ORIGINAL RESEARCH

Euthanasia: from the perspective of HIV infected persons in Europe

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Background

In the debate about legalization of euthanasia very little attention has so far been given to the opinion of the patient.

Objective

To assess the opinion of persons with HIV infection in Europe.

Methods

A cross-sectional survey of persons with HIV infection attending HIV/AIDS treatment centres or HIV support organizations in 11 European Union Member States was performed. A total of 2751 anonymous patient self-administered questionnaires were distributed between August 1996 and September 1997. The questionnaire contained 108 questions concerning a variety of topics about HIV care, including five questions on euthanasia.

Results

One thousand three hundred and seventy-one people with HIV infection completed the questionnaire, of whom 1341 (98%) responded to the questions concerning euthanasia. Seventy-eight percent of respondents agreed with the legalization of euthanasia in case of severe physical suffering, 47% if there was severe psychological suffering and 24% simply at the patient's request. For physical suffering and at a clear patient's request, accepted practices were: alleviation of pain with double effect (81%), medical euthanasia (62%) and physician assisted suicide (45%). Fifty percent would consider euthanasia for themselves if all treatment options were exhausted. Social indicators such as educational level and employment seemed to play a more significant role in determining attitudes towards legalization, and personal interest in, euthanasia than indicators related to disease status.

Conclusion

In this study a majority of HIV infected persons in Europe favoured the legalization of euthanasia.

Key words: euthanasia, HIV infection, Europe

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Introduction

Whether euthanasia should have its place within legal medical practice remains a controversial issue. Euthanasia, the shortening of someone's life with his/her full informed consent (either by administering or helping to self-administer a lethal dose), is currently not permitted by law in any European country. In the Netherlands there is a law with the following detailed list of requirements under

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which physicians are exempt from prosecution: a mentally competent patient, whose suffering in the case of an irreversible illness becomes unbearable and who has requested termination of life on repeated occasions; a second independent physician must have examined the patient; an extensive report must be handed over to the public prosecutor who decides whether the procedure conforms with the statutory criteria [1–3].

Several recent studies assessed patients' requests regarding euthanasia and physicians' views and practices [4–8]. In one study, the proportion of physicians who agreed to grant a request for physician assisted suicide (PAS)

increased from 28% in 1990 to 48% in 1995 [7]. In very few of these studies, however, were patients themselves asked to express their needs and concerns on the topic [9-12]. The survey presented in this paper is the first that investigates the opinion and concerns of people with HIV infection regarding euthanasia and its legalization on an international scale. It describes patients' opinions and attitudes towards euthanasia for themselves and regarding its legalization in general; and secondly, it explores whether physical suffering or social characteristics of the patient could be identified as determining factors. The data used were gathered by the centres and organizations participating in the Eurosupport initiative (1995-1997), a concerted action that attempted to evaluate the quality of care provided to persons with HIV infection in 11 European Union Member States and to propose recommendations for improvement [13].

Methodology

Questionnaire

Data were gathered by means of a standardized questionnaire handed out by HIV/AIDS outpatient treatment centres and non-governmental HIV support organizations (NGOs) in 16 European cities between August 1996 and September 1997. Outpatients diagnosed with HIV infection for at least one year and able to complete the questionnaire on their own were eligible to participate. Questionnaires were completed anonymously without any compensation, financial or otherwise. They were handed in or posted back to the distributing centre.

The questionnaire contained 108 questions and took an estimated 40 min to complete. The euthanasia section consisted of five questions, all of them with 18 closed and two open subquestions. Other sections of the questionnaire were on a variety of topics, such as: access to treatment and clinical trials; psychosocial support; experience with outpatient care; hospital and home care; the cost of different care/support items; the degree of satisfaction with health care services. The Eurosupport questionnaire was prepared by a multidisciplinary team (including persons with HIV infection) and was extensively pilot-tested in different countries.

For the purpose of this article definitions of euthanasia practices performed by a physician will be similar to those proposed by Starace and Sherr [4]. The question on whether euthanasia at request of the patient should be legally possible was asked in the following way: 'do you think that a doctor should have the legal right to help a seropositive person to end his or her life, when this is at the clear and considered request of that individual?' The question about

how the doctor should be able to help the seropositive person was asked in the following way: 'Do you think that when there is severe physical suffering and at a clear request from the patient, a doctor should be able to:

- 1 Give treatment that makes the end easier and free of pain but that may shorten survival? (alleviation of pain with double effect);
- 2 Give high doses of medication that ends life painlessly, e.g. by an intravenous injection (medical euthanasia);
- 3 Help with suicide, e.g. by prescribing drugs that the seropositive person can administer by him/herself (physician-assisted suicide).

