

Evolution of requests to hasten death among patients managed by palliative care teams in France : a multicenter cross-sectional survey (DemandE).

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Abstract

Background

Strongly marked ideological positions on the impact of palliative care and limited hard data plague the debate on physician-assisted death.

Methods

A national cross-sectional study on the requests to hasten death (RHD) was conducted among 789 French palliative care organizations. Data were collected for all patients with RHD encountered during year 2010. Data on patients' characteristics, medical, psychological and social context, symptoms, nature of palliative management, patient's evolution, palliative care team's interpretation of the request were obtained.

Findings

A majority of centers responded and 342 teams provided descriptions of 783 RHD, 476 by a patient, 258 by relatives or close friends, and 49 by the nursing staff. Cancer was the most frequent pathology (72%) and 68% of the patients had entered terminal stage. Patients rarely appeared with uncontrolled pain (3.7%), but had difficulties with feeding (65%), moving (54%), excretion (49%), or were cachectic (39%); 31% were considered to be anxious-depressive; 79% did not give physical reasons for their request; 37% of RHD were maintained and 24% fluctuated despite provision of regular follow-up by a palliative care team to 83% of all cases; 68% of patients died within a month; the interpretation of RHD by the staff was a wish for relief (69%), patient's inextricable situation (44%), actual desire not to continue living (36%), or to be helped to die (30%).

Interpretation

The large number of described cases provides, for the first time, comprehensive hard data on the evolution of RHDs in a country that has not legalized euthanasia. Whatever the way RHD are expressed, they are frequently maintained despite adequate palliative care with suitable control of pain and psychological support by specialists.

Keywords: euthanasia; palliative care; end-of-life; ethics.

Introduction

Physician-assisted death (PAD) has become a public issue in many countries. Two US states, Oregon (1997), Washington (2009) and three European countries, Belgium, Netherlands (2002), and Luxemburg (2009) have decriminalized PAD ¹⁻⁵. In several other countries, especially if palliative medicine has been strongly promoted, the debate on this issue is plagued by marked ideological positions. In France, a law passed in 2005 differentiated withholding or withdrawing treatments from active euthanasia ⁶; recently, the government reasserted that the 2005-law and palliative care were the sole possible responses to patients' requests for euthanasia ⁷.

Limited hard data are available and consequently, inappropriate importance is given to opinion polls the results of which vary depending on how questions are phrased, and extreme cases exposed in newspapers. In countries where PAD has been legalized, studies have provided data on its frequency and characteristics of involved patients, which helped clarify national debates on the regulation and public control of the practice ⁸⁻¹¹. However, very few studies have explored evolutions and outcomes of patients that request PAD, in countries where euthanasia remains illegal ^{12 13}.

Considering the central place of palliative care in the debate, we conducted a large multicenter survey to assess the evolution of the requests to hasten death (RHD) expressed to the different types of palliative care teams.

Methods

In France, palliative care is provided through departments that must respond to the most complex end-of-life situations, including requests for euthanasia, mobile units to meet staff needs at the bedside, designated beds included in acute care departments frequently faced

with end-of-life patients, palliative care networks that take of outpatients and the hospital at home that have an obligation to provide palliative care at home or in nursing homes.

Survey instrument

As in the MAHO study ¹⁴, a multidisciplinary team of researchers including palliative care physicians, psychiatrists, oncologists, and intensive care specialists, a psychologist and nurses was gathered. It performed an exhaustive search on studies published in English and French from 1990 to 2010, on adults requesting assistance to die. A questionnaire to identify the cases of RHDs that had been encountered in 2010 by palliative care teams was then created. For these cases, closed questions were developed. A preliminary test of the questionnaire was made with one team from each specific type of palliative care.

Definitions

End-of-life unbearable suffering was defined as a durable profoundly personal experience of actual or perceived impending threat to personal integrity or life ¹⁵.

RHD was defined as an explicit and reiterated request by a patient to a physician or a nurse for PAD, an explicit and reiterated expression to a physician or a nurse of the patient's wish not to live longer, because life had become unbearable or was considered accomplished or useless, provision by a patient of written directives in case he met some specific criteria, the physician or nurse considered present, an explicit and reiterated request by relative(s) or close friend(s) for PAD since it had been previously discussed with the patient or a RHD expressed by the nursing staff in charge.

Final survey form

It comprises 110 items, mostly multiple-choice questions exploring: (1) the main characteristics of the responding palliative care service; (2) the main characteristics of patients as regard medical, psychological and social contexts, current symptoms, patient's views on life purpose and suffering, reasons for RHD, depressive mood or suicide attempt; (3) the previous and current management by a palliative care team, patient's status and request evolution; (4) the palliative care team's interpretation of this RHD. An English translation is available from the authors upon request.

Centres were to provide data for all patients with RHDs encountered during year 2010. If they had met more than 5 such cases, they could limit their description to the most relevant five.

