

HIV NURSING

CARING FOR PEOPLE AFFECTED BY HIV

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Men and HIV

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Aims and Scope

HIV Nursing has been developed as a forum for those at the forefront of caring for people affected by HIV. The journal is supported by a highly respected Editorial Board drawn from a wide range of nursing specialties. This is further strengthened by an Advisory Panel who will be making regular contributions to the journal.

HIV Nursing is intended to provide a medium for communication on issues relating to HIV care, which will be run by the care professionals for those involved in the day-to-day matters affecting the lives of patients.

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Men and HIV: longer lives, new problems

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Now that HIV has turned 30, the subject of men and men's issues is more pertinent than ever. More reliable, effective and sophisticated treatments certainly allow people to live longer, healthier lives with HIV – but we still have a huge transmission problem as the rate of new infections continues to rise. While some groups have seen a steady, consistent increase, the 2012 statistics for MSM (men who have sex with men) were disturbing. Figures supplied by the Health Protection Agency (HPA) in November 2012 [1] showed that an estimated 73,400 people were aware of their HIV diagnosis in the UK by the end of 2011, with the highest prevalence among MSM.

New diagnoses for MSM were 3010 in 2011, which is an all-time high (2000 were diagnosed in 2002, following an initial dip in the late '80s and '90s). We now have an estimated 31,900 MSM and 14,400 heterosexual men living with HIV in the UK. Because antiretroviral medications have improved and most HIV-positive men are living longer lives, we are now seeing new problems, such as the rise of cancers (particularly anal cancers). Today's young people born with HIV are rapidly becoming sexually active young adults, with all the issues this brings. We have an older MSM population who face a potential rise in poverty, social isolation, anxiety, stress and depression because of proposed changes to the benefits system. There is an alarming increase in the use of recreational drugs, particularly crystal methamphetamine and mephedrone, with an associated rise in high-risk sexual activities.

We wanted this issue to include a variety of perspectives on the lives of HIV-positive men today. After years of hearing colleagues say that they are 'going to open a nursing home for gay men',

I wanted to look closely at the issues surrounding older gay men and HIV and consider what is key in offering effective support. David Stuart discusses the relationship between men, recreational drugs and HIV – a timely piece given recent press coverage [2] and ongoing debate around the legalisation of some recreational drugs. Meanwhile, after another record-breaking testing event, Jake Jenkins tells us about the innovative testing clinic run in one of London's gay bars, with case studies on some of the men they support – a great collaboration between the NHS and business. Alison Barnes offers a two-part article about the work that Body & Soul does with young men facing young adulthood after a lifetime living with HIV, which compliments an autobiographical piece from Terence Higgins Trust's Straight Talk group. The result is a selection of interviews and testaments from men of different ages who live with HIV – and a valuable insight on the issues they face. Juliet Bennett's 'HIV update' for this issue reviews the rise of anal cancers in HIV-positive men, plus recent developments in anal screening.

We welcome feedback and suggestions – do share your views with us and let us have your ideas for future content.

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Old, grey and gay: HIV and ageing

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Background

People diagnosed in the last few years who start antiretroviral therapy (ART) at a sufficiently high CD4 count, and stay on it, are likely to have a normal lifespan. A non-smoking, 30-year-old gay man, whose HIV is diagnosed promptly, could expect to live until he is 78 – the same age as the average UK male [1].

Research into HIV and ageing is *the* hot topic ... 30 years ago who would have predicted that we would be looking at people growing old with HIV, and the many, complex issues this presents? The reasons for this change are many and varied. As ART has become more effective and sophisticated, we are seeing a population of people with HIV living longer, healthier lives. As the devastation and complications brought by opportunistic infections have reduced, we now have the complications of ageing.

A growing population

The figures

The latest Health Protection Agency (HPA) annual HIV report [2] stated that approximately 14% of MSM living with HIV are over the age of 55 years. This percentage increases year on year as more MSM over the age of 50 are testing positive. Particularly significant, however, is late diagnosis (CD4 count <350 per mm³) in MSM aged 50 years and over: 61% of older MSM were diagnosed late, compared with 45% of adults aged 15–49 years [2].

The reasons

However, the profile here is not simply a young population growing older with HIV. Older people are also becoming infected with HIV in their later years. Obviously, testing has become easier, quicker and more accessible and there have been many campaigns to highlight the need for early diagnosis – but what else is contributing to this change? Studies have identified various factors relating to later-life infection, including:

- New drugs: introduction of medications that enhance sexual performance, such as Viagra or Cialis;
- Altered behaviour: new and multiple sexual partnerships in later life due to divorce or death of a partner, which may result in increased sexual contact and greater exposure to HIV [3];
- Physiological changes: thinner mucosal

membranes in the genitalia and anus tear more easily during sexual intercourse, creating easy access for the virus [4].

US findings

In the United States of America, data from the Centers for Disease Control and Prevention (CDC) [5] showed a similar picture for older MSM, identifying a pattern of:

- a) failure by doctors to consider HIV as a diagnosis when seeking causes of illness in older individuals;
- b) age-related faster progression to AIDS;
- c) less recourse to screening for older adults who are assumed not to be at risk.

A range of problems

There are a number of issues specific to men who have sex with men living with HIV. In psychological and socioeconomic terms, the situation is complicated – and health and social services have some way to go before they are ready for a population of older HIV-positive gay men.

Poorer prognosis

Higher HIV incidence in older adults is a cause for concern because they are more likely than their younger counterparts to be at advanced stages of the disease when first identified as living with HIV, progressing to an AIDS diagnosis more rapidly and having a poorer medical prognosis and shorter life expectancy [6]. Within this ageing population living with HIV, we now see an increased rate of chronic diseases that are typical of ageing, eg, cardiovascular disease, diabetes mellitus, osteoporosis and bone fractures, malignancies, and neurocognitive impairment [7]. Issues around dementia also come into play, so that older adults living with HIV display poorer cognitive function (attention, memory, speed of processing, reasoning) than same-aged peers without HIV, and than younger adults with HIV [8].

Harassment and marginalisation

Many older MSM have been victims of harassment and verbal and physical attacks, solely because of their sexuality. Equally, others have spent much of their lives concealing their sexuality, passing themselves off as heterosexual – some to the point of getting married and having children, thus finding it

difficult being open about their sexual orientation. Some end up feeling isolated, unwelcome, marginalised and unacceptable; they do not feel safe in the world, are unable to trust people and be proudly visible. Hiding their sexuality was, and still is for some people, an important strategy for survival and personal safety [9].

A US-based study highlighted that HIV-infected older adults are vulnerable to multiple forms of stigma and discrimination, including AIDS-related phobia, ageism and, for older MSM, homophobia [10].

Concerns around ageing

Appropriate care

As a Community CNS, I am particularly concerned about my ageing MSM patients. They tend to be isolated, independent individuals, with little or no family involved in their care or even aware of their diagnosis. Next-of-kin roles are usually filled by friends of a similar age. These individuals can be strong-willed, with a 'no residential home for me' and 'can do' mentality – which means that support services, if available, have to be both robust and adaptable, meeting all essential care needs while treading carefully around expectations and respecting independence. Gay carers or gay-friendly carers are an ideal but have proved to be a rarity, so there is a gap in the market for appropriate holistic, non-judgemental care.

Lack of recognition

In the UK, older MSM are three times more likely to be single than heterosexual men [11] but many aspects of ageing are shared by these two groups: reduced income following retirement, health concerns and the loss of friends and family members. However, there are differences. One study found that the attitudes of older HIV-positive MSM towards ageing depend on the period of time since diagnosis with the virus, and on personal experiences of the epidemic [12]. Often there is no legal recognition of their relationships (pension provision, life insurance, social security), there can be lack of acknowledgement by family members and friends (next-of-kin, funeral arrangements,) and there is little specialised provision (housing, residential care, social services or groups).

Lack of family

Further research conducted by the Brookdale Center on Aging in New York [13] found that, compared to their heterosexual counterparts, older MSM have a significantly greater dependence on professional care services because they are twice as likely to be single, 2.5 times as likely to live alone and 4.5 times as likely to have no children to call upon in times of need.

Increased frailty

As we age, we expect to become less agile and mobile. Frailty has been highlighted as a particular issue in HIV-positive MSM. Frailty is defined as a syndrome of decreased physiological reserve, which increases vulnerability to negative outcomes such as loss of independence, nursing-home admission, morbidity and mortality [14]. Recent studies demonstrate that HIV-positive individuals are at an increased risk of frailty, some manifesting frailty characteristics at a much younger age than those without HIV [7]. If unable to leave their homes, their isolation may increase, they may be embarrassed by their frailty and not want friends to see them 'in that state'. Issues may only be picked up when they fail to attend appointments or concerns are raised by friends or family.

Ageism around sexuality

One of the biggest barriers to good practice in care for older MSM is the ageist assumption that they are no longer sexual beings. Sexuality and intimate relationships are topics that are often avoided or disregarded. It is not uncommon for sexual needs never to be mentioned in a care plan – apart from where they are identified as problematic or mentioned by the patient, such as erectile dysfunction. Issues of sex and sexuality are relevant for MSM of all ages, and research investigating 'risky' behaviour among older adults has increased in recent years.

Sexual activity in older MSM

Although it is commonly thought that sexual activity and desire decrease with age, studies have shown that both men in the general population and HIV-positive men over age 50 experience sexual desire and that many men are sexually active well into their senior years [15]. In another study among 63 older individuals with HIV, researchers found that only 36% of men had been celibate for at least 2 months since their diagnosis [16]. A 2008 study [17] found that the proportion of gay men aged 50-plus reporting unprotected sex with men who were HIV-negative or whose HIV status they did not know, was similar to that reported by younger gay men. Older but not necessarily wiser!

Risk-taking and the search for intimacy

However, little is known about whether HIV risk behaviour earlier in life continues into later years, or about how HIV status and related factors are associated with risky sexual behaviour after midlife [18]. Relevant areas here may include the public perception of gay men, especially the idealisation of youth within gay culture, body image changes associated with arthritis or weight loss – and desirability, with some older MSM

looking for acceptance within gay subcultures that allow for age difference such as the 'daddy', 'bear' or leather scenes. The search for intimacy, and relationships with younger men, may also trigger riskier behaviours where an offer or request for unsafe sex is hard to refuse for fear of rejection.

Support with ageing

An ageing model

Attempts to develop models for successful HIV ageing have included a 2011 paper [19] proposing eight components:

- | | |
|------------------------|---------------------|
| ■ Length of life | ■ Social competence |
| ■ Biological health | ■ Productivity |
| ■ Cognitive efficiency | ■ Personal control |
| ■ Mental health | ■ Life satisfaction |

Non-judgemental care

Unfortunately, HIV and medication side effects can compromise these factors, thus diminishing one's capacity to age successfully with this disease. However, for the best possible outcome, health and social care staff must remember that the starting point for many older MSM is an expectation of ignorance or discrimination [20]. Part of the professional role is therefore to demonstrate being non-judgemental and free of prejudice: hopefully, this is something that HIV services have mastered but as services are spread out to primary care and generic older person's services, there may still be some work and education needed. In addition, effective interventions to reduce risky sexual behaviour need to be age-appropriate, as well as tailored to gender and sexual orientation [21], to reach the increasingly vulnerable and growing population of older adults living with HIV/AIDS.

Adapting to change

HIV has evolved over the last 30 years from an acute life-threatening illness to a chronic condition, from an illness that was mostly palliative to one controlled with medication. The lives of those living with HIV have also changed: instead of a life-limiting condition that requires a team of skilled professionals to coordinate, HIV today is an illness that for many simply requires responsibility and effective self-management.

Future care needs ...

