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External influences

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*.

People in sero-discordant relationships engage with a wide variety of other people and services on a regular basis. Whether or not they disclose the fact that they, or their partner, have diagnosed HIV is a difficult decision and is informed by how they think HIV might be perceived and what reaction they may face. In telling others they risk rejection or discrimination but without disclosure it can be hard to access support or advice. This paper starts by exploring how participants made the decision whether or not to tell their children and family about HIV before considering their approach to disclosure to the wider community. Finally it describes participants' views of the HIV support services they accessed, what was provided and how they might be improved.

CHILDREN AND FAMILY

Forty-two of the people we interviewed were responsible for the care of children and several others had children living elsewhere. Parents were thus faced with the decision of whether to tell their children. Often they were perceived as too young to understand what HIV meant or too young to deal with the consequences of knowing. However, non-disclosure made daily life difficult. In addition to having to take medications in secret, the fact that their children were not aware one partner had HIV meant their opportunities to discuss HIV and their relationship were significantly curtailed. Occasions when the diagnosed positive partner was unwell required sensitive explanation and sometimes placed a high burden of childcare on the negative partner.

Some days it can be hard. Sometimes she's poorly and the children can get on your nerves, you know they play up with you and I tell them you know, "Your mum's not well". They go, "Why?" and I go, "She's just not feeling well. You know I say go downstairs and leave your mother, you know". So sometimes it does upset me too. Sometimes I do cry, but I don't cry in front of her. I go away and sit in the room and have a little cry, you know. [man whose last test was negative]

Those who had children living away from the home (often in their African countries of origin) considered whether they

should disclose their own or their partner's HIV status and what purpose this might serve. The belief that HIV was synonymous with death in most African countries meant they often did not wish to burden their children as offering reassurance from a distance would be difficult. In the third or so of cases that people had disclosed to their children, either in England or abroad, reactions were mixed. Some children were fearful, but eventually supportive, while others sought to distance themselves from their parents or severed contact entirely.

Beyond children, both partners in sero-discordant relationships carefully considered if, how or when to disclose to other family members that they or their partner had diagnosed HIV. Nearly half of all participants had not told a single member of their family, and a further quarter had told only one or two relatives. Decisions not to disclose were grounded in a fear of rejection by significant individuals in their lives. Most participants had a clear sense of what their family thought of HIV, informed by their awareness of how HIV is perceived in the broader community in which they lived. Some participants felt that the news would be too much for their family to bear and so they did not disclose to protect them from psychological or social harm.

If I told my family then, especially my mum and dad, it would kill them. And some of my family might start blaming me, putting the, you know, fault on me. And there may be, you know, the stigma attached to it all. So they'd rather not know. [woman with diagnosed HIV]

Around a quarter of participants had disclosed to only one or two family members that they or their partner had diagnosed HIV, and a further quarter had disclosed to all family members. Unfortunately, in the majority of cases this disclosure had been met with negative reactions, ranging from insulting comments through to complete rejection. While rejection was not as common when negative or untested partners disclosed to their family that their partner had diagnosed HIV, often their families encouraged them to leave their partner or were very cold towards them.

They won't do anything or come near you. Some they don't even want to see you. So I would be out of place and should be a nobody. Once you are without your relatives around you, you are a nobody. [woman whose last test was negative]

In about a third of cases, disclosure from those with diagnosed HIV resulted in supportive words or action by family members. This was most often because other members of the family had experience of HIV in settings where effective antiretroviral medications were available. They had come to understand more about the prognosis of those with diagnosed HIV and were less likely to perceive it as a death sentence. However, fears of the effects of stigma often persisted.

It took time, it took ages as well to tell them because they're my cousins but when I was sick that's when mostly I just had to tell them about it [...] No, they just said it's, nowadays it's there, you just have to be careful. There are a lot of people with it but then when you have it it's not like the end of the world and you just have to look after yourself. [woman with diagnosed HIV]

STIGMA IN THE COMMUNITY

Beyond their immediate family, participants were faced with whether or not to disclose their HIV status, or that of their partner, to their friends or wider community. They also had to face the consequences and the impact on their relationship once they had done so. Nearly all participants were incredibly worried about people outside of their relationship, or support services, finding out. Nearly half had not disclosed to a single friend or other member of their local or faith community, and a further quarter had only disclosed to a small number of carefully selected individuals. HIV-related stigma was considered rife within African communities and nearly every participant feared being stigmatised, discriminated against or ostracised, and this undermined their willingness to be open.

If you are HIV positive then people see you as unclean. You are, nobody wants to be your friend. Nobody wants to be close to you. Actually, psychologically it's a culture because you lose friends. In the way I was brought up I've seen people that were positive that they've lost friends, they've lost relatives because they were considered unclean. [man with diagnosed HIV]

Those we interviewed believed that most black Africans think that to have HIV you must have had a high number of sexual partners, and perhaps experience of prostitution. Participants dreaded this association and were always keen to stress that their acquisition of HIV had been the result of 'normal' sexual activity or from contaminated blood transfusions.