Centers

A list of palliative care services was created with the help of several French scientific Societies (see acknowledgments). Unfortunately, while the survey was ongoing, these lists were revised, which showed that they were accurate in more than 99% of the cases, except for home care organisations, 40 % of which did not provide palliative care and should not have been contacted. The irrelevant centers are not tallied hereunder. Questionnaires to be completed by the attending physician and his/her staff were sent out in November 2010. A follow-up letter and a mail were sent every two weeks until mid-January 2011. After locking the survey database, an additional email (AddMail) was sent to a random sample of 200 palliative care providing structures that had not responded to clarify why they failed to participate. The proposed reasons were: lack of cases, excessive workload, staff shortage, inability to trace such cases, lack of interest.

Ethical considerations

The institutional review board of the French Society of Patient's Accompanying and Palliative Care (SFAP) approved the study. No identifying information was gathered on the patient or nurse. Informed consent was waived for this anonymous survey.

Statistical analysis

Cases were categorized into 3 groups: request done by patient, by a relative or a close friend, or by the nursing team. Descriptive statistics (counts and proportions or means and standard deviations) and between-group comparisons with a non parametric test (Kruskal–Wallis, for quantitative variables, Fisher's exact test for categorical ones) were calculated with, if significant, between-group pairwise comparisons using the Bonferroni–Simes correction.

A bilateral significance level of 0.05 was used.

Results

Participating centers

Among 789 French services contacted, 352 (45%) sent patients' data: 161/342 mobile teams, 47/105 departments, 44/101 units with designated beds, 37/107 palliative care networks and 63/134 home care services ; 69 (34.5 %) of 200 structures which had not sent data back responded to AddMail. Extrapolated to the 437 centers that did not respond to the survey, this leads to a survey awareness rate of 60 %. The main reasons alleged for not responding to the main survey were lack of time (insufficient staffing or excessive workload) for 36 centers, inability to retrieve data – as this type of demand was not tagged (25 centers), and no such cases in 2010 for 8 centers. None of the responding center claimed it was not interested in the survey.

Patients involved

In 2010, 1055 RHDs were encountered in responding centers (0 to 17 per center) and data were provided for 840 (1 to 17 per center). In 57 cases, data were too scarce; therefore 783 cases were analyzed.

Table 1 shows patients' characteristics. The mean age (\pm SD) was 69 (\pm 15.9) years with a sex ratio (M/F) of 0.87.

The request was expressed by the patient in 476 cases (SR group). In 68.9%, it was a definite wish for euthanasia mostly to be helped to commit suicide (49.2%) while 28.3% wanted an assurance that they would have a dignified end of life. The request came from relatives or close friends (PR group) in 258 cases, most often through children (67%) or spouse (55%). In 49 cases, the request was made by staff member (NR group), most often nurses (63%) but also staff physicians or psychologists (47%), or a primary care physician (26%).

Fifty-six percent of the patients made their initial RHD while in non-palliative care units, more frequently so in the NR group (70% versus 55%, between-group $p=0.03$). Among those already in palliative care, a little more than one fourth was at home. The median duration of palliative care management at the time of RHD was 35 days (Interquartile range 12–90 days). In 725 cases (92.6%), at least one non-medical person was caring for the patient but only 5% of the patients had designated a surrogate although a reference person could be identified by a staff member in half of all cases (between-group $P<0.0001$). Less than 2% of all patients had left written instructions in anticipation of the situation (between-group $P=0.22$, NS).

Context of request

See Table 2 for details.

Cancer was the most frequent pathology in patients with RHDs (563 cases, 71.9%), more frequently in the SR group ($P<0.01$). A neurological disease (11.9%), and geriatric polyopathy (7.7%) were also frequent.

Eighty-eight percent of involved patients had been informed of their diagnosis, 82% knew their disease was incurable and 71% were aware of the short-term prognosis ; 68% were at a terminal stage of their illness, more frequently in the SR group ($p=0.05$).

One third of all patients were considered depressed at the time of the request. The proportion was significantly higher (48% and 43%) in the SR and the PR group respectively than in the NR group (20%) ($P=0.05$). The between-group differences for a history of treated depressive disorder (20% or less of patients) or of suicide attempt (less than 10 % of patients) were not significant. Only 28% had recently withstood a loss (bereavement, separation, layout, etc.) more so in the SR group (32%) than in the PR (22%) or NR (18%) groups (between-group $p=0.03$). Recent confrontation with inappropriate treatments or euthanasia for a relative were noted in less than 3% of patients. None of the investigated psychological factors was found to be significantly associated with one of the three groups of requesters.

Symptoms and perceptions

RHDs were made despite fear of death which was admitted to by about one third of the patients (between-group $P>0.3$, NS). Types of fears about death did not differ between groups except for fear of death through hemorrhage (10% in the NR group versus 2% –SR– or 3% –PR; between-group $P=0.02$ and 0.08). The most frequent symptoms bore on feeding (65%), motricity (54%), pain (52%) and incontinence (49%). Differences in symptom frequencies were significant for motor disorders (46% –SR, 65% –PR, 74% –NR, between-group $P<0.001$ for SR–PR and SR–NR), cognitive disorders (ditto 10%, 55%, 47%, between-group $P<0.0001$ for SR–PR and SR–NR), loss of communication ability (ditto 17%, 67%, 63%, between-group $P<0.0001$ for SR–PR and SR–NR), feeding difficulties (ditto 55%, 81%, 80%, between-group $P<0.005$ for SR–PR and SR–NR) and elimination disorders (ditto, 37%,

67%, 69%, between-group $P < 0.0001$ for SR-PR and SR-NR). None of the PR-NR differences were significant. Symptoms are detailed in Table 3.

