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Assessing the treatment information needs of Africans living with HIV

An evaluation after ten years of HAART

...it is a big thing to have the confidence to think you have a right to actually ask the doctor 'can you just explain this to me more, I am not clear about the name of this drug'.

Africans do attend treatment discussion sessions and ask questions. I think that helps us a lot. Some people have had HIV for a long time but they do not know ... that to take your pills on time is very important. Adherence is an issue.

Personally I find reading very boring, it is only when I am part of a discussion like this that I enjoy myself and learn more. As they say, "knowledge is power" and learning is a continuous process. I hope we will have more discussions like this in the future and encourage other people who are afraid, still hiding, to join us. We have to help them to overcome the stigma.

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and HIV i-Base

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This report is published as a supplement to HIV Treatment Bulletin.

Executive summary

Background

It has been over a quarter of century since HIV was identified and over a decade since combination therapy was widely introduced in this country. It is therefore an appropriate time to assess current HIV information provision within African communities in the UK and to plan for a future treatment information strategy.

A lot has happened during this time. From the development and use of new drugs and treatment strategies to broader inclusion of active expert patients as partners in their own care**.** For example, HIV-positive advocates are now included in panels drafting national guidelines on all aspects of HIV care.

As advocates who have been involved in treatment advocacy for ten years, we thought it a good a time to look at how the treatment information needs of the African communities have evolved.

Use of the i-Base phoneline and information service has increased and membership of the UK-CAB advocacy training workshops roughly follows the demographics of HIV in the UK and includes 40% African members. But the effectiveness of printed information is less clear. i-Base treatment workshops with African organisations have always highlighted face-to-face training as particularly important.

By assessing and analysing the treatment information needs of HIV positive Africans in the UK we wanted to find ways to address these needs in our future programme.

Aim of the research

The purpose of the research was to undertake an assessment of the treatment information needs of African people living with HIV.

The outcome would inform a future strategy of targeted work with African communities in the UK, and help i-Base to extend its role in improving health literacy.

Methods

We conducted five focus groups with African people living with HIV in London and Luton facilitated by an independent African community consultant. Each focus group consisted of ten to fourteen participants. The focus group participants were recruited mainly from already existing support groups run by African community organisations. The focus groups in London were held in East, West, South and North West London. One focus group was held in Luton.

Four key themes were explored during the focus group discussions:

i) A quiz to gauge participants HIV treatment knowledge

ii) The importance of treatment information for people living with HIV in African communities

iii) Sources of HIV treatment information

iv) Changes that participants would like to see in provision of HIV treatment information the short and long term

Results

Sixty-two African men (25) and women (37) participated in the five focus groups held in London and Luton. Thirteen African countries were represented including the Democratic Republic of Congo (DRC), Ethiopia, Ghana, Kenya, Malawi, Nigeria, Rwanda, Somalia, South Africa, Sudan, Uganda, Zambia and Zimbabwe.

The following main issues emerged:

- African people living with HIV in Luton and London have access to enough HIV treatment information in print form. The challenge remains the language in which the information is presented. The language is too scientific and therefore difficult to understand.
- Language is a barrier in more ways than one. There are people within the communities who cannot read and others for whom written information is not very useful. For many of those that do read, English is a second language and it is not always the language of choice.
- There are very few HIV discussion forums. This is despite the finding that the majority of the participants in this research say that they would prefer to get their treatment information through participatory discussion forums. The few treatment forums that are available are irregular or not flexible. They rarely meet the needs of mothers with children or include crèche facilities.
- Stigma and discrimination within the African communities are still major barriers for some participants to accessing HIV treatment information. A significant number of African people living with HIV still cannot take HIV information home with them, or cannot be seen reading it for fear of disclosing their status.
- There are too few African treatment advocates who are able to help raise the level of treatment literacy in African communities. Peer advocacy, rather than professional healthcare services, play a key role in reducing stigma and isolation, and reducing barriers to information. This is particularly important for people who often experience a broad shared background of the impact of HIV in their home countries, and developing a new life as a migrant in the UK.

Recommendations

We would like to recommend that the issues raised in this report be taken forward as outlined below:

1. It is essential to look at the printed HIV information that already exists and see whether it can be improved to accommodate the needs of this population. A first step is to ensure that information in English, is in plain everyday non-technical language.
2. Translating HIV treatment information into key African languages should also be considered.
3. Investment in treatment discussions or workshops would directly respond to the demand that we highlighted. Many participants indicated that this would be the best way

for them to learn and actively participate. HIV treatment workshops would address the issues of people within the African communities who find it difficult to read English or people who can't read. But this would only work if there is a dedicated African support worker who would be responsible for facilitating the workshops, supported and monitored by a HIV treatment support organisation like HIV i-Base.

4. Lastly, in order to build on the work of the treatment support worker and make it more sustainable, this report would like to recommend a specific training programme for African HIV treatment advocates. As the participants clearly highlighted, there is a lack of African treatment advocates and this would be a direct effort to build this capacity.

Introduction

This report was commissioned by HIV i-Base, an HIV-positive treatment advocacy project, to better understand the needs of HIV-positive Africans living in the UK and to evaluate our existing publications and services, and inform future strategies.

In the UK, African communities remain the second group most affected by HIV after gay men. Although they account for less than 1% of the UK population, in figures from the Health Protection Agency (HPA), they account for over 40% of cases. By the end of 2005, there were almost 65,000 people living with HIV in the UK, one third of whom did not know their HIV status.

Over half of all HIV-positive people live in London. In the same year there were 44,553 HIV infections where ethnicity was reported. Almost 40% (15,750) were of Black African ethnicity compared with just 16% infections reported ten years earlier.

Additionally, among those diagnosed with HIV, slightly over 1% identified as Black African men who have sex with men (MSM) and 70% percent of heterosexuals were Black Africans. Black Africans also accounted for almost a third of all undiagnosed infections and over 50% of undiagnosed heterosexual infections.

Since the HPA started collecting data on ethnicity over a decade ago, the numbers of Black Africans diagnosed and living with HIV has consistently increased. Black African women continue to out number Black African men being diagnosed and living with HIV.

