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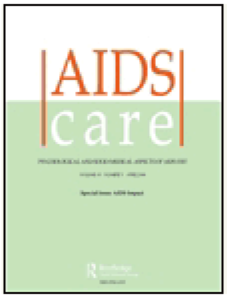

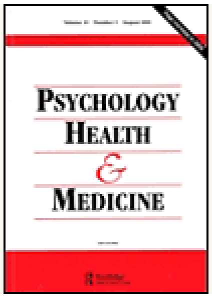

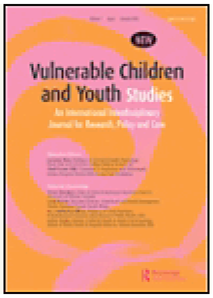

Why some MSM present late for HIV testing: a qualitative analysis.

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Table 1: Template of themes for discussion

Circumstances in which HIV was diagnosed	▪ place of testing ▪ triggers for testing ▪ health at time of testing ▪ feelings at diagnosis
Past sexual health and HIV testing	▪ sexual health clinic attendance ▪ access to services ▪ risk behaviours and number of partners ▪ previous HIV testing ▪ perception of self risk
Understanding of HIV and its transmission	▪ transmission risks ▪ past HIV knowledge/education ▪ past experience of HIV
Knowledge of HIV before and after diagnosis	▪ whether sought knowledge after diagnosis ▪ perception of HIV since diagnosis
Ideas regarding health services	▪ experiences of healthcare ▪ reasons for not testing earlier ▪ possible interventions to encourage earlier testing ▪ views surrounding health promotion of HIV ▪ ideas as to why MSM do not test ▪ ideas regarding the role of GPs in HIV testing

Table 2: Patient characteristics

Volunteer number	Age	CD4 count at diagnosis (cells/mm$^{3)}$	Presenting complaint/AIDS defining illness
1	41	102	Weight loss, lethargy and diarrhoea
2	49	184	Chronic diarrhoea
3	33	25	Herpes simplex infection, weight loss and oral Candida
4	46	48	Pneumocystis jiroveci pneumonia
5	39	26	Herpes zoster infection
6	52	13	Karposi sarcoma and oral candida
7	36	1	Pneumocystis jiroveci pneumonia
8	40	122	Regular partner recently diagnosed HIV positive
9	38	18	Pneumocystis jiroveci pneumonia
10	61	93	Burkitt's lymphoma
11	33	4	Fevers and non-specific symptoms to A&E
12	48	105	Oral thrush and Karposi's sarcoma
13	67	142	Fatigue and pancytopenia
14	33	89	Pneumocystis jiroveci pneumonia Regular partner known HIV positive for last 3 years
15	43	18	Pneumocystis jiroveci pneumonia
16	55	8	Pneumocystis jiroveci pneumonia
17	35	20	Pneumocystis jiroveci pneumonia

Why some MSM present late for HIV testing: a qualitative analysis.

Abstract

Although initiatives are underway in the United Kingdom to diagnose HIV infection early, late presentation is still a major issue and often results in serious health complications for the individual and has implications for society, including high costs and increased rates of transmission. Intervention strategies in the UK have aimed at increasing testing opportunities but still a significant proportion of those with HIV infection either decline testing or continue to test late. The main objective of this study is to identify ideas and themes as to why testing was not carried out earlier in men who have sex with men (MSM) who presented with late HIV infection.

Semi-structured interviews were carried out with MSM presenting late with a CD4 cell count of less than 200. A structured framework approach was used to analyse the data collected and generate ideas as to why they did not seek testing earlier.

17 MSM were interviewed and four main themes were identified: psychological barriers, including fear of illness and dying, stigma surrounding testing for HIV and in living with a positive diagnosis, perceived low risk for contracting HIV despite participants reporting having a good understanding of HIV and its transmission and strong views that a more active approach by healthcare services, including general practice, is necessary if the uptake of HIV testing is to increase.

Late presentation with HIV infection continues to be a problem in the UK despite government initiatives to expand opportunities for testing. Recurring themes for late testing were a low perceived risk for HIV infection and a fear of HIV and a positive diagnosis. Population-targeted health promotion alongside a more pro-active approach by healthcare professionals and making HIV testing more convenient and accessible may result in earlier testing.

Keywords: HIV, men who have sex with men, late presentation, qualitative, sexual health.

Introduction

In 2009, 30% of new HIV diagnoses in the UK had a CD4 count < 200 cells/mm^3 (Health Protection Agency (HPA), 2010). Late presentation of HIV is associated with serious health implications for both individuals and society, including high personal morbidity and mortality. Modelling has estimated that early diagnosis of men who have sex with men (MSM) with HIV infection could reduce short term mortality by 84% (Chadborn et al, 2005). Late diagnosis also results in a significant economic burden with costs in the year following diagnosis estimated to be 200% higher in those who present with a CD4 count of less than 200 (Krentz, Auld & Gill, 2004).

