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Evolution of requests to hasten death among patients managed by palliative care teams in France: A multicentre 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 organisations. 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 and palliative care team's interpretation of the request were obtained.

Findings: A majority of centres 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 anxio-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 legalised 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.

1. Introduction

Physician-assisted death (PAD) has become a public issue in many countries. Two United States (US) states, Oregon (1997), Washington (2009) and three European countries, Belgium, Netherlands (2002), and Luxemburg (2009) have decriminalised PAD.[1–5] In several other countries, especially if palliative medicine has been strongly promoted, the debate

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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 legalised, 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 multicentre survey to assess the evolution of the requests to hasten death (RHD) expressed to the different types of palliative care teams.

2. 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 care of outpatients home hospitalisation that has an obligation to provide palliative care at home or in nursing homes.

2.1. *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.

2.2. *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.

2.3. *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 five such cases, they could limit their description to the most relevant five.

2.4. *Centres*

A list of palliative care services was created with the help of several French scientific Societies (see acknowledgements). 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 centres 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 2 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 and lack of interest.

2.5. *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.

2.6. *Statistical analysis*

Cases were categorised into three 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 Bonferronni–Simes correction.

A bilateral significance level of 0.05 was used.

3. Results

3.1. *Participating centres*

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 centres 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 centres, inability to retrieve data – as this type of demand was not tagged (25 centres) and no such cases in 2010 for eight centres. No centre claimed not to be interested in the survey.

3.2. *Patients involved*

In 2010, 1055 RHDs were encountered in responding centres (0–17 per centre) and data were provided for 840 (1–17 per centre). In 57 cases, data were too scarce; therefore 783 cases were analysed.

Table 1 shows patients' characteristics. The mean age (±SD) was 69 (±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).

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[a]
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 polypathology	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 (23.1)	100 (21.0)	67 (26.0)	14 (28.5)	<0.0001
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

[a] Randomisation analogue of ANOVA.

3.3. *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 polypathology (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 was considered depressed at the time of the request. The proportion was significantly higher (48% and 43%) in the SR and the PR groups, 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

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[a]
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 prognosis	202 (25.8)	145 (19.0)	49 (19.0)	8 (16.3)	0.08
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 loss	26 (3.3)	17 (3.6)	10 (3.9)	1 (2.0)	0.05
Recent non-professional loss	142 (8.1)	95 (20)	41 (15.9)	6 (12.2)	0.44
Recent confrontation to euthanasia	11 (1.4)	5 (1.1)	41 (15.9)	1 (2.0)	0.36
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

[a] Fisher Exact test $r \times 3$.

(22%) or NR (18%) groups (between-group $p = 0.03$). Recent confrontation with inappropriate treatments or euthanasia for a relative was 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.

3.4. *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 haemorrhage (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%,

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[a]
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
Dysponoea	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 haemorrhage	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 untolerable 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 haemorrhage	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

[a] Fisher Exact test $r \times 3$.

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.

3.5. *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 1 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.

3.6. *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. Seventy nine 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 six cases. Surveyees were aware of 10 cases of euthanasia performed in nine non-palliative care wards.

3.7. *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% versus 54%), was close to significance ($p = 0.06$).

Evolutions are detailed in Table 5.

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

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[a]
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-palliative care unit – no. (%)	74 (9.4)	56 (11.8)	16 (6.2)	2 (4.0)	0.99
Home return – no. (%)	62 (7.9)	48 (10.1)	14 (5.4)	0 (0)	0.31

[a] 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[a]
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

[a] Fisher Exact test $r \times 3$.

3.9. *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 signalling 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%, $P = 0.08$), realisation that the terminal phase was at hand (51%, $P = 0.02$) or the decision to stop disease-specific treatments (41%, $P = 0.99$).

4. 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 care.[16–18] 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. Similarly, in the Netherlands, Van der Maas et al. also showed that one third of the euthanasia or assisted suicide requests were maintained despite palliative interventions.[19]

Our survey shows that despite contrary allegations,[20] 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, 5–10 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 directives.[22] This strongly suggests that in France both physicians and lay persons lack a patient's rights 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 legalisation 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% of cases.[24] These results confirm that reasons 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 suffering,[27] which may not be the primary preoccupation of these patients. As shown in Oregon,[28] 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 patient.[29] Seventy nine percentage 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 PAD.[30]

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 three groups.

Anecdotal evidence shows that the highly emotional content of end-of-life issues frequently lead 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 grudges.[32]

4.1. *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 centres 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.

5. 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 legalised 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 that are legally required to request euthanasia in the Netherlands or Belgium.[2,3]

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.

Conflict of interest statement

None declared.

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