Response

Of the 2750 questionnaires distributed, a total of 1371 persons responded to the questionnaire (50% overall response rate) [13]. Five returned questionnaires were excluded from the analysis due to a high number of inconsistent or blank responses. As the topic was deemed too sensitive in Rome, the questionnaires that were distributed there did not contain any questions on euthanasia. Thus for the purpose of this analysis 1341 responses have been considered. This number represents 0.3% of the estimated number of people living with HIV/ AIDS in the 11 participating countries by the end of 1997 [14,15]. National response rates varied from 35% in the United Kingdom (UK) to 89% in France. No information was available from non-respondents. The highest number of non-answered questions in the euthanasia section was found among respondents in Greece and Portugal. The data collection period varied from 5 months in Belgium, France, Italy, Luxembourg and Spain, to 13 months in Germany, Portugal, and the UK.

Data analysis

Data were entered in dBASE IV (Borland/Inprise, Scotts Valley, CA, USA), PARADOX (Borland/Inprise) or EXCEL (Microsoft, Redmond, WA, USA) formats in one or two centres per country, and hereafter validated and analysed with EPIINFO 6.0 (EpiInfo, Version 6, 1994, Centers for Disease Control and Prevention, Atlanta, GA, USA) and SPSS 7.5 (SPSS Base 7.5, SPSS Inc., Chicago, IL, USA) at the co-ordinating centre, the Institute of Tropical Medicine, Antwerp, Belgium. Data from 10% of the questionnaires received in each centre were re-entered for quality control purpose, and from two centres where more than 3% of data-entry mistakes were discovered, all data were entered again, and validated afterwards. Multiple logistic regression analysis was performed to determine the relationship between the characteristics of HIV infected persons and

their opinions regarding euthanasia practices. For this purpose data from two geographical regions were analysed separately: 'northern' Europe (Belgium, Denmark, France, Germany, Luxembourg, the Netherlands, the UK) and 'southern' Europe (Greece, Italy, Portugal, Spain). Variables from questions with more than 12% of answers missing were not included in the models. The following predictors related to HIV infection were tested: HIV risk category, duration of seropositivity, presence of clinical symptoms and CD4 cell count. The following social indicators were also included in the model: employment status, education level, and whether or not the respondent lived alone. Categorical variables were transformed into indicator type contrasts. Variables were selected using a discriminatory step-wise forward method based on the loglikelihood ratio. Age and sex were included in all the models as potential confounders. Significance level was fixed at P = 0.05.

Results

Study population characteristics

The mean age of respondents was 38 years (range: 18–75, SD 9 years) (Table 1). Most participants were male (81%) and the highest number of female respondents were from Spain and Italy (both 32%). Approximately half of the respondents reported HIV transmission through male homosexual contact (53%). This ranged from 22% in Spain to 79% in the UK. Heterosexual transmission was

reported in 20%, ranging from 9% in the UK to 36% in Luxembourg. Intravenous drug use was the reported means of transmission in 14% of respondents, ranging from 1% in Greece to 49% in Spain. Transmission via contaminated blood products or other means was reported in 3%. Ten percent of respondents did not respond to the question about how they thought they had acquired HIV infection.

The mean duration of seropositivity was 6 years (SD 4 years). The percentage of respondents with clinical symptoms (either with or without AIDS) varied from 34% in Greece to 70% in the UK. The percentage of respondents with AIDS was lowest in Belgium and Luxembourg (14%) and highest in the UK (31%). Most respondents (88%) could recall the result of a CD4 cell count performed in the previous 3 months. In total, 39% of respondents had a CD4 count of <200 cells/ μ L, ranging from 20% in Greece to 53% in the UK.

