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Promoting patients' rights at the end of life in a geriatric setting in France: the healthcare professionals' level of knowledge about surrogate decision-makers and advance directives.

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ABSTRACT

Objective: To assess levels of knowledge about patients' rights, surrogate decision-makers, and advance directives among healthcare professionals at three hospitals in France.

Methods: A multicenter, cross-sectional study in three geriatric hospitals in the Paris area (France) in 2015. The participants' level of knowledge was assessed via an 18-item self-questionnaire on surrogate decision-makers, advance directives, and end-of-life decision-making. The characteristics associated with a good level of knowledge were assessed using logistic regression.

Results: Among the 301 healthcare professionals (median \pm standard deviation age: 40.4 \pm 10.2 years; women: 73.4%), only 15.0% (95% confidence interval (CI): [19.7-29.5]) correctly answered at least 75% of the questions on patients' rights. Respectively 24.6% [19.7-29.5], 36.5% [31.1-42.0] and 37.5% [32.0-43.0] had sufficient knowledge regarding "surrogate decision-maker", "advance directives", and "decision-making at the end of life". In a multivariable analysis, the only factor significantly associated with a good level of knowledge about end-of-life policy was employment in a university hospital, with a non-significant trend for status as a physician.

Conclusions: Our survey of staff working in geriatric care units highlighted the poor overall level of knowledge about healthcare surrogates and advance directives; the results suggest that additional training in these concepts is required.

Practice implications: Continuing education of healthcare professionals on advance directives and surrogate decision-maker should be promoted to ensure rights of elderly patients at the end of life.

1. Background

End-of-life care is still an important, frequent issue in geriatric wards. Healthcare professionals face a number of critical challenges when managing older patients hospitalized for chronic diseases. Hospitals are the most common place of death for elderly patients, although those with marked cognitive impairments tend to die in care homes [1, 2]. Cohen *et al.* found that between 26% and 87% of cancer patients die in hospital [3]. The usual care strategy for patients with severe illnesses is based on ensuring comfort and quality of life. One of the aspects of this approach is compliance with the patient's choices regarding end-of-life care. In France, two legal procedures favor the application of the patient's choices for end-of-life care: the appointment of a surrogate (who makes health care decisions for incapacitated patient), and advance directives, i.e. directives specifying the decisions that should be taken if a patient has no longer decisional capacity. France's 2002 Patient Rights Act (the Kouchner law) promoted the principle of informed consent from the patient (or from the surrogate decision-maker in the event of the patient's incapacity) prior to any care [4]. In 2005, an updated Patient Rights Act (the Leonetti law) focused on end-of-life care, and introduced the concept of advance directives. According to the 2005 Act, healthcare professionals must check whether a patient has given advance directives before starting an end-of-life discussion. If a patient so wishes, he can transfer his decision-making authority for the acceptance or refusal of medical procedures. [5]. The concept of advance directives was reinforced by the updated 2016 Patient Rights Act [6]. The new Act introduced the right to continuous deep sedation until death in three specific situations: (i) at the patient's request when the short-term prognosis is death in case of uncontrollable symptoms; (ii) at the patient's request when the patient unbearably suffering chooses to withdraw artificial life-sustaining treatment; (iii) when the patient is unable to express his/her wishes and the collegiate medical decision is to withdraw aggressive futile life-sustaining treatment; continuous deep sedation is mandatory when the patient presents signs of suffering or when the patient's suffering cannot be evaluated due to the patient's cerebral or cognitive state [7].

Before the adoption of the update 2016 Patient Rights Act, several official reports have found that France's end-of-life legislation was poorly known, conferring weakest power to surrogate decision-maker compared to western European countries and not well applied in everyday practice [8-10]. According to Le Meur *et al.*'s study [11], only one fifth (21.7%) of family physicians in France are familiar with the country's legislation on end-of-life care and rights.

The results of a 2012 study of a random sample of newly deceased French adults indicated that only 1.5% of patients had given written advance directives [12]. In a geriatric care setting, however, there are little literature data on healthcare professionals' levels of knowledge about surrogate designation and advance directives while most of deaths occur in geriatric setting for terminally ill patients, so it is of importance to know more about implementation of end-of-life decision-making processes in this setting. Also, the question of end-of-life legislation is of particular interest in geriatrics where there is a high prevalence of dementia, indeed the surrogate decision maker has a key role among these patients.

Hence, the objective of the present study was to assess levels of knowledge about the main concepts in patients' rights, surrogate decision-makers, and advance directives among healthcare professionals working in three geriatric care units in France.

