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Variation in end-of-life care and hospital palliative care among hospitals and local authorities: A preliminary contribution of big data

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Abstract

Background: Many studies explore the clinical and ethical dimensions of care at the end-of-life, but fewer use administrative data to examine individual and geographic differences, including the use of palliative care.

Aim: Provide a population-based perspective on end-of-life and hospital palliative care among local authorities and hospitals in France.

Design: Retrospective cohort study of care received by 17,928 decedents 65 and over (last 6 months of life), using the French national health insurance database

Results: 55.7% of decedents died in acute-care hospitals; 79% were hospitalized in them at least once; 11.7% were admitted at least once for hospital palliative care. Among 31 academic medical centers, intensive care unit admissions ranged from 12% to 67.4%; hospital palliative care admissions, from 2% to 30.6%. Across local authorities, for intensive care unit days and hospital palliative care admissions, the ratios between the values at the third and the first quartile were 2.4 and 1.5. The odds of admission for hospital palliative care or to an intensive care unit for more than 7 days were more than twice as high among people $\leqslant$85 years (aOR = 2.11 (1.84–2.43) and aOR = 2.59 (2.12–3.17), respectively). The odds of admission for hospital palliative care were about 25% lower ($p = 0.04$) among decedents living in local authorities with the lowest levels of education than those with the highest levels.

Conclusion: The variation we document in end-of-life and hospital palliative care across different categories of hospitals and 95 local authorities raises important questions as to what constitutes appropriate hospital use and intensity at the end-of-life.

Keywords

End-of-life, palliative care, big data, geographic variation, odds of admission

What is already known about the topic?

- Many guidelines, worldwide, have been issued for end-of-life care, including hospital palliative care.
- According to the 2014 WHO Global Atlas of Palliative Care, there is insufficient access to palliative care services, worldwide.

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What this paper adds

- How hospital administrative data can be used to improve understanding of variation in the provision of end-of-life care in advanced health care systems.
- New information on end-of-life care and hospital palliative care, among decedents (in and outside hospitals) in their last year of life, in the French healthcare system.
- New findings on significant variations with age in end-of-life care, but also among categories of French hospitals and local authorities, including those with lower levels of education.

Implications for practice, theory, or policy

- Policy makers and medical professionals should identify barriers to the use of palliative care among patients living in areas with low levels of education.
- The approach to big data analysis we present in this paper could be used to assess variation in the provision of end-of-life palliative care and to monitor the effects of interventions designed to expand its availability.

Introduction

According to the 2014 WHO Global Atlas of Palliative Care, there is insufficient access to palliative care services worldwide,[1] suggesting "an imperative of universal health coverage."[2] How can we minimize experiences that "induce pain, discomfort, and impaired function" for patients at end-of-life and "lingering regrets regarding the care received" by their surviving families?[3] Although survey data indicate that 80% of the French population would prefer to die at home, 57% died in hospitals, 12% in nursing homes, and only 25% at home in 2012.[4] Between 1987 and 2013, the number of hospital palliative care beds, in France, increased from 150 to 1412.[5] The number of home-based palliative care teams also increased, though not nearly as fast.[5] Likewise, access to palliative care mobile units and other palliative care services have increased in French nursing homes, long-term care residential facilities, and private homes.[6]

Beyond peoples' preferences for place of death, clinicians and managers have called for guidelines on how end-of-life care, including hospital palliative care, should be managed.[7] Many guidelines have been issued, worldwide,[8–13] yet there is little consensus on these issues, leading to important cross-national variations.[14] More articles have been published on ethical and clinical issues in palliative medicine than on empirical analyses of the settings in which end-of-life care actually occurs across and within nations. Only a few articles have used French national health insurance data to investigate end-of-life care.[15,16]

In the context of disagreement among professionals, differences in patient and family preferences about how to manage care at end-of-life, Wennberg et al.[17] highlighted significant area-wide variations among what are often considered the "best" academic medical centers (AMCs) in the United States. Their study of variations in the intensity of medical care at end-of-life grew out of their earlier work on small-area variations in residence-based hospital admissions,[18] which has spawned an important area of health services research around the world.[19–21] In France, with regard to end-of-life care, Wennberg et al.[17] inspired a comparison of French practices with experience in the United States drawing on many of the indicators of healthcare used in their paper. We rely on three of these indicators—the number of different physicians consulted, the number of days spent in hospitals and the number of days spent in ICUs[17,22–28]—because they reflect the intensity of care during the last 6 months of life and have previously been used in the health services research literature on end of life care. In addition we have included admissions to hospital palliative care which can be identified thanks to French data recording procedures.