Education and employment characteristics of the respondents were as follows: 21% had completed primary schooling only, 45% secondary education, 30% tertiary education and 4% had received no formal education. Forty-seven percent were employed (range: 27% in the UK to 61% in Germany); 13% unemployed (range: 27% in Luxembourg and Italy to 26% in the Netherlands); 17% were disabled and receiving disability benefits (range: 1% in Greece to 47% in the UK); 7% were retired; 5% were students, and 8% reported other professions not listed in the above categories. Three percent of respondents did not give their employment status. Thirty-eight percent were living alone (range: 20% in Italy to 51% in the Netherlands)

Table 1 Characteristics of study population

Country	Males (%)	Age (mean)	Homosexual men (%)	Heterosexual (%)	IVDUs (%)	Duration seropos. (mean)	Sympto- matic (%)	CD4 count < 200 cells/μL (%)	Higher education (%)	Employed (%)	Live alone (%)
Belgium (<i>n</i> = 163)	87	40	61	23	4	6	58	45	37	61	44
Denmark $(n = 96)$	88	42	74	16	2	8	51	35	30	54	43
France $(n = 100)$	84	37	66	14	9	7	54	29	27	39	54
Germany ($n = 108$)	87	42	69	14	5	6	48	44	27	61	50
Greece (n = 158)	82	38	41	31	1	4	34	20	35	54	32
Italy $(n = 165)$	68	37	25	29	35	7	43	47	15	59	20
Luxembourg $(n = 44)$	77	38	55	36	7	6	59	34	16	57	36
Portugal $(n = 93)$	75	33	40	20	22	4	43	30	28	40	26
Spain (n = 155)	67	34	22	21	45	7	39	33	16	32	25
The Netherlands $(n = 65)$	79	40	63	19	6	7	65	43	28	46	51
United Kingdom ($n = 194$)	93	38	79	9	4	6	70	53	49	27	50
North $(n = 770)$	87	40	69	16	5	7	59	43	35	47	48
South $(n = 571)$	73	36	31	26	26	6	40	33	23	47	26
Total $(n = 1341)$	81	38	53	20	14	6	51	39	30	47	38

Total percentages given.

n = sample size; IVDUs = intravenous drug users; seropos. = seropositivity.

and 49% were supported by their family (range: 32% in the Netherlands to 65% in Spain). Only 4% of the study participants belonged to an ethnic minority.

Euthanasia responses

Personal interest in euthanasia

Twenty percent of respondents stated they would not consider asking for assistance to end their life if they were terminally ill and had no further treatment options, 51% would consider it and 24% felt uncertain. The highest number of uncertain responses came from the Netherlands (46%).

Discussing euthanasia with others

Roughly half of the respondents (52%) had discussed 'the possibility of intentionally terminating their life' with someone (range: 36% in Greece to 82% in the Netherlands). Most chose to talk about this issue with a friend (36%) or partner (28%). Respondents in Northern Europe, highly educated (P = 0.04), male (P = 0.007) and clinically symptomatic (P = 0.01) were more likely to have aired the topic with another person (Table 3). Only in the Netherlands was this possibility more often discussed with a physician (45%) or nurse (52%) than with any other person. Strikingly, respondents from the northern countries had discussed the subject with their physician two and half times more often than respondents from the south. In the north, those who

had attained secondary schooling were more likely to have spoken with a physician than those who had received primary schooling. In the south, discussion with the physician was more frequent (P = 0.04) among respondents with a CD4 count < 200 cells/ μ L. Overall, less than 10% of respondents had discussed this issue with a psychologist.

Expected effect of legalized euthanasia

Half of the respondents reported that the possibility of euthanasia would decrease their anxiety (range: 31% in Spain to 79% in the Netherlands). Older respondents in both regions were more likely to feel this. In the north, unemployed persons significantly more often (P=0.006) reported this compared to those in employment. In the south, intravenous drug users were also more likely (P=0.02) to report reduced anxiety levels given the possibility of euthanasia than were homosexuals.