This reflects the global statistics where 60 % of people living with HIV are women. It is also important to mention that since the implementation of the antenatal HIV testing policy in the UK a few years ago, women have more opportunities to get tested. The UK antenatal policy remains one from which women can still opt out in contrast to some developing countries where it has been made compulsory. Some clinics are now encouraging couples to get tested together which will help reduce late presentation by Black African men.

The stigma attached to HIV within the African communities in the UK, remains a barrier to both testing for HIV and accessing services. This is despite the fact that many people know friends or relatives who are living with HIV.

Black Africans continue to be diagnosed late, with advanced HIV related illnesses. It is still common for these diagnoses to take place in hospital and for some this will be too late for them to be able to benefit from treatments that would have been life saving if accessed earlier. Compared to other communities in the UK, the mortality rate from HIV related complications remains high among Africans.

Unfortunately, the stigma not only comes from the African communities themselves but from society as a whole. Increasingly Black Africans have been the focus of tabloid newspaper stories that link immigration, asylum, health tourism and HIV all together as one issue.

There is some evidence to indicate that some Africans living with HIV are now more reluctant to access support services for fear of their HIV-status being divulged to other government agencies or made public. Additionally, since the tightening up of NHS rules and with a significant number of Africans still waiting for confirmation of their immigration status, there is confusion as to who can and cannot access publically provided HIV treatment.

Needless to say, the overwhelming majority of those who are supposed to pay for treatment cannot afford to do so, and sometimes those entitled to free care are inappropriately billed, leading them to discontinue treatment. The extent that this affects those already on treatment is unclear, but it is a serious concern for both HIV organisations and health providers.

Background

It has been over a quarter of century since HIV was identified and over a decade since combination therapy was widely introduced. These two milestones make it an appropriate time to assess current HIV information provision within African communities in the UK and to plan for a future treatment information strategy.

A lot has happened during this time, from development and use of new drugs and treatment strategies to broader inclusion of active expert patients as partners in their own care. HIV-positive advocates are also now included on panels drafting national guidelines on all aspects of HIV care.

For advocates who have been involved in treatment advocacy for ten years, it is a good a time to look at how the treatment information needs of the African communities have evolved. Use of the i-Base phoneline and information service has increased and membership of the UK-CAB advocacy training workshops roughly follows the demographics of HIV in the UK and includes 40% African members. But the effectiveness of printed information is less clear. i-Base treatment workshops with African organisations has always highlighted face-to-face training as particularly important. Assessing and analysing the treatment information needs of HIV positive Africans in the UK would help HIV i-Base find ways of addressing these needs in its future treatment information strategy.

HIV i-Base is a registered charity which seeks to improve treatment-outcomes and health-related quality of life, for HIV-positive people. Our main aim is to improve awareness and understanding of treatment choices ('treatment literacy') and increase the level of involvement people have in their care.

The organisation does this through four areas of work:

- Training and Development: This is done through arranging conferences, workshops and training events. In 2002 the UK community Advisory Board (CAB) was set up. Facilitated by i-Base, it meets four times a year to train advocates across the UK. It also provides a platform for the community to meet pharmaceutical companies on issues of scientific and safety issues.
- i-Base run at leat 10 treatment workshops with HIV support groups each year.
- Production of technical information for doctors and other healthcare workers. The HIV Treatment bulletin (HTB) is produced ten times a year to review the latest research and it's implication for clinical practice. HTB is distributed to almost 5000 medical HIV practitioners and maintains a high awareness of the latest treatment developments.
- Non-technical publications for HIV-positive people, their carers, family and friends. There are five treatment guides which offer up to date information to people living with HIV in non-technical language as they start and continue through treatment.
- A Treatment Information Line. This free-phone number, available Monday – Wednesday 12.00 – 16.00, provides specialist advice, advocacy and follow up information to HIV positive people
- In 2006, i-Base distributed 4600 printed and 8,000 web based issues of HTB per month, and 40,000 treatment guides and took over 1200 calls on the treatment information line. About 50% were from London; 27% were women and 16% African. 75% received information and advocacy that directly improved their treatment.

Aims of the project

The purpose of the research was to undertake an assessment of the treatment information needs of African people living with HIV. The outcome would inform a future strategy of targeted work with this group, and help i-Base to extend its role in improving health literacy within the community.

Methods

An HIV-positive African independent community consultant was recruited, and with the support of HIV i-Base, planned how to involve participants for the study.

The African communities are generally hard to engage, and trying to recruit people living with HIV, given the stigma attached to HIV, was a challenge. We decided that it would be best to approach African community based organisations with already established support groups for Black Africans to recruit participants.

One limitation of this evaluation is that this involved working with participants who have already been able to access services and some level of support. Although we did not reach the most isolated members of these communities, people in each group had experience of live before and after they accessed these groups.

The study was carried out with Black African men and women living HIV in London and Luton. The majority of Black Africans with diagnosed with HIV live in London and the suburbs. An attempt was made to conduct a focus group with Black Africans in Scotland, specifically in Edinburgh and Glasgow, but due to unforeseeable circumstances these focus groups did not take place. Given the limited time and budget, and the distance from London, these focus groups were unfortunately not able to be rescheduled.

The study consisted of a series of five focus groups. The work was carried out over a period of five months, between June and November 2006. Each focus group had between 10 – 12 participants, three of the groups were mixed groups and the other two were either women or men only groups.

In order to try to include the views of people not currently accessing support groups, a limited snowballing system was adapted. When approaching community based organisations for participants, a special request was made to encourage the participants to talk to their colleagues who wouldn't normally attend a support group, and encourage them to attend the one off focus group. It is important to stress that this was a small study that could only represent a cross section of views of HIV-positive Black Africans in the UK.

Before participants were recruited, a topic guide was put together, by the consultant and i-Base. We decided to use an HIV treatment quiz of true or false statements to ease participants into the focus group discussion. In addition to generating a discussion, the quiz was an exercise in treatment literacy. (See appendix 1 and 2 for topic guide and quiz).

The focus group discussions lasted between one and a half and two hours. When participants arrived, they were asked to read and sign consent forms to certify that they came voluntarily. Participants then worked on the quiz individually. At the beginning of every focus group, the facilitator took time to talk about the aim of the study and sought permission to record the discussion.