2. Methods

2. 1. Study design and population

We performed a multicenter, cross-sectional study in three tertiary geriatric referral centers in the Paris area of France between March 1st and June 30th, 2015. Hence, we invited healthcare professionals (physicians, nurses, nursing assistants, social workers, psychologists, and occupational therapists) caring for patients in subacute care, rehabilitation, palliative geriatric care, long-term care, and acute geriatric care units, geriatric oncology departments, and gerontopsychiatric rehabilitation units to participate in the study. The study was performed in two general hospitals (Georges Clemenceau Hospital (Champcueil, France) and Joffre Dupuytren Hospital (Draveil, France), which are affiliated with Henri Mondor teaching hospital (Créteil, France)), and a teaching hospital (Charles Foix Hospital (Ivry-sur-Seine, France)). In each center, 150 healthcare professionals were approached by a referent geriatrician of their units to fill out a paper questionnaire on their knowledge regarding end-of-life policy. The healthcare professionals were invited randomly during their shift in proportion to their respective category's representation in the geriatric wards: 20% were physicians, 30% were nurses, 40% were nursing assistants, and 10% were other healthcare professionals (psychologists, occupational therapists, and social workers). Moreover, in France, even though physicians have the responsibility of the end-of-life decision making, the decision making results from a collegiate decision after a multidisciplinary meeting where all health care professionals can give their opinions. And it is also part of the non-physicians roles to inform the patient about the possibility of designating a surrogate decision maker.

Therefore, it was considered of importance to have all health care professionals involved in the care of end-of-life patients as they all have their say in the decision making.

2.2. Data recorded

We collected the following data on the participating healthcare professionals with a self-administered questionnaire: sex, age, occupation (physician, nurse, nursing assistant, social worker, psychologist or occupational therapist), work shift (day or night), attendance at one or more training courses on end-of-life care (yes or no), the number of years of practice in geriatrics, the number of end-of-life situations experienced in the career, the type of unit (long-term care unit, subacute unit or acute care unit) and the type of hospital (teaching hospital or general hospital).

The participant's age, the number of years of practice in geriatrics, and the number of end-of-life patient situations experienced were categorized as quartiles.

Data on knowledge about end-of-life policy in France were collected via a self-questionnaire developed by a group of geriatricians of Henri Mondor teaching hospitals, with three sections, each of which evaluated a specific domain: "the surrogate decision-maker", "advance directives" and "decision-making at the end of life". The 2016 legislation was promulgated a year after the present study. However, none of the correct answers to any of the questionnaire questions would have been different due to the 2016 new legislation. The questionnaire also comprised a separate, open question that asked the respondent to describe a difficult end-of-life patient situation. In order to assess the primary endpoint, a correct answer was scored as one point and an incorrect answer was scored as zero; this yielded an overall score with a minimum of 0 and a maximum of 18. The primary endpoint (i.e. a good knowledge of older patients' rights) was defined as an overall score of 14 or more out of 18 (i.e. $\geq 75\%$ correct answers, which was considered to be a sufficient level of knowledge). All the questions, which summarize the important elements of the legislation, were considered equal in importance in supporting patients' rights. Subscores for each section of the questionnaire were also defined, with the following thresholds for the endpoint: ≥ 6 correct answers (out of 8) for the "surrogate decision-maker" section, ≥ 6 out of 8 for the "advance directives" section, and 2 out of 2 for the "end-of-life decision-making" section.

2.3. Statistical analysis

Questionnaires with a large amount of missing data (i.e. a total of more than six missing items from at least two different sections of the questionnaire) were excluded from the analysis. (Supplemental Figure A.1).

We first described the population; categorical variables were quoted as number (percentage), and quantitative variables were quoted as mean \pm standard deviation or median [interquartile range (IQR)], as appropriate. The characteristics of participants included in the analysis and those excluded were compared. We next analyzed the numbers of correct answers in the various sections of the questionnaire as the percentage [95% confidence interval (CI)].

To assess the relationship between the healthcare professionals' characteristics and the primary endpoint (i.e. a good level of knowledge about end-of-life policy), we performed univariate and multivariable logistic regression analyses adjusted for potential confounders. The threshold for statistical significance was set to $p < 0.05$. All the statistical analyses were performed with STATA software (version 13.1, StataCorp, College Station, TX, USA).

2.4. Qualitative analysis

For the open question "Describe a difficult end-of-life patient situation experienced as a health professional", we used a theme coding method adapted from the grounded theory framework [13, 14] and then characterized the profiles.

