



The workplace experience of people living with HIV in the UK: a qualitative study

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Background

- While a number of studies have highlighted barriers to employment for people living with HIV, the experiences of HIV positive people who are actually working remains an under-researched area.

Method

- The two groups most affected by HIV in the UK are gay and bisexual men and black African heterosexual men and women.
- We conducted five focus groups between August and October 2008
 - two with HIV positive gay and bisexual men (19 participants)
 - three with HIV positive heterosexual black Africans (13 women and six men)
 - in London, Manchester, Luton and Glasgow
 - all participants were employed.

Conclusions

- Most focus group participants adjusted to their HIV diagnosis with little long term impact on their working life.
- However, there was evidence of discrimination and there appeared to be opportunities to improve people's knowledge of their rights at work and access to these rights.
- These findings informed NAT's policy recommendations for government, employers and trade unions.

Results

IMPACT

- Participants reported two 'flashpoints' when HIV most impacted upon their work: at initial diagnosis and when starting or changing medication.

- This was the case for both gay and bisexual men and black African heterosexual men and women.

"I think you're so consumed with the diagnosis that you kind of drift your way through work for a while...I think you do have a period of putting the job on hold as you go through the motions.

(Gay and bisexual men's group, London)

"When I first started medication, I had to apologise in the meetings saying that I may need to run for the toilet and sometimes I'd just had the need to go to the toilet just there and then...."

(Gay and bisexual men's group, Manchester)

- However, most people said that after a period of initial adjustment, living with HIV had few ongoing consequences for their working life.

"I'm used to the medication I'm taking, so I find that I actually take less time off sick than people who are actually not HIV positive. So for me at the moment it doesn't really have an impact on my work.

(African men and women's group, Glasgow)

DISCLOSURE

- Focus group participants said that the decision to disclose at work was a difficult one.

"I was diagnosed and I remember my counsellor...said have you thought about who you're going to tell? And she said, just think hard and fast, it's entirely your decision of course but once you tell someone you can't untell them.

(Gay and bisexual men's focus group, London)

- Many of those who did not disclose their HIV status said they simply saw no need to.

"Physically at the moment I feel perfectly well and if I'm in a job that doesn't require me to reveal my status I won't. I'm a great believer that it's my choice to tell as and when.

(African women's group, London)

- Those who had disclosed their HIV status said that it gave them an advantage when they needed flexibility at work. On the other hand, non-disclosure caused problems around taking time off to attend clinics, managing medication and side effects at work.

"It's easier to not have to lie about something and in terms of medication the best time for me to take my medication if I want a lie-in at the weekends means I have to take my medication at work.

(Gay and bisexual men's group, London)

DISCRIMINATION

- Some participants who had disclosed their HIV status had experienced discrimination. It was sometimes difficult to disentangle this from discrimination related to race or sexual orientation.

"It's quite difficult to pinpoint. Obviously people tend to be very careful you know how they do things, so you wouldn't really know whether it's really down to that [HIV] or it's something else.

(African women's group, London)

"I've just been bullied continuously. She [manager] was just doing checks on my work where she wasn't doing checks on anyone else...."

(Gay and bisexual men's group, London)

RIGHTS AT WORK

- Knowledge of legal protections under the Disability Discrimination Act 2005 and access to "reasonable adjustments" (e.g. flexible working arrangements) varied.

"I'm kind of aware but maybe I just don't take it too seriously...the practical side is when you go there, you tell them [that you need a reasonable adjustment], it's 50/50 when they say yes and they say no. So, whether it's there or not, it doesn't make me feel any more comfortable.

(African women's group, London)

Results

Read the reports

Douglas, N. (2009) *I just get on with it: A study of the employment experiences of gay and bisexual men and black African men and women living with HIV in the UK*, www.nat.org.uk

NAT, *Working with HIV: A summary of NAT's employment research*, www.nat.org.uk

About NAT

NAT (National AIDS Trust) is the UK's leading charity dedicated to transforming society's response to HIV. We provide fresh thinking, expert advice and practical resources. We campaign for change. Shaping attitudes. Challenging injustice. Changing lives.

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