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# Is Individual Educational Level Related to End-of-Life Care Use? Results from a Nationwide Retrospective Cohort Study in Belgium

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#### **Abstract**

*Background:* Educational level has repeatedly been identified as an important determinant of access to health care, but little is known about its influence on end-of-life care use.

*Objectives:* To examine the relationship between individual educational attainment and end-of-life care use and to assess the importance of individual educational attainment in explaining differential end-of-life care use.

**Research Design:** A retrospective cohort study via a nationwide sentinel network of general practitioners (GPs; SENTI-MELC Study) provided data on end-of-life care utilization. Multilevel analysis was used to model the association between educational level and health care use, adjusting for individual and contextual confounders based upon Andersen's behavioral model of health services use.

Subjects: A Belgian nationwide representative sample of people who died not suddenly in 2005–2007.

**Results:** In comparison to their less educated counterparts, higher educated people equally often had a palliative treatment goal but more often used multidisciplinary palliative care services (odds ratios [OR] for lower secondary education 1.28 [1.04–1.59] and for higher [secondary] education: 1.31 [1.02–1.68]), moved between care settings more frequently (OR: 1.68 [1.13–2.48] for lower secondary education and 1.51 [0.93–2.48] for higher [secondary] education) and had more contacts with the GP in the final 3 months of life.

*Conclusions:* Less well-educated people appear to be disadvantaged in terms of access to specialist palliative care services, and GP contacts at the end of life, suggesting a need for empowerment of less well-educated terminally ill people regarding specialist palliative and general end-of-life care use.

# Introduction

The principle of equitable distribution of health care and the commitment not only to pursuing the efficient delivery of high-quality medical care but also to ensuring equitable access to that care is widely acknowledged in individual countries, by international organizations such as OECD and supranational institutions such as the European Union. <sup>1-3</sup> Equitable access is often defined as horizontal equity ("people in equal need are treated equally") and, since access in itself is hard to measure, it is frequently conceptualized as need-adjusted health care use. <sup>4</sup> Differential health care use can be due to differences in the patient's health care seeking behavior and/or differential treatment by the health

care system. Both mechanisms are potentially influenced by the patient's educational attainment, partly via its mediator "health literacy" (defined as "the degree to which individuals have the capacity to obtain, process and understand basic health information and services needed to make appropriate health decisions").<sup>5–11</sup>

End-of-life care can be considered as a combination of general health care and (specialist) multidisciplinary palliative care, the latter skilled and experienced in specific aspects of health problems at the end of the life. Although socioeconomic inequalities in access to end-of-life care have been studied before, most studies have a limited scope (e.g., specific patient diagnosis group, small geographical areas), resulting in equivocal findings.<sup>12–20</sup> Differential end-of-life care use according to

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educational attainment in particular has hardly been studied until now.

In Belgium, the conditions for equitable access in end-oflife care are theoretically in place since Belgian health policy has provided a legal, financial and structural basis to avoid differential end-of-life care use. The Law on Palliative Care (2002), the Law on Patients' Rights (2002), and the laws regarding the right to take palliative care leave stress the importance of equal access, entitle every patient to benefit from palliative care, enable the vast majority of the population to take leave from work to care for a terminally ill relative and provide the palliative care facilities with structural funding. 21,22 Financial benefits help cover the costs of palliative medication, materials for comfort care, general comfort aid, and fees in primary care that are not covered by the compulsory health insurance, and visits of multidisciplinary palliative home care teams are free of charge for the patient. The division of the country into palliative care regions with palliative networks coordinating the multidisciplinary palliative care service at regional level, ensures the presence of at least one palliative home care support team as well as a few (mostly in-hospital) palliative care units at close proximity to the patient's residence. Moreover all Belgian hospitals and most rest and nursing homes have a palliative support team at their disposal.<sup>23</sup>

However, the question remains to what extent this egalitarian policy results in actual equitable use of end-of-life care, i.e., whether people with low health literacy/educational attainment are restricted in their use of end-of-life care or are treated differently by the health care system. Therefore, this article tackles the research question whether there is a link between individual educational attainment and end-of-life care use. The hypothesis or expectation is that, given the egalitarian policy, lower educated people have the same palliative treatment goal and the same frequency of multidisciplinary palliative care services use, of transitions between end-of-life care settings and of primary care contacts as higher educated people. Andersen's behavioral model of health services use is hereby used as a conceptual framework for the study of equitable access.