Without exception, all the focus groups declined the recording of participants introducing themselves. The introduction involved participants saying their first names, number of years they have lived in the UK, year they were diagnosed, country of origin and area of interest in terms of HIV treatment information. It is quite understandable that people living with HIV are cautious of being identified especially as the introduction involved revealing very personal information. So the recording of the focus discussions began with the reviewing of the quiz answers.

After the quiz discussion, participants were asked questions about treatment information. These included which resources they used and where they got them, their relevance, and whether there were changes or improvements they would like to see. Additionally, participants were shown different treatment information magazines (Positive Nation, AIDS Treatment Update, the i-Base Introduction to Combination Therapy, +ve magazine and the African Eye).

At the end of the discussion participants were given £20 vouchers as a token of thanks for their time.

Sample description

A total of 62 African men and women living with HIV took part in the focus groups. Participants came from 13 countries (Democratic Republic of Congo (DRC), Ethiopia, Ghana, Kenya, Malawi, Nigeria, Rwanda, Somalia, South Africa, Sudan, Uganda, Zambia and Zimbabwe.

Men: 25

Women: 37

Group	Number of participants	Duration of diagnosis (range)
Mixed group 1	12	1 – 11 years
Mixed group 2	14	3 – 22 years
Mixed group 3	14	1 – 19 years
Men only group	10	1 – 11 years
Women only group	12	3 – 17 years

Country of origin	**Number of participants**
Democratic Republic of Congo (DRC)	1
Ethiopia	1
Ghana	1
Kenya	2
Malawi	1
Nigeria	2
Rwanda	2
Somalia	1
South Africa	2
Sudan	1
Uganda	15
Zambia	15
Zimbabwe	18

Results

i) The quiz

Each participant completed a quiz on treatment issues as they arrived for the focus group discussion, immediately after signing the consent forms.

The quiz had nine statements about HIV, and the participant responses were discussed as a group at the beginning of the session. This was meant to be a warm up exercise. It was useful in helping to clarify and raise awareness of key terms and concepts about participants' understanding of their own interactions with the National Health Service (NHS) for their healthcare.

When medical terms were included, they were words that would commonly be used when seeing your doctor such as 'combination therapy', 'resistance test' and 'opportunistic infection'.

In practice, the questions created so much debate in all five focus groups that the quiz turned out to be a mini treatment information workshop of its own.

The quiz highlighted the range of treatment knowledge in each focus group. It also showed the difficultly some participants had in understanding the English language, a problem compounded by some medical terminology.

No one in any focus group answered all the statements correctly. The majority of the participants thought that the quiz was very easy, only to find out during the review that they either didn't read the statements properly, or they basically didn't understand what was being asked.

Before reviewing the quiz the participants were asked how they had found the quiz. Below were some of the responses.

For me, everything was very familiar.
Male participant (Luton)

Tricky, not straight forward
Female participant (East London)

I could not understand some of the questions
Female participant (South London)

Some statements seemed to provoke more debate than others. There were particular statements that participants in all the five focus groups seemed to have difficulties with. Although the majority of the participants identified the correct answer, some of the wrong responses showed a lack of understanding at several important levels.

'Combination therapy was introduced ten years ago this year. But anti – HIV treatments have been around for much longer' was the first statement on the quiz. The participants were supposed to acknowledge whether the statement was true or false. This is how some participants justified their answers.

AZT I think is also a combination of drugs. I do not really understand the difference between combination therapy and anti-HIV treatment.
Female participant (North West London)

I said false because there is no actual treatment for HIV. There is something that can boost the immune system but the actual treatment for HIV is not there to eradicate it completely.
Male participant from Luton group

I think is true because those of us who got HIV a long time ago, didn't have the combination therapy. But there were other drugs, I mean you could combine it yourself, we used to.
Female participant (East London)

Combination therapy was introduced 10 years ago this year but anti HIV treatment has been around for much longer. I said true because people have been on AZT long before combination therapy.
Male participant (North West London)

The second statement touched on the emotive subject of uncertain immigration status that has been identified as one of the major barriers in terms of access to healthcare and other social care services that African people need.

People with uncertain immigration status are unable to get free treatment on the NHS. Many African community-based organisations are struggling to help and advocate for free access to HIV treatment for all those living with HIV, especially those that are most vulnerable like the asylum seekers. It is important that community workers and service users are aware of the policy issues but it is not always the case.

The statement read *'Every single person living with HIV in the UK is able to access treatment free of charge on the National Health Service (NHS)'*. The following quotes show that not everybody was sure of these issues.

I think it is true because HIV is seen as an STI and STIs are treated free of charge on the NHS. Whenever you have to go for a test they tell you to go to a GUM clinic which means you have to be treated for STIs. I think it is free of charge.
Female participant (East London)

Yes, we all know that on the NHS treatment is free no one has to pay.
Female participant (Luton)

I am saying false because I have evidence of people who have been refused treatment because their asylum cases have failed or maybe because they are visitors here.
They will treat other diseases but not HIV. HIV has been separated from sexually transmitted diseases because HIV is expensive to treat.
So if your case has failed, they are likely to treat you if you have TB or those other things but they won't treat HIV.
And there is evidence of people who have been given bill in the hospital after their treatment because they do not have recourse to public funds - that is what they say.
Female participant (East London)

The sixth statement was '*Opportunistic infections are infections that can cause serious illnesses in people with low CD4 counts, and usually do not occur in people with healthy immune systems'.*

This true statement prompted long debates in all focus group discussions. A few participants had difficulty with words like 'usually' and 'opportunistic' and therefore were unable to understand the statement.

Because it says it is an opportunity sometimes to be infected, right?
Female participant (Luton)

What is an opportunistic infection?
Female participant (Luton)

Because we have opportunistic infections like malaria. Malaria is killing very many people who are not HIV-positive and yet their immune systems are usually healthy.
Female participant (North West London)

Although all the participants in all five focus groups knew that HIV is still an incurable disease, the statement abou*t 'anti – HIV drugs completely eradicating HIV from the body'* was still debated.

In some of the focus groups two of the participants thought that 'undetectable' meant 'eradication' and therefore when the HIV treatments suppress the virus to undetectable levels it meant they didn't have HIV anymore. In one group participants had trouble understanding the word eradication.

