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BodyPositive
Education

Silent Scream? The Life Histories of People Living with HIV in the North East of England (2015)

Executive Summary

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Summary:

This two year project was commissioned to explore the actual life histories and lived experiences of people living with HIV in the North East of England, in order to provide a snapshot of what it means to be living with the virus today in the UK. This research was conducted in the North East of England, as HIV experiences are frequently under-researched here, noted by the scarcity of research in this area. Nationally, the research methodology of life histories is replicable and so it is recommended that further life experiences are gathered in other parts of the UK in order to build up further evidence of how what it means to be living with HIV within the UK, and how it is felt in regional areas, but also over the country as a whole. Furthermore, it is important to note that the life histories gathered here add to the body of evidence showing that limited sex education, stigma in healthcare settings and employment as well as a growth of general HIV related stigma impact heavily on people living with HIV. As such, key recommendations to tackle these have been given at the end of this document. This project was generously funded by the 'National Lottery: Awards for All' and it has worked in collaboration with a local HIV/AIDS charity, 'Body Positive North East,' to set a working model for future research in regional areas.

This piece of research, since its publication, has helped to inform the 'Live HIV Neutral Campaign' which is the first nationwide campaign to tackle HIV-related stigma within the United Kingdom, which will be launching in late 2015/16. For a full and complete electronic or hard copy of the larger research report, and to read the life histories in depth, please contact Drew Dalton at: andrew.dalton@sunderland.ac.uk

Living with HIV in the UK:

"HIV may have slipped out of the headlines, but we should avoid any false assurances that the battle is almost won or HIV is no longer a problem" (Fowler, 2014: 253).

An estimated 107,800 people were living with HIV in the UK in 2013. Figures from 2013 show 6,000 new diagnosis of HIV and 320 of AIDS. The numbers of people living with HIV stand at 43,500 (men who have sex with men) and 59,500 (through heterosexual contact) alongside a much lower figure of 2,400 (injecting drug users). Worryingly one in four adults living with diagnosed HIV were aged 50 years and over. As a result we see a spike in the number of older people with late diagnosis and a generation who are growing older (and will retire) who are living with HIV (Crusaid, 2007). Nationally, the overall prevalence of HIV was 2.8 per 1000 population (1.9 in women and 3.7 in men). An estimated 24,000 people living with HIV were unaware of their status in 2013 and without condom use, will continue to spread the infection.

The HIV virus can be transmitted through blood or body fluids, such as semen or vaginal fluids, as well as contact with the bloodstream. HIV can also transmit through breast milk from mother to child or by crossing the placenta or in the act of childbirth and via mucous membranes such as inside the vagina, ureatha or rectum (www.avert.org, accessed 06/01/15). However, in the UK, 95% of new transmissions are through unprotected sex (NAT, 2012, Public Health England, 2013) with a much smaller number being the result of sharing needles, syringes or other drug injecting equipment. There are many cultural myths around transmission of HIV. It is important to know that HIV cannot be transmitted through sharing cutlery, cups, hugging, fish pedicures, mosquito bites, urine, biting, scratching, spitting, and kissing or by coming into contact with a discarded needle.

The National AIDS Trust (NAT) produce a longitudinal study into ‘Public Knowledge and Attitudes toward HIV’ (2014) in the United Kingdom. However, whilst the report does suggest that the public are now more aware of HIV-related stigma and believe that more needs to be done about it, it also highlights the public’s reaction to attitudinal statements which revealed social attitudes that one in four people (25%) do not have much sympathy for people living with HIV, which is a concern as it is by far the most common form of transmission among people diagnosed with HIV. Other results from the survey highlight workplace HIV-related stigma indicating that just over two thirds (67%) of respondents would be comfortable working with a colleague living with HIV. The report also showed incorrect transmission knowledge as 16% of respondents incorrectly believe HIV can be transmitted through kissing (a rise from 9% reported in 2010), over a third (36%) believe HIV can be transmitted through biting, and almost half believe HIV can be transmitted by a blood transfusion in the UK (44%). The report goes on to state that the sizeable proportion who respond with ‘don’t know’ to these statements indicates that some of the public are quite aware that their knowledge about HIV transmission is limited (NAT, 2014). The number of people living with HIV in the UK has trebled in the last ten years (Public Health England, 2014) but over the same period there has been a significant decline in public knowledge about how HIV is transmitted. Public attitudes have not kept pace with improvements in treatment.

