

ORIGINAL RESEARCH

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

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Objective

To describe HIV-infected people's experience of the HIV test procedure in Europe.

Methods

Between August 1996 and September 1997, anonymous self-administered questionnaires were distributed to HIV-infected people in 11 European countries.

Results

A total of 1366 people completed the questionnaire (50% response rate). Of these, 194 (16%) had more than five negative HIV tests before being diagnosed as HIV positive, 179 (14%) were tested without consent and 192 (15%) 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 (26%) reported that this visit lasted less than 10 min, 336 (35%) between 10 and 20 min, and 289 (30%) more than 20 min. Over half the total respondents (591, 54%) felt they did not receive adequate support when they were informed about being HIV positive, with 249 (19%) experiencing feelings of rejection. People who were diagnosed as HIV positive after 1994 reported more frequently receiving adequate support, information and understanding when the positive test result was revealed compared with those diagnosed before 1990.

Conclusion

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

Key words: Europe, HIV test, patients' perspective

Received: 03 January 2001, accepted 05 April 2001

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 but also has major psychological and social impact. International guidelines describe how HIV testing and notification of test results should be done [1–3]. Obtaining informed consent for HIV testing is essential. The main objectives of pretest counselling are to provide information on HIV, outline the possible

consequences of a positive HIV test result, assess risk and discuss methods of risk reduction. Pretest counselling should prepare the patient to receive, understand and cope with his or her test result. Disclosing a positive test result requires considerable time and skill in order 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 of HIV-infected people that was 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 in recent years.

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Methods

In 1995, an initiative was launched by the Institute of Tropical Medicine (ITM) in Antwerp to assess the quality of support for people with HIV infection in Europe. The project organized a questionnaire survey that was distributed in 11 European countries: Belgium (Antwerp and Brussels), Denmark (Copenhagen), France (13 different locations), Germany (Munich), 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) [4]. Questionnaires were distributed via HIV treatment centres and HIV support organizations (see Acknowledgements). Participating centres were contacted through an existing network of HIV professionals. In France, the participating centre was an HIV support organization that distributed the questionnaires via 13 different local offices. For practical reasons, in this article we will refer to countries rather than specific centres. The participating centres are not necessarily representative for each country.

Questionnaires were completed anonymously by HIV-infected people. People were contacted through HIV support organizations and HIV treatment centres and were eligible to participate if they had been diagnosed with HIV for at least 1 year and were able to complete the questionnaire themselves. People who did not speak one of the participating country's main languages were excluded for practical reasons. Respondents were not compensated financially or by other means. The questionnaire consisted of a broad range of 108 questions covering care and support issues, including experience with HIV testing. The questionnaire was pretested among patients to check the clarity of the questions. These questionnaires were excluded from the analysis.

Different aspects of HIV testing were examined: the number of HIV tests undergone before the positive one, whether informed consent was obtained, whether test results were given by mail, telephone or face to face, the duration of the visit when the positive test result was revealed and the patients' feelings about the HIV test procedures. After adjustment for country, comparisons according to sex, mode of HIV transmission and education level were made for the following variables: the number of HIV tests performed, the existence of informed consent and the duration of the post-test visit.

Respondents were stratified into three groups on the basis of their diagnosis: before 1990, between 1990 and 1994 and after 1994. These three groups were compared for the variables sex, level of education, transmission mode and country and adjustments made for significant differences.

All percentages were taken from the total number of respondents to each individual question. Analyses were performed using Statistical Package for the Social Sciences (SPSS), version 9.0.

Results

A total of 1366 people completed the questionnaire (50% response rate). No information was available about nonrespondents. Thirty people who had been HIV positive for less than 1 year (2%) also completed the questionnaire. These people were kept in the study. Forty-three people (3%) who did not answer the question asking the year of diagnosis as HIV positive were excluded. Finally, 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). Approximately half of the respondents reported male homosexual contact as the 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 Southern European centres. 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%) had already had one negative HIV test; 187 (16%) had two negative HIV tests; 88 (7%) had three negative tests; 62 (5%) had four negative tests; and 194 (16%) had at least five negative HIV tests. Repeat testing, defined as testing HIV negative at least five times before having a positive HIV test, was reported by 13–37% of the participants in all centres except the single Dutch one, where nobody was a repeat tester. People with a lower level of education were more often repeat testers (69, 30%) than those with a higher level of education (184, 19%), with an odds ratio (OR) of 1.41 and a 95% confidence interval (CI) of 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 risk behaviour (554, 42%), physical complaints (464, 35%), an HIV positive partner (274, 21%) or a routine medical check-up (224, 17%).

Table 1 Characteristics of the Eurosupport study participants

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

IVDU = intravenous drug user.