What does eradicate mean?
Male participant (South London)

I think it is becoming true……..well because if you take the drugs they say you become undetectable
Female participant (Luton)

Maybe some people take some other antibiotics on top of the HIV treatment and that is how come they have no more HIV in their bodies
Female participant (Luton)

What happened to the guy who came out on TV and said that he had been cured?
Female participant (Luton)

The issue of HIV and faith came up, in some of the discussion groups, specifically when it came to the healing of HIV.

The debate revolved around the interpretation of the word healing and what that involved when people living with HIV were being prayed for in their places of worship. Although all the participants understood that being healed involved taking their medication if they were on treatment as well as continuing to pray, some participants were concerned that not everybody in the African communities had the same understanding.

Some participants blamed some of the pastors for the information that lead to people rejecting medication (in favour or prayer), while others defended the pastors.

The following comments show the impact that religious leaders can have in medical issues, and highlight the need for accurate information in faith-based communities. It also challenges any assumption that these participants came to the UK with a rational approach that prioritised their own healthcare.

I am sorry I need to bring up something. There are people who still believe that they have been cured through their Faith and others who believe that because they are undetectable that HIV has been eradicated from their bodies. Many people still believe that.
Female participant (East London)

> ***I have seen that on two African Television channel - people testifying that they have been healed. It is quite sad because they did look sick.***
> Female participant (East London)

> ***Some of those pastors even tell them to fast, spend days without eating. You are HIV-positive, you have to take your medication and you are not eating. People have died!***
> Female participant (East London)

> ***Prayers work, you can be very weak, you can have no appetite, but when those pastors come to pray for you, you start eating and you wake up. But pastors do not stop people from their medication, they don't.***
> Female participant (East London)

> ***In my church where I go, I know a person and I think some of you know her. The pastors do not say to stop your medication, they just pray for you and they encourage you not to feel low. They just encourage you.***
> ***That woman stopped the medication. By the time she was taken to hospital, she was unconscious and she told me herself that, you know what, I stopped the medication, but I do not advise you to do it. When I met the pastor the following week I asked the pastor about her and the pastor told me that she was sick.***
> ***When I phoned her she couldn't even pick up the phone because she couldn't talk after being admitted to hospital. But she is now back home and back on medication. She is now fine.***
> Female participant (East London)

> ***The reason I said that pastors have a role to play in people stopping their medication is that when these pastors perform their so-called miracles, people get very excited and get about and walk in front of these big audiences.***
> ***Also some people think that if you believe in Jesus there is no need of the medication. People throw away their medication, they start fasting and then end up dying. I lost three clients who were told by the pastor that God will heal you, but they ended up dying because they stopped taking their medication.***
> Female participant (East London)

> ***I think they are some responsible pastors who say that we will pray for you to cope with the medication, but some will tell people to stop taking it all.***
> Female participant (East London)

The final statement, number nine, was one of the most medically specific - *'A resistance test is important to determine whether all the drugs in your combination are working'.*

This didn't generate as much debate, but highlighted the lack of understanding in some groups about what the word resistance meant.

Some participants were not sure if resistance tests were done each time they went to the clinic to get other blood tests, whether they had to ask for them or when to have them taken.

> ***Most people do not know what resistance means.***
> Female participant (Luton)

> ***I think you have to fail your combination first, and then you can go for a test. If everything is working properly why would you go for a test? If I go to the hospital and they tell me that my CD4 count is fine and my VL is undetectable. Why should I ask for a resistance test?***
> Male participant (North West London)

At the end of the quiz many participants were surprised that they had not got all the answers correct. Many had hoped that they would have definitely done better than they did. Whatever the outcome, many participants found the quiz interesting and informative. It certainly turned out to be a more significant part of the focus group than anticipated.

The quiz revealed both the level of knowledge and interest in the groups. It showed that some participants were unclear on many more issues than they thought and that the language issue is a major barrier to the understanding of treatment information.

It showed that the format of open discussion in a workshop with peer-advocates can quickly cover a broad range of medical and health topics and become a positive learning experience. It also showed that many commonly held views are not well-informed.

At the end of the focus group discussions participants were encouraged to say a few last words. This is a sample of what was said.

> ***I always enjoy sharing my experiences with people who are HIV positive and I found today very informative. The thing that I enjoyed most was the quiz. Although there were nine questions, there was quite a lot of information I thought I knew but didn't know. So I appreciate that information.***
> Male participant (West London)

> ***I would like to thank the facilitator for what she has contributed to the discussion this evening. The quiz was very interesting. I have attended a few of these groups but this was different. I like the way it was structured and I learned so much more than I thought I would learn, so thank you.***
> Male participant (West London)

> ***I would like to thank everyone who participated in this forum. Although I didn't speak a lot I enjoyed listening and I learned a lot.***
> Male participant (West London)

> ***I learnt so much from the quiz and enjoyed it very much. I also do not come to many discussions but I have enjoyed this one that I would like to be told when another one is happening so I can attend. I learned so much more today than I have learned from my doctor. Thank you.***
> Male participant (West London)

ii) The importance of treatment information for people living with HIV in African communities

All participants from the five focus groups acknowledged that treatment information was an integral part of their health care.

Information was crucial to help with knowing when to start HIV medication, adherence and side effects.

...because you need to know exactly what kind of treatment is good for you and which is working for you. For example, if I am on a combination, and it is not working for sometime, and by the time you know you might have developed really bad resistance to the medication.
Male participant (West London)

So that our lives can be prolonged.
Female participant (Luton)

So that we are able to deal with our condition
Male participant (Luton)

So that people can understand that if you have got HIV, it doesn't mean that you are going to die.
Female participant (Luton)

Some participants thought that although treatment information was important to all people living with HIV, not everyone was motivated enough to find additional information to that which they got from their doctors.

The stigma attached to living with HIV, came up as one of the major issues why some people did not access further treatment information, but this was not the only barrier.

Participants acknowledged that for people living with HIV who were living in fear, and were unable to disclose their HIV status to their loved ones, they would not want to be seen with printed resources. For these people, doctors were the only source of information.

However, because of the power dynamics, these people were often unable to ask questions, owing to a lack of confidence, or a lack of understanding that they have a right to information and therefore a right to ask for it.