A significant number of people continue to hold stigmatising attitudes toward those who are living with HIV (Herek, et al, 2002); alongside these attitudes come a range of difficulties in daily life for those living with HIV that lead to constant challenges. These challenges include living with noxious symptoms, side effects from treatments, periods of disability, unemployment, impoverishment and isolation from social networks (Fleishman, et al, 2000). HIV related discrimination and public perceptions of HIV is the biggest handicap to living successfully with HIV as it extends to all areas of people’s lives. Many people can also experience double discrimination as a result of their ethnicity or sexuality (Crusaid, 2007). A survey by the UK HIV/AIDS organisation Positively (2013) found that three quarters (75%) of respondents living with HIV stated that they had suffered from either depression, anxiety or ongoing emotional distress in the previous 12 months, with 40% of respondents experiencing discrimination in the past 12 months due to their HIV status. Other results from this survey appear to confirm the findings by NAT (2010) and reveal that work colleagues are the people they are least willing to disclose their positive status to, with four out of ten respondents (40%) preferring not to disclose their positive status to any of their colleagues. Whether discrimination actually occurred at work or not, the perception was that there was a real danger that they would be discriminated against. There have been no large-scale public health campaigns since 1987 and HIV has increased substantially since that time as, “ignorance of how to prevent HIV is still vast and in the absence of public health education campaigns it has increased over the last twenty years” (Fowler, 2014: X). It seems that each new generation of individuals needs to be exposed to the same information if we are to continue to lower the risk of HIV infection (Stolley & Glass, 2009). This is increasingly difficult to maintain as few resources, other than those from the voluntary sector, are being used to promote a specific large-scale HIV/AIDS prevention and an anti-stigma message.

The *Equalities Act (2010)* introduced and strengthened workplace provision and anti-discrimination legislation for disabilities, including HIV, when it was passed. However, little of this seems to have affected public attitudes or the “safety” of people living with HIV within the workplace. Legislation is used to protect those people who are living with HIV from discrimination, but this alone is unable bring about cultural change. It has been suggested that more work needs to be done to ensure that employers are aware of their legal obligation to people living with HIV (Sigma Research, 2009).

Further research has shown that stigma has discouraged or deterred people from being tested for HIV, disclosing their status to others, seeking information, and maintaining medical regimens (Mahajan, et al., 2008). Many programmes aimed at HIV education and prevention rarely address HIV-related stigma. Schools have been accused of offering haphazard sex education classes as, “recent sexual health campaigns – especially those aimed at young people – have made no mention of it at all. Young people rarely learn about HIV In schools” (Sigma Research, 2009: 19) Yet, interestingly, the vast majority (85%) of the public agree that all young people should be taught about HIV at secondary school to ensure they have a good understanding of the condition by the time they leave (NAT, 2010), which does not seem to be happening consistently.

In terms of the media, other than somewhat haphazard modern representations of living with HIV/AIDS in soap operas or films, the media very rarely write about HIV. When they do, it is often on World AIDS Day, or to report a ‘cure’ which arguably serves to perpetuate myths and misunderstanding through sensational language or misreporting of the facts (NAT, 2010) as well as reporting HIV/AIDS as something which is *always* easily managed through medication. Ultimately, this serves to increase the ‘silencing’ of HIV/AIDS further. In all, HIV is a silent virus within modern Britain, yet those who are living with it, and increasingly infected by it, have clearer needs other than just medical treatment if the social exclusion and stigma, which has existed from the emergence of the virus, is to be tackled.

Method of data gathering and analysis:

Data was gathered through fourteen in-depth life history narratives of people living with HIV within the North East and it was also supported by current and existing research. Interviews were detailed and expressed all respondent's full chronological life histories in order to provide a deeper picture of life with HIV in contemporary UK. Life histories were chosen as a research method so that respondents were defined by their life histories, memories and experiences, and not just be their HIV status.

