Waverley Care: developing HIV services that are inclusive, responsive and accurately meet the needs of Africans in Scotland

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In this article I describe how Waverley Care has developed services that are relevant to and inclusive of Africans living with and affected by HIV in Scotland. I provide a brief introduction to Waverley Care, some background information about the African Health Project and the context in which we are working, and describe the interventions we are delivering based on our experience, our own research and other relevant reports.

Waverley Care

Waverley Care was originally established as a Scottish charity in 1989 to provide care and support to people living with HIV. In 2003 the charity changed its constitution in order to work with people who are living with other blood-borne viruses (BBVs). We now have 70 staff delivering prevention and support services to a diverse client base including people from an IVDU background, gay and bisexual men, and people from sub-Saharan Africa across 10 Scottish health board areas. Our vision is that everyone living with HIV or hepatitis C should receive the highest standards of care and support to enable them to lead healthy, independent and fulfilling lives free from stigma and prejudice.

Our activities currently focus on delivering the following key outcomes:

- Reducing onward transmission of HIV and hepatitis C through services that provide high-quality information/advice on safer sex and risk reduction; peer education; an emphasis on positive prevention and behaviour change; raising awareness of testing and treatment; and support to access testing and treatment
- Reducing inequalities around sexual health and blood-borne viruses through targeting services on key groups such as men who have sex with men (MSM), Africans and people with problem drug use
- Ensuring that people living with a BBV have access to high-quality care that improves physical and mental health, promotes recovery, achieves independence and prevents hospital admissions. We work to support individuals with BBVs to enjoy healthy relationships and to access education, volunteering, employment and leisure opportunities. We additionally aim to support children and families affected by HIV and hepatitis C to enjoy positive, supportive relationships that foster resilience
- Tackling the stigma and discrimination associated with HIV and hepatitis C is seen as vital in prevention work with all communities. We aim to raise awareness of these conditions through a range of means

These outcomes are achieved through services that include residential and day-care facilities, and a range of community-based support and prevention initiatives, including an African Health Project.

Background to the African Health Project

Waverley Care has been delivering sexual health and BBV services to Africans in Scotland since 1998 and has been managing an African Health Project since 2004. The project currently has nine staff providing prevention and support services in the NHS board areas Greater Glasgow and Clyde, Lothian, Lanarkshire and Forth Valley, and a tenth national post focusing on faith and health. All the project staff are themselves African and bring a knowledge and understanding to the work that makes connections; all have been willing to work at the pace of the community and with the availability of the community. That means, for example, working evenings and weekends, attending an African church regularly so as to make a connection with the pastor, introducing themselves to people on the street to talk about the project (an approach we call Stop Talk), and spending time in the barber shops and hair salons talking to owners and customers. It means working with people's beliefs such as healing through prayer or the power of witchcraft, rather than ignoring or dismissing these, so that we can support them to stay well.

NAT identifies people from sub-Saharan Africa as comprising one of the largest and most recently arrived Black Minority Ethnic (BME) communities in the UK [1] and this is even more so in Scotland.

The 2011 Census [2] showed that 36,000 people in Scotland identified as 'African, Caribbean or Black', a more than fourfold increase since 2001. This increase is the result of the natural movement of people to work, study or visit; the dispersal of asylum seekers to Glasgow and the movement of refugees within the UK.

By the end of December 2014 there were 4,856 persons living in Scotland who had been diagnosed HIV positive. Of the 374 individuals reported during 2014, 187 (50%) are presumed to have acquired their infection outside Scotland. It is expected that this proportion will change as reports are actively followed up to acquire missing epidemiological information [3]. A recent decline in the annual number of new HIV cases has followed a prolonged and substantial upsurge in new diagnoses, with the highest proportionate increase occurring among heterosexual individuals, over 85% of whom acquired their infection in sub-Saharan Africa.

The people who use our services reflect the epidemiology of HIV and hepatitis C; so it was that, in the late 1990s, we began to see an increasing number of black Africans. While we had to very quickly learn to respond to new sets of issues, like immigration and supporting people with no recourse to public funds, it was one of our service users who challenged us to do something about HIV prevention with Africans in Edinburgh. What she said to us was 'My community is dying because of HIV but my community will not talk about HIV – you need to do something.'

