

Receiving a positive HIV test result : the experience of patients in Europe

Short title: HIV testing

Schrooten W, MD¹
Dreezen C, MSc¹
Catalan J, MD²
Fleerackers Y¹
Andrighetti R, MD¹
Finazzi R, MD³
Caldeira L⁴
Platteau T¹
Colebunders R, MD. PhD¹
and the Eurosupport group

1. Institute of Tropical Medicine, Antwerp
2. Chelsea and Westminster Hospital, London
3. Hospital San Raffaele, Milan, Italy
4. Hospital de Santa Maria, Lisboa, Portugal

Correspondence to:

R. Colebunders, MD, PhD,
Institute of Tropical Medicine
Nationalestraat 155
2000 Antwerpen, Belgium

 03/247.64.42

 03/247.64.32

Keywords : HIV test, patients perspective, Europe.

Summary

Objective

To describe the experience of HIV infected people in Europe with the HIV test procedure.

Methodology

Between August 1996 and September 1997, self-administered anonymous questionnaires were distributed to people with HIV infection at in-patient and outpatient clinics in 11 European countries.

Results

Thirteen hundred and sixty-six people completed the questionnaire (50% response rate). One hundred and ninety-four (16%) respondents had more than 5 negative HIV tests before being diagnosed HIV positive. One hundred and seventy-nine (14%) were tested without consent. One hundred and ninety-four people (14%) were informed about the HIV positive test result by mail or by telephone. Of the 963 people who received a positive test result during a consultation, 247 (19%) reported that this visit lasted less than 10 minutes, 336 (25%) between 10 and 20 minutes, and 289 (22%) more than 20 minutes. Four hundred and ninety-eight (46%) felt they did not receive adequate support when they were informed about being HIV positive; 249 (19%) experienced feelings of rejection. People diagnosed HIV positive after 1994 more often reported having received adequate support, adequate information and understanding when the positive test was revealed, compared to those diagnosed before 1990.

Conclusion

A large number of our study participants in Europe did not endorse the way HIV tests were conducted and the positive test results were revealed. Although there was an improvement over the years in the way HIV tests were done, HIV tests were often not performed according to international guidelines.

Introduction

Receiving a positive result of an HIV test is a very stressful life-event. Being diagnosed HIV positive not only has important physical consequences, it also has a major psychological, social and relational impact. International guidelines describe how HIV testing and notification of test results should be done^{1:2}.

Obtaining informed consent is a condition sine qua non for HIV testing. The main objectives of pre- and post- test counselling are to provide information on HIV, including the possible consequences of a positive HIV test result, risk assessment and risk reduction. Pre-test counselling should prepare the patient to receive, understand and cope with his or her test result. Disclosure of a positive HIV test requires enough time and skills to provide ample, adequate information and emotional support. Post-test counselling should also include a negotiated risk reduction plan.

This paper describes the results of a large scale survey among people with HIV infection, undertaken in 11 European HIV treatment centres. The aim of this study was to gain information about patients' experience with the HIV test procedure, and to look at the evolution of HIV testing over the years.

Methodology

In 1995, an initiative was launched by the Institute of Tropical Medicine (ITM), Antwerp, to assess the quality of support for people with HIV infection in Europe. Within this project, a questionnaire survey was organised in 11 European countries : Belgium (Antwerp and Brussels), Denmark (Copenhagen), France (13 different locations), Germany (München), Greece (Athens), Italy (Rome and Milan), Luxembourg (Luxembourg), Portugal (Lisbon), Spain (Madrid and La Coruña), the Netherlands (Utrecht) and the United Kingdom (London and Manchester)³. Questionnaires were distributed via HIV reference centres and HIV support organisations (see acknowledgements).

Questionnaires were completed anonymously by people with HIV infection. Outpatients, diagnosed with HIV infection for at least one year, who were able to complete the questionnaire on their own, were eligible to participate. People who did not speak one of the main languages of the participating country were excluded for practical reasons. Respondents were not compensated financially or by other means. The questionnaire contained 108 questions about a broad range of care/support issues including experience with HIV testing. The questionnaire was pre-tested among patients to check for clarity of the questions. These questionnaires were excluded from the analysis.

Different aspects of HIV testing were examined: the number of HIV tests done before the test that revealed the seropositivity, whether informed consent was obtained, if test results were given by mail, phone, or face to face, the duration of the post test counselling, the perceived feelings about the way the HIV test result was revealed. Comparisons according to sex, mode of HIV transmission

and education level were done for the variables number of HIV tests performed, informed consent and duration of post-test visit, after adjustment for country.