# Methods

# Design

The SENTI-MELC study, a nationwide retrospective cohort study, gathers patient-based information on end-of-life care via the national Belgian Sentinel Network of General Practitioners, resulting in a sample clustered by general practioners (GPs). <sup>24–27</sup>

# Data

The network consists of GPs who register weekly, using standardized registration forms, data on selected health problems. The GPs are representative for all Belgian GPs in terms of age, gender, and geographical distribution. The study referral population is the total Belgian population and, based on their annual number of patient contacts, the GPs participating in the network are estimated to cover 1.5% (or 150,000 inhabitants) of that total Belgian population.<sup>28</sup>

# Subjects

From January 1, 2005 until December 31, 2007, the GPs registered the death of every patient, aged 1 year or older,

within their practice. Both deaths certified by the GPs and deaths about which they were informed of afterwards were included. To prevent recall bias the physicians were instructed to register immediately after being informed of the patient's death. GPs used their patient records and all information they received from other medical services and physicians to complete the registration forms. In this study only data from people who, according to the GP, did not die "suddenly and totally unexpectedly" were taken into account, in order to focus on patients who were theoretically able to receive terminal care.

#### Measures

The registration form collected among others, information on sociodemographic data, general treatment goal and specific treatments, use of multidisciplinary palliative care services, transitions between end-of-life care settings, and caregivers involved. All data referred to the last 3 months of the patient's life.

In this study, educational level was categorized into (1) primary or lower, (2) lower secondary, and (3) higher secondary/higher education. Although based on socioeconomic characteristics of the individual patients and thus more valid than the majority of research studies at general practice or primary care provider level that use ecological deprivation measures because of financial and ethical constraints of accessing individual socioeconomic data,<sup>29</sup> the educational level was only assessed by the GP and may therefore lack validity.

End-of-life-care was operationalized in four ways: (1) having a palliative treatment goal, (2) use of multidisciplinary palliative care services, (3) number of care setting transitions, and (4) frequency of patient-GP contacts. For the first two outcomes, only data for 2005 and 2006 were available and for the latter two data for 2005–2007.

The main treatment goal as judged by the GP was measured at three periods of time (months 2 and 3 prior to death, weeks 2–4 prior to death and the last week of life) via the generic question, "What was the main goal of this patient's treatment?" (answering categories: "cure," "prolonging life," and "comfort/palliation"). In this study, all patients for whom the category "comfort/palliation" was checked at least once were considered having had a palliative treatment goal at some point during the last 3 months of their life.

All patients who at some point in the final 3 months used a multidisciplinary palliative home care team, a palliative support team in a care home or in a hospital, or resided in an inpatient palliative care unit or visited a palliative day care center were considered to have used multidisciplinary palliative care services

Each relocation between care settings (home, rest and nursing home, hospital and inpatient palliative care unit) was counted as a care setting transition. A total number of transitions in the final 3 months of life exceeding 2 was considered to be high.

The number of GP contacts in the final 3 months included both home (or hospital) visits and consultations.