2.5. Ethics

All the procedures were in accordance with the 1964 Helsinki Declaration and its later amendments. According to French Health Public Law (CSP Article L1121-1), this type of study did not require specific informed consent or ethics committee approval.

3. Results

A total of 301 healthcare professionals were included in the final analysis (Supplemental Figure 1). The mean \pm SD age was 40.4 ± 10.2 , and the majority of the participants (73.4%) were women. The occupations were distributed as follows: 52 physicians (17.3%), 124 nursing assistants (41.2%), 5 social workers (1.7%), 13 head nurses (4.3%), 91 nurses (30.2%), 3 psychologists (1.0%), and 13 occupational therapists (4.3%). The characteristics of the study population are summarized in Table 1.

There were no significant differences between the 301 participants with complete data and the 102 participants with missing data (Supplemental Table A.1).

The results for each section of the questionnaire are summarized in Table 2; respectively 24.6% [19.7-29.5], 36.5% [31.1-42.0] and 37.5% [32.0-43.0] had sufficient knowledge regarding “surrogate decision-maker”, “advance directives”, and “decision-making at the end of life”. Overall, only 15.0% [10.9-19.0] of the respondents correctly answered at least 75% (i.e. 14 or more) of the questionnaire’s 18 questions.

In a multivariable analysis (Table 3), the only factor significantly associated with a good level of knowledge about end-of-life policy was employment in a university hospital (odds ratio [95%CI] = 4.30 [1.82-10.16], $p=0.001$). There was a non-significant trend for status as a physician (odds ratio [95%CI] = 2.23[0.92-5.39], $p=0.08$).

The themes and subthemes in answers ($n=43$) to the open question "Describe a difficult end-of-life situation experienced as a health professional" were:

1. Patient-healthcare professional relationship ($n=11$): difficulties with the family ($n=9$), a personal relationship with the patient ($n=1$), religion ($n=1$)
2. Pain ($n=11$): perception of the patient's pain by healthcare professionals ($n=5$), no or poor pain management ($n=5$), a long end of life ($n=2$)
3. Relationships between healthcare professionals ($n=7$)
4. Physiological complications ($n=5$): deterioration in general status ($n=3$), organ dysfunction ($n=2$)
5. Mental health/wellness ($n=5$): the patient’s anxiety or fear ($n=3$), the patient’s social isolation ($n=2$)
6. Other ($n=1$)
7. No experience or no memory of an experience ($n=7$): no experience ($n=6$), no memory ($n=1$)

Some quotes were related to several themes or subthemes. All quotations are detailed in Table 4. Interestingly, knowledge on end of life legal framework were never mentioned as difficult end-of-life experience. In all theme subgroups, nearly all the subjects had poor knowledge about end-of-life legislation (patient-healthcare professional relationship: 10/11 (90.9%); pain: 11/11 (100%); relationships between healthcare professionals: 7/7 (100%); physiological complications: 5/5 (100%); mental health/wellness: 4/5 (80%). Regarding characteristics of these subgroups, the group “pain” comprised 90% non-physicians, the group “relationships between healthcare professionals” 85.7%, the group “physiological complications” 80.0% whereas the group “patient-healthcare professional relationship” comprised 54.5% non-physicians. Subjects with the longest experience in geriatric setting (>10 years) were 45.5 % in the group “pain” and 72.8% in the group “patient-healthcare professional relationship”.

4. Discussion and Conclusion

4.1. Discussion

Our study of healthcare professionals in geriatrics services revealed a low level of knowledge regarding advance directives and the surrogate decision-maker for older patients in end-of-life situations. Indeed; only 15% of the healthcare professionals correctly answered at least 75% of the 18 questions on patients' rights. Our results also showed that a good level of knowledge on end-of-life policy was significantly associated with working in a university hospital; there was a non-significant trend for status as a physician.

Working in a community hospital vs. a teaching hospital may influence practices concerning end-of-life care. Keenan et al. found that physicians working in teaching hospitals were more likely to have initiated end-of-life care than physicians in community hospitals (81% vs 61%, respectively) [15]. There are several possible explanations for better knowledge of this topic among physicians in university hospitals: a larger number of critically ill patients, organization into multidisciplinary medical teams, and continuing medical education (physicians are used to receiving training throughout their career).

We did not find a significant association with attendance at a course on end-of-life rights; this might be explained by the fact that most training is on technical issues in supportive care, rather than policy.