This low understanding of patient rights when accessing healthcare in the UK is rarely touched on with any seriousness, but it is likely to underline the potential for a very different level of care for some African patients. It is one of the areas where strengthening community advocacy can have a real impact.

Other participants said that outside of London there was very little in terms of support groups and places to access information.

In London there are many groups of HIV people and women have groups where they talk about HIV. But in Cardiff people do not have a clue about what is going on.
They go by what the doctor tells them - and that's it. There is stigma and they can't discuss HIV. So it is unfortunate that people are out there with very little information on side effects, or combinations or what to do and so they just take drugs just like that. They have no one to talk to.
Female participant (East London)

I think it depends on the individual because some people are given medicine, and when they are given that medicine they just go and keep it and they do not even know the names of the drugs they are taking or what they are taking it for.
Female participant (East London)

There are couples who hide it [HIV medication] from each other. Right from the pharmacy, to the train, to when they get home, they still have to hide it - so when will they read any treatment information?
Female participant (East London)

I think some Africans might seem that they do not care, but I think they just really find it difficult to talk to their doctors.
First, most doctors are not African, so some people will find it difficult to open up and go into deep discussion.
For some people it is language difficulties. Also, sometimes it will be because when it comes to authority, Africans in general will not question anything, so we just listen, listen and just shake our heads and agree to everything the doctor says. Also, it is a big thing to even have the confidence to think you have a right to actually ask the doctor 'can you just explain this to me more, I am not clear about the name of this drug'. What is the easiest way to pronounce it, some people instead for instance of saying AZT they say the longer clinical name, the one that is not easy to remember. So it is all those kinds of things. But Africans do attend treatment discussion sessions and ask questions. I think that helps us a lot. Some people have had HIV for a long time but they do not know that making sure that you take your pills on time is very important.
Adherence is an issue.
Female participant (East London)

We do not want to share the knowledge that we have with other people. Despite other people dying, we remain silent. Like we went out on World AIDS Day to give out leaflets on HIV, but there were many people who were hungry for this information. We only do this once a year on WAD. But I think we should look forward to having some other days other than WAD where we go out and give out the same kind of information ... because people are really dying in misery.

People are dying in isolation, people need the information. But because of the stigma that is put around HIV. It is not until we accept ourselves that other people in the community will be able to accept us. How are we going to do that? It is through advocacy campaigning and coming out. Like people talk proudly about their diabetes, people talk proudly about asthma, it is not until we accept and try and talk about our HIV proudly, that people will accept us. Because if we talk about it proudly and you really look healthy and tell them we are on treatment like cancer patients are having, then I am carrying on. I think we need

more of that but the way we can to do it is hard. We need to know how are we going to do this? How are we going to achieve that goal? That the stigma and the labeling of HIV for Black people, HIV in migrants, people who come to this country especially Africans! If we can reduce that kind of stigma, it would help. But we have to look for avenues, which kind of avenues are we going to use to bring that stigmatisation out is the most important thing.'
Female participant (North West London)

Participants were keen to point out that stigma was just one barrier but another really crucial issue was language, and this was an issue on many levels.

It was acknowledged that most information is available, but only in printed form. But not everyone in the African communities can read, nor are people willing to say they can't read. So they have to rely on other people to talk to them about treatment issues.

For some people who can read, English is a second language. Some participants mentioned that the language in treatment information leaflets and magazines was too medical.

I think treatment information is very important and we need it but the problem is that not everybody can read the English language. Not all of us can understand the medical language that is used when giving us the information on HIV treatment. If it could be simplified because there are some terminologies that are used that we do know what they actually mean. And some of the language, the English that is used, is very difficult. We try to read but because it is too hard you lose interest in what you are reading. If it could be simplified or put into some local languages to make it simpler to understand it would be better.
Female participant (South London)

There is a problem with some reading material, because some of it is very professional.
Female participant (North West London)

It is very medical and difficult to understand.
Female participant (South London)

Some participants indicated that reading was not the best way for them to access treatment information.

They said, that they preferred speakers to visit the support group and present on a specific topic and for the participants to have a chance to ask questions.

Many participants also indicated that the focus group discussion was a great way to learn.

During the focus group discussions, many participants were happy to refer to it as a treatment workshop. It was as if they consciously refused to acknowledge the focus group as a fact finding mission, but a treatment information forum, with the facilitator as the treatment information expert. The quiz also made the focus group function as a treatment information workshop.

Personally I find reading very boring, it is only when I am part of a discussion like this that I enjoy myself and learn more. As they say, "knowledge is power" and learning is a continuous process.

I hope we will have more discussions like this in the future and encourage other people who are afraid, still hiding, to join us. We have to help them to overcome the stigma.
Male participant (West London)

In addition to barriers like stigma, participants talked about the tabloid press blaming and associated HIV with Black Africans.

I think there is something that needs to change. The African HIV Policy Network that represents the African communities needs to tackle the media. I think the way we are portrayed as Africans has an impact on us, people just keep away from meetings and retreat into their shells. That is a very big organisation and they should establish a rapport with the media and deal with them. No matter what activists come up, if the media is not dealt with it will suppress those activists. When something bad happens to the indigenous people they are protected but to a Black person, the way that they are splashed all over the papers, it is terrible.
Male participant (North West London)

Another issue that came to light, was the failure of researchers or HIV treatment information providers to recognise the other issues that impact on the lives of people living with HIV.

One of those issues is poverty, the lack of basic necessities faced mostly by people who are seeking asylum or who for one reason or another still have uncertain immigration status and have no access to public funding of any sort.

They just want to educate us about medication but little effort is made in terms of financial, housing and other social support. Am I supposed to eat treatment information?
Female participant (Luton)

Another subject that came up and which has been associated with African communities, is the issue of being hard to reach or hard to engage as communities.

A lot of things need to change. Instead of sending information to the organisations, information should be sent to us directly, at least to those who need it. But the problem is that our communities are hard to reach. If you call a meeting for anything, you must be prepared to spend money. You must have a budget in order to come - but it is not the same with other communities.
Female participant (North West London)

iii) Sources of HIV treatment Information

Participants mentioned a number of places where they managed to get treatment information. The first source was their HIV doctor.