In 2005, Leonetti's law, in France, established a patient's right to request withholding of treatment, relief of pain, and mechanisms for expanded use of advance directives.[29] But even before passage of this law, and over the past decade, as well, dying patients are supposed to have had, and still have, rights to receive palliative, care and avoid futile curative therapies. Nonetheless, service intensity and the circumstances of decedents in their last year of life are not well known. Fortunately, it is possible to use French hospital administrative data to improve understanding of the care people receive at end-of-life and how this varies among regions and by hospital characteristics.

In 2008, the French *Mort-à-l'Hôpital* Group studied the circumstances of death among 294 French hospitals and 2750 departments within them.[30] They focused on the last 10 days of life and the circumstances of death as assessed by the study protocol and subjective assessment of nurses participating in the study. Written protocols of end-of-life care were available in 12.2% of participating departments and only 35.1% of nurses judged the "quality" of dying and death acceptable for themselves. The criteria for this subjective assessment of nurses were: availability of a written protocol for end-of-life care, a higher ratio of nurses to patients, anticipation of death by the nurse, designation by the patient of a surrogate decision maker, a do-not-resussitate order, or treatment limitation decision in the patient's record, adequate pain control, information from family that death was imminent, the presence of family or friends at time of death and a staff meeting with the family after death.

More recently, drawing on big data from the National Health Insurance (NHI) General Fund for Salaried Workers (77% of the French population), Poulalhon et al.[31] investigated diseases and hospitalizations, including hospital palliative care, of 61% of all decedents in 2013. In the present paper, we extend this study to include a sample of all decedents, that is, those covered not only by the General Fund but also by the other two French NHI funds—those for the self- employed and the agricultural sector. We focus on variation in hospital end-of-life care among local authorities as well as among and within categories of hospitals. We investigate variation in end-of-life and hospital palliative care across France's 95 local authorities and among different kinds of acute care hospitals, focusing on regional academic medical centers (AMCs)—*centres hospitaliers universitaires* (*CHUs*)—considered the standard setters for state-of-the art medical care. Such an approach grows out of the previously cited literature on variations in medical practice to raise questions about the factors that could explain the disparities in end-of-life care and hospital palliative care.

Methods

We conducted a retrospective population-based cohort study of end-of-life and hospital palliative care, received by 17,928 decedents, 65 years and over, in their last 6 months of life, over a 5-year period (2009–2014). We were able to distinguish categories of hospitals and units within them in which they died.

The study was approved by the National Health Data Institute (registration number 139) and conducted in accordance with the Helsinki Declaration. Written consent was not required for this study.

Data

The NHI Fund's administrative data (*Système National des Données de Santé- SNDS*) cover hospital inpatient admissions and outpatient consultations, as well community-based visits in private practice.[32,33] The SNDS includes admissions from all public and private hospitals (*Programme de Médicalisation des Systèmes d'Information*—PMSI), linked with ambulatory care use. Our dataset for this study is from the 1/97th representative random sample (*Echantillon généraliste des bénéficiaires*-EGB) of insurance beneficiaries drawn from the SNDS which covers virtually the entire resident population in France.[34]

We also draw on census data on the population characteristics of local authorities from INSEE (*Institut National de la Statistique et des Etudes Economiques*). They include socio-demographic variables for each local authority (département): average monthly income for all employees, population density, and level of education. We selected these variables because previous studies[35–37] have established significant differences in use of health services based on place of residence, income and level of education.