Working with her and a group of African women she brought together, we looked at their experience of effective HIV prevention in Africa and talked to two London-based organisations; what was then the African HIV Policy Network (AHPN) and Blackliners. In 2002, together, we put on an event that combined bringing Africans together in Edinburgh socially and talking about HIV. Whilst this might seem a very familiar and well-used approach it was the first time anything like this had been done in Scotland. Because the event was led by the African women, they advertised it and encouraged people to come, and on the evening we had over 400 Africans present. The outcomes of the event were several: the group of women who had come together wanted to continue working with us; the African woman from Blackliners who had spoken openly about living with HIV was approached by 15 other women in the course of the evening who had never before disclosed their HIV and were not in touch with any support services; people at the event were now aware of Waverley Care, what we did and what we could do.

We had begun to recognise the scale of what was needed but quickly realised that there was little if any information about Africans in Scotland generally, so that we might know where, to whom, and how to deliver HIV prevention. We little understood what it is like to be an African living with HIV in Scotland, so that we could give the right kind of services. Nor was there an African organisation in a position to take this forward, and it rested with us do to something.

With 3-year funding from the Voluntary Action Fund we employed two black African workers who produced two reports; one mapping Africans across Scotland, where people were living, why they were here, what they were doing, what family they had with them, what were their concerns and priorities [4]; and the second recording the experiences of Africans living with HIV in Scotland [5]. The latter report particularly highlighted the plight of asylum seekers and refugees in Glasgow and, based on this, in 2006 we received funding to begin to deliver services in the west of Scotland.

Approach

I've provided a bit more detail about the early days of the African Health Project because it is on this foundation that we have built the project up to the ten African staff delivering care, support and prevention services across Scotland. What we have learned is that we have to have community on board from the beginning, and genuinely on board, not as an add-on or an afterthought, but as mutual partners; we started as a white Scottish organisation wanting to connect with a black African community about a highly stigmatised topic. To get community on board we had to find the right people to speak to; the people who were seen as leaders or people of influence. We had to speak with the weight of evidence behind us so that people understood why we wanted to talk about HIV with them. We had to understand that there were other issues that felt much more important to people – immigration, employment and housing – and that these might need to be addressed first before we could pay attention to HIV [6,7]. We had to understand that all of this would take time; that we had to be patient and allow relationships to develop and trust to build, and that can sometimes take a number of years. As mutual partners we needed to pay attention to identifying what was mutually beneficial about the partnership.

Involvement by key affected communities is crucial to the effective design and delivery of interventions that target this population. We are mindful of the recommendation in the NHS Scotland guide on targeting minority ethnic communities where HIV transmission is at increased risk:

> *Planning of interventions which target people from areas of high HIV prevalence should build on an authentic engagement and partnership process; include a detailed understanding of HIV prevention approaches; and the associated health needs of the specific population(s) of concern* [8].

Prevention

Original research published in BHIVA's journal *HIV Medicine* [9] on barriers to HIV testing for migrant black Africans in Western Europe identified cultural, social and structural barriers to testing, such as access to testing and care, fear of death and disease, and fear of stigma and discrimination in the community. The article goes on to suggest that HIV testing strategies need to be grounded in outreach and community mobilisation, addressing fear of diagnosis, highlighting the success of treatment and tackling HIV-related stigma among black African communities.

In the AHPN newsletter [10], community mobilisation was a prominent feature. At the heart of such strategies were programmes that worked with local peer educators or 'champions' to address fear of diagnosis, raise awareness of the success of treatment and tackle barriers stemming from HIV-related stigma. Community preparedness and readiness were seen as paramount to the successful take-up of HIV testing. In addition, attaching HIV testing to wellness projects offering a range of health checks or other services such as advocacy and independent living skills were used to motivate uptake of HIV tests.

Taking all of this into account, we have developed a range of interventions that are outlined in Panel 1).