Respondents were stratified into 3 groups to investigate the evolution in the way HIV tests were performed: people diagnosed before 1990, between 1990 and 1994 and after 1994. These 3 groups were compared for the variables sex, education level, transmission mode and country and significant differences were adjusted for.

Analyses were performed using SPSS, version 9.0.

Results

One thousand and three hundred sixty-six people completed the questionnaire (50% response rate). No information was available about non-respondents. Thirty people who had been HIV positive for less than one year (2%) also completed the questionnaire. These people were kept in the study. Forty-three people (3%) who did not respond to the question about the year they were diagnosed HIV positive, were excluded. In total, 1323 people were included in the analyses.

Population characteristics (Table 1)

Most of the study participants were male (81%). The mean age of the study population was 38 years (range 18 -75, SD 9.4 years). Approximately half of the respondents reported male homosexual contact as HIV transmission mode, but this varied widely between the participating countries: more homosexual transmission was reported in centres in the northern countries, while

intravenous drug use (IVDU) was more frequently reported in centres in Southern Europe. The mean duration of seropositivity was 6.1 years.

Repeat testing

For 348 people (29%) their first HIV test turned out to be positive, 319 people (27%) already had one negative HIV test, 187 (16%) two negative HIV tests, 88 (7%) 3 negative tests, 62 (5%) 4 negative HIV tests, and 194 (16%) had at least 5 negative HIV tests. Repeat testing, defined testing HIV negative at least 5 times before having a positive HIV test, was reported by 13-37% of the participants in all centres, except in the Dutch centre where nobody was a repeat tester. People with a lower educational level were more often repeat testers compared to people with a higher educational level [69 (30%) versus 184 (19%); O.R.=1.41, 95% C.I.=1.00-2.00]. No significant difference according to sex or mode of HIV transmission was found.

The positive HIV test

The main reasons for having an HIV test were: because of risk behaviour (554, 42%), physical complaints (464, 35%), an HIV positive partner (274, 21%) or a routine medical check-up (224, 17%).

One hundred and seventy-nine respondents (14%) reported that their approval for the HIV test was not asked. A high percentage of HIV testing without agreement (11%-29%) was reported by participants from most centres except from the Dutch centre (5%), the Danish centre (6%) and the British centre (6%).

People who reported IVDU as transmission mode had significantly more often not given their approval for an HIV test compared to people who reported homosexual contact as transmission mode [33 (18%) versus 66 (10%); O.R.=2.54, 95% C.I.=1.29-5.01]. There were no significant differences in

percentages of people tested without consent according to sex and education level.

More than half of the study participants (759, 57%) reported that the consequences of having a positive HIV test result were not discussed during pre-test counselling.

One hundred and six (8%) participants reported that they were informed about their positive test result by telephone; 86 (7%) received the result by mail. Of the 963 (73%) who received the positive test result during a visit, 247 (26%) reported that this visit lasted less than 10 minutes, 336 (35%) between 10 and 20 minutes, and 289 (22%) more than 20 minutes. People with a higher educational level more often reported this visit lasting more than 20 minutes compared to people with a lower educational level [246 (33%) versus 41 (22%); O.R.=1.55, 95% C.I.=1.03-2.33]. There were no significant differences in duration of the post-test visit according to HIV transmission mode or sex.

When the HIV positive test result was revealed, 904 (78%) felt they were dealt with sympathetically, but 249 (23%) felt some kind of rejection; 616 (54%) reported that they received adequate information, and 498 (46%) reported that they received adequate support.

The HIV test procedure over time (Table 2)

Four hundred and sixty-five people (35%) were diagnosed as HIV positive before 1990, 558 (42%) between 1990 and 1994 and 300 (23%) after 1994.

Adjustment was done for country when comparing the way positive HIV results were given; there was no significant difference between the 3 groups in sex, education level or transmission mode.

No significant difference in the percentages of HIV testing without consent was observed between the time periods before 1990, 1990-1994 and after 1994. Post-test counselling after 1994 was reported to last more than 20 minutes significantly more often than to post-test counselling before 1990 [96 (43%) versus 68 (24%); O.R.=2.42, 95% C.I.=1.62-3.63]. People who were diagnosed as HIV positive after 1994 were more likely to report having received adequate support [153 (61%) versus 139 (36%); O.R.=2.48, 95% C.I.=1.74-3.52], adequate information [165 (64%) versus 199 (49%); O.R.=1.72, 95% C.I.=1.22-2.42] and understanding [222 (83%) versus 293 (71%); O.R.=1.78, 95% C.I.=1.18-2.68] when the positive result was revealed, compared to those diagnosed before 1990. They were also less likely to report a feeling of rejection [39 (16%) versus 104 (27%); O.R.=0.47, 95% C.I.=0.31-0.73].

