CLINICAL ETHICS

Participation of French general practitioners in end-of-life decisions for their hospitalised patients

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Background and objective: Assuming the hypothesis that the general practitioner (GP) can and should be a key player in making end-of-life decisions for hospitalised patients, perceptions of GPs' role assigned to them by hospital doctors in making withdrawal decisions for such patients were surveyed.

Design: Questionnaire survey.

Setting: Urban (districts located near Paris) and rural (southern France) areas.

Participants: GPs.

Results: The response rate was 32.2% (161/500), and it was observed that 70.8% of respondents believed that their participation in withdrawal decisions for their hospitalised patients was essential, whereas 42.1% believed that the hospital doctors were sufficiently skilled to make withdrawal decisions without input from the GPs. Most respondents were found to believe that they had the necessary skills (91.9%) and enough time (87.6%) to participate in withdrawal decisions. The last case of treatment withdrawal in hospital for one of their patients was described by 40% (65/161) of respondents, of whom only 40.0% (26/65) believed that they had participated actively in the decision process. The major factors in the multivariate analysis were the GP's strong belief that his or her participation was essential ($p=0.01$), information on admission of the patient given to the GP by the hospital department ($p=0.007$), rural practice ($p=0.03$), visit to the patient dying in hospital ($p=0.02$) and a request by the family to be kept informed about the patient ($p=0.003$).

Conclusion: Strong interest was evinced among GPs regarding end-of-life issues, as well as considerable experience of patients dying at home. As GPs are more closely connected to patients' families, they may be a good choice for third-party intervention in making end-of-life decisions for hospitalised patients.

Only 26% of deaths in France occurred at home in 2000, compared with 64% in 1964, according to data from the National Institute for Health and Medical Research. Until recently, the family doctor played a pivotal role in helping dying patients and their families at their home. Whether this is still the case given that most deaths now occur in hospital is unknown.

Among the various components of medical end-of-life care, withdrawal of life-sustaining treatments is now widely used.^{1–4} Treatment withdrawal usually occurs in complex situations and its legitimacy is often a matter of concern and debate, most notably in France, where few people appoint healthcare representatives to speak for them should they lose decision-making capacity. Sharing decisions among healthcare professionals and family members has emerged as the best means of ensuring that the decisions made are appropriate.⁵ Evaluation of practices has established and recent French legislation, passed in 2002 and 2005, has reinforced the rights of patients and defined end-of-life processes.⁶ General practitioners (GPs), however, are not usually associated with decisions to withdraw life-sustaining treatment.^{2–7–8}

Assuming the hypothesis that the GP can and should be a key player in making end-of-life decisions for hospitalised patients, we conducted a survey of GPs' perceptions, asking them to describe their perceptions of the role given to them by hospital doctors in the decision to withdraw treatment for hospitalised patients.

METHODS

Developing and testing the survey tool

We developed a standardised interview about the decision-making process on treatment withdrawal. In April 2003, a

sociologist conducted semistructured interviews of five GPs in Créteil (Val de Marne, France). We developed a questionnaire in May 2003 and validated it with three other GPs in Créteil (Val de Marne, France). The five-page questionnaire included 45 items in two sections, one describing the respondent and the other describing the last case of treatment withdrawal in which the GP had participated.

Definition

Withdrawing life-support treatment was defined as discontinuation of one or more treatments without replacement by an equivalent treatment, with the objective of allowing a disease process to run its course and with the knowledge that this may lead to the patient's death.

Recruitment

The questionnaire was mailed to GPs working in urban and rural areas. The urban areas were the Essonne and Val de Marne districts, both located near Paris. The rural area was the Aveyron district (southern France). We selected 500 GPs at random from the telephone directory, half in the urban and half in the rural area.

Administration of the questionnaire

The study was conducted in December 2003 and January 2004. We mailed questionnaires to the randomly selected GPs in December 2003 and again 2 weeks later. Respondents were asked to mail the questionnaire back within a month. The study was stopped 4 weeks after the second questionnaire was mailed, on 25 January 2004. The questionnaire collected no information that could identify the respondents or the

patients they described in the second section. It was sent with an self-addressed envelope that did not bear any information on the sender.

Ethics

Neither patients nor their family members were associated with this study, and informed consent was therefore not required. Furthermore, information on decision-making procedures was collected retrospectively and consequently had no effect on the management of patients.