Understanding the needs of local populations from areas of high prevalence strengthens the design of effective interventions. Using a methodology informed by ethnographic theory, which can include observation of local individuals and groups, or active engagement, can also ensure an authentic and effectively targeted approach [8]. Using this approach we have worked with individuals, communities and partners to deliver interventions that aim to change health-related behaviour. We have:

- Based our interventions on assessment of the target group, where they are located, and the behaviour which is to be changed; for instance through evidence and learning from the Social Network Analysis [6], the baseline report [11], and ongoing monitoring and evaluation
- Worked with other organisations and the community itself to decide on and develop initiatives, for instance the Faith and Health leaflet [12], and the Faith and Health conference [13]
- Built on the skills and knowledge that already exist in the community, for example, experiences of delivering HIV information and encouraging testing in countries of origin
- Built on the strengths of individuals and communities and the relationships within communities, for instance promoting and developing parenting skills and nurturing relationships and networks for those who are isolated and without family
- Taken account of problems that prevent people changing their behaviour, for instance lack of knowledge or confidence about accessing existing condom schemes
- Taken account of the circumstances in which people live, for instance those with no recourse to public funds and their priorities [6,7]
- Aimed to develop – and build on – people's strengths, for instance as peer educators

Panel 1: Interventions

Prevention interventions which:

- Raise awareness of HIV and how to avoid it
- Deliver condom distribution schemes
- Support initiatives aimed at target groups
- Identify community 'champions' who can work in those groups
- Deliver support to parents in talking about HIV and sexual health with their children

HIV testing which:

- Works with the target community to promote testing and challenge misinformation
- Works with testing services, including primary care
- Understands and tackles the barriers to testing

Care and support interventions which:

- Are person centred and solution focused
- Work with people on both an individual and group work level
- Support people to adhere to treatment
- Support HIV-positive mothers to sustain bottle feeding

User involvement which:

- Helps to shape the work
- Supports service users as community volunteers

Communities support which:

- Understands the priorities and issues of the communities
- Builds the capacity of communities to find their own responses and solutions

Awareness-raising and other health improvements which:

- Involve the target community in delivering interventions
- Acknowledge the need to develop work that tackles stigma and discrimination
- Build on the experience gained from prevention work and support groups

We distribute condoms, femidoms and lube in barber shops, hair salons, restaurants, at football games, to faith groups, to women and to men. Alongside this we provide accurate and up-to-date information about prevention, testing and treatment. Maintaining safer sexual practices for all people, irrespective of HIV status, is key to HIV prevention. The use of condoms remains the best means of ensuring that HIV transmission does not occur during penetrative sex. The BASS Line 2007 Survey [14], illustrates some of the issues surrounding condom use and accessibility for people from African communities. The survey states:

> *There is evidence of significant de-motivation and powerlessness with regard to condom use*

> *given that one in ten respondents lacked confidence in using condoms, one third were unsure or disagreed that they could talk about HIV or safer sex with new sexual partners, one quarter had a hard time getting condoms and just under one third would worry about the social repercussions if it was known that they carried condoms.*

Findings from the Waverley Care Baseline Survey [11] mirrored this, suggesting that African communities need culturally appropriate information about the relationship between HIV and sexual practices, relationships, sexual negotiation, reproduction and sexuality and about the implications of seroconcordant/discordant sex in order to make decisions about the levels of risk they are prepared to take. It found that African communities need to develop skills in order to deal with the cultural barriers to adopting and maintaining safer sex practices (such as gender issues, relationships, and information about the effectiveness of condoms) in reducing the risk of transmitting and/or acquiring HIV and other sexually transmitted infections.

African communities need easy access to free condoms and lubricants and to be informed of the availability and accessibility of sexual health services and HIV treatment services. In particular, femidoms should be actively promoted to females as this may be one way to overcome gender inequalities that tend to make women more likely to feel powerless about acquiring HIV.

The report highlighted the need to continue to challenge HIV-related stigma. Fear of stigma prevents people from discussing HIV risks and HIV prevention strategies, accessing HIV and sexual health services, testing for HIV, knowing their status and notifying their partners about their HIV status.

The Social Network Analysis [6] conducted by Waverley Care to inform development and delivery of effective HIV-prevention initiatives identified a number of key themes. These included:

- The challenge of stigma
- The importance of continuously refreshing the message
- Messages about testing even in the absence of symptoms
- The role of community and faith settings
- The need for generation-specific interventions
- The scale and complexity of the communication challenge

Opportunities identified included:

- Working alongside African-led churches and with African faith leaders
- Developing the relationships with community leaders, supporting community capacity and seeking their support in delivering HIV-prevention messages
- Developing the relationship with other community settings, for instance barber shops and salons, and identifying ways of using them to disseminate HIV information
- Working through informal family and friend social gatherings
- Working with generational groups

We promote HIV testing in these and other community settings and, based on our own and other research about where Africans might prefer to be offered an HIV test [15], we deliver training to GP practices about promoting HIV testing; we offer dry blood spot testing in the community and will test people at home, in their place of work, or in our premises.