Discussion

This study describes the experiences of HIV infected people in Europe with the HIV test procedure. Considerable shortcomings in the way people were tested for HIV and informed about their positive HIV test result were revealed. About 14% of the participants were tested for HIV without consent. Intravenous drug users reported being tested without consent significantly more often than homosexuals. Fifteen percent of all participants received a positive test result by mail or telephone. One out of four people who did receive the result during a consultation reported this consultation took less than 10 minutes. This was more often the case for less educated individuals. Most of the HIV testing in Europe is done in persons who test HIV negative. This study does not provide information concerning the HIV testing among this low risk population, but it is likely that the percentage of HIV testing without informed consent and without adequate

pre- and post-test counselling will be higher in this population than reported by the participants in this survey.

Over the years some improvement in the way HIV tests were done was noted. People who were tested after 1994 reported post-test counselling lasting longer than 20 minutes significantly more often than those tested before 1990. Furthermore, people who received the positive HIV test result after 1994 were also more satisfied with the post test counselling and significantly more people experienced understanding /support and were satisfied with the quality of information they received. It is important to point out, however, that even after 1994 about 16% still felt some degree of rejection by the health care provider when the positive test result was revealed.

Shortcomings in the way HIV tests are conducted were also observed in earlier studies. McCann and Wadsworth investigated the experiences of 252 gay men in London in 1988-1989⁴. Ten percent of the people interviewed had been tested for HIV without consent and 20% did not feel they were given understanding when the result was given. In another study in London, performed by Pergami et al in 1991, 13% of the study participants were tested without consent, and 30% reported dissatisfaction about the way they were given the diagnosis⁵. In a study performed in Minneapolis in 1990, only 14% of the HIV tests performed met all hospital policy requirements including pre- and post test counselling and informed consent. Risk reduction counselling was provided for only 28% of the patients⁶.

Informing someone about his/her positive HIV test is a delicate task requiring communicative talent, experience, training and sufficient knowledge about HIV. HIV counselling should therefore be emphasised during medical training. This, however, is often not the case^{7:8}.

A large number of the study participants were repeatedly tested for HIV, before they had a positive HIV test result. Repeat testing can be part of a risk reduction strategy (awareness of a regular partner's serostatus before having unprotected sexual contact), but could also reflect repeated unsafe sexual behaviour⁹. All our study participants were HIV positive, indicating that these repeat HIV testers practised unsafe sex and suggesting that HIV tests might have been used by some of them as a way not to use condoms. This also suggests that risk reduction counselling is either not part of the HIV testing procedure or is not very effective. Less educated people were also found more likely to practise repeat testing, compared to people with higher education.

The results of this study should be interpreted with caution. The participants in this survey can not be considered to be representative of all persons with HIV in the different participating centres (e.g. very few persons belonging to ethnic minorities participated in the survey because they were unable to understand the questionnaire). Participants in this study were enrolled through a limited number of HIV treatment centres and support organisations, in 11 different European countries. All the HIV treatment centres are reference centres in their countries, and they would be expected to provide optimal care. Persons with HIV infection from the regions are generally referred to these centres. This questionnaire, however, did not ask where the HIV testing and the pre- and post-test counselling was done. Often HIV testing is done outside these HIV treatment centres e.g. in local clinics or by general practitioners. It is therefore difficult to compare results from the different HIV treatment centres. The results per centre reflect more how the HIV testing is performed in the region than in the HIV treatment centre itself. In the participating centre in the Netherlands no repeat testing, and the lowest percentage of HIV testing without consent was found. This can be explained by the relatively strict implementation of the regulations concerning HIV testing in the Netherlands¹⁰.

Although there has been some improvement over the years in the way positive HIV test results were given, major deficits remain. Learning about the experiences of people receiving a positive HIV test can be a first step in improving this process. The introduction of highly active antiretroviral treatment has changed the context of the HIV test. Early detection of the HIV infection is more important because antiretroviral therapy can suppress the HIV virus and prevent further damage to the immune system ^{11;12}. Early awareness of HIV positivity can prevent the transmission of the virus to other people, and can decrease the risk of mother to child transmission during pregnancy. With increasing numbers of people being tested for HIV, the performance of HIV tests should be monitored in order to guarantee high quality testing.