The percentage of patients considering that their life had become useless, and the percentage of those fearing the poor image they would leave, be it intellectual or physical or of those fearing to become an unbearable burden for the caregivers did not differ between groups ($P > 0.1$). Details on patients' perceptions may be found in Table 3.

Nature of palliative care management

Once made, the RHD resulted in regular follow-up by a palliative care team in 83.3% of the cases but only one patient out of 6 was transferred either to a palliative care unit (13.3%) or to a bed designated for palliative care (3.8%) (between-group $P > 0.2$). A total of 219 patients (28%) were transferred to another department after making their request, more frequently in the SR group than in the 2 other groups (between-group $P < 0.001$ in both cases).

A psychiatrist and/or psychologist was consulted in 72% of RHD cases (between-group $P = 0.16$, NS); 24% of those considered depressive did not have a consultation with a psychiatrist or a psychologist.

The nature of palliative care management is detailed in Table 4.

Patients' evolution and outcomes

A decision to withdraw specific treatments was taken for 257 patients (33%) (between-group $P = 0.12$, NS) while an additional 34.5% patients refused continuation of care, significantly less in the NR group (12%) than in the SR (38%) or PR (32%) groups (between-group $P < 0.01$ in both cases). This refusal was disclosed by the patient (28.7%), a relative and/or close friend (11.1%) or through written instructions left in

anticipation (5.5%), several modes being used in about 10% of the cases. It was not considered acceptable for 32% of patients expressing it.

Twenty-two percent of patients died within a week and 58% within a month of the RHD, while 8.7% showed clinical improvement. 79 patients (10.1%) were still alive, 3 months after a RHD.

In 515 cases (65.7%), death was directly related to the patient's disease while in 8.7% of the cases it resulted from an acute unforeseen complication. Death was related to the withdrawal of specific treatments in 30 cases and suicide occurred in 6 cases. Surveyees were aware of 10 cases of euthanasia performed in 9 non-palliative care wards.

Evolution of requests

RHDs disappeared in 219 cases (28%), i.e., 29.4% of the cases in the SR group, 28.3% in the PR group and 12.2% in the NR group, the latter percentage being significantly lower ($P < 0.05$ in both cases; p for SR-PR = 0.61, NS). In 293 cases (37.4%), persistence of the RHD was noted despite palliative care management, significantly more frequently in the NR group (53.1%) than in the SR (34.5%) or PR groups (39.9%) ($P = 0.05$ in both cases). In the other cases (23.8%), requests fluctuated (between-group $p = 0.65$, NS). Globally, the difference in percentages of patients maintaining their RHD between those receiving appropriate or insufficient palliative care (42% vs 54%), was close to significance ($p = 0.06$).

Evolutions are detailed in Table 4.

Conflicts

A conflict among caregivers was noted in 238 cases, significantly less frequently in the SR than in the PR or NR groups ($P < 0.001$). There was a significant between-group difference in conflict types ($P < 0.001$); in the PR group, the most frequent conflict was between relatives or

close friends and nursing team (44% of the cases) whereas in the NR group, the most frequent conflict was between staff members (29%).

Team interpretations of request

A posteriori, the most frequent feeling was relief (540 cases, 69%, $P=0.24$). In 345 cases (44.1%), the patient's RHD was considered to be a response to an inextricable situation ($P=0.62$). In 9.1% of cases, the caregiving team felt that the patient's life had become meaningless (3% in the SR group, 8% in the PR group and 74% in the NR group; P for pairwise differences with the latter <0.002). In 279 cases (35.6%), the request was considered as an actual desire not to continue living ($p<0.0001$ for both comparisons with the SR group, $P=0.21$ for the PR–NR comparison) and in 235 cases (30%), as an actual desire to be helped to die (significantly more in the PR group than in the SR group ($P<0.0001$). In 244 cases (31.1%), the request was considered as signaling an anxiety-depression syndrome, significantly more in the SR group than in the PR or NR groups ($P<0.005$ for both differences; $P=0.56$ for the PR–NR difference).

Teams estimated that a temporal relationship existed between the request and provision of information about diagnosis (23.4%, $P=0.05$), prognosis (36.2%, $P=0.08$), realization that the terminal phase was at hand (51%, $P=0.02$) or the decision to stop disease-specific treatments (41%, $P=0.99$).

Discussion

To our knowledge, this is the first large survey assessing the context, the evolution and the outcome of patients with a RHD in a country widely promoting palliative care.

Clearly, and although euthanasia is illegal, RHDs are not uncommon. Palliative care development is not a fit-for-all solution: RHDs do exist despite extensive provision and

usage of multidisciplinary palliative care¹⁶⁻¹⁸. At least 40% of such requests are maintained despite regular palliative care support, while only 28% of all RHDs disappear. Requests persist regardless of the type of requester or of the type of structure. In the Netherlands, Van der Maas and al. also showed that one third of the euthanasia or assisted suicide requests were maintained despite palliative interventions¹⁹.