HIV testing and treatment can help reduce transmission of the virus. People who find out they have HIV may change their sexual behaviour as a result; they may start using condoms with partners who are not HIV positive or whose HIV status is unknown. In addition, they may choose to receive antiretroviral therapy, which suppresses the virus and can further reduce transmission. Regardless of the result, testing also provides an opportunity to address any unmet HIV-prevention needs that people may have. For example, their understanding and awareness of HIV risk, their empowerment and negotiation skills, or access to condoms.

Encouraging repeat testing may result in earlier detection of HIV, thereby providing greater opportunity to reduce transmission.

Results from the Waverley Care Baseline Survey [11] showed that 71% of Africans in this sample considered HIV to be an important issue for them personally. However, this did not necessarily lead to testing for HIV, as 31% of the sample had never received a test from a health professional. Of these participants, the most common reason that they believed people did not test was that they had no reason to believe they had HIV. This was also the most common reason offered for not testing in the Bass Line Survey 2007 [14]. Indeed, such self-perceived low risk is consistent with the literature that one of the main reasons people do not test is because they do not consider themselves to be at risk of contracting HIV.

Support

Waverley Care adopts a positive prevention approach in its work with people living with HIV.

Positive prevention can be defined as a set of strategies that help people living with HIV to lead longer and healthier lives. It encompasses a set of core elements that help people living with HIV to:

- Protect their sexual and reproductive health and avoid other sexually transmitted infections
- Delay HIV disease progression

Case study 1: Muwumba (sticking together)

This idea originated from conversations between the African Health Project Outreach Worker in Edinburgh and hairdressers in an African salon. The salon distributes condoms, femidoms and lube on behalf of the project and the worker meets regularly with the staff providing on-the-spot training and information about HIV and sexual health.

Women come great distances to have their hair done and will spend many hours talking to the hairdressers. The hairdressers were telling us that they often felt overwhelmed by the difficulties and problems they were hearing. The women who speak to them do not want to talk outside their community, so would not seek help or support from generic agencies and feel that they can trust their hairdressers. The hairdressers were telling us that they felt that they needed training and understanding of what they hear and how they should deal with it. They felt that there are huge difficulties being experienced within the community, which include issues around adult, intimate relationships with partners and intergenerational problems between parents and children, including specific difficulties about sex education and different cultural expectations.

We approached Relationship Scotland, the leading relationship counselling charity in Scotland, and after several meetings with the women we successfully applied for funding to deliver a pilot communities-specific training course for the hairdressers in listening skills and to provide a framework for active and supportive listening; this is due to start in August 2015. The training will be culturally specific and will be developed by Relationships Scotland alongside the hairdressers. Additionally, a support group will be provided to enable the hairdresser to deal with their own feelings about the things they are listening to and to enable them to further develop their understanding.

The first training programme has already attracted interest beyond the initial group of hairdressers, and now will include two male African barbers. We are looking for two key outcomes by the end of the pilot:

- A counselling model that works for this community and the training that goes with it
- Community members who are skilled, knowledgeable and know how they will apply the training

The training, once evaluated and revised will then be offered to others, such as pastors, within the African community.

- Promote shared responsibility to protect their sexual health and reduce the risk of HIV transmission

People living with HIV, like those who are HIV negative, play an essential role in preventing new HIV infections. Key approaches for prevention for and by people living with HIV include individual health promotion, access to HIV and sexual and reproductive health services, community participation, advocacy and policy change.

The benefits of responding to the prevention needs of people living with HIV include:

- Contributing to the full enjoyment of sexual and reproductive health and rights
- Promoting new ways to live in serodiscordant or concordant relationships
- Averting unnecessary illnesses and ensuring timely access to treatment, care and support
- Promoting adherence to antiretroviral therapy
- Contributing to opening up dialogue among health providers, people living with HIV, community members and other stakeholders about the need to promote an environment free from stigma and discrimination
- Helping HIV-positive people to be empowered to make decisions about their lives without the burden of feeling guilt or shame as a result of their HIV status

The success of treatment is also bringing new opportunities for prevention. A strong body of evidence is emerging showing the potential impacts of antiretroviral therapy on prevention. By reducing viral load through effective treatment the level of infectiousness is also reduced and therefore the risk of HIV transmission is lowered – making antiretriviral therapy potentially the best prevention strategy currently available. What this means for people living with HIV is that access to effective treatment is important not just for their own health but also in reducing the risk of HIV transmission to their sexual partners.