Intervention strategies in the UK have aimed at increasing testing opportunities but still a significant proportion of those with HIV infection either decline testing or continue to test late. Significant numbers of MSM still leave sexual health clinics with undiagnosed HIV (Department of Health (DoH), 2003) and are consequently diagnosed only with the onset of AIDS related symptoms (Couturier et al, 1998) when treatment with antiretroviral therapy has shown to be less effective (Egger et al, 2002). The “opt out” system, which has seen the number of HIV tests accepted by MSM and heterosexuals rise, has resulted in an overall reduction in undiagnosed cases of HIV; however, there remains a significant burden with 25% of infected heterosexuals and 47% of infected MSM in the UK still unaware of their infection (HPA, 2007). This study aims to identify ideas and themes as to why late presenting HIV infected MSM do not test earlier as an aid to maximising HIV testing initiatives in the future.

Methods

Participants and recruitment

MSM who had a CD4 cell count of less than 200 or an AIDS defining illness at diagnosis were eligible to take part in the study. To minimise recall bias, only those who had been diagnosed within the last twelve months were included. MSM who met these criteria were identified by searching the patient database at Brighton and Sussex University Hospitals HIV outpatients department (OPD). All those on the list were contacted by the physician under whom they received their HIV care and asked if they were willing to take part in the study. Written consent was obtained from all participants before interview.

Interviews and Analysis

The interviews were conducted by either LD or CK within a private room in the HIV OPD. Several interviews were carried out with both researchers present to ensure consistency in interview technique. Interviews ranged from 30 minutes to 1 hour 30 minutes and were recorded by digital recorder and anonymised to maintain confidentiality by using personal clinic numbers as identification.

Semi-structured interviewing was the method employed to answer the research question. This allowed a deep and detailed discussion of themes and topics and allowed for MSM to volunteer information which they felt was important to their personal experience. A predetermined template of themes for discussion was used with the aim of encouraging MSM to speak unprompted by the interviewer (table 1 near here). A non-directive approach was employed to encourage a more in-depth response and care was taken to avoid leading questions. On completion, all interviews were transcribed verbatim.

The process of data analysis was carried out throughout the data collection period so that possible new concepts emerging after each interview could subsequently be incorporated into future interviews. A framework approach (Pope, Zielband & Mays, 2000) was used to analyse the data and generate the themes, ideas and conclusions of the study. Each transcript was read several times over with the aim of recognising recurring themes and ideas; important sentences and paragraphs, those that were new, recurring, or spoken about unprompted by the interviewer, were highlighted. The ideas and themes that were identified from the interview texts were used to create a thematic framework with which all of the data could subsequently be referenced. Validation of data analysis was ensured via the above methods being applied by three researchers (LD, KC and DR) individually with subsequent comparison of each researcher's findings.

Results

22 newly diagnosed MSM were identified as being eligible participants and of these, 17 agreed to take part and were subsequently interviewed. All MSM presented with a CD4 count of less than 200 and had varying symptoms at diagnosis (table 2 near here).

Four main themes were generated from the interviews.

1. *Psychological barriers*

Most MSM had a negative perception of HIV/AIDS. Fear of HIV, becoming ill and dying from AIDS was a concern commonly expressed and paradoxically, a reason given for not testing for HIV. All MSM described friends or partners dying from AIDS and vividly remember the HIV/AIDS advertising campaign during the 1980s, to which they partly attributed their negative views of HIV. Little was known about the advances in HIV treatment over the previous 20 years and a diagnosis of HIV was still considered a "death sentence".

"…It's the fear of dying I think…I was scared, very scared before I found out." (volunteer 3)

"I didn't know much about it at all (HIV). I just thought it was a death sentence and I suppose yeah, I've just always thought of it like that, even last year when I was diagnosed." (volunteer 7)

2. *Stigma of HIV*

Stigma of having a positive diagnosis was a common theme; fear of telling friends and family, and anxiety over their reactions was expressed by almost all the volunteers. There was reluctance amongst the MSM to test for HIV and testing was sporadic with only three of the seventeen testing regularly. There was also anxiety over taking the test itself, particularly the repercussions if it became common knowledge. Fear of stigma from society in general was also commonly expressed and there were concerns over how a diagnosis of HIV would impact on day to day life, including work, insurance and travel. Several MSM admitted to having had suspicions of having HIV for some time before testing but were unwilling to have this confirmed.

