

**'INTERSECTIONALTY' OF EXPERIENCE IN THE NARRATIVES
OF AFRICANS LIVING WITH HIV IN ENGLAND**

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September 2011

EXECUTIVE SUMMARY

The experience of living with HIV cannot be reduced to HIV status alone and must be understood as being influenced by multiple intersecting factors. For Africans living with HIV in England, HIV status is merely one of a number of factors determining their experience of life in the country. As such, efforts to improve the lives of those living with HIV and support conditions for achieving good health and wellbeing must account for the multiple and often non-medical factors affecting the community's ability to do so. Through the use of individual narratives, this research explores the experiences of Africans living with HIV in England in order to gain insight into the nature of how certain state and social institutions—often seemingly unrelated to health and HIV/AIDS—may influence how individuals in the community not only experience their illness, but life in the UK more generally.

- 15 participants—9 women and 6 men—shared the narratives of their lives since coming to the UK in one-to-one interviews. All participants were HIV-positive and members of the African immigrant community of either Greater London or Bristol. Their median age was 51 and they were of varying national origins: Kenya (2), Nigeria (2), Rwanda (1), Uganda (4), Zambia (2) and Zimbabwe (4). A question period followed each narrative, during which time the participants were asked to expand upon issues they had raised, as well as speak about their experiences with HIV, their health, immigration, and life in the UK.
- Although a wide range of topics were discussed in each interview and an equally wide range of themes were raised, four dominant themes arose across the 15 narratives: 1) HIV as a 'unique' illness; 2) Structural barriers to participating in society; 3) Structural barriers to independence/control and envisioning a future 4) Support groups as spaces for empowerment.
- Many participants held the belief that HIV was a unique or 'different' illness, presenting HIV-positive individuals with challenges and needs not experienced by those with other health conditions. In particular, the high degree of stigma that continues to be prevalent in many communities and associated fears of rejection and isolation was cited as a challenge specific to those with HIV.
- The fear of stigmatization prompted a number of the participants to feel unable to be "themselves" or be completely open about their status in certain social circles, such as their faith community or even family. Whether they chose to disclose or not, the fear of rejection and subsequent isolation that arose from perceived stigma limited the range of options for support available to some of the participants, as well as their ability to participate in the broader African community.
- HIV status was often not the most emphasized issue in the narratives. A number of larger 'structural' barriers to participating in and belonging to British society were frequently cited, the most common of which being the UK immigration process and the inability to seek paid employment.

- The unpredictable nature of the immigration process and uncertainty of their future in the country was seen by many to be a barrier to feeling as though they could contribute to, belong to, or have an equal place in British society.
 - Many participants felt that they and the African immigrant community in general had much to contribute to British society and could be valuable assets to it. However, restrictions on employment were cited as a barrier to them doing so and fully participating in or giving back to society.
- The desire to be an “independent person” and have control over the direction of one’s life was expressed in many of the narratives. Having a job was seen as a means for living a “normal life” and gaining a degree of independence. Employment was believed to bring financial independence and decrease reliance on others for their wellbeing. Restrictions on seeking employment based on immigration status were thus often barriers to the participants developing a sense of independence and control over the direction of their lives.
 - The uncertainty of the immigration process acted as a barrier to setting personal goals or envisioning/planning for a future. With the process of gaining a solid immigration status often taking years, the inability to know where one will be from one day or year to the next often encouraged feelings of stagnation or lack of control in many of the participants.
 - Every participant had some experience with HIV support groups and organizations. Such groups were cited as providing people with HIV in the African community the opportunity to be open about their status, as well as be exposed to others in similar circumstances and with common experiences.
 - Support groups helped prevent isolation, encouraged active participation and socialization, promoted the exchange of knowledge and coping strategies, and facilitated the development of positive ‘social identities’ by allowing members to positively re-conceptualize their HIV status. All of these benefits
 - Although the majority of the participants had high praise for support groups and cited the benefit of participating in them, the narratives they shared often revealed that the social context in which the community exists is limiting the extent to which they can transfer these benefits to the other spheres of their lives. Despite the empowerment that can come with involvement in support and advocacy groups, prolonged struggles with immigration and achieving financial independence continue to limit the full potential of these community spaces and their ability to improve individual and community wellbeing.

KEY RECOMMENDATIONS

With the advent and success of affordable and widely available antiretroviral therapy (ARVT) in the UK, it has often been said that individuals living with HIV, if identified early, can live a largely 'normal' and long life. The importance of ARVT should be in no way undermined, but it is important to recognize that the health and wellbeing of those living with HIV is determined by much more than their HIV status and access to treatment. For the participants of this study, the immigration process and the inability to seek paid employment were very often equally significant in determining the course of their lives and wellbeing as their HIV status.

- *Recognize the uniqueness of life with HIV:* The fight to keep ARVT free and available to all, regardless of immigration status, must continue to be paramount in the efforts of HIV advocacy groups. However, the move towards viewing HIV as a chronic condition from a medical standpoint must be made cautiously. The experiences of those in this study highlight the specific needs of HIV-positive individuals and how their social circumstances dictate these needs. A continued emphasis must be placed on the importance of HIV-specific social services that are designed to address and combat the specific challenges HIV-positive individuals face.
- *Maintain a variety of support options:* Many living with HIV do not consider their status to be either the biggest challenge in their life or the defining characteristic of their identity. Given the variety of issues that many individuals face and the numerous identities they possess, it is important that the range of available sources of support reflect that diversity. If individuals do not feel as though they can identify with others in a support group, or if HIV status alone is not enough of a point of common identity and experience, some may be turned off to support and further community engagement.
- *Campaign for a streamlined immigration process:* The uncertainty and inconsistencies that characterize the UK immigration process are direct barriers to many gaining a sense of agency and control over their lives, as well as envisioning a positive future that they can influence. In addition, the stress and uncertainty commonly experienced as a result of the immigration process can have negative health consequences, particularly for those with HIV. Campaigns to influence immigration policy should highlight these issues and the immigration system's role as a barrier to individual and community wellbeing.