tell him? First it was myself. I couldn't be free, do you understand? Because I felt I looked at the inside myself I loved him so much so I decided I need to tell him before somebody, not even before somebody else, to know if he want to be with me. [woman with diagnosed HIV]*

A fear of criminal prosecution if transmission did accidentally occur (for example, condom failure) was also a motivator for six participants to disclose their status to their partner. For

those recently diagnosed and already in a relationship, disclosure often felt necessary so that existing partners could seek testing to clarify their own HIV status. A significant number of participants with diagnosed HIV expressed specific concerns about taking HIV medications in secret and some reported problems with treatment adherence when they had been in relationships where they had not disclosed.

*The days she was staying in the house it was very difficult for me to take my medication because I had to hide... I didn't want her to know. She had to ask me why I taking this medication? So it wasn't easy for me because sometimes I fail to take my medication on time [...] I kept it up for six months without disclosing. [man with diagnosed HIV]*

Despite significant motivation to disclose, 9 of the 44 participants with diagnosed HIV had not told their primary sexual partner at the time of interview. Two of these participants were male and seven were female and had been in relationships ranging from 1 month to 7 years. The reasons for non-disclosure most commonly related to a paralysing fear of rejection, fear of assault, loss of financial security, or a concern that their partner will tell others. Most had a strong desire to disclose but simply did not know the best means of doing so. Perhaps not surprisingly, those who had experienced rejection or other negative responses from partners, friends, family or their wider community in the past were most likely to be experiencing problems with disclosure at the time they were interviewed.

In all instances, non-disclosure was perceived by the person with HIV as having a significant and detrimental impact on the relationship. Trying to manage sexual behaviour, as well as their own health and well-being, while carrying this secret was a heavy burden, resulting in the breakdown of several relationships.

*I really have not been strong enough to open up to her. It's a strange feeling, a bit like I am stealing something. You know, you are holding something back [...] I used to see this girl and for sometime the relationship got serious and I knew I had to be comfortable around her so I have to say something like, you know I have to disclose. At times when you are trying to prepare people, you mention HIV and everything and you get nasty ideas of what HIV is. So what I did was I chose to end the relationship because I just could not bring myself to disclose. [man with diagnosed HIV]*

Even where the motivation to disclose outweighed concerns about the negative consequences, it was often still difficult to find the right moment to tell one's partner "I have HIV". Disclosing too early in a relationship could lead their partner to walk out, while disclosing weeks, months or years into the relationship could lead to accusations of dishonesty and a betrayal of trust. Even for those who had been living with HIV for a long time, it was difficult to know how a partner might react to the news of their status.

*I was to be honest, I was scared. I was really scared to tell her because I have never done anything like that. I was scared to tell her about my status in case she took it badly and then you*

*know because of the stigma attached to HIV you know the way people talk about HIV, it worried me. [man with diagnosed HIV]*

Twenty-seven of the participants with HIV received their diagnosis while already in their current relationship. Around a quarter of these received their diagnosis in the presence of their partner, thus freeing them from the need to disclose. However, the shock of this situation was often hard to bear and allowed no time for the HIV positive person to process the information themselves before facing their partner's reaction. Many couples in this situation also had to endure a long and difficult wait to clarify the partner's HIV status.

## REACTING TO DISCLOSURE

Receiving the news that their partner had HIV was incredibly hard for many of the negative or untested participants to hear. Again, due to the associations of HIV with death either here in the UK or in their countries of origin, most assumed that their partner would die imminently.

*I thought he was going to die and then [...] I don't know. I don't want to go back to that time, yeah it was just really, really awful around me and I was just like, it was, I was just really shaking. I was shaking. It was just the shock; the ward was just like turning upside down [...] The minute I knew I just thought, he's not going to make it. [woman whose last test was negative]*

For those receiving the news from long-standing partners (including those who had been having unprotected sex) their thoughts quickly turned to their own HIV status and fears that they must also be infected.

*But when they told me he was HIV my first thought was, all right, I'm going to die. I'm going to die [...] And then I was like, he's going to die, I'm going to die, who's going to look after my son? And at that time I was on student visa so everything was like, sorry we can't help you with this, you've no recourse to public fund. [woman whose last test was negative]*

Even following their own HIV testing process, it was very hard for such individuals to understand that they could be free of HIV while their partner was infected. Those in relationships where unprotected sex had been occurring for some time prior to diagnosis tended to assume that both partners simply must have HIV, and were left questioning who may have infected who. Even those who had been using condoms for intercourse, or having only oral sex, worried that transmission may still have occurred.

*I tried really hard to be like, someone, like someone to comfort him, to give him moral support and to make him feel like the same person [...] I tried really hard. And then I worried about myself at the same time, because we'd been having safe anal sex, but we'd been having oral sex as well, so I was a bit, I worried about it as well. [man whose last test was negative]*

A few participants described how they immediately looked upon their partner differently once they had disclosed their status. They were filled with worry and concern about what

this meant for their future together and the way they outwardly reacted to the disclosure often reinforced those fears held by the HIV positive partner as they made the decision to disclose. Many of the participants with diagnosed HIV described experiences of verbal abuse, instant rejection, threats of criminal prosecution and, in a few cases, severance of all contact with both the partner and any children from that relationship.

