P09/09



WHY ARE SOME GAY MEN TESTING LATE FOR HIV?

INTRODUCTION

It is estimated that about 5.500 people are living with HIV in Denmark (end of 2009). Between 250-300 people are diagnosed with HIV each year. Among the 274 newly diagnosed people in 2010 108 (39%) were men having sex with men (MSM) and 45% of these were late testers (CD4 count below 350) [1] leaving these men with an increased risk of illness and death. These figures do not differ significantly from those in previous years.

It is noteworthy that despite the likelihood of MSM being aware of the high risk of contracting HIV many refrain from being tested in time.

Since the introduction of combination therapy in 1996 a series of studies about possible personal barriers testing for HIV have been undertaken. In 2008 de Wit and Adams reviewed 50 articles on what they term the 'psychosocial barriers' to HIV testing in high-income countries, and concluded that; 'Studies that actually address barriers [...] of HIV testing in relatively well-adjusted individuals and communities in high-income countries are sparse' [2]. Although the various studies are difficult to compare there are a number of explanations or barriers which are repeatedly mentioned as significant in most studies of 'personal explanations' or 'psychosocial barriers' as reasons for not taking an HIV tests. Among these are 'fear of discrimination and stigmatisation' and 'fear of being HIV-positive' (terms are employed such as: fear of being diagnosed; fear of the disease itself; fear of learning that one is HIV-positive; fear of being HIV-positive).

RESULTS AFRAID TO FIND OUT

Within our respondents 63% of MSM indicated 'being afraid to find out that they had HIV' have had some or great importance for not testing earlier. This is in accordance with findings in other studies from abroad and therefore not surprising.

What is surprising is when we compare this finding with findings from a cohort of non-tested Danish MSM. In the 'Sex Life Survey 2009' the respondents were asked 'I fear the answer is HIV-positive' and only 13 % of MSM not having tested for HIV mark this as a reason for so far not testing.

Although one cannot compare the numbers directly (the way of questioning were different and the possibilities to reply were different (yes/no; graduated answers)) the huge difference is striking and it seems obvious to conclude that late testing HIV-positive MSM are (or have been!) much more afraid being HIV-positive than the non-tested MSM.

WANT TO AVOID NEGATIVE RESPONSES

The number of late testing HIV-positive MSM wanting to avoid negative responses if other people got to know about their (possible) HIV-positive status are also higher than among non-tested MSM. Remarkably, 67% of late testing MSM indicate that 'avoiding negative reaction from other people' were of some or great importance for not testing earlier.

As these reasons for not testing seem to be common for many late testers the two questions on 'fear of stigmatization' and 'fear of finding out' were included in a Danish survey carried out in 2009-2010 among late testing HIV-positive people.

The authors believe that this is the first time that personal reasons for not testing for HIV have been compared between late testing HIV-positive MSM and non-tested MSM.

OBJECTIVES

To compare personal reason for not testing for HIV in two groups of MSM:

- late testing HIV-positive MSM
- non-tested MSM.

METHODS

All known cases of HIV in Denmark are registered in 'The Danish HIV Cohort Study' – an open prospective population based cohort initiated in 1998 in collaboration between all HIV treatment centres in Denmark. In this cohort all people living with HIV (PLHIV) diagnosed with CD4 count less than 200 between January 2003 and June 2009 was selected to fill in a questionnaire at out-patient clinics from 15 September 2009 until 31 March 2010. The questionnaire had 43 questions asking about personal, social and structural reasons for late testing. 16 of these questions asked the respondents about reasons for late testing with the overall question; 'What has influenced the fact that you did not test earlier for HIV?' The following two out of the 16 optional statements were included:

- I was afraid to find out, that I had HIV

- I wanted to avoid negative responses if people got to know that I had HIV.

Also this is in accordance with findings in other studies from abroad – and therefore not surprising. Again – what is surprising is when these numbers are compared with the finding in the 'Sex Life Survey 2009', where the respondents were asked a similarly phrased question concerning the reasons for not getting a test; 'I wish to avoid negative reactions if people learn I am HIV positive'. 8% of those who had never had a test checked this response option, while among those who had not been tested within the previous 16 months only 5% ticked this box.