4.1.1. The surrogate decision-maker

In France, most healthcare professionals are aware of the concept of the surrogate decision-maker [16]. However, we observed a lack of knowledge regarding the legislation at the time of study (only 24.6% with good level of knowledge). It is likely that an even lower proportion of patients designate a healthcare surrogate. For instance, Paillaud *et al.*'s recent cross-sectional study of hospitalized patients with cancer found that only 15% had designated a healthcare surrogate [17]. The low rate may be due to poor implementation of this legal provision in healthcare institutions, despite the fact that the great majority of the general public are aware of the principle. Silveira *et al.* reported that the designation of a surrogate decision-maker is important because 29.8% of elderly patients faced with end-of-life decisions were unable to do so themselves [18]. The proportion of patients having appointed a surrogate decision-maker differs between countries [19].

Our findings suggest that healthcare professionals in charge of elderly patients are still not aware of the surrogate's role and missions. For example, 55.2% of the participants thought that the contact person noted in a patient's records was necessarily the surrogate which is in line with Le Saux et al. [20], and 64.7% thought that the surrogate was involved in discharge planning. This may be due to the social isolation and loneliness of the aged patients; Ferrand *et al.* reported that many elderly patients' relatives are not present at the bedside [21]. The lack of social interactions for most patients in geriatric wards might explain why the contact person noted in a patient's records would be considered as the surrogate. Furthermore, it has been reported that most inpatients in geriatric wards have low cognitive abilities [22]. This obliges healthcare staff to ask the patient's family members or friends about decision-making in end-of-life care, and leads to confusion between relatives and surrogate decision-makers.

4.1.2. Advance directives

Only one third of the participants in our study correctly answered at least 6 questions in the "advance directives" section of the questionnaire. These findings confirmed the literature data on the poor level of knowledge about legislation current at the time of the study [8, 9, 23]. A few studies published over the last few years have suggested that a lack of awareness of the need for advance directives remains a major reason for patients not making them [24]. Thus, Rao et al. found that the frequency of advance directives was higher among patients who knew that they had end-of-life concerns (27.4%) and those who knew that they did not have end-of-life concerns (29.9%) [24].

While nearly half of the participants in our study thought that patients were obliged by law to write advance directives, the great majority of the participants (90%) were aware that advance directives are useful for critical phases of illness. Over the last 5 years, advance care planning has been a public issue in France, and has been promoted in order to implement end-of-life care and improve quality of life for dying patients [4, 5, 25]. The most recent Patient Rights Act (enacted in 2016 - and thus not studied here) has facilitated the nationwide dissemination of the concept of advance directives [6].

4.1.3. Decision-making at the end of life

Almost a third of the participants thought that the family's opinion prevailed over the medical team's decision to apply an end-of-life clinical protocol (it does not). This might be due to the perception that the family's choice would be closer to the patient's wishes.

4.1.4. Difficult end-of-life situations

One difficulty reported by the surveyed healthcare professionals in our study was the poor quality of the communication with the patient's family; this was also found in Hanson et al.'s interviews with patients' families [26]. The families had recommendations for improving end-of-life care for older patients; 44% of the family members wanted better communication with physicians [26]. Our results also highlighted sometimes poor communication between physicians and nurses, as also observed by Puntillo et al. [27]. Even though the question about difficult end-of-life experience was at the end of the questionnaire, which may lead to a measurement bias, none of the subject stated a difficult end-of-life experience related to legislation knowledge which emphasizes the fact that poor knowledge was not considered difficult for healthcare professionals. Regarding characteristics of these subgroups, pain could be difficult to deal with for non-physicians as they are in the front lines for treatment of pain whereas they do not prescribe medications. The group "relationships between healthcare professionals" mainly comprised non-physicians who think they were not listened to enough by physicians with regard to the decision making. Conversely, the group "patient-healthcare professional relationship" comprised non-physicians and also physicians suggesting all staff could be affected by patient-healthcare relationship. Subjects with long experience in geriatric setting seemed to be more affected by patient-healthcare professional relationship rather than pain, which relates to technical issues that experienced professionals seemed to manage with more easily than human relations issues.

4.1.5. Strengths and limitations

The present study had a number of strengths. Firstly, it was performed in the units where elderly patients receive end-of-life care. Secondly, our sample size yielded a sufficient degree of statistical power, with narrow confidence intervals for our estimates. Thirdly, our study sample was representative because we sampled the various categories of healthcare professionals in proportion to their presence in geriatric wards. And, because in France, the decision making results from a collegiate decision after a multidisciplinary meeting where all health care professionals can give their opinions, this was very important not to have only physicians in our sample but also other health care professionals who take part in the care of the patients and the decision making. Indeed, the nursing assistants and nurses are in front line in the care of the patients and so also have their say in the decision making. And they also

may be the surrogate decision maker's first or only contact. So a lack of knowledge among any health care professional may have consequences for the patient.