Definitions

With respect to hospitals, our data include hospital admissions only to acute care hospitals: (1) 31 CHUs all of which are public institutions affiliated with medical schools and research faculty and cover local authorities across France; (2) 545 community public hospitals (*centres hospitaliers-CHs)*; (3) 315 private for-profit hospitals; and (4) 109 private non-profit hospitals (*établissements à but non-lucratif* (EBNL) most of which participate in public hospital services (*participant au service public hospitalier-PSPH).*

Intensive care unit (ICU) admission is determined by the presence of an ICU stay indicator (including coronary care units) in the filed claims. We identified hospital palliative care on the basis of the principal diagnosis on hospital admission coded in ICD-10 as Z515 ("Encounter for palliative care") or via the diagnosis related group 23Z02 ("Palliative care, with or without procedures"). We identified the number of different physicians, whether they were GPs or specialists, working in hospital outpatient departments or private practice, who were consulted by decedents in the 6 month period prior to their death.

Statistical analysis

We first described and compared our population of decedents between inpatients and outpatients deaths in terms of age, gender, the average number of days of hospitalization, in an ICU, the percent of decedents with an ICU stay of seven or more days, the percent admitted, at least once, to hospital palliative care, and the average number of different physicians seen—all within the last 6 months of life. We then compared these indicators in acute-care hospitals where patients died or where patients were last seen.

To study the variation of our indicators among categories of hospitals and local authorities we used measures of variation such as the interquartile ratio, and the coefficient of variation (CV) expressed as the ratio of the standard deviation to the mean. The interquartile ratio measured simply the ratio between the value of each indicator at the third quartile and this value at the first quartile.

We finally conducted two 2-level hierarchical models to account for socio-demographic factors and their variation[38] among local authorities. The dependent variable is a

Table 1. Death and end-of-life care among all 17,928 decedents (last 6 months of life).

	Number of deaths	Inpatient deaths	Outpatient deaths	p-Value
	17,928	9983 (55.7)	7945 (44.3)	
Age				<0.01
Mean ± std	83 ± 9	81 ± 8	85 ± 9	
Median (IQR)	84 (77–89)	82 (75–88)	86 (80–91)	
Age >85 (%)	7709 (43.0)	3468 (34.7)	4241 (53.4)	<0.01
Gender: female	9484 (52.9)	4864 (48.7)	4620 (58.1)	<0.01
Hospitalized (%)	14,171 (79.0)	9983 (100)	4188 (52.7)	<0.01
Number of days of hospitalization (mean ± std)	17.6 ± 23.0	22.9 ± 24.5	10.9 ± 19.0	<0.01
ICU admission at least once (%)	2744 (15.3)	2398 (24.0)	346 (4.3)	<0.01
Number of days of ICU (mean ± std)	1.4 ± 6.2	2.4 ± 7.9	0.3 ± 2.5	<0.01
ICU days ⩾7 (%)	1109 (6.2)	1018 (10.2)	91 (1.2)	<0.01
Hospital palliative care admission (%)	2096 (11.7)	1821 (18.2)	275 (3.5)	<0.01
Visit to a physician (%)	16,882 (94.2)	9471 (94.9)	7411 (93.3)	<0.01
Number of different physicians consulted	4.2 ± 4.9	4.8 ± 5.5	3.4 ± 3.9	<0.01

Std: standard deviation; IQR: interquartile range; ICU: intensive care unit.

Table 2. Summary of end-of-life care across 95 French departments where 17,928 patients died (last 6 months of life).