As many as 179 (14%) reported that their approval for the HIV test was not sought. A high rate of HIV testing without consent (11%–29%) was reported by participants from most centres, except for the Dutch centre (5%), the Danish centre (6%) and the British centres (6%). A significantly higher percentage of people who reported IVDU as transmission mode had not given consent for an HIV test compared with those who reported homosexual contact as transmission mode (32, 18% vs. 69, 10%; OR = 2.54, 95% CI = 1.29–5.01). The percentage of IVDUs tested for HIV without consent was not significantly different between countries. 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, 58%) reported that the consequences of having a positive HIV test result were not discussed during pretest counselling.

A majority of people (756, 62%) people were informed about their positive test results by the physician who ordered the test, 265 (22%) by another physician, 107 (9%) by a counsellor or social worker, 57 (5%) by a nurse and 22 (2%) by a psychologist.

Some respondents (106, 8%) reported that they were informed about their positive test result by telephone; 86 (7%) received the result by mail. Of the majority (963, 73%) who received the positive test result during a visit, 247 (26%) reported that this visit lasted less than 10 min, 336 (35%) between 10 and 20 min, and 289 (30%) more than 20 min. People with a higher level of education more often reported this visit lasting more than 20 min compared with people with a lower level of education (246, 33% vs. 41, 22%; OR 1.55, 95% CI 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 treated with understanding, 616 (54%) reported that they received adequate information and 498 (46%) reported that they received adequate support. Two hundred and forty-nine people (23%) reported feelings of rejection.

The HIV test procedure over time (Table 2)

About one-third of respondents (465, 35%) were diagnosed as HIV positive before 1990, 558 (42%) between 1990 and 1994 and 300 (23%) after 1994. There was no significant difference between the three groups in sex, educational level or transmission mode, but there were some differences according to country. Therefore, country was taken into account when comparing the way HIV test results were given. No significant difference in the percentages of HIV testing without consent was observed between the time periods before 1990, 1990–94 and after 1994. After 1994, medical consultation about a positive test result was longer than 20 min significantly more often than before 1990. People who were diagnosed HIV positive after 1994 were more likely to report having received understanding, adequate information and adequate support and were less likely to report feelings of rejection when the positive result was revealed than those diagnosed before 1990.

Discussion

This study describes the experiences of HIV-infected people in Europe with the HIV testing procedure. Considerable shortcomings in the way people were tested for HIV and informed about their positive HIV status were revealed. About 14% of the participants were tested for HIV without

Table 2 Patients' experience with the HIV test that revealed their seropositivity

	HIV diagnosis								
	Before 1990 (n = 465)			1990–1994 (n = 558)			After 1994 (n = 300)		
	n	%	OR (95% CI)	n	%	OR (95% CI)	n	%	OR (95% CI)
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 telephone	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 min	93	34	1	104	28	0.78 (0.55–1.10)	50	22	0.59 (0.39–0.90)
Between 10 and 20 min	115	42	1	143	38	0.87 (0.63–1.21)	78	35	0.69 (0.47–1.01)
More than 20 min	68	24	1	125	34	1.52 (1.07–2.19)	96	43	2.42 (1.62–3.63)
How did you feel about the way in which 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)

CI = confidence interval; OR = odds ratio.

consent, 15% of all participants received a positive test result by mail or telephone (9% of those people diagnosed after 1994) and 26% of participants, who did receive the result during a consultation, reported that this consultation took less than 10 min.

Over the years, some improvements in giving HIV tests were noted. People who were tested after 1994 reported that disclosing the positive test result took more than 20 min significantly more frequently than those tested before 1990. Furthermore, people who received the positive HIV test result after 1994 were more satisfied with the way they were informed about this result. It is important to point out, however, that even after 1994, about 16% still felt some degree of rejection by the healthcare 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 homosexual men in London in 1988–89 [5]. Ten per cent of the people interviewed had been tested for HIV without consent and 20% did not feel they were treated with understanding when the result was given. In another study in London, performed by Pergami *et al.* [6] in 1991, 13% of the study participants were tested without consent and 30% reported dissatisfaction about the disclosure of test results. In a study 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 patients [7].

Informing someone of his or her positive HIV test result is a delicate task, requiring communicative talent, experience, training and sufficient knowledge about HIV. Such counselling should therefore be emphasized during medical training. This, however, is often not the case [8,9].

A large number of the study participants were tested repeatedly for HIV before they had a positive HIV test result. Repeat testing can be part of a risk reduction strategy (for example, to learn a regular partner's serostatus before having unprotected sexual contact) but can also reflect repeated unsafe sexual behaviour [10]. 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.

The results of this study should be interpreted with caution. The participants in this survey cannot be considered representative of all persons with HIV in the different participating centres (e.g. ethnic minorities and women were under-represented in this study). Respondents were enrolled through a limited number of HIV treatment centres and support organizations in 11 different European countries. All the HIV treatment centres are reference centres in their countries and would be expected to provide optimal care. HIV testing is often done outside these HIV treatment centres; for example, tests may be given in local clinics or by general practitioners. In our questionnaire we did not ask where the HIV testing and the pre- and post-test

counselling was done. Therefore, we do not know whether these results reflect the way HIV testing was done in the participating centres or, rather, in the regions where these centres were located. 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 Netherlands [11].