Africans think that if you have got HIV you have been sleeping around. People don't want to look like they have been sleeping around [...] I've never talked about it with anybody else. [man whose last test was negative]

Those participants who were already reliant on friends for practical support, or on their faith community for emotional or spiritual support, did not want to risk disclosing. Those who had experienced ill-health related to their HIV status were often

uncomfortable discussing their ailments with friends or family in case it would make their HIV obvious. Lipodystrophy, tiredness or frequent taking of medication had affected some people's confidence to the extent that they were no longer comfortable spending time with others and had become quite isolated.

The thing I can say is having HIV you intend to withdraw from everyone. You intend to be alone, to be by yourself. You don't, the things that you do, used to do, you end up thinking that I can't do them. It's like when you know that you've got HIV it's like it's written on your face that, "I'm HIV". [man with diagnosed HIV]

Negative or untested partners of people who had diagnosed HIV also tended to be uncomfortable with talking about HIV outside the home. Often this was to protect the social and emotional welfare of their partner with diagnosed HIV, but it was also sometimes the case that they feared other people assuming that they too must also be infected. This fear of stigma by association also extended to their children.

Around a quarter of participants had told a small number of friends or other members of their community, and further quarter reported that they were open about HIV and the role it played in their lives with almost everyone. Responses to disclosure were, again, quite mixed. In only a small minority of cases had friends been supportive on a practical or emotional level. Often, but not always, this was because they had prior experience of HIV, perhaps as a result of another friend of family member having disclosed their status in the past.

I actually told myself that I've decided to tell someone because it's too much and I cannot bear it anymore. So I told someone and that person was like a, she was there for me, she was, I don't want to lie she was there for me throughout, even up till now, very supportive [...] She's got relatives here who have the disease and back home who have the disease, so she was just like, yeah we'll talk, sometimes you just need someone to trust in. [woman whose last test was negative]

Around a fifth of participants had disclosed to members of their religious community that they or their partner had HIV, although this was usually only to the religious leader and not to members of the congregation. In nearly all cases the response had been supportive in that prayer or practical support was offered. None reported a negative reaction when disclosing to their religious leader. It is likely that many of these good reactions resulted from careful selection among those making the disclosure.

They [the religious leader] are helpful and they tell me the same thing, "God is the one who knows and he's the only help for you so you just give your life to God and he'll know what to do with you. If it means that he wants you to go he will take you, but for now let's just concentrate on you being here and you're OK. You're normal so which is fine."

Is that what you expected?

No I never expected that, I expected it to be... I think nobody knows about that and just keep it as being confidential which I appreciate. [woman with diagnosed HIV]

Unfortunately, it was common that friends and community members reacted badly to the news of their or their partners HIV status: acting in a discriminatory fashion, making negative comments or rejecting one or both partners. Several participants reported being the victim of verbal abuse in public because of HIV, a situation that had left them feeling unsafe.

I was just coming back from the doctor's from getting my baby weighed walking along the street [when the abuse happened]. I was just shocked I didn't know what to say or do. And after she did that she drove off and I was literally my face my eyes I was flooding with tears [...] At that point in time all I wanted to do was just go somewhere, curl up in a ball and not wake up again. That's how I felt. [woman with diagnosed HIV]

Deciding which friends could be trusted with the knowledge of their or their partner's HIV status was a difficult matter and sometimes friends who were told did not react well, or spread the news to others. This lack of control over such sensitive information was a cause of concern for many participants and informed the decision of many individuals not to tell anyone at all. In cases where trust had been misplaced, consequences included widespread community discrimination against both members of the couple and, on occasion, their children.

We live in a house where there is a lift and maybe someone else was waiting if I'm already in the lift then no one will come in the lift [...] And we've got a nearby park and this child came, we were playing netball you know with my boys so the child came to join us and then the mother just came and grabbed the child and started beating them, the child's hand. And then I just had the courage I said, "Excuse me mum, has my child assaulted your son?" And she said, "No, no, no. But you are HIV positive which means your children they are as well". [woman with diagnosed HIV]

There were almost no cases where participants had been entirely open with all friends and other people within their community about their own or their partner's HIV status without some negative consequence. HIV-related stigma was, as described in great detail by those we interviewed, endemic within the African communities in England.

SOURCES OF SUPPORT

The relative lack of support from traditional sources, such as friends or family members, meant that an overwhelming majority of participants were reliant on services to help them cope with HIV in the context of their relationship. Over two-thirds of participants with diagnosed HIV appeared reliant on support from their local HIV charities, support groups, social worker or health care professionals to deal with many aspects of their everyday lives. Those who did not regularly access services at least took comfort that they existed. A great many participants expressed a feeling that their local HIV charity and support group was the *only* place they could be open about their HIV status, express their worries or concerns, and get advice from people who genuinely cared about their needs.