	Average and standard deviation	Value at the 1st quartile (a)	Value at the 3rd quartile (b)	Ratio between (b) and (a)	Coefficient of variation
Hospital admission (%)	79.2 ± 5.6	76.1	82.0	1.1	0.07
Number of days of hospitalization	17.5 ± 3.1	15.5	19.2	1.2	0.17
Intensive care unit admission at least once (%)	14.9 ± 5.3	10.9	17.9	1.6	0.36
Number of days of intensive care unit	1.4 ± 0.7	0.8	1.9	2.4	0.52
Intensive care unit days ⩾7 (%)	6.0 ± 3.0	3.7	8.0	2.2	0.50
Hospital palliative care admission (%)	11.7 ± 5.2	8.8	13.4	1.5	0.45

dummy that captures whether each individual in the database experienced at least one hospital admission with hospital palliative care or to an ICU for more than 7 days. In both models, we used the individual variables as 1st level and the variables related to the local authorities as the 2nd level. The first level therefore concerned individual variables (age: 65–85 years or >85 years, gender), and the second level socio-demographic variables (average monthly income, population density and the percentage of people without a college degree) by quartile, for each local authority.

SAS 9.4 software (SAS Institute Inc, Cary, NC) was used for all the analyses. In particular, we performed hierarchical models using the procedure GLIMMIX (Supplemental File 1).

Results

Among our sample of 17,928 decedents, 55.7% died in acute care hospitals (Table 1). Those who died in hospitals were younger ($p < 0.01$) and were less often women ($p < 0.01$) than those who died outside hospitals. In addition, within the last 6 months of life, we found that 79% of decedents were hospitalized at least once in acute care settings. They spent an average of 17.6 days in the hospital, and 1.4 days in intensive care. On average, they consulted 4.2 different physicians and 11.7% were admitted, at least once, for hospital palliative care.

Among our 17,928 decedents, we studied variation among local authorities, measured simply as the ratio between the value of each indicator at the third quartile and this value at the first quartile and with the coefficient of variation (Table 2). For hospital admissions and days spent in hospitals, these ratios are 1.1 and 1.2 with a respective CV of 0.07 and 0.17. For ICU days, the percent of decedents who spent seven or more days in ICUs, and hospital palliative care admissions, the ratios and the CV are: 2.4, 2.2, 1.5, and 0.52, 0.50, and 0.45, respectively.

Beyond these broad findings on the use of hospital care by decedents and the intensity of care across local authorities, we also studied variation among different categories of hospitals where patients died. Among inpatient deaths (N = 9,656), decedents died mostly in CHs (58.1%), 20.8% in CHUs, 14.2% in private for-profit hospitals and 7% in private nonprofit hospitals (Table 3). In comparing intensity of end-of-life care across different categories of hospitals, it is clear that CHUs provided significantly ($p < 0.01$) more days of care in ICUs (4 days) than CHs

Table 3. End-of-life care across different categories of hospitals where 9656 patients died (last 6 months of life).

	CHU	CH	Private for-profit hospitals	Private nonprofit hospitals	*p*-Value
Number of deaths	2010	5606	1367	673	
Number of days of hospitalization (mean ± std)	23.2 ± 25.5	21.0 ± 22.6	26.5 ± 28.8	27.1 ± 24.5	<0.01
Intensive care unit admission at least once (%)	37.2	20.7	21.8	16.8	<0.01
Number of days of intensive care unit (mean ± std)	4.0 ± 10.5	1.9 ± 6.7	2.4 ± 8.0	1.8 ± 6.5	<0.01
Intensive care unit days ⩾7 (%)	16.4	8.0	11.1	8.2	<0.01
Hospital palliative care admission (%)	14.6	14.7	27.6	36.6	<0.01

CHU: centre hospitalier universitaire (university academic medical center); CH: centre hospitalier (community public hospital); std: standard deviation.

Table 4. Summary of end-of-life care across 31 CHUs where 2010 patients died (last 6 months of life).