Participants were aware that HIV doctors had very little time and they treasured this time. Participants also indicated that they used the time at the clinic during their regular clinic appointments to read.

The hospitals and magazines.
Female participant (North West London)

I read magazines in the clinic but I also try to ask my doctor as many questions as possible.
Male participant (South London)

Very few participants mentioned the internet as a source of information.

I feel like all this paper can sometimes be a waste, so I find places like drop in centres where I can access the internet for free and get the information I need.
Female participant (East London)

Another main source of information was support groups. and this seemed to be the favourite way to receive information. Participants indicated that it was the best way for them to learn, especially for those who could not read or found it difficulty understanding English.

Some participants indicated that they were always ready to translate for those who didn't understand English.

What happens when people come to a support group is that they want to hear about those things rather than take a book home. They do not want to take anything home, they do not want any mail.
Female participant (Luton)

To me, it is like the support groups they are more informing, when they bring in people to talk about up-to-date treatment. I find it more interesting and I learn more than on my own because you can have a chance to ask questions and know more about the latest treatment.
Female participant

I remember when I first started treatment I noticed that my nails were turning black. So when I went to a support group near King's Cross, someone at the group told me that it was a side effect from one of the medication I was taking. I changed my medication.
Female participant (South London)

It is also good to talk to other positive people in support groups and learn from their experiences.
Male participant (South London)

Others were not so sure if support groups were the best forums for treatment information for a number of reasons. Not only do some people not go to support groups, or can hardly go regularly, but some see support groups as a social group club and not an information source.

It is easy to miss the treatment information at the support groups, people do not go all the time and others strictly go for the social side.
Female participant (East London)

Other participants preferred to have more treatment focused forums, but other issues, such as the time of day, crèche facilities, refunding transportation and food to snack on during the workshops, needed to be considered.

Workshops are really important because people can learn from each other. For example, for me, the only time I get to read anything is when I am waiting for my doctor or on the train. When you have children it is very difficult to find any other time to read.
Female participant (East London)

The time is not convenient (for the treatment workshop already available on every last Monday evening of each month). There is not even childcare provision most of the time. That is why only the gay men attend. Parents are usually taking care of the children, helping them with their homework and getting them ready for bed
Female participant (East London)

Some participants were of the view that treatment information need not be just for people living with HIV.

But treatment workshops shouldn't just be for us. Negative people should also be targeted and carers because they should know these things as well.
Female participant (East London)

iv) Way forward: changes you would like to see happen in the short and long term

Participants had a number of suggestions in terms of what changes they needed to see concerning treatment information. These included simplified written information. The majority of the group were of the view that the scientific language used in magazines didn't encourage them to read.

It was very clear throughout the different focus group discussions that participants enjoyed treatment discussions as they kept repeating the request over and over again.

More discussions like this. I found this very helpful.
Male participant (Luton)

I enjoyed the discussion very much I hope we can have more of these discussions. I just want to encourage everyone to continue to participant whenever they have a chance and to encourage others who are not here, that are struggling to appreciate what we have.
Male participant (West London)

I was very happy to be one of the participants of this treatment information focus group because whenever I participate in these groups I leave with something new.
I always look forward to coming to these groups because I always know I will learn something and

> ***do take something positive with me.***
> ***What I would like to say to all of us, is that whenever we hear of these focus groups or are invited to participate can we please, please make an effort and come early so that we can talk more in details. Just like now we had very little time and as the discussion was getting interesting we have to be cut off. That is all I have to say.***
> Male participant (West London)

Other participants worried about those who didn't access support groups and how they could be reached. Additionally, because of the challenge that some people faced in reading and understanding English, some participants suggested that getting treatment in audio form would be a good idea.

> ***I think it would be good to have some information in audio form. Then people would not be afraid to access treatment information. You can listen to the information over and over again as if you are listening to your walkman and no one will bother you because people won't know what you are listening to. Like I listen to my sermons on the bus.***
> Female participant (East London)

Some participants also thought that it was not enough just to deal with people living with HIV. They thought that the wider public, especially the African communities, need to be targeted with the aim of reducing the stigma attached to HIV. Some of the suggestions that were made were to make information widely available so that other people could learn about HIV.

They also highlighted concerns relating to access care via a GP, especially in relation to confidentiality.

> ***I think the way forward is to tackle the stigma with awareness programmes within the community. Also, to encourage people living with HIV to come to terms with their illness, because if they don't and they are still hiding and you are not going to read the information. It is a vicious cycle.***
> Female participant (East London)

Another specific group of people to train on HIV awareness and treatment issues were the healthcare workers. Participants were clear that this would help reduce the stigma as well as make the lives of people living with HIV a lot easier.

> ***The stigma is still high everywhere in the UK. It is going to get worse because we are now being told to go to the GPs. That means you should disclose to the GPs. At the GPs there is no information and they lack training. You find other leaflets at the GPs but you cannot find an HIV leaflet hanging around.***
> ***The receptionists at the GPs are so anti-HIV and have no idea what confidentiality means.***
> ***I think the awareness programmes are very important especially with the health providers like these GPs, dentists and nurses. People living with HIV have to accept our diagnoses, get enough support to talk about it. Challenge those who want to prejudice you. Me I do not take any nonsense.***
> Female participants (East London)

Lastly, participants thought that it would be very useful if some of them were trained as treatment activists so that they could help others in the same situation as themselves. This would also help with the language barrier as they could help deliver treatment information in their indigenous languages.

> ***It is important that we have health promoters in HIV education participating in forums like what we are having today. Suppose it was a drop-in centre it would have covered 50 people coming for socialising and they would have been able to carry the information.***
> ***As a facilitator you would have been able to simplify the information because you are talking to many people, if someone doesn't understand the English I would be able to tell them in my local language. If health promoters can be allowed to come into drop-ins it would be good for service users and maybe also minimise the costs at the same time and it can be something we can debate together. I am sorry I can't express myself better.***
> Female participant

> ***We need activists who are Africans because we reject ourselves due to the situation in which we are. I go to a lot of places where there are gay people. They open the door and hug and kiss each other and you know they are all positive.***
> ***For us, because we are foreign and Black means death there is no passion in it at all. There is a lot of rejection from all corners, whether educated or not educated.***
> ***We need activists - maybe those who have papers - to start campaigning, to lead the way then we shall follow.***
> Female participant

Discussion

This project set out to identify the treatment information needs of African people living with HIV. It was clear from all five focus group that the issues affecting access and availability are complex. It was also evident that the level of treatment literacy varied widely within each group. What wasn't clear was whether it was because there were many newly diagnosed people in some groups or whether people had more or less access to treatment depending on where they lived or accessed services. The clearest message that came out of the study was that HIV treatment information is as important to African people living with HIV as it is for any group of people.