Legalizing euthanasia

The vast majority of respondents (78%), in all participating countries, stated that euthanasia should be made legal at the request of patients in the case of severe physical suffering (Table 2). This ranged from 56% in Greece to 90% in Belgium. No determinants were found significant in the stratified logistic regression model for this outcome (Table 3). Support for the legalization of euthanasia was less (47%) in the case of severe psychological suffering

Table 2 Responses to selected questions concerning euthanasia

	Euthanasia at request of patients should be legal					Which euthanasia practice should be legal?						- Possibility of		Discussed euthanasia				
Country	Physical suffering		Psychological suffering		At patient request alone		Alleviation pain with double effect		Medical euthanasia		Physician assisted suicide		euthanasia would reduce anxiety		With physician		With someone	
	Yes	No	Yes	No	Yes	No	Yes	No	Yes	No	Yes	No	Yes	No	Yes	No	Yes	No
Belgium (<i>n</i> = 163)	90	6	65	22	28	61	87	4	80	14	59	27	52	33	25	73	61	33
Denmark (n = 96)	79	18	43	50	21	72	94	4	74	22	47	49	52	41	9	87	65	32
France $(n = 100)$	82	13	52	42	24	67	89	7	60	34	47	46	56	36	26	67	66	24
Germany ($n = 108$)	83	14	33	58	19	74	82	14	68	31	57	40	58	34	9	86	56	41
Greece (n = 158)	56	30	13	58	15	59	54	29	36	44	18	60	41	44	6	77	36	49
Italy $(n = 165)$	70	23	31	61	21	73	75	20	44	48	29	64	41	46	5	90	38	50
Luxembourg $(n = 44)$	82	18	43	52	14	80	89	7	57	34	43	46	48	39	16	80	46	48
The Netherlands $(n = 65)$	88	11	74	23	32	65	92	5	72	25	68	31	79	19	45	55	82	17
Portugal $(n = 93)$	65	18	36	42	23	56	58	24	41	40	28	53	46	30	7	74	49	33
Spain ($n = 155$)	81	10	70	18	37	55	88	6	66	26	48	40	31	58	10	80	39	45
United Kingdom (n = 194)	85	9	56	36	28	65	91	5	77	18	61	33	61	28	16	80	60	26
North $(n = 770)$	85	11	53	37	25	67	89	6	72	23	56	37	58	33	20	76	62	31
South $(n = 571)$	68	21	38	45	24	61	70	19	47	39	31	54	39	46	7	81	39	46
Total $(n = 1341)$	78	15	47	41	24	65	81	12	62	30	45	44	50	38	14	78	52	37

Total percentages given.

n =sample size.

Table 3 Results of multiple logistic regression stratified by northern and southern regions

			North (n = 770)			South $(n = 571)$		
Outcome	Determinants	n	P	OR	95% CI	n	P	OR	95% CI
Futhanaia shanli ba lanal a	4								
Euthanasia should be legal a		010				007			
With physical suffering	None	612	-	-	-	337	-	-	-
With psychological suffering	<u> </u>	589				317			
	Level of education (primary school)		0.004	0.17	10.00				
	High/technical school		0.002	2.17	1.3-3.6		-	-	-
	University/higher degree		0.005	2.07	1.2-3.4		-	-	-
A	Other		0.002	3.96	1.6-9.6		-	-	-
At patient's request alone		595				324			
	Level of education (primary school)		0.03				0.001		
	High/technical school		0.07	1.84	0.9-3.6		0.0125	0.64	0.8-3.0
	University/higher degree		0.009	2.42	1.3-4.7		0.03	2.32	1.1-5.0
	Other		0.02	3.2	1.2-8.3		0.2	3.7	0.5-25.5
	Transmission method (homosexual men)						0.02		
	Heterosexual		-	-	-		0.05	2.27	1.0-5.1
	IVDU		-	-	-		0.004	2.98	1.4-6.4
	Blood products/other		-	-	-		0.07	4.6	0.8-23.7
Which euthanasia practice s									
Alleviation of pain with do		610				338			
	Level of education (primary school)		0.06						
	High/technical school		0.1	2.0	0.8-4.9				
	University/higher degree		0.01	3.9	1.4–10.7				
	Other		0.9	1.1	0.3-4.4				
	Transmission method (homosexual men)						0.003		
	Heterosexual		-	-	-		0.1	0.5	0.2-1.2
	IVDU		-	-	-		0.3	1.6	0.7-3.8
	Blood products/other		-	-	-		0.006	0.1	0.0-0.5
Medical euthanasia		610				331			
	Occupation (employees)		0.02						
	Unemployed		0.3	1.3	0.7-2.4		-	-	-
	Disabled/retired/student/other		0.005	1.81	1.2-2.8		-	-	-
Physician assisted suicide		596				330			
	Level of education (primary school)		0.02				0.0001		
	High/technical school		0.03	1.73	1.1-2.8		0.13	0.6	0.3-1.1
	University/higher degree		0.002	2.22	1.3-3.7		0.03	2.23	1.1-4.6
	Other		0.6	1.3	0.6-2.9		0.06	9.4	0.9-98.7
	Transmission method (homosexual men)						0.002		
	Heterosexual		-	-	-		0.9	1.03	0.5-2.2
	VDU		-	-	-		0.0009	3.18	1.6-6.3
	Blood products/other		-	-	-		0.6	1.6	0.3-9.1
The possibility of euthanasia	would reduce anxiety	579				324			
	Occupation (employees)		0.008						
	Unemployed		0.03	1.88	1.1-3.3		-	-	_
	Disabled/retired/student/other		0.006	1.69	1.2-2.5		-	-	_
	Transmission method (homosexual men)						0.04		
	Heterosexual		_	_	-		0.6	0.9	0.4-1.7
	VDU		_	_	_		0.02	0.5	0.3-0.9
	Blood products/other		_	_	_		0.2	4.3	0.5-39.1
Discussed euthanasia:	,								
With physician		609				330			
	CD4 cell count ($< 200 \text{ cells/}\mu L$, $> 200 \text{ cells/}\mu L$)		_	_	_		0.04	0.4	0.2-0.9
	Level of education (primary school)		0.03				•		
	High/technical school		0.005	2.9	1.4-6.1		_	_	_
	University/higher degree		0.6	2.1	1.0-4.5		_	_	_
	Other		0.2	2.1	0.7-6.5		_	_	_
With someone	-	586			0.0	325			
someone	Sex (female, male)	230	0.007	0.4	0.2-0.8	020	_	_	_
	Clinical status (asymptomatic, symptomatic)		0.007	1.61	1.1-2.3		_	_	_
	Level of education (primary school)		0.01	1.01	1.1-2.3				
	High/technical school		0.04	2.04	1.2-3.5		_	_	_
	University/higher degree		0.009	1.9	1.1-2.3		_	_	_
	Other		0.02	1.9	0.5-2.8		_	_	_
	VIIICI		0.7	1.2	0.5-2.6		-	-	-