	Average and standard deviation	Value at the 1st quartile (a)	Value at the 3rd quartile (b)	Ratio between (b) and (a)	Coefficient of variation
Number of days of hospitalization	22.9 ± 5.1	17.3	27.6	1.6	0.23
Intensive care unit admission at least once (%)	34.7 ± 12.3	21.4	50.0	2.3	0.35
Number of days in intensive care unit	3.6 ± 2.1	1.6	5.5	3.4	0.59
Intensive care unit days ⩾7 (%)	15.2 ± 7.7	7.0	27.4	3.9	0.50
Hospital palliative care admission (%)	12.3 ± 7.4	3.8	22.2	5.8	0.60

(1.9) and private hospitals (for-profits-2.4; nonprofits-1.8). Likewise ($p < 0.01$), the percent of ICU days equal to or over 7 days was highest in CHUs (16.4), twice that of CHs (8.0) and private nonprofits (8.2), and higher than in private for-profit hospitals (11.1). As for hospital palliative care admissions, they were far higher ($p < 0.01$) in private hospitals (27.6% in for-profits; 36.6% in nonprofits) than in public hospitals—both CHs (14.7%) and CHUs (14.6%).

Among the 31 CHUs where patients died ($N = 2010$), the average number of inpatient days varies from 13.9 to 37.3; the percentage of decedents with an ICU admission varies from 12 to 67.4; the percent of decedents admitted at least once to hospital palliative care varies from zero, in one case, to 2.0 in another, and a high of 30.6. The coefficient of variation (Table 4) is high for hospital days (0.23), ICU admissions (0.35), percent of decedents who spent 7 days or more in ICUs (0.50), but even higher for ICU days (0.59), and admission to hospital palliative care (0.60).

Among our 17,928 decedents, the odds of admission with hospital palliative care (Table 5) are two times higher among people under the age of 85. The odds of admission are about 25% lower among decedents living in local authorities with the lowest levels of education than among those living in the local authorities with the highest levels of education. The odds of admission are higher whatever the type of hospital compared to CHU. None of the other factors we examined were statistically significant.

The odds of admission to an ICU for more than 7 days (Table 5) are almost 2.5 times higher among people under the age of 85. The odds of admission are more than 50% higher for men than women. The odds of admission are lower whatever the type of hospital compared to CHU. None of the other factors we examined were statistically significant.

Discussion

Based on our analysis of hospital use, including hospital palliative care at end-of-life (the last 6 months) in our sample of decedents, we find significant variation among categories of hospitals and local authorities in France. CHUs provide more intensive care services. The share of decedents admitted at least once for hospital palliative care is similar among CHUs and CHs where most decedents died, whereas in private hospitals admission to hospital palliative care was highest (27.6% in for-profits and 36.6% in nonprofits many of which are specialized in cancer care). Across local authorities, measured as the ratio of those in the third to the first quartile, for decedents' admissions and days spent in hospitals, these ratios are 1.1 and 1.2, with a coefficient of variation of 0.07 and 0.17; for ICU days, the percent of decedents who spent 7 days or more in ICUs, and for hospital palliative care admissions, the ratios are 2.4, 2.2, and 1.5, with a coefficient of variation of 0.52, 0.50, and 0.45.

The high levels of variation, by region and hospital category, raise concerns that end-of-life care in France fails to respond adequately to patient needs and may reflect practices that are at odds with existing guidelines and espoused values of patients and their families, inappropriately substituting the goal of caring with the goal of life extension, irrespective of quality of life.[39,40] Given the uncertainty about time-to-death, differences in physician practice styles and the preferences of patients and their

Table 5. Factors associated with admission to hospital palliative care or to ICU >7 days among all 17,928 decedents (multilevel regression).

	Admission to hospital palliative care		Admission to ICU >7 days	
	Odds ratio	Confidence interval	Odds ratio	Confidence interval
Age (ref: >85)	2.11*	1.84–2.43	2.59*	2.12–3.17
Gender (ref: woman)	1.00	0.88–1.12	1.39*	1.19–1.63
Type of hospital (ref :CHU)				
CH	1.19*	1.00–1.42	0.49*	0.40–0.60
Private for-profit hospitals	2.46*	2.02–2.99	0.68*	0.53–0.86
Private nonprofit hospitals	3.62*	2.89–4.54	0.40*	0.28–0.57
Average monthly income[1]				
Lowest quartile	0.86	0.59–1.27	0.99	0.59–1.68
Second quartile	1.11	0.78–1.56	1.02	0.64–1.63
Third quartile	0.92	0.67–1.27	0.71	0.47–1.09
Population density[1]				
Lowest quartile	0.99	0.68–1.45	0.63	0.38–1.03
Second quartile	0.83	0.58–1.17	0.60	0.38–1.002
Third quartile	0.90	0.66–1.24	0.71	0.47–1.09
Percent no diploma[1]				
Lowest quartile	1.28[1]	1.01–1.74	0.95	0.63–1.43
Second quartile	1.11	0.85–1.46	0.82	0.57–1.18
Third quartile	1.17	0.98–1.61	0.92	0.67–1.25