HIV is increasingly described as a long-term condition, and Waverley Care has taken the lead in Scotland in developing a self-management programme for HIV, supporting people at an individual and group level. This is underpinned by the training in solution-focused therapy, which is an integral part of this programme.

Solution-focused therapy is a person-centred and individualistic approach which allows people to look

Case study 2: Lanarkshire African Women's Group

A women's group work programme for African women living in North Lanarkshire was piloted as a partnership between Waverley Care, NHS Lanarkshire and North Lanarkshire Council between 2012 and 2014. The majority of the participants were refugees or new migrants.

The aim of the group work programme was to encourage community engagement and participation, develop language skills and support participants to cascade health information to the African community in an informal manner.

Thirty-six women accessed the group; the issues and needs that came up included: isolation and being stuck at home, lack of confidence, not linking in to the community or meeting others, language and literacy issues, having the right skills and finding a job.

Meeting together weekly and offering different kinds of activities and support helped the women to grow in confidence, to speak out, to share experiences and express themselves. This in turn helped with their confidence in language and in further training. Women have built up friendships and support each other outside of the group.

The group has been supported by Waverley Care to constitute itself as a community-based voluntary organisation. This allows for community ownership and helps to ensure the sustainability of the group beyond the involvement of Waverley Care and other partners, although all three partners continue to support the group at the weekly meetings, in applying for funding and sit as non-voting members on the Management Committee.

The group has gone from strength to strength and now has involvement from over 50 women; the women initiate conversations about health issues, including sexual health and HIV, and have been instrumental in linking male partners in to health checks and health services, HIV testing and the local free condom scheme.

at their life in a very constructive and positive manner; by shifting focus from a person's condition or barriers that are holding someone back, the solution-focused approach recognises that a person has innate resources, motivation and capabilities that allow them to identify their preferred future. By tapping into these resources, motivation and capabilities, the clients themselves have the ability to discover solutions and find their own way forward.

Monitoring and evaluation of our current programmes identify a range of issues that impact on the lives of HIV-positive Africans in Scotland. These include: isolation, lack of confidence, poverty and destitution, immigration and uncertain immigration status, self-stigma, disclosure of their HIV status, sexual and reproductive health, poor mental health and poor physical health, poor understanding of their HIV diagnosis and adherence to treatment. We have addressed these through individual and group support and referral to other services within and outside Waverley Care. The project has made a significant difference in people's lives. It has been a home, a family, a friend, a confidant and a place of safety.

'I come here because I am coming to my family, we have something in common'

'I don't feel lonely or isolated. Group meetings help me to feel at home'

Future work

We've continued to undertake or commission research (our latest is an in-depth look at Scotland's African MSM [16]) and to scope opportunities. We continually reflect, review and develop – it's an iterative process. We'll work on taking forward the recommendations from the MSM report and will be building on our faith and health work through our new national post. We're expanding our parenting work and our work with African men through football.

We are involved in supporting external research, for example on HIV, human rights and asylum seekers [17], treatment as prevention [18] and are currently part of the HAUS study which seeks to develop and test an intervention of targeted distribution of self-sampling kits (SSK) for HIV testing within health care and community services to determine if this will increase HIV testing in African communities.

We'll continue to deliver the work I've touched on throughout this article; however, as the project has become more established, we are moving away from large, general community events to targeting opportunities to deliver more measurable interventions with clearly defined outcomes. We'll continue to raise awareness through our Voice of Hope Choir, our condom distribution and our Health Ambassadors; but we want to focus much more on those interventions where we can identify impact and measure change.

We continue to work with the community, involving them as staff, as volunteers, as peer educators and as partners in planning and delivery. The impetus for change, development, and integration, for better economic, physical and emotional health lies with communities – and it is community ownership of HIV that is going to help to break down the biggest barrier of HIV stigma. However, a desire and need for change will not, on its own, help change to happen. This takes place in the context of living, working, studying and growing up in Scotland; rather than thinking about African communities as 'hard to reach' we should be asking ourselves how we adapt what we do to meet the needs of the community and support the drivers for change.

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