Our survey shows that despite contrary allegations²⁰, in progressive diseases, RHDs rarely occur early, when the patient has not been informed of the nature and severity of his/her disease. Almost 60% of patients died within a month of the request.

Surprisingly, although most patients are in the terminal phase of a long-standing illness, less than 2%, whatever the group, had left written advance instructions and that less than 10% had designated a surrogate, five to ten years after enactment of laws on these topics^{6 21}. A recent US study has shown that 67.6% of adults aged 60 years or more had provided advance directives²². This strongly suggests that in France both physicians and lay persons lack a patient's right culture^{12 14}.

Very few patients were reported to have had intractable pain. This should alleviate the concerns of opponents to euthanasia who fear that its legalization would lead to have it disproportionately chosen by, or forced upon, patients in this situation. This also holds for social isolation^{20 23}.

Instead, reasons such as "loss of dignity", "fear to lose intellectual abilities", "fear to give an unbearable image", "unworthy life", "useless life", or "guilt on increased burden for families" are expressed in 79 percent of cases²⁴. These results confirm that factors associated with RHDs are complex and multifactorial^{23 25}, while reasons that are critical for patients are often underestimated by physicians^{26 27}. Both the Dutch and Belgian euthanasia acts state that the

attending physician must be convinced that the patient requesting hastening of death is in a situation of unbearable suffering²⁷, which may not be the primary preoccupation of these patients. As shown in Oregon²⁸, only 11% of patients with RHDs had a depressive disorder. However, distinguishing depression and hopelessness is particularly difficult in the context of terminal illnesses and the more challenging question is often to address hopelessness, in a non-depressive terminally ill patient²⁹. 79% of our patients had been seen by a psychiatrist or a psychologist which is important, as it is difficult to adequately determine if a psychiatric disorder is impairing the judgment of patients requesting PAD³⁰.

If patients, healthcare professionals, and relatives appear in the literature to have their own clusters of motivations^{23 27 31}, our study shows similar rates for a majority of perceptions and symptoms in our 3 groups.

Anecdotal evidence shows that the highly emotional content of end-of-life issues frequently leads to conflicts among those confronted to such issues. Such conflicts were noted in about 30% of our cases, but were more frequent when the request was made by relatives or nurses. This figure may have been underestimated due to the short elapsed time since patient's death, which may lead to suppression or hiding some difficulties or grudges³².

Methodological limitations

However, since it is a retrospective survey, some ratings are difficult to interpret while the anonymity of data collection makes it impossible to check whether respondents' descriptions accurately represent what had actually occurred. Equally, only 53% of palliative care teams responded which may have introduced a selection bias. It is unlikely for a sample of this size to be totally non representative; the motivations given by centers that were questioned on their non-response, do not suggest any hidden bias hindering the quality of our data.

Finally, although RHD were surveyed, we cannot determine if any of these patients would have requested hastened death if it had been legal.

Conclusion

This nationwide survey provides for the first time comprehensive hard data on the evolution of RHDs expressed into the different types of palliative care services in a country that has not legalized euthanasia. RHDs are frequent and are frequently maintained despite appropriate palliative care. Our findings show how problematic it may be for a patient to express such a request. Terminally ill patients try to cope with loss of autonomy, difficulties for feeding, incontinence, a major feeling of loss of dignity and an absence of realistic treatment alternatives. It is disturbing to note that these factors are quite similar to those the presence of which is mandatory for euthanasia to be envisaged in the Netherlands or Belgium²³.

Contributors

Edouard Ferrand, and Jean-François Dreyfus were involved in the study conception and design, data analysis and interpretation, and writing of the article. Mélanie Chastrusse, and Françoise Ellien were involved in the study conception and design. François Lemaire, and Marc Fischler were also involved in data analysis and interpretation.

Acknowledgments

We thank the French Society of Patient's Accompanying and Palliative Care (SFAP), the French Hospital Federation (FHF), the National Federation of Hospital at Home (FNEHAD) and the National Federation of Palliative Care Networks for their support of the study.

We are indebted to all the members of the palliative care teams who provides the study data.

Conflict of interest statement

The authors have not potential conflict of interest.

References

1. Oregon Death with Dignity Act, Oregon Revised Statute 127.800-127.995. Available: <http://www.ohd.hr.state.or.us/cdpe/chs/pas/ors.htm> (accessed 2011 Apr. 2).
2. Law concerning euthanasia. Belgian official collection of the laws - 2002 June 22 [Dutch]. Available: www.health.fgov.be/euthanasie (accessed 2011 Apr. 2).
3. Termination of Life on Request and Assisted Suicide (Review Procedures) Act [Dutch]. The Hague (the Netherlands): Government of the Netherlands; 2002. Available: www.toetsingscommissieseuthanasie.nl/wetgeving (accessed 2011 Apr. 2).
4. Proposition de loi sur l'euthanasie et l'assistance au suicide [dossier parlementaires no 4909]. Government of Luxembourg; 2008. Available: www.gouvernement.lu/salle_presse/actualite/2008/12-decembre/18-chd/18-4909.pdf (accessed 2011 Feb. 3).
5. Washington Death with Dignity Act, Initiative measure 1000. RCW 70.245. Available: <http://wei.secstate.wa.gov/osos/en/Documents/I1000-Text%20for%20web.pdf> (accessed 2010 Apr. 2).
6. Loi du 22 avril 2005, n° 2005-370 relative aux droit des malades et à la fin de vie. Journal Officiel de la République Française du 23 avril 2005 Available: http://www.legifrance.gouv.fr/html/actualite/actualite_legislative/decrets_application/2005-370.htm (accessed 2011 Feb 10).
7. Fillon F. Fin de vie : plaidoyer pour un dialogue serein et un débat responsable. Le Monde. 2011 24-25 Jan, 2011.
8. Chin A, Hedberg K, Higginson G, Fleming D. Legalized physician-assisted suicide in Oregon--the first year's experience. N Engl J Med. 1999;340(7):577-83.