Statistics

Results for quantitative variables are reported as means (SD) or as medians (between the 25th and 75th centiles). Results for qualitative variables are reported as percentages with a 95% confidence interval (95% CI). Comparisons of quantitative variables relied on Student's *t* test if distribution was normal and on Wilcoxon's non-parametric test if it was not; qualitative variables were compared with χ^2 test or Fisher's exact test. All statistical tests were two tailed and $p < 0.05$ was considered to be significant. To identify the independent factors associated with the participation of GPs in treatment withdrawal from hospitalised patients, variables with $p < 0.10$ in univariate analysis were then considered for multivariate analysis and were analysed in multiple 2×2 analyses to assess first-order interaction and confounding by fitting multiplicative models. Finally, variables identified from this selection were entered into a backward step-by-step logistic regression model. SAS V.8.02 (1999–2001) was used for all statistical tests.

RESULTS

Characteristics of the respondents

The response rate was 32.2% (161/500): 53.4% ($n = 86$) in the rural area and 46.6% ($n = 75$) in the urban area. The mean age of respondents was 49.2 (SD 6.5) years, and the male-to-female ratio was 4.6. Time in practice was more than 10 years in the case of most ($n = 146$, 90.7%) respondents.

Only 65 (40.6%) of respondents had received training in end-of-life care, 56 (34.8%) in their continuing medical education, and 17 (26%) with a perception that this education was not sufficient; 108 (67.9%) believed that this training would help them in their everyday practice.

Level of collaboration between GPs and hospital doctors on management of patients, with or without end-of-life decisions

The level of collaboration differed considerably between teaching and non-teaching hospitals. GPs were more satisfied with the overall working relationship with hospital doctors, the information received about their patients and their participation in the management strategy in non-teaching hospitals ($p < 0.0001$). Regarding place of practice, considerably greater satisfaction regarding the overall working relationship between GPs and hospital doctors was noted in rural practice (table 1).

Participation of GPs in end-of-life care of patients at home

The median (range) number of patients in palliative care per respondent was 1 (0–2). The proportion of respondents with patients in palliative care was higher in rural than in urban practice (58.3% *v* 31.1%, $p < 0.05$). In all, 142 (88.2%) respondents reported having provided end-of-life care at home to at least one patient within the past year, and 26 (18.3%) hospital doctors had a role in the decision to refrain from hospital admission.

Table 1 Satisfaction of general practitioners with their working relationship with hospitals in rural and urban areas

	Rural ($n = 86$), n (%)	Urban ($n = 75$) n (%)	OR (95% CI)	p Value*
Satisfied with teaching hospitals regarding				
Overall working relationship	48 (56)	29 (39)	2.0 (1.1 to 3.8)	0.03
Information received	55 (64)	49 (65)	0.9 (0.5 to 1.8)	0.92
Participation in management strategies	9 (10)	10 (13)	0.8 (0.3 to 2.0)	0.63
Satisfied with non-teaching hospitals regarding				
Overall working relationship	64 (74)	42 (56)	2.3 (1.2 to 4.4)	0.01
Information received	59 (69)	49 (65)	1.2 (0.6 to 2.2)	0.71
Participation in management strategies	26 (30)	16 (21)	1.6 (0.8 to 3.3)	0.22

*Calculated using χ^2 or Fisher's exact test.

Experience of withdrawal decisions in a hospitalised patient

In total, 126 (78.8%) respondents reported that one or more of their patients died while in hospital within the past year. This proportion was not considerably different between rural and urban areas. Of these, 71 (56.3%) of the respondents were that a withdrawal decision had been made for their patient told during their stay in hospital, but only 33.3% ($n = 42$) were asked to attend a conference at the hospital to discuss the appropriateness of treatment withdrawal.

Perception of the GPs of their optimal level of participation in withdrawal decisions

Of the 161 respondents, 114 (70.8%) believed that their participation in withdrawal decisions for their hospitalised patients was essential, whereas 67 (42.1%) believed that the hospital doctors were sufficiently skilled to make withdrawal decisions without input from the GP. Most respondents believed that they had the necessary skills (148/161, 91.9%) and enough time (141/161, 87.6%) to participate in withdrawal decisions. Many respondents (105/161, 65.2%) believed that hospital doctors should promote participation of GPs by emphasising the importance of their role, and 38 (23.6%) respondents believed that they should be paid for the time spent participating in withdrawal decisions. The preferred methods of communication for participating in withdrawal decisions were telephone for 129 (80.6%) respondents; meetings at the hospital for 44.7% of respondents; and mail, fax or email for 30.6% of respondents.