Our study also had several limitations. Firstly, our study did not look at whether the patients being cared for by the study participants had actually designated a surrogate decision-maker or had given advance directives during the study period; we decided to first focus on the healthcare professionals' point of view. In the future, we shall study patient-related determinants of the lack of implementation of these legislative provisions. Secondly, we did not address aspects of the most recent Patients' Rights Act (passed by the French Parliament in February 2016) because our study was performed before that date. However, the correct answers to all of the questionnaire questions would have been the same after the 2016 new legislation. But health care professionals' knowledge could have been better because of the publicity surrounding the new law.

4.2. Conclusion

Our survey of staff working in geriatric care highlighted the poor overall level of knowledge about patients' rights at the end of life, healthcare surrogates, and advance directives – emphasizing the need for additional professional education. In 2017, all the establishments in the Paris Public Hospitals Group (including the three hospitals involved in the present study) started to organize training courses with a view to improving the implementation of the Patients' Rights Act in routine clinical practice. However, geriatric units caring for patients with impaired decision-making abilities (due to dementia, for example) may still need to deal with end-of-life issues. Our results raise the question of how the legislation is applied in this fragile group of patients, and also highlight the need to take the involvement of caregivers into account – a situation that has yet to be explored.

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Table 1: Characteristics of the study population (N= 301)

Variable	n (%)
Type of hospital*	
General hospital	201 (66.8)
University hospital	100 (33.2)
Type of unit[‡]	
Long-term care unit	69 (22.9)
Subacute care and rehabilitation units	178 (59.1)
Acute care unit	54 (18.0)
Occupation	
Not a physician	249 (82.7)
Physician	52 (17.3)
Female sex	221 (73.4)
Age (years)	
≤ 30	64 (21.3)
[30-40]	94 (31.2)
[41-50]	81 (26.9)
>50	62 (20.6)
Day shift	226 (75.1)
Attended a course on end-of-life care	122 (40.5)
Number of years of practice in geriatrics (years)	
[1-3]	57 (18.9)
[4-10]	109 (36.2)
[11-20]	68 (22.6)
>20	67 (22.3)
Number of end-of-life patient situations experienced in the career[§]	
[0-5]	65 (21.7)
[6-15]	88 (29.3)
[16-30]	84 (28.0)
>30	63 (21.0)

*University hospital: Charles Foix Hospital; general hospitals: Georges Clemenceau Hospital and Joffre Dupuytren Hospital

[‡]Acute care unit = acute geriatric care units and palliative care units; subacute care and rehabilitation units = oncogeriatric, gerontopsychiatry, subacute care, and rehabilitation units; long-term care unit.

[§] n=300

Table 2: Data from the questionnaire regarding surrogate decision-maker, advance directives and end-life decision making (filled out by the 301 healthcare professionals). Correct answers are given in bold type.

	n (%)
Surrogate decision-maker	
Which legislation introduced the concept of the surrogate decision-maker?	
I do not know	64 (21.3)
The 2002 Patient Rights Act (Kouchner law)	86 (28.6)
The 2005 Patients Rights Act (Leonetti Law)	151 (50.2)
Is it mandatory to give the patient information about the appointment and role of a surrogate decision-maker? *	
I do not know	31 (10.4)
No	36 (12.0)
Yes	232 (77.6)
Is the contact person necessarily the surrogate decision-maker?	
I do not know	22 (7.3)
No	113 (37.5)
Yes	166 (55.2)
Must the surrogate decision-maker be contacted if the patient's health status worsens? †	
I do not know	9 (3.0)
No	11 (3.7)
Yes	280 (93.3)
Must the surrogate decision-maker be contacted in the event of administrative problems?	
I do not know	86 (28.6)
No	67 (22.2)
Yes	148 (49.2)
Must the surrogate decision-maker be contacted when the patient is scheduled for discharge? †	
I do not know	47 (15.6)
No	59 (19.7)
Yes	194 (64.7)
Must the surrogate decision-maker be contacted with regard to making medical appointments? †	
I do not know	81 (27.0)
No	94 (31.3)
Yes	125 (41.7)
Should the surrogate decision-maker be contacted when a medical decision must be made? †	
I do not know	16 (5.3)
No	22 (7.4)
Yes	262 (87.3)
The "surrogate decision-maker" section (8 questions)	
≥ 6 correct answers	74 (24.6)

Advance directives

Which legislation introduced the concept of written advance directives?