Recommendations:

On the whole, living with HIV within the North East of England was not seen favourably by many of the people who took part in this research. The findings from this research show how different and striking individual lives are. However, trends emerged so there are clear national policy changes to be made as well as regional points to consider. The findings represented a snapshot of the UK in the North East. They feed into larger national research and so these recommendations should be addressed on a national level as they inform other research. There were four common themes running throughout the research, and so findings and recommendations are as follows:

1. Tackling HIV related stigma through campaigns:

Aligning with a previous survey's finding completed by the author (see Dalton, 2014, available at www.bpne.org), HIV-related stigma was common for those living with HIV in the North East of England. However, sections of the North East community discussed how this affected them differently. Predominantly, gay men spoke of the high levels of stigma on the gay scene and how they had discovered evidence regarding disclosure of their HIV status to others without their permission. Many of the gay men and transgendered respondents felt that HIV stigma was particularly high, and they felt it keenly from some other HIV negative gay and bisexual men within the commercial gay scenes. This is an interesting finding as the LGBT community has been a target of HIV testing schemes from the outset of the HIV epidemic. Similarly, the BME communities felt HIV myths and stigma abound and were unable to speak about their status within their community and only instead, with peers within specialised support groups. Overall, all respondents reported HIV-related stigma, regardless of sexual orientation or ethnicity. Accordingly, the following points are local in nature, but also relate to national recommendations to tackle this stigma:

- **Regional: A local campaign with a regional identity:** HIV testing messages are dominant primarily within the physical spaces of the gay communities and sexual health clinics, and so HIV messages are largely invisible in other spaces. There is a clear need within the region to tackle HIV testing as well as HIV-related stigma through a poster and flyer campaign on all sides; including bars, nightclubs, community centres (Black Minority Ethnic [BME] spaces and otherwise), plus other social spaces frequented by heterosexuals, in addition to the LGBT bar and club scene. It must also be acknowledged that the LGBT and BME community do not necessarily socialise in one key area; and so the need for more targeted advertising of a campaign in other social spaces is a vital step. Furthermore, this campaign should not only be focused on HIV testing (although it is important), but it should also be a campaign to reduce the stigma associated with HIV and to normalise it.

- **National: Inform UK based HIV-related stigma campaigns:** There needs to be a wider UK based HIV anti-stigma campaign. It is recommended that life histories of people living with HIV form part of this to bring the realities of living with the virus to the forefront. It is recommended that this research informs the 'Live HIV Neutral Campaign', which is the first anti HIV-related stigma campaign of its kind to be launched in the UK.

- **Regional and National: The lack of a recognised 'HIV community' and its voice in the North East**: Whilst many respondents felt that their support services were usually good, many noted the lack of a HIV 'community' when compared to some areas within the UK. This is becoming increasingly difficult under times of austerity, when HIV specific services and provisions are being hit by funding cuts and staff are stretched potentially even further than before. A recommendation of this research is to develop a 'HIV voices project' using digital storytelling through online life histories of people in the region living with HIV. This could be a central place where local life histories are presented for people to read or listen to and be used for educational purposes. Furthermore, links to other local HIV-related organisations and support could also be included on the site and advice pages offered as a regional 'first port of call' for those seeking information and advice about HIV and related conditions (such as dual diagnosis). This website could be monitored by several local HIV groups and organisations (but not owned by one outright) and updated by a team of volunteers similar to the Terrance Higgins Trust model of support found in their online chatrooms, support and blogs. This could begin to encourage a regional community of people living with HIV to come together and to tell their life histories, seek advice and support, as well as support each other and work to remove the invisibility of HIV in the North East. This model should be rolled out nationally.

- **National:** Hate crime organisations and hate crime statistics must aim to highlight information around HIV-related hate crimes and to reflect this in public discussion. Many respondents living with HIV, whilst unaware of it, were direct recipients of Disability Hate Crime.