CHU: centre hospitalier universitaire (university academic medical center); CH: centre hospitalier (community public hospital).

[1] Ref: highest quartile.

*p-Value: 0.05.

families, the extent of variation we have uncovered raises many questions about how to manage care at end-of-life, including hospital palliative care. We highlight two important and well-documented policy issues that deserve further attention: (1) Responsiveness to patient and family values; and (2) Availability of palliative care.

Responsiveness to patient and family values

End-of-life care often fails to respond to the values of patients and their families and, in some cases, may involve the use of interventions that offer little clinical benefit.[41] Effective advance care planning helps to prepare for end-of-life care scenarios and enables patients and families to advocate for care that is consistent with their values. In addition to a better quality of life near death, end-of-life care discussions are associated with lower healthcare costs in the last week of life.[42] As we have documented in this paper and as Groff et al.[43] explain, despite ". . .consistency in end-of-life preferences, there is wide regional variation in the intensity of, expenditures on, and locations of care provided during the last 6 months of life." Although the data we present in this paper do not allow us to investigate whether the individuals in the dataset received care at the end of life that was inconsistent with their values and preferences, previous studies that suggest this is likely.[7,40,41,44–47] Furthermore, the concerns raised by the apparent mismatch between public preferences for less intensive care at the end of life and actual practice are not unique to France. Scholars commenting on end of life care in the U.S. and other countries expressed similar concerns.

Callahan[44] argues that "the culture and ethos of hospitals is biased toward aggressive care" and this works against, "the control of pain, the avoidance of unnecessary diagnostic and treatment procedures, well-coordinated care, and family satisfaction." High hospitalization rates and number of days in ICUs are, in Callahan's view, evidence that the goals of medicine are often at odds with the value of caring. He notes, for example, that "the technical skills they [medical professionals] deploy are impersonal, directed to organ and system failures, to the particularities of human suffering. . .the enterprise itself is so decisively oriented toward cure, toward aggressive action, toward mastery of the body. That bias pushes, and must push care to the side. Care will only become central if, and when, medicine shifts its goals and ends."[40] We should not conflate limiting aggressive intervention at the end-of-life with abandonment or a failure to care for patients. On the contrary, intensive care of this sort gets in the way of genuine caring.[40,41]

The idea that end-of-life care is often marked by excessive and inappropriate care use is broadly shared.[7] As we noted at the outset, French surveys find that most people express a preference for dying at home, but most people die in hospitals.[45] Within hospitals, there are concerns that medical staffs are inadequately attentive to the preferences of older patients. A survey of over 2000 patients 80 years and over, with decision making capacity, found that most are not consulted before admission to ICUs.[46] Although Le Guen et al.[46] provide no evidence that older patients objected to placement in the ICU, they argue that the routine failure to seek patient input is inconsistent with international guidelines and French law and demonstrate a lack of respect for the autonomy of these patients among French physicians. They also note variation in practice by hospitals, but could not determine whether it reflected differences in institutional policies and training or individual physician practice. Based on our analysis, it is clear that it reflects both the characteristics of hospital institutions as well as those of local authorities in which they operate.

In the United States, over the past few decades, far more than in France, policy makers and advocates have emphasized the use of legal documents to improve the responsiveness of the health care system to patient preferences, but the results have been disappointing.[44] Although the use of written advance directives is associated with lower rates of feeding tube insertions,[47] few adults in the U.S. have some form of advance directive and even when people complete these legal documents, their physicians often don't know about them. Furthermore, advance directives usually fail to provide sufficient instructions.

