Selective disclosure of HIV-positive status in the era of HAART. Perspectives of immigrant Black African men, and their families, in the UK.

John Owuor¹, Abigail Locke², Bob Heyman² & Andrew Clifton²
1. Karolinska Institutet, Stockholm, Sweden
2. University of Huddersfield, Huddersfield, UK

Background
Black Africans, individuals who identify themselves as Africans either by birth or descent, make up less than 1% of the UK population [1]. But they are the heterosexual group most affected by HIV in the UK [2], and the whole of Western Europe. Advances in HIV treatment and care means that HIV-infected individuals who test early enough for the disease and have access to treatment can now aspire to a near normal lifespan [3]. Health promoters encourage disclosure of HIV-positive status to social networks to facilitate access social support [4] and to prevent onwards HIV transmission [5]. However, little is known about how affected families deal with daily life with HIV. In most western European countries, HIV testing and treatment are free yet Black Africans continue to test very late for HIV and are prone to HIV-related mortality and morbidity [6]. The current study explored the participants’ perceptions on what it means to live with HIV and how services can better serve such individuals.

Methods
This paper reports the findings of a qualitative study involving in-depth interviews with 11 HIV-positive individuals, 6 HIV-positive women, 1 HIV-negative man and 5 employees of HIV service-provider community organisations in London, UK. Data were analysed using grounded theory’s cyclic three-stage process: open coding, axial coding and selective coding.

Acknowledgments
This study was funded by St Patrick Stewart PhD Scholarship, University of Huddersfield. Our sincere gratitude to the participants whose real life experiences informed this study.

References

For further information
Please contact John Owuor - john.owuor@ki.se

For further information
Please contact John Owuor - john.owuor@ki.se

2013 Gibrán Sterky Fellow
Karolinska Institutet, Tomtebodavägen 18A
S-171 77 Stockholm, Sweden

Conclusion
Whereas HAART has tremendously improved lives of HIV-positive individuals, the present findings suggest that for some individuals, successful treatment has invalidated the need for disclosure of their HIV status to their social networks. However, all the participants in the present study had revealed their status to their sexual partners. Thus selective disclosure of HIV status did not seem to create a risk of onward infection between sexual partners. But the apparent concealment of HIV-positive status by the participants facilitates self-isolation, and inhibits access to and use of the wide range of available HIV services and social support, thereby inhibiting the potential to live a fulfilled life on successful HIV therapy.

Results

The tree represents an HIV-positive participant and the branches represents the people they interact with in their daily life with HIV. The green boxes represent those they were likely to confide in whereas red boxes represents social groups that the participants were likely to conceal their HIV-positive status from.

Apart from HIV clinicians, the men and their partners, selectively revealed their HIV-positive status to carefully selected individuals while concealing it from the rest of their social networks. While they acknowledged the importance of disclosure of HIV-positive status in accessing social support, the relevant participants framed selective disclosure in terms of need. Disclosure was necessitated only by perceived need to do so, such as to access treatment. The relevant participants argued that they were on successful HIV treatment, did not exhibit any markers of HIV such as severe weight loss and they did not have to reveal their status to people who would not be of any help. They preferred to reveal their status to their HIV clinicians, sexual partners and selected close family members. The participants weighed between risking stigmatization versus social support, many opting for their confidentiality.