

ORIGINAL ARTICLE

Utilization of healthcare services by people living with HIV/AIDS in Europe

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Summary: Our objective was to compare the utilization of healthcare/support services for people with HIV infection in Europe. Between August 1996 and September 1997 self-administered anonymous questionnaires were distributed by reference HIV treatment centres and HIV support organizations. The questionnaire was completed by 1366 people living with HIV/AIDS. A small number of people had received influenza or pneumococcal vaccinations (34% and 19% respectively). Many patients did not receive dental care (48% of participants from the southern countries) and only 72% of the women had a gynaecological examination. More participants from the south reported insufficient access to healthcare/support services, particularly for nursing care (19%), psychological support (33%), nutritional advice (45%), access to support organizations (36%), and legal advice (46%). In conclusion, many people living with HIV/AIDS in Europe do not benefit from certain annual medical procedures proposed by international guidelines and consider themselves to have insufficient access to health/support services.

Keywords: Utilization, healthcare services, HIV/AIDS, Europe

INTRODUCTION

Caring for patients with HIV has presented an ongoing challenge to medical staff and healthcare workers for the last decade. The introduction of highly active antiretroviral therapy (HAART) has transformed the illness into a chronic condition. The very nature of HIV infection permeates the psychological and social well-being of the HIV-infected individual. They require a continuum of care and a range of healthcare services, which address their complex physical and psychosocial needs.

Medical care of people with HIV infection is complex. Patients need to be monitored for changes in viral load and CD4 lymphocyte counts and given advice about antiretroviral therapy. Any opportunistic infection must be treated and palliative care given, where necessary. They also need support in other aspects of their lives affected by their HIV status, such as housing, employment and relationships. It is important that people living with HIV/AIDS should be enabled to optimize

their own health and prevent further spread of the infection.

We know little about the utilization of health services by people living with HIV/AIDS. Relatively few studies have presented information, describing utilization of medical services according to sociodemographic factors and disease stage¹⁻⁵. Most of these studies have been done in the USA and very little information is available from Europe.

This article will describe and compare utilization of health services by HIV-infected persons in Europe. The paper will examine the effect of sociodemographic characteristics on service utilization and will estimate the extent to which patterns of utilization differ across European regions. This information will help optimize access to healthcare for persons with HIV infection in Europe and will assist in the dissemination of good practice models.

MATERIALS AND METHODS

The following centres were included: Antwerp and Brussels (Belgium), Copenhagen (Denmark), 13 different locations in France, Munich (Germany), Athens (Greece), Rome and Milan (Italy), Luxembourg (Luxembourg), Lisbon (Portugal), Barcelona

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and La Coruña (Spain), Utrecht (The Netherlands) and London and Manchester (UK). For practical reasons we will refer to countries rather than specific centres in this article. The participating centres are not necessarily representative for each country.

In each country, one HIV/AIDS treatment centre or an HIV support organization was identified to coordinate the project activities. Between August 1996 to September 1997, self-administered anonymous questionnaires were distributed to persons with HIV infection at inpatient and outpatient departments of each participating HIV/AIDS treatment centre and to 50 persons with HIV infection reached by HIV/AIDS organizations. A wide range of topics were covered in the questionnaire, such as the individual's access to treatment and clinical trials, psychosocial support, experience with outpatient care, hospital care, home care, support organizations, euthanasia, the cost of different care/support items and the degree of satisfaction with healthcare services (copies of the questionnaire can be obtained from the author). The data collection period varied from 5 months in Belgium, France, Italy, Luxembourg and Spain to 13 months in Germany, Portugal and the UK.

For the purpose of analyses, the countries have been grouped into: *North* (Denmark, The Netherlands and the UK); *Central* (Belgium, France, Germany and Luxembourg) and *South* (Greece, Italy, Portugal and Spain).

The persons who met the following inclusion criteria were eligible to participate in the study: diagnosis of HIV infection for at least one year and ability to fill in the questionnaire independently (ability to read, write and understand the questions).

Comparability across countries was achieved through a standardized design and common implementation procedures, with centralized support and coordination of the national surveys by the Co-ordinating Centre at the Institute of Tropical Medicine. Transcription of a blueprint patient questionnaire into national formats involved both its translation in 9 languages and its adaptation to national conditions (such as currencies, educational levels, etc.).