Availability of palliative care

Despite the growth in availability of palliative care, in France, recent studies suggest that supply is still inadequate to meet the growing need. For example, a nationwide study of patients with metastatic melanoma found a high prevalence of aggressive cancer care use during the last 3 months of life.[48] The palliative care needs of these patients were assessed in more than 80% of cases, but only 17% died in a palliative care unit. As we have found in this study, decedents who lived in local authorities with lower levels of education are less likely to be admitted to a palliative care unit. This finding is consistent with a large body of literature indicating that people with lower levels of education are less likely to complete advance directives.[49] If this reflects a limited understanding of end-of-life options on the part of people with lower levels of education, it may be useful to redesign relevant materials so that they are easier to understand.[50] On the other hand, because our measure of education is ecological, it is possible that this finding reflects an inequitable distribution of palliative care at the end-of-life. These findings are consistent with a multi-country study of end-of-life care among patients who died from one of 10 underlying conditions (including metastatic cancer and nine other life-limiting illnesses) often used to identify patients in need of palliative care.[51] Moreover they are consistent with the call for greater availability of palliative care.[5,46,47,51,52] Future research should investigate the relative contribution of these factors to the relationship between education and use of palliative care. If this relationship is driven primarily by awareness, policy makers should place a greater emphasis on educational efforts. If, however, this reflects availability, policies need to focus primarily on addressing structural inequities.

Limitations

A limitation in the variation we document among CHUs is the lack of adjustment for severity of illness among patients. But as Wennberg et al.[17] have noted, patients in the last 6 months of life are all severely ill, so the high level of variation we document is striking. Another limitation of our study is that we did not have access to the palliative care services that patients may have obtained in rehabilitation units, hospital-at-home services and nursing homes. Similarly, we do not have access to other health care services that patients may have received on an ambulatory care basis prior to their hospital admission. We also do not have access to the availability of palliative care for the different local authorities included in the study (availability is only available regionally). Moreover, as we used administrative data, we do not know what patient and families wanted concerning their end-of-life and palliative care. Also, our identification of hospital palliative care stays only includes those where patients spent more time than in other acute services. Finally, when interpreting our findings on the impact of lower educational levels on use of hospital palliative care, it is important to note that since we do not have educational information at the individual-level this may reflect a possible ecological fallacy.

Conclusion

We have shed more light on the care pathways French decedents have followed in the 6 months prior to death. Analysis of this kind has been conducted frequently in the U.S., but there is much less information about care at the end-of-life in France. Based on our analysis, we suggest that policy makers, in France, consider integrating community-based palliative care with hospital services rather than keeping the hospital and community roles as separate as they appear today. If France adopts interventions designed to expand the availability of palliative care, it could use the approach to big data analysis we present in this paper to monitor its effects.

Findings from France can provide useful lessons for policy makers in other countries with national health insurance systems that rely on a mix of public and private hospitals for the delivery of care. The significant variation among categories of hospitals and local authorities, which we have documented, exposes the gap between suggested guidelines, patient and family preferences and actual practice. Research on the entire SNDS database for more recent years and taking into account all stays in hospital palliative care would be useful. Comparable analysis could be replicated in other countries because most countries with national health systems have the infrastructure for routinely collected electronic health data. We recommend that future work include a multi-country comparison of regional variation in hospital care at the end of life. Such a comparison would allow policy makers assess whether the variation in care in their country is out of line with international standards and would also allow them to better understand the degree to which their unique system characteristics are contributing to existing variation in care.

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Research ethics and patient consent

This study was approved by the National Health Data Institute (registration number 139) and conducted in accordance with the Helsinki Declaration. Written consent was not required for this study.

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Data management and sharing

The EGB data are from the National Health Insurance Fund (CNAM), which extracts these data from the "National System of Health Data" (SNDS database). We are not allowed to transmit these data. These confidential data are available from the National Health Insurance Fund for researchers who meet the criteria for access.
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Supplemental material

Supplemental material for this article is available online.

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