Description of the last case of treatment withdrawal in a hospitalised patient

Two fifths of the respondents ($n = 65$, 40.4%) described the last case of treatment withdrawal for one of their patients in hospital.

Characteristics of the patients in hospital subjected to treatment withdrawal decisions ($n = 65$)

Of the 65 patients in hospital subjected to treatment withdrawal decisions within the past year, 50 (78.1%) were in medical departments, 8 (12.3%) were in surgical departments, 6 (9.4%) were in intensive care units and 1 (1.6%) was in an emergency room. One third ($n = 23$, 35.4%) of the patients were in palliative care before the time of the withdrawal decision. Nearly one fourth ($n = 15$, 23.4%) had

Table 2 Univariate analysis of factors associated with active participation of general practitioners in the decision on treatment withdrawal for hospitalised patients

	No participation, n = 39 (%)	Participation, n = 26 (%)	OR	95% CI	p Value
Characteristics of GPs					
Sex, male	30 (79)	23 (92)	3.1	0.6 to 15.8	0.29
Age in years, (mean (SD))	49.0 (6.1)	50.2 (8.0)	1.0	1.0 to 1.1	0.50
Rural practice	16 (42)	19 (73)	3.7	1.3 to 11.0	0.01
Works in a hospital	3 (8)	6 (23)	3.5	0.8 to 15.5	0.14
Trained in end-of-life care	12 (32)	12 (46)	1.9	0.7 to 5.2	0.24
Characteristics of patients					
Sex, male	17 (45)	11 (44)	1.0	0.4 to 2.7	0.95
Age in years (mean (SD))	67.4 (13.7)	74.4 (9.8)	1.1	1.0 to 1.1	0.05
In palliative care	12 (32)	11 (42)	1.6	0.6 to 4.5	0.38
Asked to receive no further care	6 (16)	9 (35)	2.7	0.8 to 9.0	0.09
Others					
Information on admission of the patient by the hospital department	17 (45)	19 (73)	3.4	1.1 to 9.8	0.02
Information on patient admission by the family	25 (66)	9 (35)	0.3	0.1 to 0.9	0.01
Request by the family to keep GP informed about the patient	16 (43)	23 (88)	10.1	2.6 to 39.5	0.0003
Visit to patient dying in the hospital	24 (63)	22 (88)	4.3	1.1 to 16.9	0.03
GP's strong belief that his or her participation was essential	23 (61)	24 (92)	7.8	1.6 to 38.1	0.005

GP, general practitioner. ORs for ages of GPs or patients were calculated with a simple logistic regression (1-year increments).

p Value was calculated with χ^2 or Fisher's exact test for qualitative variables and Student's t test for quantitative variables.

told their GP that they did not want further medical treatment.

Process used to inform GPs of the decision on treatment withdrawal

The GP was informed about the decision on treatment withdrawal by the hospital doctor in 36 (55.4%) cases and the family was informed in 23 (35.4%) cases. In the remaining 6 (9.2%) cases, the GP called the hospital doctor to ask about treatment withdrawal. The GP was informed after the patient's death in 10 (15.4%) cases; in these situations, the information usually came from the family (66.6%).

Modalities of participation of the GP in decisions on treatment withdrawal

Only two fifths (26/65, 40.0%) of the 65 respondents who described withdrawal decisions believed that they had participated actively in the decision process. Among the factors markedly associated with participation of the GP

according to the univariate analysis (table 2), those significant in the multivariate analysis were the GP's strong belief that his or her participation was essential ($p = 0.01$), information on admission of the patient given to the GP by the hospital department ($p = 0.007$), rural practice ($p = 0.03$), visit to the patient dying in the hospital ($p = 0.02$) and a request by the family to be kept informed about the patient ($p = 0.003$; table 3).

Advice from the GP was sought over telephone in 69.2% (18/26) cases and during meetings at the hospital in 30.7% (8/26) of the cases. The points raised most often were former quality of life of the patient ($n = 21$, 80.8%), family members (65.4%), medical treatments that should be stopped or limited (65.4%), medical history of the patient (57.7%), patient's wishes (46.1%) and whether discharge could be considered (30.8%). No conflicts were reported.

Of the 65 GPs who participated in withdrawal decisions, 39 (60.9%) were asked by the family members for information on the withdrawal decision. After the patient's death, 47

Table 3 Multivariate analysis of factors associated with active participation of GPs in treatment withdrawal of hospitalised patients

	OR	95% CI	p Value
Rural practice	6.8	1.2 to 38.3	0.03
Visit to patient dying in hospital	19.3	1.6 to 227.3	0.02
Information on patient admission by the hospital department	13.5	2.0 to 89.5	0.007
Request by the family to keep GP informed about the patient	20.7	2.7 to 157.6	0.003
GP's strong belief that his or her participation was essential	19.7	1.9 to 199.2	0.01

GP, general practitioner.