I do not know	54 (17.9)
The 2002 Patient Rights Act (Kouchner law)	25 (8.3)
The 2005 Patients Rights Act (Leonetti Law)	222 (73.8)

Is writing of advance directives mandatory?

I do not know	66 (21.9)
No	175 (58.1)
Yes	60 (19.9)

Is it mandatory to give the patient information about advance directives?

I do not know	61 (20.2)
No	36 (12.0)
Yes	204 (67.8)

Must the medical team refer to the advance directives if the patient's health status worsens?

I do not know	24 (8)
No	6 (2)
Yes	271 (90.0)

Must the medical team refer to the advance directives in the event of administrative problems?

I do not know	109 (36.2)
No	107 (35.6)
Yes	85 (28.2)

Must the medical team refer to the advance directives when the patient is scheduled for discharge?

I do not know	98 (32.6)
No	107 (35.6)
Yes	96 (31.8)

Must the medical team refer to the advance directives with regard to making medical appointments? †

I do not know	104 (34.6)
No	101 (33.7)
Yes	95 (31.7)

Must the medical team refer to the advance directives when a medical decision must be made?

I do not know	25 (8.3)
No	11 (3.7)
Yes	265 (88.0)

The "advance directives" section (8 questions)

≥ 6 correct answers	110 (36.5)
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Decision-making at the end of life

Does the family's opinion prevail over the medical team's opinion? *

I do not know	61 (20.4)
No	144 (48.2)
Yes	94 (31.4)

Does the medical team participate in the end-of-life decisions?

I do not know	19 (6.3)
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No	66 (21.9)
Yes	216 (71.8)
The “end-of-life decision-making” section (2 questions)	
2 correct answers	113 (37.5)
Entire questionnaire (out of 18 questions)	
≥ 14 correct answers	45 (15.0)

* n=299; †n=300.

Table 3: Factors associated with a good level of knowledge (score $\geq 14/18$) about end-of-life policy among healthcare professionals, in univariate and multivariable analyses.

Variable	Univariate			Multivariable		
	OR	95% CI	p	OR	95% CI	p
Type of hospital[¥]						
General hospital	1					
University hospital	6.00	[3.01-11.95]	<0.001	4.30	[1.82-10.16]	0.001
Type of unit[‡]						
Long-term care unit	1			1		
Subacute care and rehabilitation units	2.53	[0.85-7.59]	0.097	1.30	[0.40-4.29]	0.66
Acute care unit	7.47	[2.34-23.85]	<0.001	2.74	[0.75-10.00]	0.13
Occupation						
Non-physician	1			1		
Physician	4.94	[2.46-9.90]	<0.001	2.23	[0.92-5.39]	0.08
Sex						
Male	1					
Female	0.87	[0.43-1.76]	0.70			
Work shift						
Night shift	1			1		
Day shift	3.93	[1.36-11.38]	0.01	1.74	[0.54-5.55]	0.35
Attended a course on end-of-life care						
No	1			1		
Yes	1.34	[0.71-2.54]	0.36	1.43	[0.63-3.27]	0.39
Age (years)						
≤ 30	1					
[30-40]	0.22	[0.09-0.51]	0.001			
[41-50]	0.26	[0.11-0.61]	0.002			
>50	0.22	[0.08-0.59]	0.003			
Number of years of practice in geriatrics (years)						
[1-3]	1			1		
[4-10]	0.32	[0.14-0.70]	0.005	0.50	[0.20-1.24]	0.13
[11-20]	0.29	[0.11-0.73]	0.009	0.86	[0.29-2.60]	0.79
>20	0.17	[0.06-0.51]	0.001	0.57	[0.16-2.03]	0.39
Number of end-of-life patient situations experienced in the career						
[0-5]	1					
[6-15]	0.35	[0.14-0.85]	0.02			
[16-30]	0.46	[0.20-1.08]	0.07			
>30	0.45	[0.18-1.13]	0.09			

* the overall score was defined as a binary variable: $\geq 14/18$ correct answers vs. $<14/18$ correct answers

¥ University hospital: Charles Foix Hospital; general hospitals: Georges Clemenceau Hospital and Joffre Dupuytren Hospital

‡ Acute care unit = acute geriatric care units and palliative care units; subacute care and rehabilitation units = oncogeriatric, gerontopsychiatry, subacute care, and rehabilitation units; long-term care unit.