Baseline parameters considered as potential predictors of antiretroviral (ARV) therapy were: age, sex, CD4+ cell count, education, income, HIV transmission category, stage of HIV disease and region. Bivariate analysis was done to explore these potential covariates. To check for possible

Table 1. Sociodemographic characteristics of respondents

Sociodemographic characteristics	Countries/regions*			No. (%) of total patients
	North n=355 (%)	Central n=415 (%)	South n=596 (%)	
Age				
Mean	39	40	36	
Minimum–Maximum	21–72	24–74	18–75	
Gender				
Male	316 (89)	353 (85)	435 (73)	1104 (81)
Education level				
Primary	48 (14)	77 (19)	157 (27)	282 (21)
Secondary/higher education	144 (41)	187 (45)	277 (47)	608 (45)
University education	142 (41)	124 (30)	140 (24)	406 (30)
Other	15 (4)	24 (6)	12 (2)	51 (4)
Mode of HIV transmission				
Homosexual contact	265 (79)	263 (69)	192 (37)	720 (58)
Heterosexual contact	44 (13)	82 (21)	154 (30)	280 (23)
Intravenous drug use	14 (4)	27 (7)	156 (30)	197 (16)
Blood transfusion	10 (3)	9 (2)	9 (2)	28 (2)
Other	4 (1)	3 (1)	6 (1)	13 (1)
HIV status				
HIV without symptoms	113 (32)	175 (42)	297 (51)	585 (44)
HIV with symptoms	128 (37)	165 (40)	146 (25)	439 (33)
HIV with AIDS	98 (28)	66 (16)	90 (16)	254 (19)
Patient did not know	12 (3)	7 (2)	45 (8)	64 (5)
Duration seropositivity				
Mean (years)	6.6	6.5	5.5	
Standard deviation	3.7	3.8	3.8	
Minimum–Maximum	1–15	0–18	1–16	
Living alone	171 (48)	195 (47)	157 (26)	523 (38)
Living with someone	184 (52)	219 (53)	437 (74)	840 (62)

*North=Denmark+The Netherlands+United Kingdom; Central=Belgium+France+Germany+Luxembourg; South=Greece+Italy+ Spain+Portugal

confounding, these factors were entered into a multivariate logistic regression model using a backward procedure (entry level 0.05, removal level 0.10). Region was in general the most significant predictor. For simplicity reasons, only region is shown in the tables. The data were managed using commercial programs (Access and Excel) and analysed using SPSS for Windows.

RESULTS

Sample characteristics (Table 1)

A total of 1366 people completed the questionnaire, which was 50% of the distributed total. Of the respondents, 355 (26%) were from the North region, 415 (30%) were from the Central region and 596 (44%) were from the South region. While the majority of the respondents were male in all the regions, there were significantly more female respondents from the Southern region (27% vs 15% in the Central and 11% in the Northern region). Southern respondents were also significantly younger. Participants in the North tended to be more highly educated than those in the Central and Southern regions: 41% in the North had finished secondary or higher education compared with 31% in the Central region and 24% in the South.

Homo/bisexual contact was reported by 265 (79%) respondents in the North and 263 (69%) respondents in the Central region, whereas only 192 (37%) respondents in the South acquired HIV through homo/bisexual contact. In the South, 156 (30%) respondents acquired HIV through drug use compared with 14 (4%) in the North and 27 (7%) in the Central region.

Slightly more participants considered themselves to have AIDS in Northern Europe (28%), compared with 16% in Central and 16% in Southern European countries. The known duration of the seropositivity was also slightly longer in the North: mean of 6.6 years compared with the South: mean of 5.5 years.

Medical care/utilization of health/support services (Tables 2 and 3)

Only a relatively small number of people living with HIV/AIDS have received influenza/pneumococcal vaccinations. Only 48% of participants from the Southern countries reported that they had dental care since they were known to be seropositive. People with a low monthly income (less than 40,000 Belgian Francs/992 Euros) were significantly receiving dental care less often compared with those with a higher income (46% vs 54%, odds ratios [OR]=0.701; confidence intervals [CI]=0.534–0.920). Only 72% of the women had a gynaecological examination since they were diagnosed seropositive. Fewer participants from the Northern countries reported that they had 'a skin test for tuberculosis', compared with participants from Southern Europe: e.g. only 28% of Danish participants reported tuberculin testing, compared with 87% of the Spanish participants.