Seven values were missing for the response or explanatory variables.

A multiple logistic regression analysis was carried out. The dependent variable was the participation of GPs in the decision on treatment withdrawal for hospitalised patients. The independent variables used to generate this model were those with $p < 0.10$ in the univariate analysis. The Hosmer and Lemeshow goodness-of-fit test gave $p = 0.77$, which indicated that the logistic model was a good fit.

(72.3%) respondents discussed the withdrawal decision with the family; in 38 cases, this discussion was requested by the family members.

DISCUSSION

The main finding from our survey was that only one fourth of the GPs were contacted by hospital doctors about treatment withdrawal for their patients in hospital, and as many as 15% learnt of the decision only after the patient had died. Furthermore, among the GPs who were contacted, only one third participated in the decision. These results are consistent with a prospective survey⁹ of 54 hospitals in France and Belgium, which evaluated the incidence and circumstances of deaths in the emergency room: among the decisions on treatment withdrawal, 63% were taken by the doctors in the emergency room alone, and only 4% were taken after discussion with the regular GP.⁹ In a 1998 survey of 233 GPs, 64% of the respondents reported never having been asked for advice about treatment withdrawal for their patients in hospital.¹⁰ This lack of involvement of GPs may partly be ascribable to deficiencies in decision sharing among hospital staff members.^{2,7,9} In both the SUPPORT study in the US⁷ and the LATAREA study in France,² half the decisions on treatment withdrawal were taken without the participation of the nurses, who nevertheless carried out the withdrawal procedure² or had knowledge about the patients' wishes.⁷

Among our respondents, more than 90% believed that they had enough time and skill to take an active part in decisions on treatment withdrawal. Less than half believed that the hospital staff members were sufficiently skilled to take the decision without input from others. Poor communication between office-based physicians and hospital doctors has been reported previously, and negative feelings have been described, such as an impression that hospital doctors have little respect for, and trust in, their office-based colleagues.^{11–15} This may seem surprising, as GPs have a pivotal role in delivering palliative care at home and in determining when hospital referral is inappropriate.^{16–18}

Another interesting result from our study is that more than half of the families asked their GP to discuss the death of their relative with them. Thus, in practice, the GP may serve as the representative of the patient and the family, even after discharge or death,¹⁹ and may provide valuable mediation in the event of a conflict between the family and hospital doctors.⁴ Hospital doctors, however, rarely ask GPs to help mediate conflicts with families of dying patients.^{20–22} Thus, in a study conducted in France by Pochard *et al*²³ in 2000, only 29% of 301 intensivists supported third-party involvement in an ethics consultation.²³ Nevertheless, among third parties, the GP was viewed more favourably (57% of respondents) than the ethics committee. Among the respondents, 80% stated that the main obstacle to third-party involvement was lack of time and skill.²³ Should our finding that GPs are willing to participate be confirmed in further studies, then they may emerge as the best third party, given their unique role within families.

Only 23% of the respondents in our study believed that they should be paid for their time spent participating in end-of-life decisions for hospitalised patients. By contrast, in studies from other countries, many GPs were strongly for regulatory changes allowing them to bill the time needed for patients in palliative care.^{11,24,25} Although routine hospital visits may be beneficial,^{26,27} most of the GPs in our study suggested the telephone for communicating with hospital doctors. As GPs in France have limited time and receive no payment for participating in end-of-life decisions in hospital, the telephone may be a good method for communicating with their hospital colleagues.

Our study has several limitations. We used a self-administered questionnaire that was completed on a voluntary basis. GPs who are often associated with or particularly interested in end-of-life care may have been more likely to return completed questionnaire. Thus, our sample may not be representative of the overall population of GPs in France. Moreover, our design required a description of the perceptions of GPs on their working relationship with hospital doctors; this may have led respondents to recall their most vivid experiences, which may well have also been the most negative ones.

In conclusion, our data suggest that efforts by hospital doctors in communicating with GPs regarding decisions to withdraw treatment may be extremely limited. Nevertheless, we found evidence of strong interest among GPs regarding end-of-life issues, as well as considerable experience with patients dying at home. Because GPs have a unique role within families, they may be a good choice for third party intervention in making end-of-life decisions for hospitalised patients, which is recommended in current guidelines.⁴

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