9. Deliens L, Mortier F, Bilsen J, Cosyns M, Vander Stichele R, Vanoverloop J, et al. End-of-life decisions in medical practice in Flanders, Belgium: a nationwide survey. *Lancet*. 2000 Nov 25;356(9244):1806-11.
10. Deliens L, van der Wal G. The euthanasia law in Belgium and the Netherlands. *Lancet*. 2003;362:1239-40.
11. van der Heide A, Onwuteaka-Philipsen BD, Rurup ML, Buiting HM, van Delden JJ, Hanssen-de Wolf JE, et al. End-of-life practices in the Netherlands under the Euthanasia Act. *N Engl J Med*. 2007 May 10;356(19):1957-65.
12. Ferrand E, Rondeau E, Lemaire F, Fischler M. Requests for euthanasia and palliative care in France. *Lancet*. 2011 Feb 5;377(9764):467-8.
13. Laval G, Villard M, Liatard K, Picault C, Roisin D. Persistent request for euthanasia and masked euthanasia practices: are they so frequent. *Med Pal*. 2007;6:88-98.
14. Ferrand E, Jabre P, Vincent-Genod C, Aubry R, Badet M, Badia P, et al. Circumstances of death in hospitalized patients and nurses' perceptions: French multicenter Mort-a-l'Hopital survey. *Arch Intern Med*. 2008 Apr 28;168(8):867-75.
15. Cassell EJ. The nature of suffering and the goals of medicine. *N Engl J Med* 1982;306:639-45.
16. Materstvedt LJ, Clark D, Ellershaw J, Forde R, Gravgaard AM, Muller-Busch HC, et al. Euthanasia and physician-assisted suicide: a view from an EAPC ethics task force. *Palliat Med* 2003;17:97-101.
17. Emanuel EJ, Fairclough D, Clarridge BC, Blum D, Bruera E, Penley WC, et al. Attitudes and practices of U.S. oncologists regarding euthanasia and physician-assisted suicide. *Ann Intern Med*. 2000 Oct 3;133(7):527-32.

18. Van den Block L, Deschepper R, Bilsen J, Bossuyt N, Van Casteren V, Deliens L. Euthanasia and other end of life decisions and care provided in final three months of life: nationwide retrospective study in Belgium. *BMJ*. 2009;339:b2772.
19. Van der Maas PJ, Van Delden JJM, Pijnenborg L, Looman CW. Euthanasia and other medical decisions concerning the end of life. *Lancet*. 1991;338:669-74.
20. Task Force on Euthanasia. Pole and Research Ethics. Société Française d'Accompagnement et de Soins Palliatifs. Facing a request for euthanasia; 2004.
21. Loi du 04 mars 2002, n°2002-303 relative aux droits des malades et à la qualité du système de santé. *Journal Officiel de la République Française* du 5 mars 2002 Available: <http://adminet/jo/20020305/MESX0100092Lhtml> (accessed 2011 Feb 10).
22. Silveira MJ, Kim SY, Langa KM. Advance directives and outcomes of surrogate decision making before death. *N Engl J Med*. 2010;362(13):1211-8.
23. Wilson KG, Chochinov HM, McPherson CJ, Skirko MG, Allard P, Chary S, et al. Desire for euthanasia or physician-assisted suicide in palliative cancer care. *Health Psychol*. 2007;26(3):314-23.
24. Quill TE. Legal regulation of physician-assisted death—the latest report cards. *N Engl J Med*. 2007;356:1911-3.
25. Emanuel EJ, Daniels ER, Fairclough DL, Clarridge BR. The practice of euthanasia and physician-assisted suicide in the United States: adherence to proposed safeguards and effects on physicians. *JAMA*. 1998;280:507-13.
26. Dees M, Vernooij-Dassen M, Dekkers W, van Weel C. Unbearable suffering of patients with a request for euthanasia or physician-assisted suicide: an integrative review. *Psychooncology*. 2010;19(4):339-52.