"It was quite taboo... going to get things like an HIV test" (volunteer 11)

"Well if you do test positive... then you have to count yourself as belonging to a group that maybe isn't regarded very highly in society" (volunteer 12)

"…I suppose I lived through the 80s…there was a lot of negative publicity, so I've got quite, I suppose, a negative view around it (HIV)." (volunteer 2)

"…I worry about it from a social point of view more than a health point of view... Does it mean I've got to talk to my parents, can't do the job I do. Does it mean my life starts being affected? When they did the medical in September, they picked up that there were some irregularities with my blood… but I foolishly pushed it to the back of my mind, I didn't want to confront it." (volunteer 4)

3. Perceived low risk

Although the MSM generally had an adequate understanding of HIV transmission, this did not always correlate with assessment of self risk. Greater than half expressed total surprise at their HIV diagnosis due to having perceived themselves as only practising safe sex or being predominantly involved in what they considered to be low risk sexual activities, such as oral sex or using a condom when having sex with a known HIV partner. High risk behaviours were generally thought of as having large amounts of sex, a number of different casual partners or taking part in "high risk" sexual acts.

"...There was I suppose a little bit of frustration because as I say I haven't been excessively sexually active over the previous 4 years." (volunteer 1)

"...You know in the early days, people who were at risk generally were people who had ferocious sexual appetites, you know they had sex several times a day, every day of the week" (volunteer 10)

"... I thought it can't possibly happen to me (contracting HIV) because I'm not doing all these high risk things." (volunteer 16)

Despite having a good general knowledge of HIV, MSM seemed to have a poor understanding of the implications of late diagnosis or that HIV could be carried without causing ill health for long periods of time. Belief that a lack of symptoms meant they could not have HIV was common. In retrospect several MSM admitted to having a high suspicion they had HIV but were reluctant to recognise this; it was only when these symptoms became increasingly severe that HIV testing was sought. Similarly, the absence of certain symptoms, which were seen as being associated with HIV, reassured them that they were healthy.

"...I thought, well all the time it's not affecting me...if I don't have to deal with it and it's not affecting me then I don't...I didn't feel the need (to test for HIV)." (volunteer 4)

"…what's the point if I've got it (HIV) and I'm healthy, so what? If I've got it and I'm safe, so what…?" (volunteer 5)

"I thought I might get PCP or sarcomas… people always told me "I had that" or whatever and so I thought I would probably get a particular HIV illness." (volunteer 2)

4. Barriers in healthcare

A universal theme was that a more pro-active approach to HIV testing by general practitioners would be beneficial in increasing testing for HIV. Several MSM freely admitted to having declined HIV testing in the past, although attributed this to a lack of explanation of the importance of testing by the healthcare professional offering the test. The majority agreed that they would have tested for HIV had it been offered to them by their general practitioner. MSM said that testing at the surgery would be preferable to testing at the sexual health clinic; this was more convenient, a theme that recurred as being important for testing, as visits to the GP are more frequent and caused less embarrassment.

The possibility of peer education was also raised. It was suggested that MSM may respond better to education from men who had been diagnosed with HIV and had experienced becoming ill due to late testing.

"…they offered me an HIV test… they said "do you want an HIV test?" and I said "no" and that was it, end of story." (volunteer 3)

"…if you can go to your own doctor and not have the stigma of going to the, you know, the clinic as such." (volunteer 3)

"…you've got to have someone who, like myself, who's been through the highs and lows of it, talk, and talk very realistic to them about what it (HIV) is about and what this really means…" (volunteer 4)

Discussion

Four main themes have been generated in this study as influencing late presenting MSM HIV testing behaviour. Psychological barriers, including fear of HIV, stigma surrounding a diagnosis of HIV and low self-perceived risk, in addition to beliefs surrounding their general health, all influenced testing behaviour. MSM expressed strong views over past experiences of healthcare and suggested a more active approach by healthcare services to make testing more accessible is necessary if the uptake of HIV testing is to increase.

In general, volunteers held negative views about HIV primarily due to past experiences of HIV/AIDS resulting in death and memories of the 1980s campaign, which they feel was responsible for promoting fear and stigma. Stigma surrounding HIV is essentially attributable to the nature of its spread through marginalised groups and has been recognised as a potential reason for declining or delaying HIV testing in MSM (DOH, 2001).

Health promotion aimed solely at high risk groups was seen as fuelling stigma by the MSM in the study. It was felt that HIV is still perceived as a gay disease by the general public who hold an out-of-date view of the reality of living with the virus today and that initiatives aimed at normalising HIV are necessary on a national scale.