*She took it very badly. She took it very badly. You know she, she wanted me to be prosecuted but then they tested her and she was negative so they couldn't go on with the prosecution [...] I didn't tell them [my children] myself. I didn't tell them myself because I thought they were too young to understand. But my wife decided to tell them that I am positive. I am not happy with that because I wanted myself personally to tell them. Since they have been told I have not been in touch with them. [man with diagnosed HIV]*

In the cases where relationships broke down following disclosure, we have only the voice of the person with HIV left to tell the story.

Those partners who stayed sometimes immediately reacted by distancing themselves from their HIV positive partners, avoiding physical contact for fear of infection, and forbade them from discussing their HIV status outside the home lest anyone in the family be assumed HIV positive by association. Misunderstandings about the impact of HIV and how it is transmitted were often at the heart of these responses, as was HIV-related stigma in the local black African community.

*"I can't go out with someone who's sick, no, I can't be seen with someone who is" [...] Yeah, that's what he said, he said, I asked him, "Are you comfortable going out with someone who's HIV positive?" He's like, "No, why would I?" [woman with diagnosed HIV]*

Not all reactions were like this, and about a third of the negative or untested partners we interviewed appeared relatively comfortable with the situation from the outset. They were keen to know how, when, and where their partner had contracted HIV, but it was also common for them to ask numerous questions relating to their partner's HIV and health status.

*What kind of questions did he asked? Well, generally, "Are you okay health wise?" "Yes, I am". And, "How often do you see the doctor? Are you on medication and how is that? How are you finding that? When did you find out?" Obviously there's a flood of questions. [woman with diagnosed HIV]*

When those participants with diagnosed HIV were able to answer these questions, the resulting information often helped to allay their partner's fears. This was a long process of discussion however, and it was not uncommon for negative or untested partners to ask for some time to reflect before deciding whether this was a relationship they wanted to maintain.

*You know when she told me it just, it was a shock and she wanted to know if I would stay with her and I said, "Well I*

*can't answer that straight away. You told me, I'm happy that you told me, but I need some time for myself to think". So I went away for a few days and thought about it. And I came back to her and said, "Yeah we can have a relationship". She was shocked because she thought she would never see me again. I said, "I am not like other people. I am not ignorant like other people". [man whose last test was negative]*

A supportive reaction to a disclosure could be affirming for the partner with HIV. Acceptance from partners helped many to feel more confident about themselves and more settled with regards to their own HIV status.

*I just wish men, most men could be like him because it is not easy to get someone like that. It's not, it's terrible because before I met him I went through um, I met people who just wouldn't answer the phone, wouldn't talk to you [...] It makes me feel twenty years younger, he makes me feel um, this is something I have been dreaming of all my life. [woman with diagnosed HIV]*

There were other negative and untested partners whose initially unsupportive reactions changed as they came to learn more about HIV.

*His fears were being infected as well with HIV, and so, so what he decided to do was start doing some read ups and erm he would go on the internet and research HIV transmission and things like that and that's how he kind of educated himself. [woman with diagnosed HIV]*

Some immediate responses also revolved around conception

concerns, with most assuming that conception was no longer possible without significant risk of infection both to themselves and to any child. Further information and advice regarding conception was sought by a significant number of participants, both with diagnosed HIV and without (discussed further in Report 4 – Sex and Risk).

## SUMMARY

Diagnosis with HIV was met with shock, fear and uncertainty. Inaccurate beliefs that HIV always results in serious ill-health and untimely death dominated their response and made it difficult to come to terms with HIV as a part of their lives. Whether or not to disclose their status to their partner was a difficult decision for the person with diagnosed HIV to make and this was informed by their perception of HIV-related stigma, prior experiences of disclosure and a need to maintain their personal integrity. Sometimes individuals with diagnosed HIV did not feel sufficiently empowered to disclose and thus found themselves in unhappy relationships where they felt burdened by their secret. Those who were informed of their partner's HIV status also experienced shock and fear and they had numerous questions about their partner's prognosis and the possibility they too might be infected. In some cases, the reaction of the partner without diagnosed HIV included verbal assault or rejection, whereas other partners were supportive and concerned for their mutual well-being. Awareness that HIV formed part of their everyday lives was difficult for both partners to accept and required time, sensitivity and, quite often, external support.

## 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](http://www.kwp.org.uk) provides concise descriptions of aims and related interventions.

1. Provide and continually reinforce culturally appropriate HIV prognosis information for black African people and their partners and ensure that clinical information relating to viral load and CD4 is clear and accessible.
2. Deliver targeted one-to-one and couple-based therapeutic support for those in emotional and psychological need following an HIV diagnosis.
3. Numerous interventions already exist to support and empower people with diagnosed HIV to disclose to their sexual partners, should they wish to do so. These need to be bolstered and significantly extended, with sharing of best practice between community and clinical providers.
4. The partners of people with diagnosed HIV require tailor-made written information about HIV prognosis and transmission as well as safer conception options.

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