Table 4: Difficult end-of-life patient situations experienced as described by health professionals: quotes by themes and subthemes (n=43)

Theme and subtheme	Quotes
Patient - Healthcare professional relationship	
<i>Difficulties with the family</i>	<p>“A patient at the end of her life, the family couldn't accept it. The patient had an endoscopic percutaneous gastrostomy, her condition worsened, she had difficulty swallowing. The family did not understand why the endoscopic percutaneous gastrostomy was removed. Previously she had a feeding bag (prescribed to “satisfy” the family”). The family finally accepted its removal. She died soon afterwards. Another end of life patient had difficulty swallowing, which was worsened by aspiration pneumonias. The family had difficulties waiting for the feeding to stop. They were told we would try to stop in case of difficulty swallowing, in order to reassure them. The patient was transferred in palliative care, referred by the doctor after request by the family.”</p> <p>“My difficult end-of-life experience took place in a hospital with the children. The very sick little patients of the heart sometimes died. It was very traumatic because the parents, although warned of the precarious state of their children who had serious heart diseases, could only be traumatized by the death of their children. Some mothers dragged themselves on the ground crying because they no longer had the strength to move forward because the news decimated them so much, that we caregivers had a hard time comforting them because we were sad for them. It reflected on my life. As soon as my child became ill, I dramatized the event and worried a lot about him until he was cured. The end of life of the elderly person is easier to live with even if it remains sad (because we are very attached to our residents). As long as the person is not suffering, we accept to let them go.”</p> <p>“The management of a patient at the end of life is difficult because, in addition to the care that involves the patient, listening, the sense of reserve, i. e. without judgment, it is also necessary to take care of the family. It is a double workload, because the family sometimes blames itself, becomes demanding because it wants to show that it is not abandoning its parent, so at each visit it wants the maximum of things. For the care of people at the end of their life, training is therefore required to highlight the qualities necessary to work in palliative care.”</p> <p>“A person cured of facial cancer could not bear to be disfigured by many surgical procedures and asked to be helped to end it all. One of her sons agreed with her. The medical team was divided, so were the caregivers. The patient, after a psychiatric consultation, was diagnosed with severe depression. After many adventures, the patient is alive and undergoing antidepressant treatment. The son says he's ashamed, a nurse quit.”</p> <p>“The case of a patient who does not leave advance directives. The patient is in a comatose, painful, end-of-life condition, and the family demands an excessive or prolonged therapeutic intervention despite the contrary advice of the medical and paramedical team.”</p> <p>“End of life of a melanoma of the lower limb and whose four sons opposed the prescription of effective analgesic treatment for fear of morphine.”</p> <p>“96-year-old patient hospitalized for umpteenth cardiac decompensation with a very present family and requesting resuscitation, invasive treatments such as feeding tube even when removed by the patient. Palliative team intervention with an attempt to reconcile with the family. No advance directives paperwork signed by the patient. Difficulties in setting up, limiting, stopping treatments.”</p> <p>“Irreversible worsening of a patient's condition, the family did not adhere to care plan which was accompanying their loved one's towards end-of-life.”</p>

“Sudden worsening of the state of health of a 48-year-old female patient after 2 years of long-term care. This death occurred so brutally that the family had not accepted the death. In fact, it was not prepared in advance and the family still had hope for a cure.”

A personal relationship with the patient

“Close acquaintance who died in the service.”

Religion

“In the event of death in palliative care, in the face of religion.”

Pain

Perception of the patient's pain by healthcare professionals

“Painful moans at the end of life.”

“Painful end of life.”

“Painful end of life.”

“Painful patient at the end of life.”

“Painful end of life.”

No or poor pain management

“On pain management for services other than palliative care, the physician should listen to the requests of caregivers who are on the front lines. The strength of caregivers is that they move the patients.”

“The management of pain at the end of patients' life is not always up to what it should be (e.g. no implementation of electric syringe pump, caregivers not listened to or ignored)”

“I remember a painful experience that marked me throughout my career... A patient whose agony was very long and who for me as a caregiver was not prepared for such a psychologically difficult situation. It is true that it was in the 1980s, but I will never forget it. This poor woman would take long respiratory breaks for days, I couldn't bear to walk past her room because her agony was so hard on me. One day, the doctor arrived, it was a Saturday. I wonder if that day was not chosen for how calm the ward is on Saturdays. I heard him talking to the nurse who replied with a loud definite NO. Which surprised me a lot. He told her to prepare a drip, and that he would come back. As promised, he returned and went alone to the patient's room with a prepared syringe and then returned to the care room. The nurse was pouting. There was a heavy silence. I understood what had happened when the patient died a few moments later. I have seen many painful and unbearable situations to deal with over the past 35 years, and it continues. We don't participate in all medical decisions, I think it's a way to protect ourselves, but we're not stupid.”