Although there has been some improvement over the years in the way positive HIV test results are 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 HIV testing. Early detection of HIV infection is crucial because antiretroviral therapy can suppress the HIV virus and prevent further damage to the immune system [12,13]. Early awareness of HIV infection can prevent transmission of the virus to other people and decrease the risk of mother-to-child transmission during pregnancy. With increasing numbers of people being tested for HIV, the testing procedure should be closely monitored. This could be done by surveys of HIV-positive people and also of healthcare workers such as general practitioners, gynaecologists, dermatologists and paediatricians. In addition, health services where HIV testing is often performed should be regularly audited.

Acknowledgements

This work would not have been possible without the enthusiastic co-operation of the staff at all centres and organizations involved in the Eurosupport project: Mrs B Goffin (Institute of Tropical Medicine, Antwerp), Dr S Dewit (Hôpital Universitaire St Pierre, Brussels), Mrs C Eggermont (HIV Vereniging Vlaanderen, Antwerp), Dr B Kvinesdal and Mrs K Schmidt (Hvidovre Hospital, Copenhagen), Mr S Bouchoucha (AIDES-Fédération Nationale, Paris), Dr H Liess (Klinikum Innenstadt, Munich), Dr J Kosmidis and Mrs M Manola (General Hospital of Athens, Athens), Dr G Saroglou and Mrs K Mane (Evangelismos Hospital, Athens), Dr I Stratigos and Dr C Botsi (Hospital Syngros, Athens), Mr N Papadopoulos (Elpida, Athens), Dr R Finazzi (Ospedale S Raffaele, Milan), Dr R Hemmer (Centre Hospitalier de Luxembourg, Luxembourg), Mrs C Stadelmann (Croix Rouge Luxembourgeoise, Luxembourg), Dr L Caldeira and Mrs A Sequeira (Hospital de Santa Maria, Lisbon), Dr N Ferro (Liga Portuguesa contra a SIDA, Lisbon), Dr F Garcia, Mrs T Mejias and Mrs M Poal Marcet (Hospital Clinic, Barcelona), Mrs J Cobena i Guardia (Associacio Ciutadana

anti-SIDA de Catalunya, Barcelona), Dr A Castro (Complejo Hospitalario J Canalejo, La Coruña), Mr H Vrehan (University Hospital Utrecht, Utrecht), Mr P De Prouw (HIV Vereniging, Utrecht), Dr EG Wilkins (North Manchester General Hospital, Manchester), Dr D Tomlinson (St Mary's Hospital, London). The study was funded by the European Commission (DG-V).

References

- 1 US Department of Health and Human Services, Public Health Service, Centers for Disease Control and Prevention. *HIV Counseling, Testing, and Referral Standards and Guidelines*. Washington, DC, CDC, 1994.
- 2 Joint United Nations Programme on HIV/AIDS. *Tools for Evaluating HIV Voluntary Counselling and Testing*. Geneva, UNAIDS/00.09 E, 2000.
- 3 Witt RC, Silvestre AJ, Rinaldo CR Jr, Lyter DW. Guidelines for disclosing HIV-antibody test results to clients. *Nurse Pract* 1992; **17**: 59–63.
- 4 Tomlinson DR, Colebunders R, Coppieters Y *et al.* Primary care involvement in human immune deficiency virus infection – a pan-European view. *Fam Pract* 2000; **17**: 288–292.
- 5 McCann K, Wadsworth E. The experience of having a positive HIV antibody test. *AIDS Care* 1991; **3**: 43–53.
- 6 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**: 21–27.
- 7 Pomeroy C, Sandry J, Moldow DG. HIV antibody testing: the gap between policy and practice. *J Acquir Immune Defic Syndr* 1994; **7**: 816–822.
- 8 Campbell E, Weeks C, Walsh R, Sanson-Fisher R. Training medical students in HIV/AIDS test counselling: results of a randomized trial. *Med Educ* 1996; **30**: 134–141.
- 9 Cook RL, Steiner BD, Smith AC III *et al.* Are medical students ready to provide HIV-prevention counseling? *Acad Med* 1998; **73**: 342–346.
- 10 Leaity S, Sherr L, Wells H *et al.* Repeat HIV testing: high-risk behaviour or risk reduction strategy? *AIDS* 2000; **14**: 547–552.
- 11 Dijkgraaf MG, Vrehan HM, De Prouw P, Borleffs JC. Report on the Eurosupport project in the Netherlands. In: Colebunders R, eds. *The Quality of Support in European HIV/AIDS Treatment Centres 'Eurosupport'* Brussels, European Commission Directorate General V, 1997; 124–132.
- 12 Garofalo R, Makadon HJ. Management of the asymptomatic HIV-infected patient: an update. *Hosp Pract* 2000; **35**: 89–101.
- 13 Volberding P. When and where to start: guidelines for the initiation of antiretroviral therapy. *AIDS Read* 2000; **10**: 150–155.