With changing demographics, we will have an increasingly older HIV-positive population as the decades pass, with all the issues this involves. However, for a rapidly ageing HIV-positive MSM population, what care is needed and who and where will provide it? Whether the choice is residential or nursing-home care, home with

support or home alone, there is no easy answer. I have seen HIV-positive MSM within their own home hiding evidence of their sexuality so they would not upset carers (this has been reflected in various Stonewall and Age UK reports) and feeling unable to discuss their thoughts, views and needs openly and honestly for fear of being judged. I have supported older MSM who are fiercely independent and refuse any offer of extra help, to the detriment of their health. One of the most concerning issues for many healthcare professionals working within HIV is where older HIV-positive MSM patients will be cared for when they become too frail to care for themselves. They are often socially isolated or only have friends of the same age who are similarly frail, with no children to offer additional support.

... and ways to meet them

With an awareness that people usually present well in the clinic environment, it could be beneficial to regularly reassess our older HIV-positive MSM with particular reference to home life. Useful pointers could include:

- How are they coping at home – what is the set-up?
- Who is supporting them – would they like extra support?
- Are they living with someone – or alone?
- What physical problems do they have – how could these impact on them?
- Are they looking frail – could they have had more falls?
- Are they becoming forgetful with medications?

Looking ahead

As our entire HIV-positive population grows older, healthcare and social services will need to accommodate increasing demand for specialised, supportive services. Existing awareness of the needs of older HIV-positive MSM will be a good starting point. Legal and policy changes supporting MSM (as well as lesbian and transgender) have already been put in place, and various reports commissioned and published by Age Concern [22], Stonewall and Age UK have explored MSM-specific needs as regards residential, nursing-home care, carers and resources for training and support.

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Sexualised drug use by MSM: background, current status and response

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Background

Substance misuse and HIV have never been strangers to each other: the injecting use of opiates has always presented a considerable BBV (blood-borne virus) threat to injecting drug users. Health services (particularly sexual health and drug support services) have demonstrated excellent awareness and practice in responding to these risks, constantly re-thinking and improving needle-exchange services and finding ways to better understand and engage this patient group. Additionally, the chaotic sexual behaviours associated with homelessness, sex working and drug addiction are well understood, with workers being highly skilled in HIV management and prevention messages for this vulnerable group.

Recent developments

The last 5 years, however, have seen emerging trends in substance misuse that are not only challenging HIV and drug services, but may also be responsible for the increased numbers of HIV transmissions reported lately – namely, the rise observed by drug support services and sexual health clinics in the sexualised use of crystal methamphetamine, mephedrone and GHB/GBL by MSM populations. One service in particular, the Antidote* substance misuse service, has been overwhelmed by gay men presenting with complicated sexual health consequences from the sexualised use of these drugs. Crystal methamphetamine, mephedrone and GHB/GBL have all become (arguably) a normalised part of sexual recreation amongst gay men in London, and all have the effect of increasing libido and confidence, while decreasing sexual inhibition (Table 1).

This is further enabled by the proliferation of online sites and mobile apps used by gay men to find sex partners, many of which are used with search tools and code words/phrases to help site visitors find 'chem-sex'. While under the influence of these powerful drugs, many users find that any boundaries they may have had around their own sexual activity or adherence to ART (antiretroviral therapy) become inconsequential as chaotic sexual marathons of up to 3 days with multiple partners become a drug-induced priority.

Data sources

I have been observing the epidemiology of these trends over the last 7 years, from my vantage point of managing Antidote, the UK's only lesbian, gay, bisexual and transgender (LGBT) drug and alcohol support service, based in London. Antidote is currently part of the London LGBT health and wellbeing charity, London Friend, and attracts many MSM who may be reluctant to present at statutory or NHS services [1].

Much of the evidence in this paper is based on currently unpublished data monitored at Antidote. Notably, few sexual health or HIV clinics monitor drug use in a way that reflects these trends, instead focusing on injecting opiate use (fewer than 2% of LGBT people presenting at the Antidote service use heroin or crack cocaine, preferring instead to use drugs that serve the context of clubbing and sex). The focus on heroin and crack cocaine use by statutory drug services is associated with classification policy dictated by the National Treatment Agency, whereby heroin, crack cocaine and alcohol are classed under PDU (problematic drug use), and everything else as 'non-problematic'. Many of these services are adapting to these changing trends (as is government drugs policy), with varied success; but, as with all new trends, changes are often reflected first in smaller communities before spreading to the wider population, and this is the reason for a current lack of data from statutory services.

Beyond the data monitored at the Antidote service, we do at least know that:

- there are 25,000 fewer heroin/crack addicts in the UK population since 2005 [2], suggesting that either fewer people are taking these drugs, or that users are switching to new drugs and being less accurately monitored;
- 300,000 people in the UK report having used mephedrone in the last year [3] (as opposed to 0 in 2006);
- gay and bisexual men in the UK used five times more drugs than their heterosexual counterparts in 2010 [1], compared to seven times more in 2012 [4].

Old habits

Seven years back HIV was, unsurprisingly, an issue for MSM, though not directly as a result of drug use.

Table 1: Popular 'chem-sex' drugs: summary

Known as / abbreviation	Full name	Usage
Crystal meth, Tina	Crystal methamphetamine	Smoked or injected
GBL, G	Gamma butyrolactone	Ingested orally
GHB, G	Gamma hydroxybutyrate	Ingested orally
Micauw micauw, drone, MCAT	Mephedrone	Snorted or injected
IDU	Injecting drug use/r	
PDU	Problematic drug use/r	

The most commonly used drugs by gay men in 2005 were ecstasy and cocaine. While many clubbers from that time might have cited hugging a new friend in a nightclub for too long, or entertaining a stranger with one's life story, as the most harmful effects of ecstasy use, it was not contributing in a significant way to HIV transmission. Equally, chatting overenthusiastically at a dinner party, or enjoying some clumsy, twitchy sex may have been a reason to address one's cocaine use, but it would not have been responsible for any significant increase in GUM presentations. However, the data below reflect the dramatic change in MSM drug use over the last 6 years, as seen by the Antidote service, which has contact with over 8,000 LGBT individuals per year, and annually puts 800 people through structured treatment (95% being MSM).

- ▶ In 2005, crystal meth, mephedrone and GHB/GBL were responsible for only 3% of all presentations (the remaining 97% relating mostly to alcohol, cocaine and marijuana; and to a lesser extent, ecstasy, heroin and crack cocaine).
- ▶ In 2012, crystal meth, mephedrone and GHB/GBL were responsible for 85% of all Antidote presentations.
- In 2005, referrals from sexual health services accounted for 8% of our Antidote presentations.
- In 2012, the same referral sources were accounting for 63% of Antidote presentations, a direct reflection of the increased sexual health consequences of these drugs.

Current behaviours

Leap to 2013, where the most commonly used drugs by gay men in London are crystal methamphetamine, known colloquially as 'Tina', mephedrone (referred to in the press as 'micauw micauw') and GHB/GBL (casually referred to simply as 'G'); all are used to varying degrees in a sexual context, with some alarming sexual health consequences.

Data from Antidote presentations are as follows:

- 99% of crystal meth users are using the drug solely to facilitate sex;
- 75% of mephedrone users are using the drug solely to facilitate sex;
- 85% of GBL users report using the drug to facilitate sex;
- 80% of crystal meth and mephedrone users are now injecting in a sexual context (a rise from 20% in 2011);
- 70% report having shared needles to inject their drugs.

75% of these drug users are HIV positive, and of these:

- 60% report a failure to adhere to an ART therapy regime while under the influence of drugs;
- 90% attribute their HIV (or hepatitis C) diagnosis to drug or alcohol use.

In comparison, of Antidote's HIV-negative clients:

- over 50% have had one or more courses of PEP (post-exposure prophylaxis) in the last year (some reporting as many as 10 courses).

Anecdotally:

- most report preferring to use 'bareback' sites to find sex online; usually because of the increased probability of finding chem-sex partners or drug availability on these sites, as well as a desire not to discuss or disclose HIV status while under the influence of drugs;
- most report an average of between five and ten partners per drug-using episode.

The obvious and alarming conclusion to be drawn from this data is that there are large numbers of HIV-positive men, more virulent than they may know due to poor adherence, each having unprotected sex with approximately ten men on most weekends, while under the influence of powerful drugs. This behaviour will be responsible for numerous (and costly) PEP courses, increased HIV diagnoses, as well as other sexually transmitted infections that may make HIV-negative people more vulnerable to HIV, or complicate the health of HIV-positive men.

Obstacles and disincentives

In a gay media climate of HIV prevention messages, there can be a *stigma* that prevents this patient group from accessing support or disclosing risky sex or drug use. There is also a *sense of shame* experienced by many Antidote clients about their behaviour, whether conscious or internalised. They can experience *confusion* as to why they are driven to such sexual extremes while 'high', or compelled to repeat this behaviour despite accessing support. This client group can also perceive *judgment* of such behaviour, real or imagined, by health services [1]. Additionally, there is much *ignorance*

Case study

To illustrate the context and motivations for this behaviour, the following anonymised case study is typical of the client group presenting at the Antidote service.

PJ is a 35-year-old gay man, 7 years HIV positive (asymptomatic) and taking antiretroviral therapy (ART). He first tried smoking crystal meth 5 years ago when a relationship failed, and began using online 'hookup' sites more actively. He found he could have more confident sex which he describes as 'porn-star sex', which would last an entire weekend and gave him a sense of inclusion, satisfaction and sexiness he'd never felt before. He visited saunas and joined sex parties more confidently and frequently, and enjoyed a playground where HIV was never discussed (which he described as 'a relief'); where it was also assumed that all players were HIV positive, and where condoms were rarely used. He soon began missing days at work, was often exhausted and unmotivated and found that his non-sexual social life was diminishing.

Having been made redundant 4 years earlier, his use increased and he was introduced to injecting. He preferred to take his chances sharing needles than getting his own following a visit to a statutory drug service where, despite having disclosed his crystal meth use, he was given injecting equipment and information relevant to heroin injecting (crystal meth injecting practice being quite different). Though he did not disclose his drug use to his HIV healthcare team, he was prescribed anti-depressants which he claimed helped him to manage his comedowns.

PJ was referred to the Antidote service 8 months ago following an A&E admission with drug-induced psychosis (a common side effect of crystal meth

when used without sleep for 2 or more days). He had claimed there was a Satanic cult of crystal meth users at a sex party that had forced him to perform dangerous sex and share blood through syringes and had generally terrorised him. (He later acknowledged that this was transference and that internalised shame of his own drug-induced sexual desires had manifested those beliefs.)

During assessment, PJ disclosed he had not had sober sex in 4 years, and had no desire to do so, claiming it was 'boring compared to chem-sex'. Though ambivalent about making changes to his drug use, he did want to learn how to avoid psychotic episodes and other unpleasant side effects; he was also pleased to access accurate injecting information/equipment, and to discuss his use with an LGBT worker, which he found less shaming than a mainstream clinical setting. He committed to six structured sessions to discuss these issues.

Motivational interviewing techniques were employed to help PJ reflect on the possible benefits of sober sex and intimacy, and to familiarise him with any fears or issues that might be driving his sexual behaviour. The same techniques helped PJ to address a fear of disclosing his status and to acquire the communication skills to do so. He learned to negotiate the risks of drug use and condomless sex so he was more enabled and informed to make safer, more esteemed choices. Work was done to help PJ apply learned boundaries to his online profiles and communication. After 12 weeks of structured sessions (that involved two relapses), PJ was referred to a counsellor to address the impact of his HIV diagnosis on his failed relationship, intimacy issues and post-trauma management from 5 years of self-harm and isolation through drug use.

about newer drug trends from non-LGBT drug services, or the sexual context may be *challenging* for some non-LGBT drugs-workers [1].