Although one cannot (as also mentioned above) compare the numbers directly again the huge difference is striking. And again it seems obvious to conclude that late testing MSM are (or have been!) much more afraid of negative reactions than the non-tested MSM in the 'Sex Life Survey 2009'.

Among the late testing HIV-positive MSM only 51% had ever been tested before – and 40% of those with a previous negative test had tested more than 10 years ago. In the 'Sex Life Survey 2009' 79% of all respondents have ever been tested. This is indicating that late testing HIV-positive MSM are not testing as often as the the general group of MSM.

CONCLUSIONS

The difference of 'being afraid to find out' and 'wanting to avoid negative responses from other people' between late testing HIV-positive MSM and non-tested MSM are striking. The difference indicates that stigma on HIV-positive people among MSM continue to have great significance when deciding to test or not to test for HIV.

One might actually consider whether these late testing MSM have in fact chosen not to be tested rather than they more or less by coincidence have not been tested. And further consider whether this group of men are possible to reach through the offer of 'rapid test' (CheckPoint Testing).

And the respondents were given the choice to mark one of these three degrees of importance:

- No importance
- Had some importance
- Had great importance

100 out of 397 distributed questionnaires were returned, which is equivalent to a response rate of 25.5%. The overall results from this study have been published by HIV-Danmark in the report 'Late Presenters – for HIV in Denmark' [3].

The results from the selected personal reasons for late testing among the group of HIV-positive MSM were compared with data from the 'Sex Life Survey 2009' carried out among non-tested MSM in Spring 2009 [4].

From the 2011 evaluation of the 'CheckPoint' in Copenhagen [5] it is mentioned that 38% of the users are men being tested regularly (once or twice a year). As the late testing HIV-positive MSM are not testing on a regular basis and if they chose not to test it is not expectable that exactly this group will be visiting the CheckPoint for an HIV-test.

According to the report 'HIV and Living Condition – a survey of living conditions and quality of life among people living with HIV in Denmark' [6] there were signs of increased stigmatization in the gay community. An investigation was recommended to check whether this was/is actually the case. Increased stigma in the gay community, where it is estimated that one in every 20 MSM is infected with HIV, could not only counteract the general preventative measures among MSM but also deter men from getting tested.

Fear of stigmatization appears to be the biggest challenges in propelling MSM away from early testing and if late testing MSM have in fact more or less chosen not to be tested for HIV the challenges of reaching this group are huge.

REFERENCES

[1] EPI-NYT, Statens Serum Institut, Week 45, 2011.

- [2] John B. F. de Wit & P. C. G. Adams; To test or not to test: Psychosocial barriers to HIV testing in high-income countries. HIV Medicine (2008) 9, (Suppl. 2):20-22.
- [3] Anders Dahl & Morten R. Eiersted: Late Presenters for HIV in Denmark. Hiv-Danmark, 2011.
- [4] Jakob Haff & Susan Cowan; Sexlivsundersøgelsen 2009 hiv og sex blandt mænd, der har sex med mænd. Statens Serum Institut, 2009. (Sex Life Survey – HIV and sex among men having sex with men).
- [5] Evaluering af CheckPoint København 2011. STOP AIDS, n.d. (Evaluation of CheckPoint, Copenhagen).
- [6] Mie Carstensen & Anders Dahl; HIV and Living Condition a survey of living conditions and quality of life among people living with HIV in Denmark.

AUTHORS

Anders Dahl (Anthropologist) & Morten R. Eiersted (MSc Political Science), Hiv-Danmark

The report 'Late presenters – for HIV in Denmark' is accessible from the link: http://www.hiv-danmark.dk/fileadmin/user_upload/hiv-danmark/pdf/Late_presenters-FINAL.pdf

Hiv-Danmark, 2008.

HIV-DANMARK IS A NATIONWIDE ORGANISATION FOR PLHIV, RELATIVES AND BEREAVED IN DENMARK. HIV-DANMARK IS AN NGO ADVOCATING PATIENT RIGHTS, ENABLING NETWORK FOR PLHIV AND FRIENDS AND PROVIDING UPDATED INFORMATION ON MEDICINE, HEALTH AND SOCIAL ISSUES.

> FIND US AT HIV-DANMARK.DK