# Conceptual model

Andersen's behavioral model of health services use provides a conceptual framework to study equitable access. The model is based on the idea that understanding health services

use is best accomplished by focusing on contextual and individual determinants and process of care, and encompasses predisposing, enabling and need factors at both individual and contextual level. Andersen defines equitable access to health services as "...occurring when predisposing demographic and need variables account for most of the variance in utilization, whereas inequitable access occurs when social structure, health beliefs, and enabling resources determine who gets medical care..."<sup>30</sup>

In line with Andersen's model, the association between end-of-life care use and educational level was further adjusted for individual and GP-related variables. Independent variables at the individual level included predisposing demographic (age, gender) and social variables (living at home/ care home, living alone); enabling factors (the GP's estimation of the financial status), and need factors (the underlying cause of death serves as a proxy for diagnosis and medical need and the place of death was considered to be a proxy for need of GP contacts in the final days). At the contextual level, there was adjustment for the predisposing demographic factor 'region', the enabling factor "urbanization level" and for characteristics of the GP (age, gender, region or language, size of the practice, solo/group practice and whether there was a trainee in the practice) that can be considered as enabling organizational factors. In 19 practices more than one GP registered cases and there age and gender of the longest participating GP was taken.

# Analysis

The bivariate association between educational level and the binary outcome measures main treatment goal, high number of care setting transitions, and use of multidisciplinary palliative care services was tested by means of a Fisher's exact test (categorical variables with any cell size less than 10) or  $\chi^2$  test (other categorical variables). To test the relationship between educational level and number of GP contacts the Kruskal-Wallis equality-of-populations rank test was used.

For each outcome, a multivariable hierarchical model was fitted, in order to study the association between end-of-life care use and individual educational level, adjusting for both individual and contextual variables and taking into account the clustered sampling design. The binary outcome measures main treatment goal, use of multidisciplinary palliative care services and high number of care setting transitions were analyzed via logistic regression models and the continuous outcome measure intensity of GP contacts was analyzed by means of linear models. Each time, first a generalized estimating equations (GEE) model (taking into account the dependence among patients nested within the same GP and assuming a compound symmetric correlation structure) was fitted in order to obtain odds ratios that are interpretable at the population level.

Statistical data analysis was carried out in SPSS 16.0 (SPSS Inc., Chicago, IL) and STATA 10 (StataCorp, College Station, TX).

# **Results**

# Sample

In the period 2005–2007, in total 188 GPs provided data on 2445 patients dying not suddenly and in the subsample of

2005–2006 184 GPs registered data on 1690 patients. The basic characteristics of the sample of not suddenly dying patients are shown in Table 1.

# Association between end-of-life care use and educational level

We found no bivariate relationship between the patient's educational level and the main treatment goal in the last three months of life, but people who had at received no more than primary education used multidisciplinary palliative care services less frequently, were less likely to experience more than 2 care setting movements and had fewer GP contacts in the last 3 months of their lives (Table 2).

These results still held when adjusting for individual and contextual variables that also have the potential to influence health care use. Although patients with a different educational level did not have a different treatment goal in the last three months of life, people who had received more than just primary education were 1.3 times more likely to use multidisciplinary palliative care and 1.5 to 1.7 times more likely to move between care settings more than twice. Moreover, not suddenly deceased patients with more than primary education had 1 GP contact more in the last 3 months than less educated people (Table 3).

#### Discussion

The basic hypothesis of the study was that lower educated people have the same palliative treatment goal and the same frequency of multidisciplinary palliative care services use, of transitions between end-of-life care settings and of primary care contacts as higher educated people. However, notwithstanding the egalitarian health policy regarding end-of-life care in Belgium and in spite of having the same main treatment goal in the final three months of life, lower educated people with a life threatening disease receive multidisciplinary palliative care services less frequently, move between care settings less frequently and have fewer contacts with the general practitioner than better educated people. Since education is a predisposing social variable, certain aspects of end-of-life care use in Belgium are thus not entirely equitable. Moreover, the findings are not quite internally consistent as some outcome measures suggest less educated people are provided with lower quality of end-of life care, but another measure (lower number of health care setting transitions) suggests the opposite.

Treatment goal depends partly on the decision of medical caregivers and the patient's preferences. Although the latter could be related to social structure (other studies showed that patients experiencing financial problems are more likely to prefer comfort care over life-extending care, <sup>31</sup> or that people with low health literacy are more likely to prefer aggressive treatments at the end of life<sup>32</sup>), educational level of the patient did not affect treatment goal here. In comparison with the other three aspects of end-of-life care studied here, treatment goal may be decided relatively more on clinical grounds and less be subject to patient preferences. Moreover, this study looks at treatment goal as evaluated by the GP and therefore may take less into account the actual preferences of the patient.