n = sample size; OR = odds ratio; 95% CI = 95% confidence interval. Blank values represent insignificant predictors eliminated from the step-forward model. Reference categories indicated by *italic print*.

alone (range: 13% in Greece to 74% in the Netherlands). A minority of respondents (24%) was in favour of legalizing euthanasia at patient request only, even without severe physical or mental suffering.

Level of education played a role in determining acceptance of the legalization of euthanasia. Respondents who had received at least secondary education were more in favour of legalization in cases of psychological suffering, or simply at the request of the patient, than those who had received the minimal primary-school education. This was statistically significant in the northern region in the case of psychological suffering (P=0.004), and in both regions for patient request (P=0.03 north, P=0.001 south). Respondents in the south who reported contracting HIV infection from intravenous drug use, compared to homosexual contact, were also significantly (P=0.004) more likely to favour legalizing euthanasia simply at patient request.

Euthanasia practices to be allowed by law

In the event of severe physical suffering and given a clear patient request, 80% of respondents were in favour of pain alleviation with a double effect being allowed by law. This ranged from 54% in Greece to 94% in Denmark. In the southern countries, respondents who reported HIV transmission via blood products or other modes were highly significantly in favour of allowing the practice of alleviation of pain with a double effect (P = 0.006). No other determinants were found to be significant for this outcome in either the northern or southern region.

While 62% of respondents agreed with the legalization of medical euthanasia, this ranged from an acceptance rate of 36% in Greece to 80% in Belgium. Only having employment in the north was a significant factor in determining acceptance of medical euthanasia. Respondents who were disabled, retired, students and unemployed were more likely to accept medical euthanasia than those who were employed (P=0.005).

Overall, legal acceptance of PAS through the prescription of lethal medication was 45% (range: 18% in Greece to 68% in the Netherlands). Respondents who had received more than primary schooling in both the north (P=0.02) and south (P=0.0001) were more likely to favour PAS. In the south, older respondents or intravenous drug users (compared to homosexuals) were more likely to favour PAS (P=0.006 and P=0.0009, respectively).