There is also a greater sense of *ambivalence towards change* where these drugs are concerned, compared to the traditional heroin or crack. Even the most reluctant-to-change opiate user will have an understanding of the chaos his/her drug use causes, an understanding that any sense of a stable life means abstaining from using; they may even be more willing to identify as an 'addict'. In contrast, crystal meth, mephedrone and GHB/GBL are often a normal part of this client group's sex lives, weekends and general lifestyle, *considered acceptable and normal* as a form of weekend recreation. Thus traditional models of treatment that are abstinence-focused become unattractive and

unsuccessful. Advertising campaigns, harm-reduction messages or assessments that use *traditional terminology* such as 'addict', 'addiction', 'substance misuse' (as opposed to substance use) can be the very things that prevent people from accessing our services, or disclosing fully when they do. A standard question on a GUM assessment that asks a new patient to identify as an injecting drug user may get an honest response from an opiate injector, but it will only elicit *defensive, dishonest responses* from a recreational crystal meth injector, who *does not identify* as such.

Response to change

These trends have transformed the Antidote service from, some would say, a fluffy, 'TLC' kind of service, to one of urgent interventions with adapted/tailored

new treatments, a robust training/education programme and, most importantly, newly formed relationships with NHS sexual health/HIV services. We very quickly learned that Antidote could not exist in this changing climate as a silo, and invited ourselves to as many academic and clinic meetings as we were welcome, to share knowledge and experience, improve referral pathways and (frankly) to seek as much support around these alarming trends as was available to us.

One of the very first discoveries we made was that the 800 or so people accessing support at Antidote each year was just the smaller underbelly of a larger group of drug-using MSM who, though not ready to seek help from a drugs service, were accessing sexual health clinics in large numbers, with frequent STIs or PEP requests as a result of chem-sex.

These clinics were not formally monitoring drug use among these patients; certainly, at least, not in a way that differentiated between a heterosexual opiate injector and a gay man using crystal meth or GHB/GBL for sex. Some informal needs assessments conducted at the busiest London GU/HIV clinics found anecdotal reports of very large numbers of patients disclosing 'party drug' use. It found many nurses and sexual health advisors feeling overwhelmed and under-informed, or learning very quickly and having to think creatively when faced with the chaotic sex lives of their patients, some of whom were presenting – four to six times a month, in various states of intoxication – with STIs, requesting PEP, or alarmed at having missed their HIV medications while on a 3-day 'bender'. Some sexual health clinics also found that patients were presenting for help with drug use, feeling more confident to approach their more familiar GU/HIV clinic, than presenting to a (possibly) frightening, or perhaps poorly informed drug support service.

Addressing needs

1. Training and techniques

Antidote's first response was to develop a training programme [5] for GU staff to instill confidence, to familiarise them with these drugs, contexts of use, associated risks and motivations for this behaviour. It included motivational interviewing techniques that could be applied to this group, to address reluctance and ambivalence about making changes to drug use, condomless sex, number of sex partners or frequency of testing. Take-home questionnaires were designed to help patients reflect on choices, risks and behaviours, again using the motivational interviewing model [6,7].

2. Improved communications

New assessments and waiting-room questionnaires were designed, using colloquial/street terms or slang familiar to the patient group, giving a range

of options associated with hardcore sex practices and drug use [8]. A non-NHS website [9] featuring more explicit harm-reduction information around drug use and sex practices was developed, and a video was produced promoting the clinic [10], which was intended to go viral – all designed to reassure the patient group that they would not experience ignorance of their lifestyles at the clinic.

3. Partnership clinics

A partnership was formed with the busiest of these clinics, the Chelsea and Westminster NHS Foundation Trust's Soho-based clinic, 56 Dean Street, which saw 41,000 new patients in 2011; of whom 482 were MSM newly diagnosed with HIV. That constitutes one in every six new HIV diagnoses amongst MSM in England [11]. If all those had been monitored for sexualised drug use, the results would most certainly have informed this paper better.

This partnership started with the weekly evening clinic, 'CODE'. Targeted solely at MSM who use drugs for sex, CODE was staffed by specially skilled or trained, MSM-identifying drugs workers, peer mentors, doctors, nurses and sexual health advisors. It was marketed as a non-judgmental safe space where all things sex and drugs could be discussed. (We were fully aware that very few clinics are in fact judgmental; however, because there may have been more shame associated with this group, the non-judgmental, drug-aware message was made loud and clear in the publicity.)

A second partnership was formed with Central North West London's (CNWL) Club Drug Clinic at Chelsea and Westminster Hospital that worked exclusively with crystal meth, mephedrone and GBL (as well as some other novel psychoactive substances) – though no alcohol, marijuana, opiates or crack cocaine. Using a CNWL Innovation grant, it broke the impractical mould of borough-exclusive care and borrowed from the sexual health model of pan-London access. Despite being open to all (LGBT and non-LGBT), it was immediately at capacity, with 80% of attendees being MSM using drugs to facilitate sex [12].

Conclusion

It is arguable that the sexualised use of crystal meth, mephedrone and GHB/GBL is now the greatest threat to MSM health and wellbeing, with the consequences broadening from a small London charity to numerous statutory health services, and similar evidence appearing in larger cities around the globe. Providing holistic care for our patients has never been more relevant, with sexual behaviour and substance use being more closely connected than any time in the history of HIV. The evidence also suggests that these trends are continuing to rise rather than level out, and the projected costs to MSM wellbeing and NHS budgets could be considerable.

Workers in substance misuse and sexual health/HIV could address these behaviours and consequences with greater confidence, simply by having access to available training and improved multidisciplinary collaborative work with third-sector organisations that may be better acquainted with this patient group's needs. The language and appropriateness of assessments could be tailored to gain trust and increase disclosure from patients. The (informed) monitoring at GU/HIV clinics of patients' drug use, as well as sexual behaviour monitoring of people presenting at drug services, would enhance insight into these trends. Raising the general public's awareness of these trends will help address ignorance of these dangers both among users and within NHS services. It is also important to address loss of faith among MSM in the ability of the NHS to provide informed and tailored care around these issues.

An enormous amount of HIV prevention work is being done with this client group by Antidote workers, including ART adherence while 'high', safer online sexual behaviour, ambivalence around HIV disclosure, condom use, regular screenings and issues contributing to chaotic sexual behaviour. Although much prevention, campaign work and funding is directed at HIV-negative people, the evidence above suggests there are large numbers of HIV-positive MSM that may be in need of more focused care to address what is clearly a developing epidemic of risky, drug-fuelled sexual behaviour by some very vulnerable people.

**Antidote is an LGBT drug and alcohol support service. Data were drawn from assessments, surveys and recounted experiences, 2005 to 2013. Tel: 020 7833 1674
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Outreach HIV testing in Soho's G-A-Y bar

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Background

HIV prevention needs to remain high on the agenda in order to reduce onward transmission, improve health and save lives. The Department of Health (DH) has stated that prevention should be the main focus of the response to HIV [1]. Advantages of prevention include: preserving individual health, protecting partners and reducing the spread of the virus. Advances have allowed us to go beyond education about condom use, with recourse to options such as treatment as prevention (TasP), post-exposure prophylaxis (PEP) and now pre-exposure prophylaxis (PrEP).

However, let us not forget the importance and strengths of our existing armoury in the fight against HIV. Providing fast, free, confidential and easy HIV tests is key in preventing HIV transmission, to help individuals find out their status and have earlier access to care. The Health Protection Agency (HPA) has estimated that 1 in 11 gay men in London are HIV positive, and 24% of these are unaware of their status [2]. Not only is their own health at risk, but they may also be infecting others. The HPA has also found that over half of the UK HIV diagnoses in 2010 were late [above the CD4 cell count where guidance (3) recommends starting treatment] [3]. Further, British HIV Association (BHIVA) guidance [4] states that late diagnosis may have long-term implications for mortality, comorbidities and response to treatment, thus highlighting the benefits of early diagnosis to the individual.

Knowing you have HIV can save your life, or add years to it. Therefore perhaps we need to rethink the 'is it right to test?' approach by considering the implications of not testing. With the right support and easy transition into HIV care, we really can make a difference.

Current NICE guidance recognises the importance of 'normalising' HIV testing [5]. As a test is only accurate before the window period, and people's status is subject to change, HIV testing is not a once-in-a-lifetime event. Therefore 'normalising' may ease the burden and empower people to return for regular testing. There are several key elements which make this happen, based around the practitioner's ability to make the patient feel safe, empowered and not judged. Also, we must keep in mind that presenting for a HIV test can be a major event for an individual, particularly someone who may have had risk, and the possibility of a positive result may present more

anxiety than the uncertainty of not testing [6]. Therefore, if someone has the courage to attend for a test, it is imperative that this is acknowledged and the test provided in a way which ensures the patient feels supported and able to return for regular testing.

The set-up

UNAIDS has recognised that providers must be able to access and empower vulnerable populations in order to reduce sexual transmission of HIV [7]. Further, several studies have indicated that some people prefer to test in non-clinical settings within the community [6]. That is why 56 Dean Street and G-A-Y bar came together to design a service for those who are at risk and unlikely to access current services. We send two nurses to G-A-Y bar (one of the most popular gay bars in central London's gay district, Soho) to provide instant, safe, confidential HIV tests and hepatitis B vaccinations every Wednesday.

A person attending a clinic and being offered a test is a product of individual choice and available opportunity; whereas our outreach service at G-A-Y bar not only offers the opportunity but also takes a more targeted and proactive approach to testing as prevention.

The basement bar is temporarily closed and the area is transformed into a pop-up HIV test and hepatitis B clinic. There is a large area that we use to register patients and give hepatitis B vaccinations. We have access to a private cloakroom which benefits from a discreet exit away from the bar into the street. This is where we conduct the HIV point-of-care test and give the result immediately. As the clinic is just around the corner, we advise all patients that confirmation tests and further support are available in the clinic – and ideally we take them straight across following a positive result. Many patients agree to this before the test but some change their mind when given a positive result. Therefore, we provide immediate essential support, give out an advice and information leaflet to ease transition into our HIV care clinic and obtain telephone support via Terrence Higgins Trust. We record a mobile number prior to testing and check that our health advisor can contact them to arrange follow-up.

We work with our charity partner GMI (Gay Men's Interactions) who help to inform people that this service is available. GMI is currently conducting a survey of gay men's understanding of safer sex and

will provide information and further intervention when necessary. We also advertise on the electronic message board and display posters throughout the bar. People are not pressured into testing and if they choose to attend are still encouraged to access full screening services in our clinic after their test. During our pre-test discussion we assess risk, understanding of HIV and ability to handle a positive diagnosis, explaining also issues such as window periods and false positives. We are

also likely to be assessing peer pressure, alcohol consumption and ability to consent. We communicate how we will support the patient following the result, with advice to stay negative, or support following a positive diagnosis and referral into our HIV care service.

The following two anonymised case studies offer some insights into how our service operates, how people respond and what we aim to achieve long term.

Case study 1: 'Adam'

Adam is 19 and moved to London 4 months ago to study drama. His personality is outgoing and when talking to him, it's hard not to smile. Before he moved here he was in a monogamous relationship with a man for six months and, after both testing HIV negative 3 months into their relationship, decided to stop using condoms. We discussed his previous relationship and the fact that he has not tested since then.

Adam has had approximately 10 partners in the past 3 months. He always uses condoms but said he often gets asked if he will have bareback sex. Sometimes he feels pressured and finds it difficult if a potential partner rejects him. He is confident that his only unprotected sex was with his ex-boyfriend. He is aware of HIV and other sexually transmitted infections (STIs) but he told me, 'it will never happen to me'.

He trusts his ex-partner and we discussed the pros and cons of negotiated risk. I challenged his views about it never happening to him and explained that it can happen to anyone. I also acknowledged that it was really good that he had not been pressured into taking risks with his casual partners. I asked if he would be more worried about this test if he had been taking risks with more people, which he said he would. We agreed that life is less

complicated when people look after themselves and enjoy a healthy, safe sex life.