Notwithstanding the equality in treatment goal, the results of this study in a representative sample of terminally ill patients suggest inequitable use of multidisciplinary palliative care 1138 BOSSUYT ET AL.

Table 1. Characteristics of the Sample of Patients Dying not Suddenly, Belgium, 2005–2007

· · · ·	All deaths	
Total number of cases	N 2445	% 100
Independent variables		
Education level patient		
Primary or lower	950	39
Lower secondary /bigher education	637 591	26 24
Higher secondary/higher education Missing data	267	11
GP's estimation of the patient's financial status <sup>a</sup>	207	11
Low	474	28
Average	859	51
High	331	20
Missing data	26	2
Gender of patient		
Female	1264	52
Male	1181	48
Age group of patient	210	12
1–64 yrs 65–84	319 1306	13 53
85 +	790	32
Missing data	30	1
Place of death		
Home	587	24
Care home	642	26
Hospital	958	39
Palliative care unit	254	10
Missing data	4	0
Usual place of residence patient	4.440	
Home	1640	67
Care home or other	767 38	31
Missing data	30	_
Living alone <sup>a</sup> Alone	315	19
With others	1373	81
Missing data	2	0
Cause of death		
Cardiovascular diseases (except stroke)	367	15
Malignancies	1028	42
Respiratory diseases	222	9
Diseases nervous system	105	4
Stroke Other	171 532	7 22
Missing data	20	1
Level of urbanization of patients'	20	-
place of residence		
Urban	1341	55
Rural	1099	45
Missing data	5	0
Region GP		
Flanders region	1530	63
Walloon region	731	30
Brussels region	184	8
Language GP	Ω24	20
French speaking	924 1521	38 62
Dutch speaking	1941	02
Type of practice	773	32
Group practice Solo practice	1645	67
Missing data	27	1
U		

Table 1. (Continued)

	All deaths	
	N	%
Total number of cases	2445	100
Gender of GP		
Woman	479	20
Man	1960	80
Missing data	6	0
Age group of GP		
<40 yrs	108	4
40–59 yrs	1992	81
>59 yrs	339	14
Missing data	6	0
Size of practice		
Small (<975 patients)	802	33
Medium ( 975–1425 patients)	834	34
Large (>1425 patients)	809	33
Trainee in the practice		
Yes	2193	90
No	214	9
Missing data	38	2
Outcome measures  Main treatment goal in the final 3 months <sup>a</sup>		
Curative/life-prolonging	280	17
Palliative	1365	81
Missing data	45	3
Use of multidisciplinary specialist palliative services in the final 3 months		
No	1404	57
Yes	951	39
Missing data	90	4
Numbers of care setting transitions in the final 3 months <sup>a</sup>		
<3 transitions	1508	89
3 or more transitions	173	10
Missing data	9	1
Number of GP contacts in the		
final 3 months Median (IQR)	8 (5–11)	

<sup>&</sup>lt;sup>a</sup>Data available for 2005–2006 only.

according to educational attainment. Palliative care use may be better explained by cultural preferences and health beliefs rather than by material circumstances as, among cancer patients, some (but not all<sup>13</sup>) Canadian and Italian studies found higher use of palliative care services and referral to palliative home care among more educated persons, <sup>14,33</sup> whereas occupational class appears not to be related to access to or utilization of health care, specialist palliative care services, or hospice deaths. <sup>12,16–18,20</sup> As well as potentially having different preferences, more educated patients may also be more aware, eloquent and assertive when demanding additional multidisciplinary palliative care.

Movements between care settings at the very end of life should be in line with the patient's medical condition, treatment goal, and the patient's wishes. Frequent and certainly unnecessary movements between care settings at the very end

GP, general practioner; IQR, interquartile range.