“A person who gets worse and suffers and is left to suffer without relief.”

“Pain management: not always at the top.”

A long end of life

“A patient who takes a long time to die.”

“I remember a painful experience that marked me throughout my career... A patient whose agony was very long and who for me as a caregiver was not prepared for such a psychologically difficult situation. It is true that it was in the 1980s, but I will never forget it. This poor woman would take long respiratory breaks for days, I couldn't bear to walk past her room because her agony was so hard on me. One day, the doctor arrived, it was a Saturday. I wonder if that day was not chosen for how calm the ward is on Saturdays. I heard him talking to the nurse who replied with a loud definite NO. Which surprised me a lot. He told her to prepare a drip, and that he would come back. As promised, he returned and went alone to the patient's room with a prepared syringe and then returned to the care room. The nurse was pouting. There was a heavy silence. I understood what had happened when the patient died a few moments later. I have seen many painful and unbearable situations to deal with over the past 35 years, and it continues. We don't participate in all medical decisions, I think it's a way to protect ourselves, but we're not stupid.”

Relationships between healthcare professionals

“On pain management for services other than palliative care, the physician should

listen to the requests of caregivers who are on the front lines. The strength of caregivers is that they move the patients.”

“The management of pain at the end of patients' lives is not always up to what it should be (e.g. no implementation of electric syringe pump, caregivers not listened to or ignored).”

“I remember a painful experience that marked me throughout my career... A patient whose agony was very long and who for me as a caregiver was not prepared for such a psychologically difficult situation. It is true that it was in the 1980s, but I will never forget it. This poor woman would take long respiratory breaks for days, I couldn't bear to walk past her room because her agony was so hard on me. One day, the doctor arrived, it was a Saturday. I wonder if that day was not chosen for how calm the ward is on Saturdays. I heard him talking to the nurse who replied with a loud definite NO. Which surprised me a lot. He told her to prepare a drip, and that he would come back. As promised, he returned and went alone to the patient's room with a prepared syringe and then returned to the care room. The nurse was pouting. There was a heavy silence. I understood what had happened when the patient died a few moments later. I have seen many painful and unbearable situations to deal with over the past 35 years, and it continues. We don't participate in all medical decisions, I think it's a way to protect ourselves, but we're not stupid.”

“A person cured of facial cancer could not bear to be disfigured by many surgical procedures and asked to be helped to end it all. One of her sons agreed with her. The medical team was divided, so were the caregivers. The patient, after a psychiatric consultation, was diagnosed with severe depression. After many adventures, the patient is alive and undergoing antidepressant treatment. The son says he's ashamed, a nurse quit.”

“Conflicts between doctors to make the decision and management.”

“When the medical decision is not understood by the caregivers.”

“When the medical decision is not shared with the caregivers.”

Physiological complications

<i>A deterioration in general status</i>	“The body of a patient who was in a very damaged state and who was still alive despite her condition and at the end of her life.” “Odour of cancer patients.” “Funeral care for the first death.”
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<i>Organ dysfunction</i>	“In the case of an amyotrophic lateral sclerosis, the person loses autonomy until the loss of swallowing, and can no longer breathe.” “Congestions with dyspnoea.”
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Mental health/wellness

<i>The patient's anxiety or fear</i>	“To see a person at the end of their life, to feel like they are dying without being able to do anything except be there for them, to see in their eyes their fear.” “None in particular. All end of life experiences when the person remains conscious and anxious.” “Anguish of a person at the end of life (fear of dying).”
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<i>The patient's social isolation</i>	“Single person without a family at the end of life.” “Patient without kin or support”
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Other

“Disappointment of a patient transferred to another hospital”

No experience /no memory of an experience

<i>No experience</i>	“No experience.” “I haven't known any.” “No experience.” “I didn't have a difficult experience.”
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“No experience.”

“None in geriatrics.”

*No memory of
an experience**

“I can't remember.”

N=43; one patient's quote was “I don't know.” so this quote was reclassified as missing data.

*The quote “I can't remember.” which was classified as no memory of a difficult experience was grouped with no experience, considering that if the subject had no memory of a difficult experience, it meant that the subject did not have any difficult experience.