Discussion

Despite euthanasia being a highly emotive issue, the euthanasia section of the questionnaire had a generally good response. The majority of persons with HIV (78%)

were in favour of legalizing euthanasia where there was severe physical suffering, 47% for cases of (severe) psychological suffering and 24% favoured euthanasia at the request of the patient alone. In our study, 51% of respondents stated that they would consider euthanasia when their treatment options had been exhausted. Notably, half of the persons living with HIV/AIDS reported that the possibility of euthanasia would reduce their anxiety about the future. This might indicate that strategies to cope with illness are influenced by the freedom patients do experience in making their own decisions about the end of their life. When terminally ill patients are allowed to express their last wishes, even when this means simply refusing treatments, they preserve at least some autonomy, and thus maintain an aspect of quality of life.

Other studies examining the attitudes of HIV patients towards euthanasia have reported similar results. Eightytwo percent of respondents in a Belgian study felt that physicians should be able to help terminate life at the explicit request of a patient who has severe physical suffering [10]. In an Australian study, 94% of persons with AIDS and AIDS-related complex (ARC) responded that individuals with a life-threatening illness should have the option of euthanasia [11]. In a study in the USA, 63% of patients supported policies favouring legalization of PAS and 55% had considered PAS for themselves [9].

Agreement with the legalization of euthanasia was guarded in certain circumstances (i.e. in the case of psychological suffering or at patient request alone), and varied according to the country of origin of respondents. Our results thus indicate that attitudes towards euthanasia are complex, well considered and influenced by social and cultural background. Patients with AIDS may be more likely to consider euthanasia than patients suffering with other diseases. Besides the severe physical suffering, the stigmatization linked with AIDS further compounds the psychological suffering inherent to any incurable disease. Patients with AIDS are generally young, well informed about their disease, and they have often seen friends die of the same illness. In a study performed in Australia among persons with advanced HIV infection, 86% reported fear of suffering, while only 19% feared death [11]. Other studies have found the wish to avoid dependence, loss of dignity and loss of control in the final stages of the disease were motivating reasons for AIDS patients to consider requesting assistance to hasten death [16,17].

On the whole, whether they were asked their opinion about legalization, their personal attitude, or of the discussion of the topic with others, respondents from Greece and Portugal tended to be consistently less in favour of euthanasia than those from Belgium, the Netherlands or Denmark.

In all European countries, except the Netherlands, euthanasia was most often discussed with a friend, partner or family member. Respondents from the Netherlands, probably because patients are aware that physicians are able to practice euthanasia under certain conditions, were the most able to discuss this issue with a physician or nurse.

AIDS continues to confront health care workers and to challenge the physician-patient relationship. More and more physicians are compelled to openly discuss treatment options, quality of life and the dying process with patients and their carers. While a growing number of patients may find comfort in having the option of euthanasia, open discussion or requests may increasingly place physicians in a difficult legal position [6,8]. In a national survey in the USA, where euthanasia is illegal in almost all states, 18% of physicians reported receiving requests for PAS and 11% for medical euthanasia [18]. About 16% reported having written at least one prescription to be used to hasten death and 5% had administered at least one fatal injection. Similarly, one-third of physicians working for the National Health Service in the UK had complied with requests to take active steps to hasten a patient's death, and almost one half would have been prepared to do so if it had been legal [19].

Our results need to be interpreted with caution. Different methods of questionnaire distribution, non-random sampled study participation and a large percentage of non-participation may make it difficult to compare attitudes to euthanasia between the 11 participating European countries.

People belonging to ethnic minorities were underrepresented in the study sample. It is possible these people may have different attitudes towards euthanasia compared with other European citizens.

A weakness in this cross-sectional study is the inability to assess changing attitudes. The majority of respondents were ambulatory and relatively healthy. It must be borne in mind that reported attitudes towards euthanasia might change in the course of the disease. Indeed, there is a difference between people who are dying and people who are suffering from an incurable disease, and those who are in its terminal stage [20]. Despite this, results of the Eurosupport survey indicate that a considerable interest exists in euthanasia, whether or not such an avenue is pursued.