27. Pasman HR, Rurup ML, Willems DL, Onwuteaka-Philipsen BD. Concept of unbearable suffering in context of ungranted requests for euthanasia: qualitative interviews with patients and physicians. *BMJ*. 2009;339:b4362.
28. Ganzini L, Harvath TA, Jackson A, Goy ER, Miller LL, Delorit MA. Experiences of Oregon nurses and social workers with hospice patients who requested assistance with suicide. *N Engl JMed*. 2002;347:582-8.
29. Chochinov HM, Wilson KG, Enns M, Mowchun N, Lander S, Levitt M, et al. Desire for death in the terminally ill. *Am J Psychiatry*. 1995;152:1185-91.
30. Ganzini L, Fenn DS, Lee MA, Heintz RT, Bloom JD. Attitudes of Oregon psychiatrists toward physician-assisted suicide. *Am J Psychiatry*. 1996;153:1469-75.
31. Breitbart W, Rosenfeld B, Pessin H, Kaim M, Funesti-Esch J, Galietta M, et al. Depression, hopelessness, and desire for hastened death in terminally ill patients with cancer. *JAMA*. 2000;284(22):2907-11.
32. Comby M, Filbert M. The demand for euthanasia in palliative care units: a prospective study in seven units of the Rhône-Alpes region. *Palliative Medicine*. 2005;19:587-93.

Table 1: Principal characteristics of patients involved by a request for hasten death.

| | Total n=783 | Requests expressed by patient n=476 | Requests expressed by relatives and close circle n=258 | Requests expressed by nursing team n=49 | P § |
|--|----------------|--|--|---|---------|
| Age (years) [mean ± SD] | 69 ± 15.8 | 70 ±14.6 | 69 ±17.0 | 63 ±20.0 | 0.08 |
| Sex Ratio M/F | 0.87 | 0.85 | 0.87 | 1.08 | 0.72 |
| Main diagnosis— no. (%) | | | | | |
| - Onco-haematological disease | 563 (71.9) | 378 (79.4) | 159 (61.6) | 26 (53.1) | <0.0001 |
| - Neurological disease | 93 (11.9) | 36 (7.6) | 48 (18.6) | 9 (18.4) | <0.0001 |
| - Organ failure | 37 (4.7) | 21 (4.4) | 15 (5.8) | 1 (2.0) | <0.0001 |
| - Geriatric polyopathy | 60 (7.7) | 28 (5.9) | 25 (9.7) | 7 (14.3) | <0.0001 |
| - Other | 30 (3.8) | 13 (2.7) | 11 (4.3) | 6 (12.2) | <0.0001 |
| Place where request has been expressed — no. (%) | | | | | |
| - Hospital Unit | 364 (46.5) | 225 (47.3) | 108 (41.9) | 31 (63.3) | <0.0001 |
| - Palliative care Unit | 146 (18.6) | 96 (20.2) | 50 (19.4) | 0 (0) | <0.0001 |
| - Nursing home | 92 (11.8) | 55 (11.5) | 33 (12.8) | 4 (8.1) | <0.0001 |
| - Home | 181 | 100 (21.0) | 67 (26.0) | 14 (28.5) | <0.0001 |

| | | | | | |
|--|------------|------------|-----------|------------|---------|
| | (23.1) | | | | |
| Designation by patient of a surrogate decision-maker — no. (%) | 40 (5.1) | 28 (5.9) | 7 (2.7) | 5 (10.2) | 0.02 |
| Identification by family or nursing staff of a reference person— no. (%) | 391 (49.9) | 227 (47.7) | 142 (55) | 22 (44.9) | 0.05 |
| Written anticipated directives — no. (%) | 14 (1.8) | 11 (2.3) | 3 (1.2) | 0 (0) | 0.22 |
| Refusal of care expression — no. (%) | | | | | |
| - By patient | 225 (28.7) | 174 (36.6) | 46 (17.8) | 5 (10.2) | <0.0001 |
| - By family of friends | 87 (11.1) | 21 (4.4) | 61 (23.6) | (10.2) | <0.0001 |

§ Randomization analog of ANOVA

Table 2: Medical, psychological and social context of patients, involved by a request for hasten death

| | Total n=783 | Requests expressed by patient n=476 | Requests expressed by relatives and close circle n=258 | Requests expressed by nursing team n=49 | P § |
|---|----------------|--|--|---|----------|
| Context of request with regard to evolution of disease— no. (%) | | | | | |
| - Related to learning diagnosis | 162 (20.7) | 119 (25.0) | 37 (14.3) | 6 (12.2) | 0.05 |
| - After a severe episode | 139 (17.8) | 86 (18.1) | 48 (18.6) | 5 (10.2) | 0.40 |
| - After several severe episodes | 504 (64.4) | 288 (60.5) | 178 (69.0) | 38 (77.6) | 0.02 |
| - Related to learning entry in terminal phase | 271 (34.6) | 189 (39.7) | 73 (28.3) | 9 (18.4) | <0.00001 |
| Context of request as regard patient's information— no. (%) | | | | | |
| - Knowledge of diagnosis | 691 (88.3) | 456 (95.8) | 200 (77.5) | 35 (71.4) | <0.0001 |
| - Knowledge of disease incurability | 648 (82.8) | 440 (92.4) | 175 (67.8) | 35 (67.3) | <0.00001 |
| - Information on | 202 (25.8) | 145 (19.0) | 49 (19.0) | 8 (16.3) | 0.08 |