> **"The reaction you get on the gay scene. I felt, y'know, whispers would go round [and] that sort of stuff it wasn't supportive. It wasn't nice, it wasn't helpful. It was fear."**
>
> **"My views about HIV have changed a lot. I didn't know anything about it before I became positive. It was just some virus that no one ever spoke about or educated anyone about. I did not have any clue about it; it just seemed some horrible killer disease."**

2. GPs, mental health and healthcare:

Many respondents' experiences with their local GPs were disappointing; failure to offer testing or misdiagnosis (even in late stages of HIV) was common. Many felt that their patient confidentiality had been compromised; mainly - though not exclusively - by clerical staff in GP surgeries, and some cases, also by medical personnel. Whilst respondents often praised the work of staff in local GUM clinics, this was usually due to their knowledge of HIV and sympathetic treatment of people living with it. Mental health was discussed at length, and whilst understanding the virus and its treatment was vital to respondents, many felt that there is an imbalance; with the physical medical side taking the forefront. Many respondents expressed how HIV manifests side effects such as social isolation, stigma, depression and self-harm that, whilst not always directly caused by the virus, can be related to people's methods of coping with HIV.

- **National: Training for healthcare and mental health professionals on HIV awareness:** There is a clear need to ensure that balanced care is given for people living with HIV. Care must include mental health support (within and outside a hospital environment) as well as a much greater multi-disciplinary support approach utilising the talents and skills of mental health professionals and third sector organisations. This effort should also encompass training for third sector organisations unfamiliar with HIV, to enable them to work effectively with issues presented by people living with HIV. A recommendation of this research is that mandatory training sessions on 'HIV/AIDS awareness' be offered to targeted third sector workers dealing with vulnerable adults, counsellors, GPs and their support staff, therapists and psychiatrists. Further on-going support is required via a working panel of those who attended the training to share good practice, including mental health issues, and adopt HIV friendly policies for treating those living with HIV.

“I would say for the first year after I was diagnosed I constantly thought about it. I hated myself, I felt dirty, horrible depression, horrible, and then gradually I’ve came out of that and I just think well, it’s just another illness that I’ve got to deal with. Oh I had suicidal thoughts and all sorts. For the simple fact that I knew I would hurt too many people who cared about me. If it hadn’t been for them I would have.”

“In the space of a few weeks I went to my GP over 30 times. Not once was I offered an HIV test. I showed all the clear signs of having late diagnosis HIV.”

“I never got offered the chance of going on PEP, nothing; I got no counselling from the NHS, at all.”

“It is so depressing when someone goes out there and talks about your status. I had a very bad experience with some people. So when I was in hospital, someone said to my friends that, “oh you know what, Felly is in hospital because she’s HIV” and that is the time when my roommate heard in the house. She’s a nurse, the one who told them, she said, “oh there’s one of the African girls, the African woman here she’s called Felly and actually she’s positive.””

3. Employers:

Whilst the Equalities Act (2010) added further protections to those living with HIV, many employers are unaware that HIV is included within this legislation. Many respondents felt fearful of telling employers their status (even though they do not have to reveal it) and also felt uncomfortable with revealing reasons why they need time off work or require reasonable time adjustments for hospital and doctor trips. The climate within some workforces discourages many respondents from revealing their status and thus challenging the invisibility of HIV within the region.

- **National: HIV ‘Awareness Certificate’:** A recommendation of this report is for regional HIV organisations, and importantly, other employers who do not work directly (or at all) within HIV care or support, to develop a ‘HIV Awareness Certificate’ as a national working group, that gives recognition for good practice by employers. This should be based upon standards set out by the working group, for example, ensuring that all key staff have HIV awareness training; a recognition of World AIDS Day and its importance to the organisation; establishing appropriate policies developed with staff living with HIV, as well as measuring how far safe employees feel within the workplace culture to reveal their status, should that be their choice.

> **"They were really not very helpful from that point of view. Anything they could make difficult for me they did. I did not feel supported in the danger part of it; and as far as am aware, I never saw a risk assessment. But that aside, they never seemed to consider how that made me feel. If they wanted to get rid of people, I was top of the list, but I got out with my redundancy and having done that and first sought out some advice and help."**

4. Education:

Education was a dominant theme throughout this research; and many respondents pointed to their own lack of HIV prevention education in school and college, as well as their concern regarding the lack of appropriate sex education for young people in the present education system. Effective and appropriate sex education is increasingly difficult in schools because HIV and sex education are still under-recognised; and teachers find it difficult to incorporate the subject given the many demands placed upon them within the curriculum. However, specific regional meetings of key PHSE Coordinators / Heads of Departments within schools could be a successful route to establish a mutual plan to tackle HIV awareness locally.