The *HIV related stigma and discrimination action plan* drawn up by the DOH, (DOH, 2007) aims to implement national strategies, including education of the public as well as working closely alongside non-government organisations and offering counselling and support to those affected by stigma and discrimination. The recently published White Paper *Healthy Lives, Healthy People: Our strategy for public health in England* (DOH 2010) discusses the importance of moving away from targeting high risk groups and puts emphasis on public health and health initiatives at a population level. An example of this is the National Chlamydia Screening Programme, which has seen an increase in those under the age of 26 testing for the STI.

Self-perceived risk of HIV acquisition was an important theme in this study. Generally, the volunteers considered themselves at low risk of HIV and reported feeling surprise at their HIV diagnosis. However, it became apparent with further discussion that they were in fact taking part in high risk sexual behaviours, and had just not recognised them as such. Assessment of self sexual risk is largely subjective and has been found to be poor in MSM; men were found to distance themselves from high risk behaviours when questioned but contradicted this with admissions of unprotected anal intercourse (Sayer et al, 2008).

MSM also described watching and waiting for specific symptoms which they associated with HIV before testing and reported a lack of symptoms and general good health as being reassuring. Non- specific symptoms experienced, for example lethargy and weight loss, which in retrospect were found to be HIV related, were often reported to have been attributed to other causes such as stress, age or other coinciding medical conditions.

This is somewhat surprising as the men in this study described themselves as having a comprehensive knowledge of HIV. The fact that only 3 MSM acted on this knowledge and sought testing, suggests a reluctance to test and that a more pro-active approach in education of MSM may be warranted. However, there is currently no evidence to suggest that HIV education would result in MSM making an accurate assessment of self risk or whether this would influence testing behaviour. Indeed it is unclear whether MSM would even be receptive to teaching about HIV.

Experiences of healthcare services and frequency of sexual health screening and HIV testing varied among the MSM; those who had declined an HIV test in the past explained that their refusal was easily accepted. This suggests reluctance on the part of the healthcare professional to offer HIV testing despite HIV testing in MSM being one of the primary aims of HIV/sexual health services. MSM gave a sense that they would have tested had they been further encouraged, an important missed opportunity. Missed opportunities in HIV testing, in both primary and secondary care, are widely recognised (Stekler & Golden, 2009).

Routine testing in primary care was an idea suggested by the MSM and was considered to be preferable to testing at sexual health clinics due to convenience and reduced stigma.

All of the men said that HIV testing would be taken up earlier if their GP offered them a routine test annually. This would be in line with HIV testing guidelines in the UK which recommend testing of all those registered to primary care and all acute medical admissions to hospital in populations with a high prevalence of HIV (British HIV Association, British Association for Sexual Health and HIV & British Infection Society, 2008). This could also be implemented by offering financial incentives for GPs, for example as part of the NHS *Quality and Outcomes Framework* (QOF) initiative; a voluntary annual reward and incentive programme which pays general practitioners to hit targets for clinical data collection.

Convenience of testing was a recurring theme and suggested MSM are not unwilling to test but find visiting the sexual health clinic to test inconvenient. Possible initiatives to increase uptake of HIV testing include rapid HIV testing and widening access to testing, such as at pharmacies and other non-doctor lead healthcare settings. The UK based charity, The Terence Higgins Trust, runs a “fastest” programme in which rapid HIV testing is offered in a variety of nurse-led clinics in different community settings. Outreach programmes and self-testing are also convenient, move away from a doctor-centred approach and have seen success in targeting high risk MSM in the past in testing for syphilis and other STIs. (Speilberg et al., 2003; Lambert et al., 2005; Wayal et al., 2006) The findings from these studies are positive and indicate that MSM are not unwilling to test for STIs when offered, an opinion echoed in this study.

The participants in this study suggested that education of MSM might be more effective coming from those who have HIV as they could give a more realistic account of what living with HIV is like. The Terrence Higgins Trust has a variety of volunteer projects throughout the country including the *Positive Voice Speakers*, a group of HIV positive individuals who visit organisations, including schools and community groups, and share their personal experiences of living with HIV. However, at present there is contradictory evidence surrounding peer education in MSM and its effect on influencing changes in sexual and testing behaviours with studies in the USA and UK finding conflicting evidence (Kelly et al., 1997; Elford et al., 2002; Flowers et al., 2002;).

Conclusion

Negative perceptions of HIV, concerns surrounding stigma of HIV and self-perceived low risk are reasons why MSM in this study did not test earlier for HIV.

Health promotion needs to be used as a screening tool at population level rather than targeted at high risk groups if stigma of HIV is to be reduced.

A more active approach by healthcare professionals, most importantly primary care, is necessary if the number of undiagnosed HIV cases is to fall and testing needs to be easier to access and more convenient. Possible initiatives to facilitate this include increased routine testing by GPs, self-testing, access to testing in non-doctor led settings and peer education.

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