I think they [the local HIV charity] are doing a great job. Really when they're talking to you they talk to you like a human being and then you can feel that you are normal here. Not because you've got the virus or whatever, and you feel comfortable telling them what you're going through. [woman with diagnosed HIV]

Support groups provided an opportunity to make friends with people who were in similar circumstances and who could share their experiences and advice. Given the fear, or experience, of rejection from friends who did not have HIV, the opportunity to form such friendships was invaluable to many participants.

No one is going to judge you, you know. If you have got a friend to support you, you can talk about this and that and they give you information when you ask. You get a sense of peace (cries). [woman with diagnosed HIV]

In addition to this opportunity to talk openly about HIV within support groups or other social activities, local HIV charities were able to offer information regarding prognosis following infection, treatment options, advice regarding disclosure to one's partner and advice about managing sexual transmission risk. However, as Report 4 (*Sex and risk*) identified, some basic information needs had not been met for a number of individuals, particularly relating to PEP, condom variability and safer conception options. In general however, most participants felt that engagement with local HIV charities had helped them come to terms with HIV. Beyond emotional support, information and advice relating to HIV specifically, a few agencies were also able to provide more practical support with issues such as immigration, financial worries or childcare.

And it [the local HIV charity] has been a great help in terms of anything, anything. Immigration advice, referring you, whatever else. It's always been my first port of call and I've found that they've actually been very supportive that way. [woman with diagnosed HIV]

Over three-quarters of those we interviewed reported that they were really happy with the support provided to them by their local HIV charity and valued the input into their lives. Where they reported dissatisfaction this most often related to a lack of variety in services provided in their local area and a perception that 'tea and sympathy' type support groups were not appropriate for all people – especially men, who may be uncomfortable talking in such environments. There was also a clear desire expressed by at least half of all participants for more one-to-one therapeutic interventions. Those who were fortunate enough to have accessed counselling via their local charity spoke very highly of the experience and felt it had helped them come to terms with their or their partner's diagnosis, and what this meant for their future. 'Couples counselling' was also requested by a significant number of participants. While sharing of information and experiences in support groups was welcomed by most, many participants still felt that focussed, private discussion of the issues facing them in their relationship would be of huge benefit.

Is there anything else that could be done to improve the relationship you have with your partner?

The counselling because sometimes we tend not to listen to each other because I will be forcing my beliefs and my boyfriend will be forcing his beliefs without understanding [...] We jump guns you know we are not listening to each other because I don't want to hear it and sometimes I am not saying exactly what I want to say [...] so if you can be helped to listen in a place where people can go and learning and taught how to listen to each other.[woman with diagnosed HIV]

There was also a suggestion made by a majority of participants that local HIV charities could do more to specifically meet the needs of the negative or untested partners of people with HIV. While many recognised that their partner may not access such services anyway (for fear of stigma and negative association) they wished that their partner had more opportunities to access information and advice about HIV, which may help to alleviate many of the problems they faced.

I think what is lacking, and this is what gave me interest in the study, is that I may be getting support and service by my, I don't know how my husband is coping with living with a positive person. I just think there is nothing out there for them [...] He needs some, some kind of service to answer all those concerns, all the questions he has because I can tell there is nothing and he has those questions. [woman with diagnosed HIV]

Availability of written information tailored to the negative or untested partner was rare. Some were aware that online

resources about managing HIV were available but these were often inaccessible due to a lack of internet connection at home and a reluctance to access such sensitive resources in public internet spaces.

SUMMARY

The participants of this study described extensive HIV-related stigma at the community level. This added to the existing pressures on relationships and made it difficult to access social support from family or friends. Many had not disclosed their own or their partner's HIV status to dependent children, which meant keeping a difficult secret in the family home and further reducing the time and space available to discuss HIV-related issues. A significant number of those we interviewed had faced serious abuse or rejection by family, friends or their wider community when they had disclosed that HIV was present in their relationship. This often resulted in a loss of self-confidence and a profound sense of social isolation.

While there were examples of support from friends, family and faith leaders, many people we interviewed were reliant on support services to help them cope with everyday life. Support groups at local HIV charities offered an opportunity to be open and honest about the nature of HIV in their relationships and to share experiences and gain advice from people in similar circumstances.

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 provide concise descriptions of aims and related interventions.

1. HIV-related stigma is widespread and its impact is considerable. Wide-ranging interventions to address HIV stigma must be strengthened and consolidated. Effective anti-stigma interventions from elsewhere should be studied and translated for use in England.
2. Devise a general campaign targeting black African people in England to increase general awareness of improved HIV prognosis for those on anti-retroviral treatment.
3. Facilitate social spaces in which black African people in sero-discordant relationships can meet other couples in the same circumstances.
4. Maintain and expand services that provide a safe and supportive environment for people living with or affected by HIV to discuss their concerns and experiences in relation to HIV and other significant life stressors.
5. Provide tailored written resources for the children and other family members of people living with diagnosed HIV and their partners that explain what health related issues they may face and what support they may require.
6. Provide social, as well as private therapeutic, spaces for the male partners of people with diagnosed HIV to discuss their concerns and experiences. Wherever feasible, parallel services should also be developed for female partners, for children and for other family members.

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