Adam said, 'I'm not scared of HIV but I'd rather not have it' which, after further discussion, reassured me that he was okay to proceed with the test. BHIVA testing guidelines advocate that lengthy pre-test discussions are unnecessary unless specific need is identified [4]. We discussed HIV a bit more and it turned out that Adam has a friend who has been living with HIV for 3 years who is well and not currently on treatment.

I told him about the window period and false positives with the test. His test was negative so I took the opportunity to explain PEP and testing for other infections. The importance of regular testing and early diagnosis were also emphasised. It emerged that he had not had a course of hepatitis B vaccinations so I gave him his first vaccine and explained the rapid course of the disease, and that he can walk in to our clinic for the further injections. I also recommended a full STI screen and emphasised the prevalence of these infections.

As he was leaving, he thanked me for doing his test and I told him that he should continue to use condoms as well as he has been, and to test for HIV at least once a year.

Case study 2: 'Pablo'

Pablo is a 38-year-old gay man who does not like to visit health settings. He has been worried that his behaviour may have put him at risk of acquiring HIV. As he is not keen to attend a clinic or his GP, he has been putting off testing for the last 5 years. He saw the signs in the bar and decided he wanted to find out his status today. He has had unprotected sex with a number of casual partners in clubs and saunas; plus his regular partner of 3 years is HIV positive, and they have unprotected sex. He told me his partner is on treatment and undetectable but that he is unsure of the status of the casual partners.

When he has sex he is mainly passive, but he told me that he is versatile. He said that the men he had unprotected sex with must be negative – as positive men would always use condoms. Available data support advice on the danger of assuming status when deciding to take sexual risk [8], so I pointed out that his positive partner has unprotected sex with him, and also that people could be unaware of their status, or assume he is positive. Therefore, it is better to ask and be sure, but ideally he should always use condoms to protect himself.

I advised Pablo that ideally it would be better to test in clinic, as he has had risk and we could provide

continued over

continued

better support in that environment. I offered to take him over at the time but he said he would rather test in the bar. He agreed, however, that if the test was positive he would attend the clinic the following day for the confirmation test and follow-up care. When I asked him, Pablo was realistic that he might have a reactive test in the bar.

Pablo had a drink in his hands, but said he had only had two drinks and was aware of what he was doing. When we discussed his history and I assessed his understanding of HIV, it was clear that he had capacity to consent: his partner is well and he also has friends who are positive. He said he was aware of post-exposure prophylaxis (PEP), having taken it 3 years ago.

He has good supportive friends and his partner has been encouraging him to get a test for months. His partner was sitting in our waiting area (the basement bar) and Pablo told me he was 'on hand if needed'.

I discussed the window period and explained that, as he had unprotected anal sex with his regular partner a week ago, if this test was negative we would need to repeat it. I also said that, realistically, there is a strong chance this test could be reactive, and gave a second opportunity to test in clinic.

As we had expected, the result was reactive. Pablo did not seem overly surprised. I asked him how he was feeling, he looked me in the eye and said, 'I knew it would happen at some point, now I have to deal with it'. I gave him a hug and reassured him that we would make sure he got the support and care he needed. I also reinforced to him the advantages of knowing his status, such as taking control of his health, protecting his partners and starting treatment to prevent ill-health. Hopefully, he will have some time to come to terms with his diagnosis before he needs to start treatment. As he last tested 5 years ago, it is difficult to know when he contracted HIV.

People react in various ways when given an HIV diagnosis and it is a highly sensitive, personal experience. It is not always possible to predict how someone will react within the bar, as opposed to a clinic setting – and situations can be more volatile and difficult to manage. We are guests in the bar and sometimes people accidentally enter the room, it can be noisy or there could be a party

atmosphere around you. We try to minimise this and make the best of the situation. Another factor is different levels of preparedness for a positive result, comparing attending a clinic and being offered a test, to spontaneously choosing to test in a bar. Every setting has its own issues, but the patient experience within the clinic setting is likely to be smoother. Luckily, on this occasion we had complete privacy during the test, Pablo was prepared for a positive result and his partner was supportive.

Pablo has not had sex in the last 72 hours so at this stage we were not considering contacting anyone urgently to get PEP. However, I advised Pablo that we would need to do that confirmation test, talk about informing partners and take his bloods to confirm his status and better understand his current health. He asked me if I could fetch his partner so he can tell him and they can attend the clinic together. I explained to him that it was important to think very carefully before disclosing to anyone as people may not react in the way we may expect. Pablo explained that he wanted to tell his partner then and was certain that he would be understanding and supportive. I discreetly went to his partner and asked him to come into the room. The three of us left the bar (after I informed my colleague) and went to the clinic, straight into a consultation room. I left the couple for a few minutes, after explaining that the health advisor would perform the confirmation tests and handle the rest of his care that day. A health advisor was on hand, I gave her my notes and handed over the patient. I then introduced her to Pablo and his partner.

The next day I discussed the patient with the health advisor, who said that Pablo had handled the news well. He had said he was grateful for the test being provided in the bar and felt he had been well informed and supported throughout. In addition to the confirmation test, a fast CD4 check was performed, with a result of 766. He has subsequently seen the health advisor on three occasions for counselling and appears to be doing well. His first medical appointment concluded that he did not need to start treatment immediately and, following initial counselling, will have his bloods checked every 3 to 4 months.

World AIDS Day record

On World Aids Day 2011, in collaboration with G-A-Y bar, we took the opportunity to set the Guinness World Record for most HIV tests in a single location in an 8-hour period. Although the nature of the event attracted plenty of free media coverage and wide community support, our central aim was to increase awareness and testing rates of HIV in

our area of London. Building on our experience of testing in the bar, we worked with community partners to maximise engagement and relevant skills in supporting patients on the day. We tested 467 patients and none were lost to follow-up.

Evaluation of the event showed that attendees were younger, more at risk and less likely to have previously tested compared to a control sample in

the clinic [9]. Thus the success of the event was confirmed, as were the common characteristics that we have observed in the cohort who access our outreach service at G-A-Y bar.

On World Aids Day 2012 we beat our own record, with 745 tests, and are currently in the process of auditing the data.

Conclusion

Our HIV testing and hepatitis B pop-up clinic at G-A-Y bar sees a range of patients of various ages with different care needs. We send our experienced team to the bar to provide tests and we do see people who would not attend our normal services. Working in the bar is not without its challenges. In addition to the routine complex assessment of someone's ability to handle a HIV diagnosis, we are also faced with a challenging environment of patients drinking alcohol and in a social setting. It can require extra input to ensure a patient stays following the result and then attends normal services for follow-up care. Luckily, through the procedures in place and the hard work of our nurses and health advice team, it is rare that we lose a patient to follow-up.

The UK National Screening Committee has stipulated, 'the benefit from the screening programme should outweigh the physical and psychological harm (caused by the test, diagnostic procedures and treatment)' [10]. Our clear view is that the risk of undiagnosed HIV to the health of the individual is greater than the potential harm (when managed) in providing testing in this setting. It is hard to imagine the service not being provided, as a number of the patients attending regularly say they do not attend other services. The Department of Health reports the UK government belief that increasing HIV testing should be a prevention strategy to reduce HIV in high-prevalence areas [2]. Without this service, a number of people in our current cohort might not be tested for HIV or engage in health promotion activity which can reduce their risk of acquiring HIV.

This outreach service has been designed to best facilitate testing in this environment and agreements with the bar manager help us to provide a service which is both acceptable and safe to our patients. The relationship between the clinic and the bar has enabled us to provide care beyond the confinements of our clinic location and test those who are unlikely to attend.

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Thinking positive

A heterosexual man's account of diagnosis, adjustment and securing a new future

I've been asked to write an article about the kind of issues a heterosexual HIV-positive man might face or has faced in the current climate and time we live in. This is not the first time I have been asked to do this – although I have declined in the past.

The main thing I have realised about being HIV positive is that you can face different issues at different times, many of which arise from the infrastructure you have around you. This infrastructure has nothing directly to do with living with HIV as a heterosexual man, but it can have a direct effect on how you're able to cope. These factors, which can be many or few, may have a bearing on your diagnosis – in a significant way, in a small way, or not at all:

- Do you have a good job and if so is it likely to be affected by your diagnosis? If you're unemployed then is your diagnosis going to affect your chance of the work you want to do?
- Do you have supportive friends and family that you could trust with your diagnosis or are there strained and uncertain relationships that could lead you not to tell them?
- Do you have a comfortable lifestyle? Do you live in a stress-free environment at home, with your own space, or do you share a house with others – and what would happen if they found out?
- Are you in a relationship and is there a person or person(s) you have to disclose to – or are you single?
- Are you healthy or do you have other medical issues that could be compounded by HIV? Are you going to start antiretrovirals straight away, or are you going to wait?

These are just some of the questions that might occur to someone when newly diagnosed, and pretty much all of them could also apply to a woman or a homosexual. Many of the issues that may or may not impact on how we deal with our diagnosis, and subsequently with living with HIV, are fairly universal; equally, some are definitely more relevant to specific groups. However, what is clear from the list above is that your own life circumstances influence and overlay the process of dealing with HIV as a whole – and how unhelpful it can be to try and put people dealing with HIV into boxes. One thing I have learnt since my diagnosis in 2001 is that you really

shouldn't try. Everyone's experience of living with the virus is different: for some, it has had a major impact on their lives, while for others it has been a nuisance but changed little for them on a daily basis.

I fall somewhere between the two. When diagnosed I had a good job, working fairly steady nine-to-five hours in an office environment. My diagnosis was a shock but I decided not to tell my family and told almost none of my friends. I wasn't sure how I had caught the virus – but I had to get someone to test whom I had recently had unprotected sex with. This was the first issue I faced. Even though I was still reeling from my own diagnosis, ironically my biggest concern at the time was whether I had unknowingly infected someone else. Although I could have had a doctor contact them anonymously, I preferred to tell them myself. At the time I lived just outside London and am now aware that consistency of care in the NHS, especially around the time of diagnosis, is something that was not, and still isn't, how it should be. I was told first over the phone, probably at my own insistence – but nevertheless, this should have been handled more appropriately.

'A member of staff told a family member of my condition, resulting in my whole family finding out.'

Support groups

For almost a year I told no one. I was single, did not embark on any attempts at a new relationship and kept myself to myself. At first it was okay, but then I became ill and spent a week in hospital. Two things went wrong there. First of all, a member of staff told a family member of my condition, resulting in my whole family finding out; and secondly, I realised I didn't have anyone to talk to about it. I felt isolated. I told one friend who I knew was bisexual so I expected her to be a little more liberal in her views. She was very supportive and told me she already had another friend who was positive who she went to a support group with – so I got some information on this group and attended a few times. While it was great to meet some other people in a similar situation and I made a few friends there, I did not feel I was spoken to as an adult by the staff. I went to a second group which was more mixed and included some gay men. I didn't have a problem with this at all and in some ways found the group better than the first one, but it lost its funding and closed. I kept in touch with a

'Although I could have had a doctor contact them anonymously, I preferred to tell them myself.'

few people and, until about 6 months before I decided to start medication, I dealt with it all fairly well.

My family had been supportive – they let me know they were there if I needed them but didn't intrude. Probably some 2 years after my diagnosis I started to have some real issues. Firstly, my skin became so

'In the first couple of years, a relationship had never occurred to me, but now I was lonely.'

bad that I didn't want to go swimming, which was my favourite hobby. Secondly, I started really getting tired and suffering from an extreme lack of energy. When I started the tablets I had (wisely) taken some time off work. The first type I went on, I didn't get on with at all, and the second settled down after a few

months, but for 6 months I was all over the place. I had a lot of problems sleeping and was getting into trouble at work.