| | | | | | |
|-----------|--|--|--|--|--|
| prognosis | | | | | |
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| Context of request: medical strategy — no. (%) | | | | | |
|---|------------|------------|------------|-----------|--------|
| - Previous request | 241 (30.8) | 169 (35.5) | 63 (24.4) | 9 (18.4) | 0.0008 |
| - Previous encounter with palliative care team | 354 (45.2) | 203 (42.6) | 116 (45.0) | 35 (71.4) | 0.0007 |
| - Recent change in therapeutic strategy | 246 (31.4) | 149 (31.3) | 82 (31.8) | 15 (30.6) | 0.93 |
| - Withdrawal of specific treatment | 134 (17.1) | 76 (16.0) | 49 (19.0) | 9 (18.4) | 0.99 |
| Psychological and psychiatric context — no. (%) | | | | | |
| - Previous suicide attempt | 32 (4.1) | 20 (4.2) | 9 (3.5) | 3 (6.1) | 0.57 |
| - Prior depressive syndrome | 55 (7.0) | 39 (8.2) | 9 (3.5) | 0 (0) | 0.26 |
| - Current depressive syndrome | 88 (11.2) | 66 (13.9) | 16 (6.2) | 0 (0) | 0.02 |
| - Recent bereavement | 61 (7.8) | 47 (9.9) | 22 (8.5) | 1 (2.0) | 0.02 |
| - Recent separation | 28 (3.6) | 47 (9.9) | 13 (5.0) | 1 (2.0) | 0.95 |
| - Recent professional | 26 (3.3) | 17 (3.6) | 10 (3.9) | 1 (2.0) | 0.05 |

| | | | | | |
|--|------------|------------|------------|-----------|--------|
| loss | 142 (8.1) | 95 (20) | 41 (15.9) | 6 (12.2) | 0.44 |
| - Recent non-professional loss | 11 (1.4) | 5 (1.1) | 41 (15.9) | 1 (2.0) | 0.36 |
| - Recent confrontation to euthanasia | | | | | |
| - Recent confrontation to inappropriate treatment of a family member or a friend | 23 (2.9) | 17 (3.6) | 6 (2.3) | 0 (0) | 0.50 |
| Social context — no. (%) | | | | | |
| - Social isolation | 101 (12.9) | 78 (16.4) | 14 (5.4) | 9 (18.4) | 0.0001 |
| - At least one person involved in underlying disease management | 725 (92.6) | 432 (90.8) | 247 (95.7) | 46 (93.9) | 0.65 |

§ Fisher Exact test $r \times 3$

Table 3: Clinical symptoms and perceptions of patients, involved by a request for hasten death.

| | Total n=783 | Requests expressed by patient n=476 | Requests expressed by relatives and close circle n=258 | Requests expressed by nursing team n=49 | P § |
|-------------------------------|----------------|--|--|---|---------|
| Clinical symptoms— no. (%) | | | | | |
| - Pain (controlled) | 409 (52.2) | 263 (55.3) | 118 (45.7) | 28 (57.1) | 0.06 |
| - Pain (uncontrolled) | 29 (3.7) | 24 (5.0) | 5 (1.9) | 0 (0) | 0.22 |
| - Cognitive impairment | 214 (27.3) | 48 (10.1) | 143 (55.4) | 23 (46.9) | <0.0001 |
| - Communication impairment | 285 (36.4) | 80 (16.8) | 174 (67.4) | 31 (63.3) | <0.0001 |
| - Dyspnea | 211 (26.9) | 121 (25.4) | 77 (29.8) | 13 (26.5) | 0.41 |
| - Feeding impairment | 509 (65.0) | 260 (54.6) | 210 (81.4) | 39 (79.6) | <0.0001 |
| - Cachexia | 306 (39.1) | 178 (37.4) | 103 (39.9) | 25 (51.0) | 0.14 |
| - Motor impairment | 423 (54.0) | 219 (46.0) | 168 (65.1) | 36 (73.5) | <0.0001 |
| - Excretion impairment | 383 (48.9) | 175 (36.8) | 174 (67.4) | 34 (69.4) | <0.0001 |
| - Bedsores | 123 (15.7) | 53 (11.1) | 56 (21.7) | 14 (28.6) | <0.0001 |
| - Other | 261 (33.3) | 151 (31.7) | 90 (34.9) | 20 (40.8) | 0.03 |
| Patient's perception— no. (%) | | | | | |