Table 2. Frequency of End-of-Life Care Use in the Last Three Months of Life According to Educational Level Among Patients Dying not Suddenly, Belgium, 2005–2007

Frequency of end-of-life care in the final 3 months	Primary education or lower % <sup>a</sup>	Lower secondary % <sup>a</sup>	Higher secondary/higher education % <sup>a</sup>	p value <sup>b</sup>
	·		<u> </u>	<u> </u>
Having a palliative treatment goal <sup>c</sup>	82	83	84	0.545
Use of multidisciplinary specialist palliative services	35	42	46	< 0.001
>2 care setting transitions <sup>c</sup>	7	13	11	0.006
0	Median (IQR)	Median (IQR)	Median (IQR)	p value <sup>d</sup>
Number of GP contacts	7 (5–10)	8 (5–11)	8 (5–11)	0.019

<sup>a</sup>Column percentages.

of life may be burdensome to the patient, who also runs the risk of discontinuity of care.34 The fact that less educated people have fewer transitions than their more educated counterparts may be due to a difference in preference regarding place of care, or due to an incapacity to organize a desired transition. Although seemingly contradictory, the findings regarding multidisciplinary palliative care services use and care setting transitions could both be explained by the fact that better educated people may be more assertive when demanding additional care that cannot always be provided at home, which may result in having more care setting transitions. Another hypothesis is that not all patients have already a palliative treatment goal 3 months before death and that higher educated people could have a another pattern of care consumption in the phase preceding the palliative phase. Differentials in transitions could also be due to GP related factors, e.g., GPs may refer patients with a different educational level differently. As we corrected for place of residence, differential presence of nursing home patients (usually a lower educated group with less care setting transitions at the end of life<sup>24–27</sup>) cannot explain the findings. Further research into individual needs and preferences regarding place of care as well as into prerequisites of transitions at the very end of life is therefore warranted.

Within the general population, there is inconclusive evidence of differential volume of general practice utilization according to educational level or income. <sup>6,11,35</sup> In the final months of life, despite the provided financial measures in order to ensure an egalitarian health policy regarding utilization of general practice and in contrast with other studies on differentials according to financial status, <sup>19</sup> we found that less educated patients have significantly fewer encounters with their GP in that period, even after accounting for place of death. Possible explanations are the health literacy being too low for adequately seeking medical care in general practice, a potentially higher hospitalization rate among the less educated and higher GP care consumption in the pre-palliative phase among more educated patients.

Table 3. Multivariable Multilevel Analysis: Association Between Individual Educational Attainment and End-of-Life Care Use, Adjusted for Individual and Contextual Factors, Belgium, 2005–2007

End-of-life care in the final 3 months	Primary education or lower adjusted OR <sup>a</sup>	Lower secondary adjusted OR <sup>a</sup> (95% CI)	Higher secondary/ higher education adjusted OR <sup>a</sup> (95% CI)	p value
Having a palliative treatment goal <sup>b</sup>	1	1.12 (0.76 - 1.67)	1.07 (0.69 - 1.64)	0.846
Use of multidisciplinary specialist palliative services <sup>c</sup>	1	1.28 (1.04 - 1.59)	1.31 (1.02 - 1.68)	0.028
$\geq 2$ care setting transitions <sup>b</sup>	1	1.68 (1.13 - 2.48)	1.51 (0.93 - 2.48)	0.033
Ü	regression coefficient	regression coefficient	regression coefficient	p-value
		(95 % CI)	(95 % CI)	
Number of GP contacts <sup>d</sup>	0	0.93 (0.26 - 1.60)	1.03 (0.34 - 1.72)	0.002

<sup>&</sup>lt;sup>a</sup>Results from a marginal logistic regression model with GEE approach.

<sup>&</sup>lt;sup>b</sup>p value of Fisher's exact test for categorical variables with any cell size less than 10 and of  $\chi^2$  test for categorical variables with all cell sizes 10 and above.

<sup>&</sup>lt;sup>c</sup>Only data available for 2005–2006.