- **National: 'HIV Scheme of Work':** A meeting or workshop for teachers of relevant subjects including RE, PHSE and Citizenship, should facilitate discussion whereby an HIV/AIDS scheme of work could be developed. A recommendation of this report is that schools and colleges develop a national flexible, interdisciplinary scheme of work on HIV awareness. For example, the history of HIV in PHSE as well as protection against HIV transmission methods, a reflection of the meaning of World AIDS Day through HIV/AIDS activist poetry, or the life histories of people living with HIV would be appropriate. The scheme of work could also cover how the virus works and its impact within medical science or economics. Social conscious awareness and links to Religious Education and Citizenship could be emphasised. This scheme of work could be monitored by local HIV organisations in partnership with schools and colleges to judge its effectiveness in raising awareness of living with HIV.

> **"It was never mentioned in school. Which it should be taught in school, it should be one of the main things that is taught in school. No point in teaching teenagers about infections where you pop a pill and it goes, you need to educate them about serious side effects of having unprotected sex. I wouldn't even call it sex education to be honest. It was just basically putting a condom on some unrealistic, plastic penis for a few minutes. That is not education, teaching them about chlamydia, gonorrhoea or something, STI's where you literally just take a few pills and it's gone in a week. That's not sex education at all."**

“I started for maybe a week or so thinking it’s happened; I’m riddled with AIDS. I didn’t know a lot about it, but even as a gay man I was shocked really as when I started learning a bit more about it, as to how even naïve I was as a gay person regarding HIV. Before I thought it was the old-fashioned days of the whole, “can’t sit on the same toilet seat or you can’t brush your teeth,” I don’t know, whatever it was, but only knowing that its transmission is through blood-to-blood or blood-to-semen, I never knew that.”

Conclusions:

Overall, these findings reflect a much larger trend of national research that shows the consequences of stigma, HIV awareness and education are needed alongside the traditional HIV testing messages to ensure a better quality of life for those living with HIV; not only within the North East of England, but also within the United Kingdom as a whole. Behind these recommendations are the lives of those who took part in this publication and who are currently living with HIV. Whilst their HIV status is not the key component of any of the respondent’s identities, it was deeply important to them and so many requested that the outcomes and the recommendations of this research deal with tackling HIV related stigma in the region and begin a larger HIV dialogue outside of the traditional sexual health and HIV organisations. A final recommendation of this report is to ensure that this research is not left as a ‘stand-alone’ effort. HIV-related social research must continue so that organisations and activists have evidence-based research available for use to secure funding in increasingly difficult (and more evidence-based) times to establish projects to change the way in which HIV is perceived and treated, and those with HIV live without stigma.

Author of this Research:

Drew Dalton, BSc (Hons) MSc, MA, is a Sociologist and a Lecturer of Social Sciences at the University of Sunderland. He has spent over 16 years working within two fields; teaching and youth and community work, particularly working with, and alongside, marginalised and vulnerable groups.

An HIV/AIDS activist himself, he is currently studying for a PhD in Sociology at Leeds University, exploring how HIV stigma affects intimacy and dating in an ageing population of people living with HIV in the UK. Drew previously completed the region's first '*Survey of Public Knowledge and Attitudes toward HIV in the North East of England' (2013),* which highlighted interesting and often surprising views and attitudes toward HIV within the region. A free copy of the survey can be downloaded via the Body Positive North East website: www.bpne.org

Drew was formerly a volunteer and Board Member at Body Positive North East, where he primarily supported the Men's Group (Body Positive Men) as well as delivering training workshops to various organizations on 'HIV and AIDS Awareness.' As an outcome of this research, Drew is also a newly appointed Regional Coordinator for the nationwide 'Live HIV Neutral Campaign' which aims to tackle HIV-related stigma on a national level. He welcomes opportunities to work with other HIV professionals and organisations to engage in future research around HIV/AIDS, on behalf of the Centre for Applied Social Sciences (CASS) at the University of Sunderland.

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