In the end I took my boss to one side and I told him what had happened. He was a partner at the firm and the first thing he said to me was, 'I didn't know you were gay' (this was in 2005!). When I told him I wasn't, he was even more surprised – stating that he 'thought only gay men and drug addicts could get it'. To be fair to him, he took time to educate himself on the subject, too much perhaps, as he was always prompting me to read one article or another. However, the pressure was taken off at work and I became better at my job as a result, with no issues there since.

In the first couple of years after diagnosis, a relationship had never occurred to me, but now I was lonely and wanted one. After a while I was also having a lot of problems sleeping and wanted to change my medication again. My consultant told me about a group meeting where a man called Robert Fieldhouse was speaking. I went along, and

'It was great to hear how people had overcome such difficulties and to share information with peers.'

there were around 40 people there, one of them being someone I knew from a different group I had been to. Mr Fieldhouse was very good at giving a 'warts and all' patient's perspective on medication issues and, with his help, I was able to resolve

mine. I also went to the pub afterwards with about 20 people who had been at the meeting and ended up dating a girl from Eastern Europe for a while. It ultimately didn't go anywhere, but it made me feel human again and also made me realise that if I was to date someone who was positive, they should be someone I would date normally, someone I had other things in common with, not just our HIV.

Swiss Study

The group that had organised this meeting was run entirely by HIV-positive facilitators, which made a

big difference for me and I went to a few more of their meetings and met a really wide range of people. Over time, I realised just how different everyone's issues can be. Some people had fallen out with all their family or friends because of their diagnosis, others had lost their jobs, and some had other issues – be they mental, physical or financial – that were just made all the worse by their HIV diagnosis. However, it was also great to hear how people had overcome such difficulties and to share information with peers. This was extremely helpful. It was here that I found out about the Swiss Study, when one person in the group talked about how this had made it easier for them to disclose to the person who is now their partner, and how they had just had a negative baby.

I read up on this further and realised how helpful it would be with my own disclosure issues. I was now on meds, doing well, undetectable and had no sexual partners ... so, armed with his information, I went and got myself one. That person turned out to be the first friend I told. We had got very close over the years and I realised one day I was in love with her. When I told her this, she told me much to my

'It is a mistake to put us all into boxes and assume the issues we face will all be the same.'

surprise that she was in love with me too but she had thought her bisexuality would put me off. It didn't and we got married a couple of years ago. The peer support I had and the information on the Swiss Study were major factors in overcoming the HIV issues we faced as a couple.

Compared to some, I think I have had it quite easy. My most difficult times with HIV have mostly been because of stress caused by other factors. I am not a doctor, but it seems that HIV loves stress. Some of us have a lot of things and people we can depend on in difficult times, but sadly some people have no one and nothing at all. As I am keen to reiterate, it is a mistake to put us all into boxes and assume that the issues we face will all be the same. I've also realised that it is important to give something back, so I return to the group when I can and find myself giving advice to people who are now at the stage of early diagnosis – helping them in my own way is very rewarding.

■ **Straight Talk** is a support group that operates in a social setting, for heterosexuals living with HIV. They can be contacted in confidence at:
str8talksg@yahoo.co.uk;
or through **Positively UK** at:
info@positivelyuk.org

The writer wishes to remain anonymous. However, correspondence can be sent via the Editorial team: naomi@mediscript.ltd.uk

Boys will be boys: risks and realities for young men with perinatally acquired HIV

Alison Barnes

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Introduction

Adolescence (when a person is aged 10–19) [1] is a time of profound physical, cognitive, emotional, and social development, change and exploration. Because of medication improvements and reduction in mother-to-child transmission (MTCT), most children living with HIV in the UK are now adolescents, and the median age of a child in the CHIPS population (a multi-centre cohort study of children infected by HIV in the UK and in Ireland) is 13.1 years. Approximately one-third of all children living with HIV in the UK are over the age of 15 [2]. While the mortality rate of children living with HIV has greatly decreased since the availability of HAART, it is still disproportionately higher than in non-infected populations.

There are substantial population data about the clinical outcomes of these young people, thanks to the CHIPS study, and a range of high-quality data, abstracts and presentations is available, most of which can be found through the BHIVA, CHIVA, and NHIVNA websites. There is also specific, published information about HIV-positive young women's sexual health practice and outcomes [3]. Unfortunately, there is currently a dearth of information about the psychosocial experience or needs of adolescent males living with perinatally acquired HIV in the UK [4].

This article aims to provide a clearer picture of what life is like for adolescent males living with perinatally acquired HIV in the UK. It will use data from a 2012 risk assessment conducted by Body & Soul, a third-sector organisation. While the assessment is only a snapshot of this remarkable population, it will hopefully help to inform practice. Three of the participants agreed to provide anonymised one-to-one interviews: see Growing up with HIV.

Reasons for the risk assessment

Body & Soul (B&S) is a third-sector organisation whose aim is to provide front-line, transformative services to people of all ages living with and affected by HIV (PLHIV), in order to improve their health, wellbeing and quality of life.

During its 16 years of operation, through its adolescent programme, Teen Spirit, Body & Soul has witnessed the impact of HIV on young people's self-worth, self-confidence, self-image and perceptions

of the future. For young people living with and affected by the virus (YPHIV), the diagnosis can bring fear and uncertainty about their future life roles, whether in families, in relationships or in their careers.

Due largely to the stigma and hostility surrounding HIV, YPHIV are incredibly marginalised. Because most are from ethnic or sexual minorities and thus already experience social discrimination, there is a compounding effect of layered stigma. Young people often struggle to overcome the impact of an HIV diagnosis and move forward with their lives. Poor resilience (due to early life trauma) magnifies these difficulties.

Without knowing what these teens need, we cannot know which programmes will best help them. Since the experience of growing up infected with or affected by HIV is so vastly different from that of other young people (due to stigma, isolation, bereavement, and care-giving responsibilities, to name a few confounding factors), simply studying youth trends across different boroughs is not helpful here.

While we can infer certain things about their lives based on health outcomes, service utilisation, general youth population trends, and a few research papers, these sources provide insufficient insight into this population. The majority of academic studies about HIV and adolescents do not illustrate the realities of being a perinatally infected adolescent living in the UK. This is because:

- *either* they are sited in resource-poor developing countries, or the United States, where most HIV-positive young people are horizontally infected and have therefore demonstrated prior engagement in high-risk behaviours;
- *or* they focus too strongly on the female experience for the purposes of balance.

Research methods

To improve our services, Body & Soul needed to identify key risks and risk behaviours for the young people in Teen Spirit, by identifying and then modifying an appropriate teen risk survey. Initial survey contenders included: the DASH survey, the Youth Risk Behaviour Survey (YRBS) and the Tellus survey. All were designed to measure teen risk behaviour, but varied in length and content. Body & Soul felt that modifying the YRBS would best target the Teen Spirit population.

The YRBS is a survey administered to over 16,000 young people aged 14–19 in schools throughout the US [5]. In its full form, it consists of about 86 questions. It reviews:

- behaviours that result in unintended injuries or violence;
- tobacco use, alcohol and other drug use;
- sexual behaviours that contribute to unintended pregnancy or STIs (including HIV);
- poor dietary habits;
- obesity and weight issues.

In order to retain youth interest, Body & Soul wanted the survey length to be manageable in the context of a normal service night, as well as capturing what we considered the key data. Starting with the 86 questions, Body & Soul eliminated questions deemed irrelevant or inappropriate for a UK cohort (using a list of desired indicators), arriving at a final total of 47. Given the potential overlap between general risks and HIV-related behaviours, we also included further questions about HIV. While some question content might have been sensitive for participants, equally the health behaviour areas covered all related to Body & Soul's usual work and thus were necessary for service improvement. For example, Body & Soul regularly discusses HIV with young people, so asking about HIV status or adherence was a clear requirement and would not be distressing to the young person.

Surveys were administered anonymously, youth were informed prior to the survey's administration about its possible uses, and young people were able to opt out of participation. This was a needs assessment for service improvement rather than research, so no ethical approval was required – although we minimised risk by piloting the survey with adolescents and young people, to determine whether content was appropriate. Participant involvement was anonymous and voluntary, and each youth was given a safe environment to fill out the survey. All surveys were completed in pencil to avoid recognition of specific individuals, with data entry by a Master's student to prevent Body & Soul workers from recognising participants based on demographics.

We would define the survey as a needs assessment aimed at improving our services. The results indicate risky (or health-promoting) behaviour amongst our teens, and allow us to compare behavioural risk based on age, gender and other characteristics. The aim is to isolate risk-behaviour trends, rather than identify causes for risk behaviours. The survey could tell us, for example, that HIV-positive 16-year-olds who responded are more likely to eat curry ... but will do nothing to illustrate why. Equally, this survey can only tell us about the behaviours and experiences of the group with which we work and there could be major incongruities in the findings, if comparisons were

ever made with other HIV-positive young people. Ultimately, our survey cannot illustrate what life is like for all teens whose life is directly impacted by HIV, but the hope is that this group's results will demonstrate some trends.

Survey results

Fifty-three adolescents completed the survey, of whom 20 were male and HIV-positive. This report will focus on the male responses. In the absence of an appropriate community comparison, it is impossible to say whether the findings are typical outside the survey group.

The mean and median age of respondents was 16. Seventy per cent of respondents self-identified as 'Black African', 20% as 'Black British', and 5% each as 'Black Caribbean' or 'Mixed Ethnicity'. Most were from the London area. Given the usual African family living with HIV in London, and consistent with individual needs assessment and case management work that Body & Soul conducts regularly with the respondents, we can confidently say that respondents all come from impoverished socio-economic backgrounds [6].

All but one of the respondents were currently in education or vocational training. While we are unable to compare this result to a community cohort, it might reflect the high level of educational support received through the Teen Spirit project and might not be indicative of population trends as a whole.

Life at home

Respondents have overwhelmingly experienced early bereavement and early carer responsibilities, which can have knock-on effects to their abilities to participate in activities outside the home. Seventy-five per cent of the respondents had had a parent or sibling die. An equal percentage regularly took care of a family member. Amongst those who regularly cared for family members, 37.5% cared for a family member at least 3 hours a day, 50% cared for family members 1–2 hours a day and the remainder either cared for a family member for less than 1 hour a day or provided the non-quantitative answer, 'depends'. Despite the fact that all respondents acquired HIV either perinatally or in early childhood, 60% reported never talking about HIV with their family.

Life at school and in the community

The young men responding to this survey generally felt safe in their communities. All reported always feeling safe enough to go to school. Only two respondents reported experience of bullying (one of whom additionally experienced electronic bullying). One person reported bullying someone else.

Violence, criminality and perceived criminality were relatively common in this group. One individual reported carrying a weapon occasionally. Two people identified themselves as gang members. Fighting was also commonly reported.

In addition to addressing experience of bullying, feeling unsafe at school, or fighting (Figure 1), the survey asked about criminal activity, past arrest, and stop-and-search. Stop-and-search is the name given for the right of the police to stop and question any person that they believe needs to be questioned and then to search them if they find reason [7]. Young people targeted through stop-and-search can find it a deeply demoralising experience that contributes to feeling 'different' or socially unwelcome. Because ethnic and socio-economic bias or discrimination is a common component of stop-and-search, we felt data on experience of stop-and-search, on actual past illegal activity, and on past arrest should be explored in this survey (Figure 2). It is important to note that young males experience stop-and-search far more frequently than young females.

Physical health patterns

Health patterns established in adolescence often persist into adulthood, so this survey also looked at current physical health patterns. Thirty-five per cent reported exercising daily, 30% almost every day, 20% 1–2 times weekly, while 15% almost never exercised. Television habits were slightly less encouraging, with 20% watching a minimum of 4 hours daily, 45% at least 2–3 hours daily, and the remaining 35% 1 hour or less of television daily.

Most young people (55%) remembered learning about HIV in school, although a similar needs assessment with the same cohort showed an incredibly low understanding of specific concepts around HIV (such as CD4 and viral load). Seventeen respondents were on treatment, one was not, and two did not answer this question. There was variation between individuals in patterns of taking treatment and attending appointments (Figure 3).