<sup>&</sup>lt;sup>d</sup>p value of the Kruskal-Wallis equality-of-populations rank test.

IQR, interquartile range; GP, general practitioner.

<sup>&</sup>lt;sup>b</sup>Adjusted for the independent variables mentioned in <sup>a</sup> and additionally for living alone and financial status.

<sup>&</sup>lt;sup>c</sup>Adjusted for the patient's educational level, gender, age group, place of residence, cause of death and level of urbanization of the place of residence) and the GP's age group, gender, region, type of practice, size of the practice and trainee in the practice) and significant two-way interaction terms.

<sup>&</sup>lt;sup>d</sup>Adjusted for the patient's educational level, gender, age group, place of death, cause of death and level of urbanization of the place of residence) and the GP's age group, gender, region, type of practice, size of the practice and trainee in the practice) and significant two-way interaction terms.

OR, odds ratio; CI, confidence interval; GEE, generalized estimating equations; GP, general practioner.

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A major strength of collecting data via the GP is that Belgian GPs can provide useful and representative information on endof-life care in the Belgian population of people dying not suddenly. General practice is highly accessible and very frequently used in Belgium.<sup>36</sup> Belgian GPs have a pivotal function in both general health care and multidisciplinary palliative home care, given their longstanding relationship with the patient and their close collaboration with palliative home care support teams. They receive and centralize the majority of the medical information on the encounters with other medical services. The representativeness of this sample regarding gender, age and cause of death was proven by comparing it with other published Belgian studies on end-of-life care. 37,38 Since the study is based on this nationwide representative sample of the population of terminally ill patients across all health care settings and diagnoses and because several aspects of health care organization have been taken into account, the results are applicable nationwide. Because of the specific Belgian context, the results cannot be generalized internationally, but the methodology can easily be applied in the many countries that also have sentinel networks of GPs and where the GP has a comparable role in health care.

Several limitations of our study should be noted. Both the independent variable educational level and the outcome measures for end-of-life care were reported by the GP and not validated against external sources in this particular study. Regarding the study outcomes, GPs may indeed have underreported information concerning care at other settings than the home situation, because this information may not have been known to them and there may be a certain degree of recall bias due to the retrospective design. The educational level may also not been be known by the GP, as this type of information may be considered out of the scope of his activities. Future research into the validity of information on the socioeconomic status of the patient reported by the GP is thus needed. However, the vast majority of the Belgian population has frequent contacts with a regular GP, including a high percentage of home visits.<sup>36</sup> Given his longstanding and close relationship with the patient and his family, the GP is in a good position of obtaining valid information on the social situation and sociodemographic background of his patients, especially in this study population of mostly elderly and chronically ill patients. Moreover, past registrations and other outcomes of this registration of end-of-life care demonstrated good external validity when comparing the results to data from external resources. 39-41 Therefore, we consider the GP a reliable information provider, which justifies the use of these data.

Another related weakness of the analysis is that data on educational level was missing in 10% of the cases. Although the multiple imputations analysis suggests that a complete case analysis is justified, this analysis is inefficient and possibly biased. Furthermore, the fact that the model leaves a lot of variance unexplained can be due to the fact that many determinants of health care use were not accounted for. An important determinant is individual need, which in this study was only substituted by its proxy measure "main diagnosis." A closely related determinant, the individual preference of the patients regarding end-of-life care, was not measured here and should be further explored in future research.

In conclusion, significant differences were found according to the patient's level of educational achievement. They

call for empowerment of less educated terminally ill people regarding specific aspects of palliative and general end-oflife care use.

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L.v.d.B., V.v.C., and L.D. were involved in the conception and design of the study. K.M., L.v.d.B., and N.B. carried out data cleaning. Statistical analyses were carried out by N.B. and critically revised by all authors. The manuscript was drafted by N.B. with critical input from all other authors. All authors read, revised and approved the final manuscript.

#### **Author Disclosure Statement**

No competing financial interests exist.

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