| | | | | | |
|--|------------|------------|------------|-----------|-------|
| - Fulfilled life | 224 (28.6) | 156 (32.8) | 59 (22.9) | 9 (18.4) | 0.06 |
| - Useless life | 295 (37.7) | 203 (42.6) | 80 (31.0) | 12 (24.5) | 0.11 |
| - Unworthy life | 296 (37.8) | 172 (36.1) | 109 (42.2) | 15 (30.6) | 0.007 |
| - Fear of death | 285 (36.4) | 185 (38.9) | 81 (31.4) | 19 (38.8) | 0.32 |
| - Fear of death with physical pain | 231 (29.5) | 153 (32.1) | 64 (24.8) | 14 (28.6) | 0.32 |
| - Fear of death with moral pain | 238 (30.4) | 154 (32.4) | 71 (27.5) | 13 (26.5) | 0.74 |
| - Fear of death by suffocation | 117 (14.9) | 74 (15.5) | 36 (14.0) | 7 (14.3) | 0.92 |
| - Fear of death by hemorrhage | 21 (2.7) | 9 (1.9) | 7 (2.7) | 5 (10.2) | 0.008 |
| - Fear of excruciating pain | 311 (39.7) | 196 (41.2) | 96 (37.2) | 19 (38.8) | 0.99 |
| - Fear of losing intellectual functions | 242 (30.9) | 161 (33.8) | 69 (26.7) | 12 (24.5) | 0.50 |
| - Fear of presenting an intolerable image of oneself | 389 (49.7) | 237 (49.8) | 127 (49.2) | 25 (51.0) | 0.22 |
| - Guilt on the burden put on family or close friends | 359 (45.8) | 244 (51.3) | 95 (36.8) | 20 (40.8) | 0.1 |
| Perceptions by patients— no. (%) | | | | | |
| - Perception of a fulfilled life | 224 (28.6) | 156 (32.8) | 59 (22.9) | 9 (18.4) | 0.06 |
| - Perception of an useless life | 295 (37.7) | 203 (42.6) | 80 (31.0) | 12 (24.5) | 0.11 |
| - Perception of an unworthy life | 296 (37.8) | 172 (36.1) | 109 (42.2) | 15 (30.6) | 0.007 |
| - A fear of death: | 285 (36.4) | 185 (38.9) | 81 (31.4) | 19 (38.8) | 0.32 |
| - by physical pain | 231 (29.5) | 153 (32.1) | 64 (24.8) | 14 (28.6) | 0.32 |
| - by moral pain | 238 (30.4) | 154 (32.4) | 71 (27.5) | 13 (26.5) | 0.74 |
| - by asphyxiation or suffocation | 117 (14.9) | 74 (15.5) | 36 (14.0) | 7 (14.3) | 0.92 |

| | | | | | |
|---|------------|------------|------------|-----------|-------|
| - by hemorrhage | 21 (2.7) | 9 (1.9) | 7 (2.7) | 5 (10.2) | 0.008 |
| - A fear of an unbearable pain | 311 (39.7) | 196 (41.2) | 96 (37.2) | 19 (38.8) | 0.99 |
| - A fear of losing intellectual functions | 242 (30.9) | 161 (33.8) | 69 (26.7) | 12 (24.5) | 0.5 |
| - A fear of presenting an unbearable image of oneself | 389 (49.7) | 237 (49.8) | 127 (49.2) | 25 (51.0) | 0.22 |
| - A perception of guilty or burden to the relatives | 359 (45.8) | 244 (51.3) | 95 (36.8) | 20 (40.8) | 0.1 |

§ Fisher Exact test $r \times 3$

Table 4: Type of palliative care support for patients, involved by a request for hasten death.

| | Total n=783 | Requests expressed by patient n=476 | Requests expressed by relatives and close circle n=258 | Requests expressed by nursing team n=49 | P § |
|---|----------------|--|---|---|------|
| Consultations by a palliative care team — no. (%) | 732 (93.5) | 446 (93.7) | 241 (93.4) | 45 (91.8) | 0.99 |
| Assistance by a social worker — no. (%) | 321 (41.0) | 204 (42.9) | 97 (37.6) | 20 (40.8) | 0.30 |
| Consultation by a psychologist — no. (%) | 553 (70.6) | 344 (72.3) | 172 (66.7) | 37 (75.5) | 0.31 |
| Consultation by a psychiatrist — no. (%) | 68 (8.7) | 48 (10.1) | 17 (6.6) | 3 (6.1) | 0.22 |
| Transfer of the patient in a palliative care unit — no. (%) | 104 (13.3) | 74 (15.5) | 26 (10.1) | 4 (8.2) | 0.31 |
| Transfer to a room designated for palliative care — no. (%) | 30 (3.8) | 22 (4.6) | 7 (2.7) | 1 (2.0) | 0.13 |
| Transfer to a non- | 74 (9.4) | 56 (11.8) | 16 (6.2) | 2 (4.0) | 0.99 |

| | | | | | |
|-----------------------------------|----------|-----------|----------|-------|------|
| palliative care unit — no. (%) | | | | | |
| Home return — no. (%) | 62 (7.9) | 48 (10.1) | 14 (5.4) | 0 (0) | 0.31 |

§ Fisher Exact test $r \times 3$

Table 5: Evolution of the requests.

| | Total n=783 | Requests expressed by patient n=476 | Requests expressed by relatives and close circle n=258 | Requests expressed by nursing team n=49 | P § |
|------------------------------|----------------|--|--|--|------|
| Disappearance — no. (%) | 219 (28.0) | 140 (29.4) | 73 (28.3) | 6 (12.2) | 0.03 |
| Persistence — no. (%) | 293 (37.4) | 164 (34.5) | 103 (39.9) | 26 (53.1) | 0.04 |
| Fluctuation — no. (%) | 186 (23.8) | 117 (24.6) | 57 (22.1) | 12 (24.5) | 0.65 |
| Not reevaluated — no. (%) | 85 (10.8) | 55 (11.6) | 25 (9.7) | 5 (10.2) | 0.6 |

§ Fisher Exact test $r \times 3$