Mental health and substance misuse

Adult populations of PLHIV demonstrate high rates of mental health comorbidities. This survey asked two questions directly related to mental health, one being the basic depression screening question, 'Have you ever felt so sad or hopeless that you stopped doing your usual activities for 2 weeks or more in a row?' – to which 40% answered yes. Thirty per cent reported having thought about attempting suicide. While mental health screening is included in BHIVA and CHIVA standards, it is important to note that cohorts such as this might have a particularly high risk of mental health

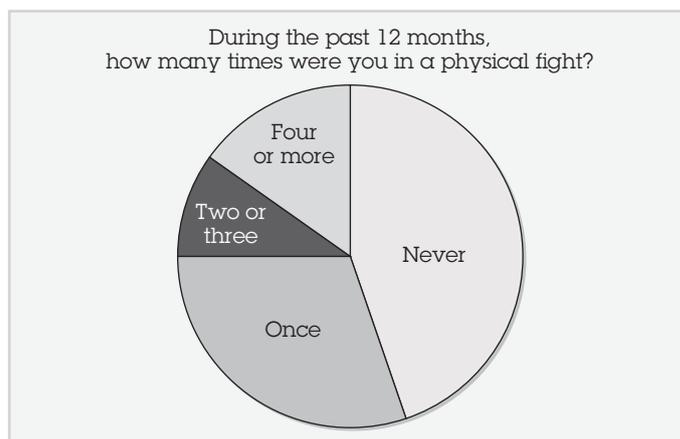


Figure 1: Reported involvement in physical fights during last 12 months

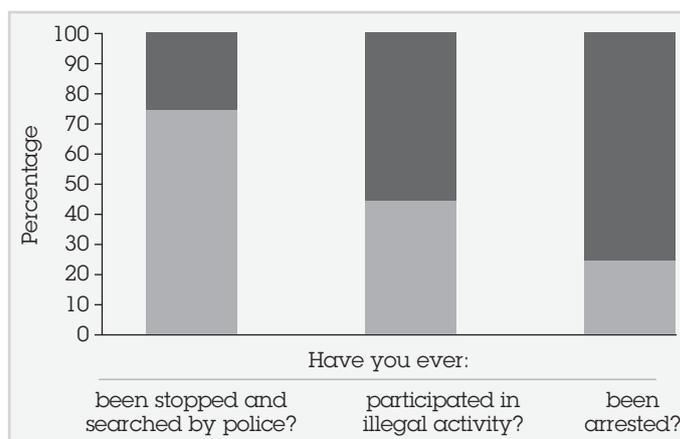


Figure 2: Comparison between frequency of stop-and-search experiences; actual illegal activity; and arrest. ■ Yes. ■ No

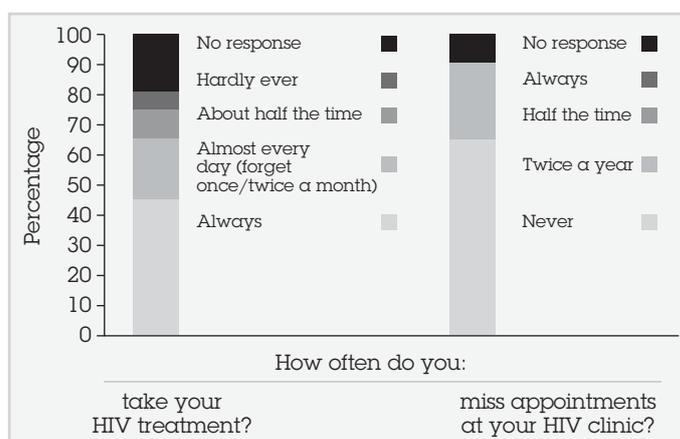


Figure 3: Treatment adherence and clinic attendance

complications due to multiple social, personal and health factors.

Most respondents did not smoke: only one had started smoking before age 12, and three between the age of 13 and 15. Only one respondent reported a current smoking habit. No respondents reported having ever used inhalants to get high (in contrast, sniffing glue was relatively common amongst adolescent females – more than 1 in 5 answered yes to this question). Only one respondent had used cocaine, crack, ecstasy or heroine, and he reported using drugs 'three or more times'.

Alcohol and marijuana use was more common and had been started younger than cigarette smoking or other drug use. Thirty-five per cent reported having their first 'real' alcoholic drink before the age of 12; 25% said this had happened between the age of 13 and 16; while 40% reported never having had alcohol. Regular drinking of alcohol was reported by 20%, of whom 50% reported regular binge-drinking of five or more drinks within a couple of hours. One person had tried marijuana before the age of 12, eight between the ages of 13 and 16, and one after the age of 17. Fifteen per cent reported regular marijuana use.

Sexual behaviours

In answer to the question, 'Have you ever had sexual intercourse (sex)?', 55% said that they had, 35% said that they had not, and 10% responded 'not sure'. Future use of this survey will include clarification of what is meant by 'sexual intercourse', as we appreciated in retrospect that this wording was too vague. One respondent reported experiencing domestic violence and one reported perpetrating domestic violence (which he chose to write in the accompanying survey feedback, as it was not an included question). Amongst those who have had sex, more than half (55%) reported having had sex when aged 14 or younger. Young people living with chronic illness as a whole receive minimal sex education in paediatric settings; the early sexual debut reported in this survey might reinforce standards that promote earlier discussions around HIV and sex in clinical, school, and home environments. Amongst sexually active young men, almost one-half have drunk alcohol or used drugs before sex. Condom use was also inconsistent, with one-third of the sexually active teens reporting using a condom only sometimes. Only one respondent was aware of getting a girl pregnant.

Discussion

Adolescence is a challenging time for most young people, and having an HIV diagnosis can magnify this. In order to have the maximum chance for success, these young people must have their needs met by appropriate programming and interventions. Given the small sample size and the fact that everyone questioned accessed the same support service, the results outlined above are not necessarily reflective of the realities for all adolescent males with perinatally acquired HIV in the UK. If this were a research study rather than a needs assessment, there would undoubtedly have

been different decisions on sampling and approach. As a population-level needs assessment, used in conjunction with more in-depth individual needs assessments, this survey's results fed well into Body & Soul's goal of service improvement.

These results have informed service programming, interventions, and intervention approach. For example, in response to this survey there are regular age- and gender-specific support sessions around life course-relevant topics within the Teen Spirit group. Additionally, a young person who himself is in recovery for addiction is now peer-mentoring other at-risk young men. Young people receive regular information about their legal rights in the context of stop-and-search, and Body & Soul's legal clinic has taken on several young people's legal cases.

Most of the young people who participated in this survey are either transitioning to adult services or will be transitioning in the next few years, so it is crucial that the adult services are aware of the experiences of this incredible group of young people. We hope that this survey provided some useful insights into a highly specific population at a very timely juncture. Further information about the survey, including the adolescent females data, is available on request.

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Growing up with HIV: three young men tell their stories

Alison Barnes

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In the UK, we are entering the fourth decade of the HIV epidemic. It has touched hundreds of thousands of lives both directly and indirectly, and left its mark on individuals, families and communities. These semi-structured interviews highlight the experiences of three young men who were either perinatally infected with HIV or perinatally exposed to HIV (and living in families affected by the virus). Interviewees were participants in the 2012 risk assessment conducted by Body & Soul (Boys will be boys, page 17).



Brian's story (age: 27)

How is HIV in your life?

I am HIV positive – my dad is too, but my other brothers and sisters are not.

When did you find out?

When I was about 11, I had my tonsils out and started getting a lot of infections, so they did the test. They did not tell me right away. I remember going to the hospital every other week and I did not find out anything while I was there about what was wrong with me. There would always be a period where I would be in the doctor's office with my mum and then they would make me leave and go wait outside. The doctor finally told me after I kept asking what was going on.

Do you think it is different for young people growing up living with/affected by HIV? Why or why not?

I mean, personally, for a while I was really going with it and taking loads of medication – some were fine, but some were huge tablets. I remember swallowing these horse pills and just vomiting afterwards. But my mum gave me a lot of support, and I did it.

As I got a lot older, teenage years, there was a big part of me that did not want to deal with it any more. Because there are not any outside symptoms, I convinced myself I did not want to deal with HIV, could not deal with it, and that I could forget about it if I did not acknowledge it. I completely stopped taking the medicine around 15 to 16 and stopped going to the hospital. I pushed it to the side and dealt with other things, which were complicated anyway. Also, seeing my dad being sick because

of his HIV made it hard – is that what I was going to have to deal with? Looking at my siblings who were completely fine was really tough as well. They were nice about it but did not understand. Even though I did not want to deal with it, there was always that nagging feeling in the back of my head that it was there regardless of what I did.

Do you think HIV has impacted on your relationships? With family? With friends? How about your dating life?

Umm ... family – I am a lot closer with my mum because she had been there a lot during all my operations and going to clinics. With my brothers and sisters, sometimes they do not understand.

As to the relationship side, I think there is a whole challenge trying to get to know someone but also holding back. I can tell you lots of stories about me – about my family, my activities, going out, drinking – and I'll be really open about it all, but not about HIV. So, that level of connecting shut down after a bit because there was always that part that I held back.

I got to the state where I didn't want to let someone be with me – it was easier to just push them away. I've always been able to deal with the outside stuff, but letting someone see the vulnerable side, the HIV, it's too hard. Recently, I'm seeing someone, and I just told her and my last partner about my status. It was probably my wanting to build something that was real and based on honesty. It wasn't enough to have fun and laugh – I'm looking for something real and long-lasting now, probably because of where I am. It is easier if you know it [your status] is out there because if they are going to deal with it, they will deal with it ... and if not, they will leave and you won't have grown close to them. I've started taking it out of my head and putting it out there, rather than holding it in.

What challenges have you faced?

I think it's probably made me less trustworthy but, that being said, it's also taught me to be open and honest with the people who care about me. I've also had alcohol problems, which I've blamed sometimes to explain disappearing and withdrawing, when it was really my feelings around HIV that made me pull away from people. It is more to do with understanding myself and learning to deal with it. With the alcohol, I was

using it to cope with the thing about myself that's somewhat different and that no one else can understand. Personal relationships have always been difficult for me, but I'm working on it and starting to get some normalcy.

What has been helpful in coping with HIV?

Getting support from B&S [Body & Soul] is a little bit like going to AA – you all have the same secret, you all have different ways of dealing with it and different bad and good moments, and you can talk freely. I don't have to go through all the crazy thoughts in my head, I just can speak with people.

If you could tell nurses working with PLHIV or their families one thing, what would it be?

I'd probably say that everyone is different. People find out [about HIV] in different ways, and deal with it differently. Sometimes it is all the information that is out there which helps you get to the point where you are ready to go to clinic, take treatment, go through the steps.

I blocked it out for 5 or 6 years – not going to clinic or taking treatment. But the information helped me keep myself safe and those around me safe. The information about HIV has also taken me back to looking after myself. The more I find out about it, the more at ease I am. You'd think it'd be the opposite.

You just have to find the things that will enable you to be healthy in who you are and not let the things you struggle with control you. If you're not at that point, just do whatever you can to keep yourself safe. Be yourself: it's a part of me, it doesn't control me. It has gotten easier as I get older. The 27-year-old me can handle things the 21-year-old me could never ever have handled – but it's a journey and there's nothing you can't do. I've learned a lot from my mistakes and the advice of others, and hope other people will do the same. It is important to be grateful for the things you have got and not beat yourself up if you are not there in every aspect of your life yet.



Bob's story (age: 16)

How is HIV in your life?

I was born with it – it used to be a real big deal, but not any more.

When did you find out?

When I was 11. It was basically told to me at home by a doctor who used to visit my mum and he wanted to chat to me one time, and that's when I found out.