There were significant differences between the regions in terms of utilization of health services. Respondents in the Northern and Central regions were about twice as likely to visit a specialist HIV physician than people in the Southern region. Respondents in the Central region were twice as likely to have general practitioner (GP) involvement than respondents from the North and 4.6 times more likely than respondents from the Southern region: e.g. only 9% from the Portuguese respondents reported to having a GP involved in HIV care, compared with 83% of the Dutch respondents. People in the South of Europe also visited a dentist, a dietician or a social worker less often.

Perceived access to healthcare services (Table 4)

More participants from the South reported insufficient access to health/support services, particularly for nursing care (19%), psychological support (33%), nutritional advice (45%), access to support organizations (36%), and legal advice (46%). A relatively large percentage of respondents, particularly in the South, complained of insufficient

Table 2. Medical treatment of respondents across the regions since diagnosis of respondents' seropositivity (mean 6.1 years)

	North (n=355)		Central (n=413)		South (n=596)	
	%	OR (CI)	%	OR (CI)	%	OR (CI)
Chest X-ray	86	0.75 (0.45–1.23)	88	1	79	0.63 (0.40–0.99)
Skin test for tuberculosis	30	0.34 (0.24–0.48)	52	1	54	0.87 (0.63–1.20)
Influenza vaccination	33	0.67 (0.49–0.92)	41	1	31	0.84 (0.61–1.15)
Pneumococcal vaccination	31	1.43 (1.01–2.04)	21	1	12	0.51 (0.34–0.76)
Dental care	74	1.21 (0.86–1.71)	68	1	48	0.55 (0.40–0.75)
Gynaecological examination (women n=258)	70	0.17 (0.03–0.80)	77	1	71	0.24 (0.41–0.77)
Examination of the eyes	68	0.77 (0.55–1.08)	70	1	48	0.56 (0.41–0.77)
Electrocardiogram	39	0.36 (0.26–0.50)	60	1	42	0.58 (0.43–0.79)

OR=odds ratios, CI=confidence intervals

Table 3. Multivariate linear regression of health services utilized by respondents in a 6-month period prior to study

	North (n=355)		Central (n=415)		South (n=596)	
	%	OR (CI)	%	OR (CI)	%	OR (CI)
GP involvement	50	0.51 (0.38–0.69)	64	1	30	0.22 (0.16–0.30)
GP at office	61	0.49 (0.35–0.68)	73	1	50	0.31 (0.22–0.43)
GP at home	14	0.50 (0.34–0.75)	23	1	9	0.29 (0.18–0.45)
Specialist HIV physician	88	0.94 (0.57–1.56)	87	1	74	0.52 (0.34–0.81)
Dentist	70	1.31 (0.94–1.83)	62	1	39	0.57 (0.42–0.77)
Dietician	21	1.87 (1.78–4.14)	12.1	1	4	0.32 (0.17–0.57)
Alternative healer	25	2.72 (1.78–4.14)	10	1	9	0.98 (0.61–1.60)
Social worker	57	3.15 (2.28–4.36)	31	1	23	0.58 (0.41–0.82)
Counsellor	29	11.67 (5.77–23.60)	3	1	4	1.08 (0.47–2.50)
Psychologist	21	0.80 (0.56–1.12)	24	1	21	0.74 (0.52–1.07)
Psychiatrist	14	0.85 (0.55–1.29)	16	1	11	0.71 (0.46–1.11)
Legal advisor	16	1.70 (1.07–2.69)	10	1	10	0.89 (0.53–1.47)
Support group	31	1.19 (0.85–1.66)	27	1	22	0.78 (0.56–1.10)

GP=general practitioner, OR=odds ratios, CI=confidence intervals

Table 4. Multivariate linear regression analysis of respondents' perceptions of insufficient access to healthcare services at the time of the questionnaire