Further focused studies are needed to answer the numerous remaining questions. Since it is illegal, little is known about the extent of euthanasia practices within or outside (i.e. 'clandestine') the health care system. What are the consequences of euthanasia for relatives: might there be social withdrawal because of a sense of guilt? Their

health status, social experience and beliefs influence patient acceptance of euthanasia. The rapidly changing field of HIV/AIDS treatment with the availability of new medications, such as combination antiretroviral drugs, may offer hope to infected persons and change their attitudes towards euthanasia. Our study was performed at the time protease inhibitors were being introduced in Europe. The introduction of highly active antiretroviral treatment (HAART) in industrialized countries has led to a sharp decrease in the incidence of AIDS and associated mortality. So far, however, there is no cure for AIDS. We do not know how long HAART regimens will remain effective and to what degree salvage regimens will be able to prevent disease progression. In the future, the issue of euthanasia may become less relevant for persons with HIV infection but will remain extremely relevant for patients with other incurable diseases, who do not want to continue with palliative care and who continue to suffer because they do not have an euthanasia option.

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References

- 1 van den Boom F. AIDS, euthanasia and grief. AIDS Care 1995;7 (Suppl. 2): 175–185.
- 2 Laane HM. Euthanasia, assisted suicide and AIDS. AIDS Care 1995; 7 (Suppl. 2): 163–167.
- 3 Gevers S. Euthanasia: law and practice in The Netherlands. *Br Med Bull* 1996; 52: 326–333.
- 4 Starace F, Sherr L. Suicidal behaviours, euthanasia and AIDS. *AIDS* 1998; 12: 339–347.
- 5 Groenewoud JH, van der Maas PJ, van der Wal G, *et al*. Physician-assisted death in psychiatric practice in the Netherlands. *N Engl J Med* 1997; 336: 1795–1801.
- 6 Back AL, Wallace JI, Starks HE, Pearlman RA. Physicianassisted suicide and euthanasia in Washington State. Patient requests and physician responses. *JAMA* 1996; 275: 919–925.
- 7 Slome LR, Mitchell TF, Charlebois E, Benevedes JM, Abrams DI. Physician-assisted suicide and patients with human immunodeficiency virus disease. N Engl J Med 1997; 336: 417– 421
- 8 Slome L, Moulton J, Huffine C, Gorter R, Abrams D. Physicians' attitudes toward assisted suicide in AIDS. *J Acquir Immune Defic Syndr* 1992; 5: 712–718.
- 9 Breitbart W, Rosenfeld BD, Passik SD. Interest in physicianassisted suicide among ambulatory HIV-infected patients. Am J Psychiatry 1996; 153: 238–242.

- 10 Fleerackers Y, Colebunders R, Fonck K, Depraetere K, Pelgrom J. Euthanasia and physician-assisted suicide. *Lancet* 1996; 347: 1046.
- 11 Tindall B, Forde S, Carr A, Barker S, Cooper DA. Attitudes to euthanasia and assisted suicide in a group of homosexual men with advanced HIV disease [letter]. *J Acquir Immune Defic Syndr* 1993; 6: 1069–1070.
- 12 Bindels PJ, Krol A, van Ameijden E, *et al.* Euthanasia and physician-assisted suicide in homosexual men with AIDS. *Lancet* 1996; 347: 499–504.
- 13 Colebunders R, Fleerackers Y, Andraghetti R, Wellens R. The quality of support in European HIV/AIDS treatment centres – 'Eurosupport'. Brussels: European Commission – Directorate General V (CE-V/4-98-013-EN-C), 1998.
- 14 World Health Organization. Global AIDS, Surveillance part I. Why Epidemiol Rec 1998; 76 (48): 373–376.
- 15 World Health Organization. Global AIDS, Surveillance part II. Wkly Epidemiol Rec 1998; 76 (49): 381–384.
- 16 Seale C, Addington-Hall J. Euthanasia: why people want to die earlier. Soc Sci Med 1994; 39: 647–654.
- 17 Green G. AIDS, euthanasia. AIDS Care 1995; 7 (Suppl. 2): 169– 173.
- 18 Meier DE, Emmons CA, Wallenstein S, Quill T, Morrison SR, Cassel CK. A national survey of physician-assisted suicide and euthanasia in the United States. *N Engl J Med* 1998; 338: 1193–1201.
- 19 Ward BJ, Tate PA Attitudes among NHS doctors to requests for euthanasia. BMJ 1994; 308: 1332–1334.
- 20 Chochinov HM, Wilson KG. Assisted suicide for HIV patients. *Am J Psychiatry* 1997; **154** (294–295): 23.