Do you think it is different for young people growing up living with/affected by HIV? Why or why not?

It's the same, because you've still got a personal life. Nothing has really changed, it just replays with a personal twist. I think most young people probably feel the same way. They don't want to make it a big issue in their lives so the goal is to find something that keeps them busy. Get involved in something that you care about – if you've got that, you don't end up wrapped up in the HIV. If you were all wrapped up in it then you would freak out and be depressed. I'm not that bothered any more because my life is too busy. I just can't put it first.

What do you think the differences are?

It depends what you make into the differences, or how you make yourself feel about it.

Do you think HIV has impacted on your relationships? With family? With friends? How about your dating life?

Umm ... it all depends on how you see it. If you put it on a pedestal, you would focus on it a lot. If you don't consider it high up in your life, you won't consider it and it won't be a big deal. It won't prevent you from being the person you want to be or the friend you want to be.

What has been helpful in coping with HIV?

What's helped me grow is this, I guess – support from other people and people who I've met through social groups, like B&S and camp. We talk about everything and trust each other and know we're going through the same thing, but we don't always directly talk about it. It almost doesn't exist in your life because you don't bring it up often. Because, if you focus on it, it'll make it harder to do everything. Like taking medicine – if you're too focused on the fact that you're HIV [positive], then things like taking just one pill one time a day become difficult things to do, and they shouldn't be. Friends have mostly helped me.

If you could tell nurses working with PLHIV or their families one thing, what would it be?

Not wanting to be unreasonable ... but what I could tell a nurse is that, if someone's in a hurry and they've got a whole bunch of things to deal with, it's really hard to take 3 or 4 hours out of the day every couple of months to go to clinic. And then you get frustrated and angry, and you take it out on them but it's not them, it's just how long clinics take.

For young people, going to clinics is like stopping their day, stopping everything they do, and their lives.

With appointments dragging on for 3 or 4 hours, you end up taking away their day. It doesn't make people happy. It's best to set up more different times cause it's, like, if you're paed's or transition, the clinic is always on one day at one time. If you can't make it at the same time, then make it so they can go in

the adult clinic hours. You just want to swing by and then leave – not wait for hours.



Dave's story (age: 24)

How is HIV in your life?

For me, it's my mum and formerly my brother who had HIV. I guess, further than that, after being in Body & Soul, it's a few of my friends as well.

When did you find out?

I found out at Body & Soul when I was 12 or 13. It started at Body & Soul with my brother, and he told me there. Afterwards, we went home and talked to my mum about it. I had a small idea – not that it was HIV, but that there was something going on. With my mum, she used to always tell me, 'remind your brother to take his meds', so I knew he needed meds but had no idea why.

What was it like finding out?

I don't know, it was ... it was a big wake-up call in a sense. I was, like, I need to know what exactly HIV is. Beforehand, I thought it was only something people got from sex. But it wasn't that surprising because I knew they were impacted by something. But knowing that it was HIV meant that I needed to think about all the ignorance and stigma and misconceptions that a lot of people have when they first find out, I guess.

Do you think it is different for young people growing up living with/affected by HIV? Why or why not?

Oh yeah. 100%. No doubt. For those who haven't disclosed to anyone, it's, sort of, like living a double life. For those who have, it's dealing with that extra part of your life.

What do you think the differences are?

I don't know – although I don't personally have HIV, I have a disability myself. But when you're young, you forget about it sometimes and then you realise ... Whoah – it's different! For example, with my brother it would be the medication and sometimes the side effects that it would bring. Even past that, it's sort of thinking about things in the future. When you're young, you think about it in all the relationships you get into and if you want to become sexually active, it's up to you to disclose. It just pops up here and there.

Do you think HIV has impacted on your relationships? With family? With friends? How about your dating life?

Oh yeah, it's definitely brought us that much closer in terms of family and friends. Just general situations. Before I knew, I would just tell my brother to take

meds but now I ask more personal questions. Like, more empathy for friends and family. You have that bit more concern for each other.

It's also impacted on my dating life. It's sort of eliminated that stigma and discrimination, so I wouldn't shy away from dating someone who is living with HIV, it's made me more open and receptive. Like, don't judge a book by its cover. Take the time to get to know someone properly and give them the benefit of the doubt.

What challenges have you faced?

The biggest challenge by far is the ignorance and stigma around it. Even after I had found out, a year or two later someone came in to teach us sex education and she didn't even know that there was a difference between HIV and AIDS. She was teaching us and had no clue! I wasn't surprised that my classmates, who had no idea of HIV before that class, were then thinking afterwards that HIV is just a death sentence and something that people are dying with. Even today, when I speak with some of the teens, they say nothing has changed. The information they have is still just about it being a death sentence, because this is what is being taught in school.

What has been helpful in coping with HIV?

Body & Soul has been helpful. There is only so much you'll understand when you're affected, but just to come here and be able to freely have conversations about HIV has been helpful. And understanding what it is, 100%. If I were to rely on schools to give me information, I would have a real lack of knowledge. To be honest, outside of Body & Soul I couldn't see myself going out there and researching it unless a family member actually told me about it. So, family and friends and Body & Soul.

If you could tell nurses working with PLHIV or their families one thing, what would it be?

One thing would be: as well as just the patient you see, there is often a family dealing with it as well. So it's not just the patient, it is all the people who are close to the patient who are living with that.

Sometimes, in some families, people won't talk – so whoever they have opened up to, it's important to know that those social relationships exist and are part of how people cope with HIV. It's also really important to know what their relationships are and who they are getting support from. Also, how it affects their lives – they might have been outgoing before, but have now become closed up. So, ask if things have changed. Also, let them know that something like Body & Soul exists, especially if they are going through it alone.

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Know your enemy

Juliet Bennett

Independent Nurse Advisor

Anal cancer is increasing among both gay and heterosexual men – although research on the efficacy of screening and interventions is yet to deliver a consensus. Despite the lack of a cohesive management policy at present, nurses should be proactive in their role as health educators and in continuing work to determine the efficacy and acceptability of screening and of clinical interventions.

Introduction

Last October the US-based *HealthDay News* headlined: 'New research on anal cancer, a rare disease that's often caused by a sexually transmitted virus, found that nearly one-third of men with this form of cancer were HIV-positive'. The article was citing a publication from the October 2012 issue of the *Journal of the National Cancer Institute* [1].

We also know that anal cancer occurs far more commonly in HIV-positive (and HIV-negative) men who have sex with men (MSM) compared with the general population, with recent US findings revealing rates 30 to 100 times higher than that of the general population [2,3]. The entire male population has seen almost a threefold rise in incidence of infection with the human papilloma virus (HPV) in the past 30 years [4], the relevance of which will be discussed later in this article.

Anal intraepithelial neoplasia (AIN) has been rather overlooked historically by both researchers and healthcare providers (HCPs). There has been a lack of large-scale prospective studies showing whether or not screening is beneficial and cost-effective, and there continues to be much debate around treatment efficacy. Perhaps a degree of 'embarrassment factor' associated with the nature of this disease, on the part of both HCPs and patients, or an unwillingness to acknowledge the threat it poses to certain populations, have also contributed to its low profile. In addition, and perhaps surprisingly, even the success of HAART in recent decades has conferred no substantial benefit in reducing incidence of neoplasia [5]. In fact, several studies have demonstrated a higher incidence of anal cancer since the introduction of HAART [6], although of course this may be due to disease progression in people who are now living longer with HIV and HPV infection.

Causes

Anal cancer has many parallels with cervical carcinoma, in that HPV is thought to be the main

Table 1: Risk factors

(a) for anal HPV infection	(b) for anal squamous intraepithelial lesions (ASIL)*
Higher number of sexual partners	HIV infection
High frequency of sexual activity	Low CD4 count
Sexual partners with genital warts	Persistent HPV infection
Receptive anal intercourse	High-risk HPV genotypes
HIV infection	Infection with multiple genotypes
Low CD4 cell counts	History of anal intercourse
Use of recreational drugs taken per rectum	Intravenous drug use history
	Cigarette smoking†

* Adapted from [7].

† Smoking 20 cigarettes or more per day is thought to affect the anal mucosa, both directly through circulating carcinogens and indirectly through suppression of cell-mediated immunity.

causative factor in nearly all cases. While 'HPV' is a less familiar acronym for the non-medical population than 'HIV', it is an extremely prevalent infection worldwide. Among HIV-positive MSM, the prevalence of anal HPV infection ranges between 72% and 90%, and infections with multiple HPV strains are common [8]. In HIV-negative MSM the prevalence ranges from 57% to 61% [9,10]. As a result, HPV-associated malignancies occur with high frequency in patients with HIV infection [10], including AIN which has a prevalence of around 45% in HIV-positive MSM [11].

In heterosexual patients, the causes of anal HPV infection may not be as obvious, yet still the prevalence of anal HPV infection in heterosexual men, even without a history of anal or oral sex with a man, has been shown to be around 25% [12]. Risk factors for heterosexual men include a large lifetime number of female sex partners and a high frequency of sexual intercourse just before HPV diagnosis. An increased prevalence of HPV in those who have not been circumcised has also been noted [4]. Other possible means of HPV transmission include self-initiated or partner-initiated anal massage with an object, anal massage or insertion with a finger, and other non-penetrating sexual contact (Table 1a). Non-sexual behavioural risk factors can also occur, for example, the virus being carried on the hands [13].

AIN and disease progression

Persistent HPV has the ability to trigger abnormal cell growth, which includes warts and carcinogenic changes/neoplasia. Certain strains of HPV are

considered 'high-risk', in particular HPV-16 and HPV-18, which are the usual cause of anal and cervical cancers. It is important to note, however, that infection with these types does not always lead to cell changes, and even when dysplasia does occur, it does not always progress to neoplasia or to cancer. Having said this, a recent Spanish study of HIV-positive men [14] reported nearly 40% with low-grade anal neoplasia progressing to high-grade neoplasia or anal cancer. Younger age and shorter duration of HIV infection were also deemed risk factors for worsening of neoplastic disease [14]. Deterioration in the immune system is also thought to accelerate the development of malignancies [10], and infection with multiple genotypes of HPV also appears to be a risk factor (Table 1b).

Symptoms

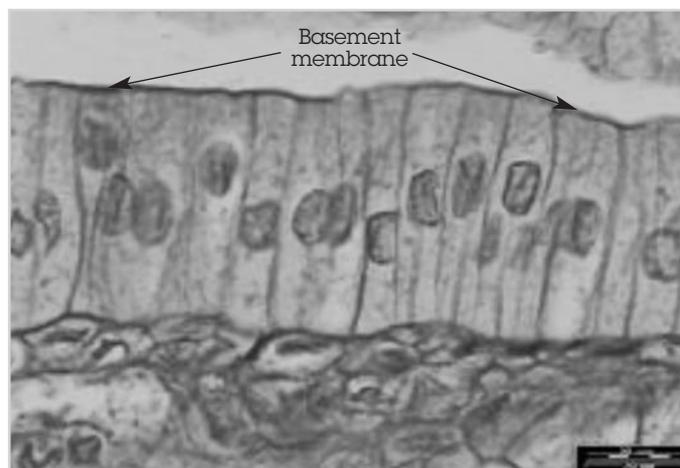
It is important to note that HPV-associated malignancies can have a latency period of between 5 years to several decades in people with intact immune systems – and even in those who are immunocompromised, precancerous changes can take several years to progress. As with cervical cancer, the precancerous stages of AIN are generally asymptomatic until there is invasion beyond the epithelial basement membrane (Figure 1). Severe dysplasia is unlikely to cause any symptoms beyond low-grade changes although some patients may experience bleeding, irritation, pruritis or a burning sensation. Where cancer has become invasive, common complaints include anal abscesses, lumps, ulceration, anal discharge, changes in bowel habit and tenesmus. Importantly, men who have anal sex will often have benign conditions such as fissures or infections that may mask AIN and deflect the correct diagnosis. Rectal bleeding, which is the most common presenting symptom of anal cancer, is often attributed to haemorrhoids. As a result, late clinical presentation of anal cancer is common.