One underlying issue that was articulated time and again as a barrier to access treatment information was stigma. Twenty-five years into the epidemic, stigma attached to living with HIV and AIDS in the African communities continues to impact hugely on the lives of those living with the virus. Many people living with HIV do not want others to find out they are living with HIV. This impacts on people in different ways, including the way that they access treatment information. Some participants indicated that the only chance they had to read about HIV treatment was at their clinic while waiting to see a doctor. They didn't want to be seen with anything relating to HIV outside of the clinic.

One issue that came out of the study as a barrier to African people accessing treatment information, and therefore treatment, was the influence of religion on the lives of people in African communities. It has been an on going debate. Some people have either been told, or have decided for themselves, to stop taking HIV treatment as well as accessing treatment information because they believe they would be healed through their individual religious faiths. As anecdotal as this practice might be, it was a concern of the participants in these groups, who indicated that they had seen people giving testimonies on African religious broadcasts.

Another issue was the form in which HIV treatment information is available to users. There are already a wide range of printed resources that users were familiar with but it was very evident that within this population there are major barriers relating to literacy. The interactive nature of treatment workshops within an existing peer support network was seen as one of the most positive formats for community-based treatment information. This is not a new revelation, and has been reported previously. What hasn't occurred yet are actions and funding in order to make these interactive discussions a reality.

Conclusions

The treatment needs project highlights the strength of interest that African people living with HIV have in treatment information. There has been little research of this nature in this population, and very little follow up done after previous projects. There is a need to improve HIV treatment awareness and to build on ongoing work for African communities. The levels of knowledge in some discussion groups was quite shocking, but what was more worrying was the fact that some participants thought they were more informed than the research suggested. Other problematic issues centred around the understanding and interpretation of the English language. However, the hunger for knowledge of the participants more than makes up for any deficiencies. It should be acknowledged that despite the findings, the level of treatment knowledge among participants is still very high compared to other chronic common diseases.

It would be unfortunate if there was no plan of action, to follow up on some of the issues that were raised during the focus group discussions. There is a need to capitalise on the knowledge and enthusiasm of this population for the future. The following are proposed recommendations on how to take forward the issues that have been highlighted through the research.

Recommendations

Recommendation 1

It is essential to look at the printed HIV information that already exists and see how it can be improved to accommodate the needs of this population. During the focus group discussions, what kept coming up over and over again was that HIV treatment information was too scientific or just difficult to understand. No one suggested that more leaflets or magazines are required, but it is more about looking at how information could be simplified in the magazines, newsletters or leaflets already available.

One of the ways that this could be done would be to include a survey in the resources that are used. Involving African communities in producing resources and including readers questions. Lastly, there is a great opportunity with the recently launched African Eye Trust magazine, which is an HIV treatment information magazine specifically targeting African communities. This magazine could easily incorporate the issues highlighted during the course of this research and become the platform of change that African people living with HIV hope for. The magazine already has some African writers but can continue to build the this base up by encouraging African people living with HIV to write, produce and comment on articles, to make any suggestions and to develop a sense of ownership by the community.

Recommendation 2

To pilot information in key African languages. The long running issue of whether HIV treatment information should be printed in other African languages because of the concern around literacy challenges of some people within this population, should not stop this from happening. This is hugely complex issue because of the number of possible languages. There is also the argument that even though many people can speak their African languages, that doesn't necessarily mean they can read in these languages. Very few funders have agreed to provide even basic treatment information in predominant mother languages. It is an idea that can easily be evaluated in a pilot project where HIV treatment information could be translated into two or three popularAfrican languages. Something similar was done with the African AIDS helpline that delivers information in five different African languages. Funders had to be convinced that the project was worth continuing to fund by commissioning an evaluation report. Some lessons could be learnt from what happened with that project.

Recommendation 3

One of the most viable and cost effective ways forward would be to invest more resource in treatment discussions or workshops. This is a method that many participants indicated would be the best way for them to learn and actively participate. HIV treatment workshops would address the issues of people within the African communities who find it difficult to read English or people who can't read. Treatment workshops or discussion forums make the most sense for African people living with HIV because there is plenty of evidence to suggest that this population come from a background of oral tradition. It has been the way that they have been used to getting information since time immemorial. Treatment discussion forums would also be a cost effective way forward and not an entirely new experience for this group. African people living with HIV have been having one off discussion forums within their support groups or one or twice a year as organised by HIV organisations. A few reports by other HIV organisations have suggested more participatory treatment workshops but nothing has been done before. Having these forums will also help make the support groups much more effective in terms of building the HIV treatment capacity of participants, a support as well as social environment. It is time to fulfill the needs of the participants who give their time to take part in research projects so that they can be encouraged to continue to have an input and feel that what their contributions are both valid and taken seriously.

There is one aspect to the HIV treatment information forums that is absolutely critical and would make them more effective, a dedicated African treatment support worker. There is evidence that participants would respond, participate and would learn better if a knowledgeable treatment advocate facilitated a discussion. This was continually echoed throughout the focus group discussions. So it is the recommendation of this report that an investment is made to fund a post for a dedicated worker for one to two days a week to carry out the work of facilitating structured and effective treatment workshops or discussions with support groups of African people living with HIV in London and Luton.

The treatment worker would be based and supported by HIV i-Base and would also be available to offer treatment information and advice on the already available service of the HIV i-Base treatment phone line. The treatment worker would also write and help edit the African Eye newsletter to be able to reach African people living with HIV who do not necessarily attend support groups. There is also a benefit in being able to reach the broader African communities which might include, partners of people living with HIV, carers and African people interested in treatment information.