	North (n=355)		Central (n=415)		South (n=596)	
	%	OR (CI)	%	OR (CI)	%	OR (CI)
Medical treatment	5	1.06 (0.52–2.17)	4	1	9	2.44 (1.30–4.55)
Nursing care	9	1.06 (0.61–1.85)	8	1	19	2.50 (1.54–4.00)
Psychological support	14	0.56 (0.37–0.85)	18	1	33	2.08 (1.43–2.94)
Practical assistance	18	0.71 (0.47–1.06)	19	1	37	3.23 (2.17–4.76)
Nutritional advice	21	0.64 (0.44–0.94)	24	1	45	2.86 (2.00–4.17)
HIV support organizations	12	0.67 (0.42–1.05)	14	1	36	4.17 (2.78–6.25)
Financial support	28	0.58 (0.40–0.83)	33	1	54	2.27 (1.56–3.23)
Legal advice	21	0.61 (0.41–0.91)	24	1	46	3.45 (2.33–5.00)

OR=odds ratios, CI=confidence intervals

financial support (Northern Europe 28%, Southern Europe 54%). Thirty-six per cent of Portuguese reported having difficulties paying for medical care, compared with only 6% in The Netherlands and Germany. No significant differences in access to healthcare services were found according to mode of HIV transmission: intravenous drug users were not found to have less perceived access to healthcare services.

DISCUSSION

This study shows that the care/support for people living with HIV/AIDS in Europe is far from ideal. A relatively large group of people living with HIV/AIDS in Europe does not seem to benefit from the annual medical procedures proposed by international guidelines, such as dental care and gynaecological examinations. The benefit of influenza and pneumococcal vaccinations for HIV-infected people has not been clearly demonstrated^{6–8}. This probably explains why such vaccinations are not often offered to patients. An annual dental examination and gynaecological examination however, is a universal recommendation for someone

with HIV infection⁹. Reasons why these procedures are not being offered should be studied. One of the explanations that only a limited number of persons receive annual dental care, might be that certain dentists remain reluctant to take care of HIV-infected people and that patients remain afraid of revealing their seropositivity to dentists^{10,11}.

The country where GPs were most frequently involved in HIV care was The Netherlands, as has been reported previously^{12,13}. Particularly in Southern Europe, but also in certain Northern countries, such as Denmark, GPs are less involved in the care for people with HIV infection. Since the availability of HAART the percentage of GPs involved in HIV care is decreasing even more. HIV treatment strategies are evolving very fast, so it is very difficult for a GP, who most often only has one or a few patients with HIV to stay up to date. It has been shown that patient survival is significantly correlated with the physician's experience of HIV^{14,15}. Therefore, patients with HIV need to be treated by specialist physicians. There are reasons why people with HIV infection do not consult a family practitioner, e.g. they fear their diagnosis would not stay confidential, particularly with

regard to family members and friends. A good collaboration, however, of GPs with special expertise in HIV and HIV specialists in HIV treatment centres has many advantages. Such a system offers a continuum of care, persons with HIV infection can also be visited at home and have access to adequate medical care, 24h a day. For people treated with HAART, a GP may provide additional support, resulting in a better adherence to treatment.

A large number of people, particularly in Southern European countries reported that they had insufficient access to certain health/support services, such as nursing care, psychosocial support, nutritional advice, access to HIV support organizations and legal advice. This could be explained partially by the fact that in Southern European countries there is a high percentage of intravenous drug users, with psychosocial problems. However, multivariate analysis showed that this difference in access to psychosocial services between Southern and Northern and Central European countries was correlated with region and not with mode of transmission, or other predictors.

The results of this study should be interpreted with caution, as participants in the survey cannot be considered as representative of all persons with HIV infection living in the different European countries. Centres involved in the Eurosupport initiative were HIV reference centres in their respective countries. It is possible that in smaller centres and by including people belonging to ethnic minorities, the access to health/support services would have even been less. Study participants were contacted through HIV clinics and support organizations. People having no access to these facilities were therefore not included in this study. Moreover, we do not know to what degree the answers of the participants were reliable and corresponding with actual practices. No information about non-respondents was available.

This study took place at the time when HAART was being introduced in Europe. Such treatment has now transformed the way in which we care for people with HIV infection. Medical care is now becoming more complex, but this treatment has also created new psychosocial problems, such as coping with difficult treatment regimens and side effects, adapting the lifestyle, making new plans for the future, desire for pregnancy etc. The way in which we treat people with HIV changes continually. It remains important to monitor how the care/support for people with HIV infection is organized and ensure an equal access to health/support services, regardless of their gender, ethnicity or mode of HIV transmission.

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