Diagnosis

AIN typically presents as lesions in the transformation, or transitional zone, of the anal canal – which is where the squamous epithelium of the anus meets the columnar epithelium of the rectum (Figures 1 and 2). These lesions are frequently referred to as anal squamous intraepithelial lesions, or ASIL.

Visual inspection may identify warts, hypopigmented or hyperpigmented lesions or lesions that bleed. For more accuracy and detail, anoscopy using a proctoscope is performed and biopsies taken and sent for histology. In screening for cervical changes, cytology appears to be over 90% specific although debate continues around the sensitivity and specificity of pap smear tests versus newer technologies such as liquid-based cytology [15]. However, cytology appears to be less

accurate in diagnosing AIN. In one study researchers found that it only correctly predicted the AIN grade in 40% of cases examined [16]. We must therefore acknowledge that diagnosis, especially in the early stages, is far from straightforward.



The anal canal is divided into three parts. The zona columnaris is the upper half of the canal and is lined by simple columnar epithelium. The lower half of the anal canal is lined by stratified squamous epithelium, above which is situated the basement membrane, as indicated [17]. Image licensed under a Creative Commons Attribution Share-Alike 3.0 License

Source: <http://anatomyscience.wikispaces.com/Epithelial+Tissue>

Figure 1: Composition of the anal canal

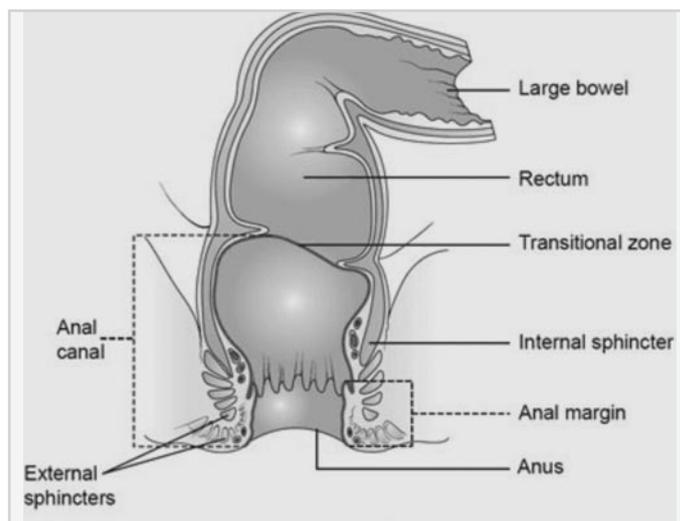


Figure 2: Anatomy of the anus [18]. Taken from CancerHelp UK, the patient information website of Cancer Research UK: www.cancerresearchuk.org/cancerhelp

Because of similar histopathological features, anal dysplasia is graded using the same scale as that used in cervical screening [the Bethesda classification 2001 (19)]. AIN is classified into three grades based on the extent of penetration of the abnormal cells: AIN 1 describes involvement of the lower third of the epidermis; AIN 2, the lower two-thirds of the epidermis; and AIN 3, the entire thickness of the epidermis. AIN 3, severe dysplasia or carcinoma *in situ* (also known as HSIL, or high-grade ASIL) is progressive and requires intervention as a small proportion may develop into invasive carcinoma if left untreated.

Screening

Several different screening tools have been used to try and detect cell abnormalities including anal cytology testing as mentioned above, high-resolution anoscopy and biopsies of anal tissue. However, there remains a dearth of information about the relative accuracy of these screening methods and still no consensus of opinion on their use. Furthermore, the limitations of research in this area are obvious, in that running randomised controlled trials of any condition associated with malignancy would clearly be unethical.

In addition, screening for AIN clearly has cost and resource implications, especially if it is to be rolled out on a wider scale as a screening programme. Some studies have found that screening MSM offers life-expectancy cost benefits [20]; and cost-efficacy modelling has also favourably evaluated cytology screening in HIV-positive men with immunodeficiency. However, other more recently reported modelling has drawn conclusions to the contrary [21–23]. It is important to remember that any conclusions about cost-effectiveness of screening programmes are based on assumptions, for example, about rates of AIN regression and response to treatment, for which long-term data is currently lacking.

Professor Mark Bower, Consultant at Chelsea and Westminster Foundation Trust, discussed his views on the issue of routine screening with Aidsmap in 2011 [24]. He reported that there is still insufficient evidence to recommend routine screening for AIN. In the Chelsea and Westminster cohort at that time only 60 cases had been identified from the 11,112 patients who had ever attended the clinic, including those who had been referred from elsewhere for specialist opinion. In patients attending the general HIV clinic, the Trust saw less than one new case a year [16]. Professor Bower highlighted the continued lack of clarity around why some dysplasia progresses to invasive cancer and other lesions do not.

Internationally, there is also a lack of agreement regarding screening policy (one approach is set out in Figure 3). The 2012 EACS guidelines [25], for example, suggest 1- to 3-yearly digital rectal

examinations and smear tests in gay men, with anoscopy if the smear test is abnormal, although the Society says that this is yet to be evidenced. Recommendations from the New York State Department of Health from 2007 are more directive [26] and, although now due for revision, these guidelines state that for all HIV-infected adults, regardless of age, clinicians should enquire about anal symptoms, perform a visual inspection of the perianal region and perform a digital rectal examination, at baseline and then annually. The NYSDH guidelines also suggest obtaining anal cytology annually in HIV-positive MSM, from any patient with a history of anogenital condylomata, and from women with a history of abnormal cervical histology. Clinics appear to be devising their own standards of care. One large centre, at Ruhr University in Germany, has screened all HIV-infected MSM using anal pap cytology since 2003, believing that 'the clinical effectiveness and cost-efficiency of such screening procedures is clearly supported' [10].

In the UK on the other hand, BHIVA states in its most recent clinical guidelines (2012) [27] that 'there is insufficient evidence currently to recommend routine screening for AIN; however, this recommendation should be regularly reviewed in light of the increased research in this area'. BHIVA advises close monitoring and follow-up of all those with any cell abnormalities, with a high-resolution anoscopy being performed in those with high-grade dysplasia.

Treatment for AIN

- Infrared coagulation therapy for high-grade anal dysplasia appears to be the current choice for many clinicians. The treatment is carried out under local anaesthetic in an outpatient setting and for most people there is discomfort for just a few days afterwards. One retrospective clinical study reports on a cohort of 68 HIV-positive MSM (with AIN 1 to AIN 3) treated with this intervention. The treatment showed 64% efficacy for all treated lesions and the authors felt it showed promise as a strategy within the HIV population [28]; however, high recurrence rates were an issue.

Panel 1: Classification levels for dysplasia in anal epithelium

- Negative: no intraepithelial lesion or malignancy found.
- AIN: anal intraepithelial neoplasia, as seen in histology.
- ASCUS: atypical squamous cells of undetermined significance.
- ASC-H: atypical squamous cells suspicious for HSIL.
- LSIL: low-grade squamous intraepithelial lesion (corresponds to AIN 1 histopathologically).
- HSIL: high-grade squamous intraepithelial lesion (corresponds to AIN 2–3 histopathologically).
- SCC: squamous cell carcinoma.

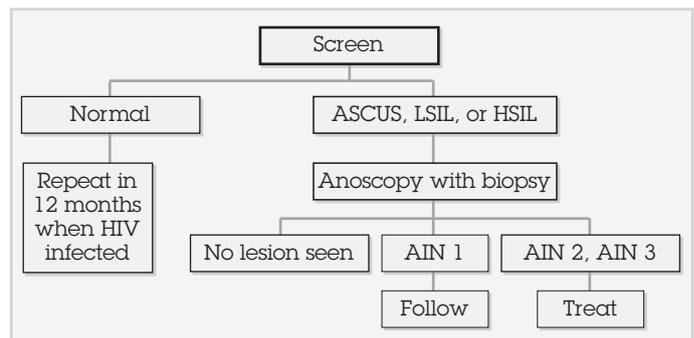


Figure 3: Algorithm for response to abnormal anal pap screening [data from 12] (Abbreviations: see Panel 1)

- Topical treatment with Imiquimod cream has also shown some promise. One study of Imiquimod therapy, in HIV-positive MSM with condylomata and low-grade AIN, saw complete resolution of all lesions in 46% of subjects – but again, 29 % had recurrent lesions after treatment ended [29].
- Electrocautery ablation of high-grade AIN has also been deemed 'a safe and effective clinic-based procedure comparable to others available'. Again, continued follow-up was felt to be important because rates of recurrence were similar to other treatments. As a result of their findings, the authors did not advocate a 'watch and wait' approach [30].
- However, some clinicians do advocate a more conservative approach, of closely monitoring high-grade AIN and only treating if early cancer develops, backed by the argument that many patients with high-grade AIN never progress to cancer and those who do would be caught early if followed up closely. Current opinion largely counters this approach, given the likelihood of even an early anal cancer requiring more intensive interventions, radiation or more invasive surgery with subsequent reduced quality of life. BHIVA [27] supports close monitoring and evaluation whenever a diagnosis of any degree of dysplasia is made; with high-resolution anoscopy offered to all patients diagnosed with high-grade cell changes.

There has been considerable debate about the efficacy and cost-effectiveness of vaccinating adult, HIV-positive MSM using the quadrivalent HPV vaccine currently offered to teenage girls in the UK.

For example, Palefsky and colleagues reported high rates of efficacy for this HPV vaccine against anal intraepithelial neoplasia related to HPV-6, 11, 16, or 18 in MSM [31]; while other studies found almost one-third of biopsies from similar cohorts contained only high-risk HPV types not covered by the vaccine; and further relevant studies have reported higher percentages of anal cancers which are not related to HPV-16 or 18 in HIV-positive patients, as compared with HIV-negative counterparts [32,33].

In October 2011, the Advisory Committee on Immunization Practices (ACIP) for the Centers for Disease Control and Prevention in the US recommended routine use of the quadrivalent HPV vaccination for males aged around 12 years. For MSM, the committee has recommended routine vaccination for all males, and vaccination up until age 26 for those who have not been vaccinated previously or have not completed the three-dose series [34].

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A potential role for nurses in the UK and Europe

As more HIV-positive people, and MSM in general, learn about the risks of anal cancer they are more likely to request screening. As nurses we need to anticipate and be equipped to facilitate this increased and justified demand. Various techniques for screening and treating anal neoplasia and cancer have been identified, and nurses would appear to be well placed to offer these – with access to the specialised training, support and resources that all healthcare providers will need to offer screening and care of a high standard. Without a clear management strategy or a national screening policy at this time, we should be seeking opportunities to run pilot programmes offering anal cytology screening, at least in centres with large numbers of HIV-positive MSM and perhaps in other targeted settings too. There is a clear need to gain further long-term prospective data on the progression of AIN and to identify and recruit people who may be eligible for studies on the efficacy and acceptability of different treatment options.

While some at-risk groups are 'on our radar', we must also be aware that, for a multitude of reasons, men

who do not identify themselves as gay or as MSM are also at risk. Patterns of human sexual behaviour have been changing, for example, with the use of agents to enhance sexual performance, with greater numbers of sexual partners and with diversifying risk behaviours. We need to be aware of these factors and ensure we include enquiry of anal symptoms at routine follow-up appointments, with digital rectal examination and testing for anal dysplasia and cancer as appropriate [35].

We need to promote awareness of the risk factors discussed in this article and work with all our patients towards risk reduction, helping to facilitate regular assessment and physical examination and educating patients on regular self-examination. Patients should be advised on the symptoms and urged to report these early. If nurses proactively contribute to normalising screening procedures and ensure that patients feel at ease raising intimate concerns, we will help to increase early detection and optimise treatment outcomes.

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