Table 1 : Characteristics of the Eurosupport study participants

	Males (%)	Mean age (years)	Reported mode of transmission			University or higher education (%)
			Homosexual (%)	IVDU (%)*	Heterosexual (%)	
Denmark (n=94)	87	42	73	2	16	31
The Netherlands (n=65)	79	40	65	6	19	28
United Kingdom (n=182)	93	38	81	4	8	50
Belgium (n=158)	87	40	65	4	22	39
France (n=98)	84	37	67	10	15	27
Germany (n=103)	86	42	70	5	12	27
Luxembourg (n=42)	79	39	57	7	36	14
Greece (n=152)	82	38	44	0	30	36
Italy (n=187)	69	36	32	34	28	18
Portugal (n=91)	76	33	45	24	22	28
Spain (n=151)	67	34	23	49	23	17
Total (n=1323)	81	38	55	15	20	30

* (IVDU : intravenous drug users)

Table 2 : Patient's experience with the HIV test that revealed their seropositivity

	HIV DIAGNOSIS								
	before 1990 (n=465)			1990-1994 (n=558)			after 1994 (n=300)		
	N	%	O.R. (95% C.I.)	N	%	O.R. (95% C.I.)	N	%	O.R. (95% C.I.)
No approval given for the HIV test	71	16	1	63	12	0.63 (0.43-0.92)	45	16	0.71 (0.46-1.11)
Informed about positive HIV test									
by phone	44	10	1	46	8	0.89 (0.57-1.39)	16	5	0.59 (0.32-1.10)
by mail	35	8	1	39	7	1.06 (0.64-1.77)	12	4	0.52 (0.26-1.06)
during a medical visit	315	69	1	406	73	1.16 (0.87-1.56)	242	81	1.78 (1.20-2.62)
Post test counselling									
less than 10 minutes	93	34	1	104	28	0.78 (0.55-1.10)	50	22	0.59 (0.39-0.90)
between 10 and 20 minutes	115	42	1	143	38	0.87 (0.63-1.21)	78	35	0.69 (0.47-1.01)
more than 20 minutes	68	24	1	125	34	1.53 (1.07-2.19)	96	43	2.42 (1.62-3.63)
How did you feel about the way you were informed?									
You received understanding	293	71	1	389	81	1.68 (1.22-2.33)	222	83	1.78 (1.18-2.68)
You received adequate information	199	49	1	252	53	1.16 (0.88-1.53)	165	64	1.72 (1.22-2.42)
You felt adequately supported	139	36	1	206	45	1.38 (1.03-1.85)	153	61	2.48 (1.74-3.52)
You felt rejected	104	27	1	106	23	0.80 (0.58-1.10)	39	16	0.47 (0.31-0.73)

Reference List

1. U.S.Department of health & human services.Public health service.Centers for disease control and prevention. HIV counseling, testing, and referral standards and guidelines. 1994.
Ref Type: Generic
2. Witt RC, Silvestre AJ, Rinaldo CR, Jr., Lyter DW. Guidelines for disclosing HIV-antibody test results to clients. *Nurse Pract.* 1992;**17**:55, 59, 63.
3. Tomlinson DR, Colebunders R, Coppieters Y, Dreezen C, Andraghetti R, Fleerackers Y *et al.* Primary care involvement in human immune deficiency virus infection-a pan-european view [In Process Citation]. *Fam.Pract.* 2000;**17** :288-92.
4. McCann K.,Wadsworth E. The experience of having a positive HIV antibody test. *AIDS Care* 1991;**3**:43-53.
5. Pergami A, Catalan J, Hulme N, Burgess A, Gazzard B. How should a positive HIV result be given? The patients' view. *AIDS Care* 1994;**6**:21-7.
6. Pomeroy C, Sandry J, Moldow DG. HIV antibody testing: the gap between policy and practice. *J.Acquir.Immune.Defic.Syndr.* 1994;**7**:816-22.
7. Campbell E, Weeks C, Walsh R, Sanson-Fisher R. Training medical students in HIV/AIDS test counselling: results of a randomized trial [see comments]. *Med.Educ.* 1996;**30**:134-41.
8. Cook RL, Steiner BD, Smith AC, III, Evans AT, Willis SE, Petrusa ER *et al.* Are medical students ready to provide HIV-prevention counseling? *Acad.Med.* 1998;**73**:342-6.
9. Leaity S, Sherr L, Wells H, Evans A, Miller R, Johnson M *et al.* Repeat HIV testing: high-risk behaviour or risk reduction strategy? *AIDS* 2000;**14**:547-52.
10. Colebunders, R. Eurosupport I report. 2000.
Ref Type: Generic
11. Garofalo R, Makadon HJ. Management of the asymptomatic HIV-infected patient: an update. *Hosp.Pract.(Off Ed)* 2000;**35**:89-8, 101.
12. Volberding P. When and where to start: guidelines for the initiation of antiretroviral therapy. *AIDS Read.* 2000;**10**:150-5.