The shape which this project would take would be to provide at least two to three structured treatment information workshops for up to six support groups in and around the London and Luton areas. The treatment worker would liaise with the African community based organisations which organise the support groups in order to draw up a plan for the workshops. Fortunately, links with the community based organisation have already been established and further strengthened through this research project. The way the workshops would be structured is to have a question and answer session to initiate discussion and then to address different topics that may be pre-planned that participants would want to know about. The sessions would last between one and half to two hours each. If the structure of the HIV treatment workshops was successful, then the model could be rolled out with other treatment support groups in the UK catering for African clients.

Recommendation 4

Lastly, in order to build on the work of the treatment support worker and make it more sustainable, this report would like to recommend a separate training for African HIV treatment advocates. This is another idea that was highlighted as a useful thing to do in order to improve access to HIV treatment information for the African population. There is a lack of African treatment advocates and this would be a direct effort to build the capacity with in this population.

A structured intense HIV treatment training programme would be put together and facilitated by HIV i-Base to help train HIV treatment advocates who would in turn be able to do outreach work within the African communities as well as support the African treatment support worker. The training would have a total of six sessions with each session lasting at least three hours. The sessions would be held over a period of six months and on completion participants would get certificates. In order to make sure that treatment advocates were able to work as soon as they completed training, HIV i-Base would help make sure the training encompassed a placement programme where people would either would either work for African community based organisations and support specific support groups or they would do outreach work for other organisations within the HIV sector but focusing on supporting African people around HIV treatment literacy.

The benefits these recommendations have are that they are evidence based, building on already existing work and partnerships and very cost effective. Additionally, the recommendations if fulfilled, have the potential to plug existing gaps that have never been properly addressed in the past and the potential to create more effective work for African communities in the UK.

What needs to be pointed out here is that while the strategies outlined are not exceptionally new, they have not been seen as a priority for funding. What needs to happen is to be more focused on the issues that affect this group and then invest in those schemes that are accepted, effective and beneficial for the African population.

Appendix 1: Quick quiz

Check out your HIV treatment knowledge

1. Combination therapy was introduced ten years ago this year. But anti – HIV treatment has been around for much longer.

True False

2. Every single person living with HIV in the UK is able to access treatment free of charge on the National Health Service (NHS).

True False

3. The main purpose of taking anti-HIV treatment is to reduce HIV in the the body.

True False

4. Current treatment guidelines recommend starting anti-HIV therapy when CD4 counts are between 200 – 350 cells/mm3.

True False

5. Of those living with HIV globally, about 50% have no access to life prolonging treatment.

True False

6. Opportunistic Infections are infections than can cause serious illnesses in people with low CD4 counts, and usually do not occur in people with healthy immune systems.

True False

7. Babies born to HIV positive mothers will always born with maternal HIV antibodies.

True False

8. Anti-HIV drugs will completely eradicate HIV from the body.

True False

9. A resistance test is important to determine whether all the drugs in your combination are working.

True False

Useful Numbers

THT Direct Phoneline – 0845 1221 200

African AIDS Helpline – 0800 0967500

i-Base treatment phoneline – 0808 8006 013

Appendix 2: Topic guide for treatment focus groups

Introductions

I would like to thank you for agreeing to participate in today's focus group. I have been commissioned by HIV i-Base (a treatment information organisation) to facilitate a number of focus groups with African people living with HIV, to find out what your needs are regarding treatment information.

For the duration of the focus group, we are going to talk about what you know, what subjects you would like to know more about, what, if anything you would like to see change, improve or happen with the way you receive HIV treatment information.

Before we start I would like to ask that we all respect each others' views, that whatever personal information is discussed in the group remains in this room and that we stick to that subject matter as much as possible.

Lastly, I would like to ask the you sign some consent forms for me to basically acknowledge that you attended this focus group on your own free will and that no

one forced you. And finally, I would like your permission to record what you say during the focus group. This will enable me to listen to what you have to say other than try to write down everything you say. You will probably speak faster than I can write. Anyway, I will be the only one who will listen to the tape and once I am done writing up my notes the information on the tape will be deleted.If it is okay with everyone and there are no questions, I will now switch on the tape…..

1. Group Introductions

First we are going to have a round of introductions. I would like to ask everyone to say just five things

- Your first name (only)
- Your country of origin
- How long you have lived in the UK
- How long you have been diagnosed
- What treatment subject most interests you?

2. Testing your HIV treatment knowledge – Treatment Quiz

Now we are going to go through each question on by one and find out how well you did

Discussion of the answers for the quiz

- How did you find the quiz?
- Did any issues come up for you?
- Was there a question that surprised you
- Anything that particularly new?

3. Questions

- Do you think that HIV treatment information is something that people need or care about in the African communities?
- Do you think that there are enough places that people can get information from?
- Do you think that the HIV treatment information on offer at the moment is adequate and understandable? If not how do you think it can be improved?
- What are some of the difficulties you have where treatment information is concerned?
- What are the issues that you do not understand?
- Which subjects would you like to know more about and why?
- Where do you get your HIV treatment information from?
- Do you spend time reading through treatment information in clinics or do you read it in the privacy of your own home?

4. Introduce a variety of treatment magazines

- Are people familiar with all the treatment magazines?
- What are your thoughts on each of them in terms of providing HIV treatment information?
- Would you like to see any changes in these magazines?

5. Concluding

- Are there any others way you would like to receive treatment information? If so what are they?
- Is language an issue at all where treatment information is concerned? If so what would you like to see happen?
- Overall, what are the changes you would like to see happen right away in order to increase accessibility of treatment information for Africans in the UK? Change in the short term and the long term.

Thanks so much for your contributions and your time today. We will now give out the vouchers and ask you to sign for them. Many thanks for your time!

We try to read but because it is too hard you lose interest in what you are reading. If it could be simplified or put into some local languages to make it simpler to understand it would be better.

To me, it is like the support groups they are more informing, when they bring in people to talk about up-to-date treatment. I find it more interesting and I learn more than on my own because you can have a chance to ask questions and know more about the latest treatment'

I think it would be good to have some information in audio form... You can listen to the information over and over again as if you are listening to your walkman and no one will bother you because people won't know what you are listening to.

We need activists who are Africans because we reject ourselves due to the situation in which we are in.

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