

## Transitions between health care settings in the final three months of life in four EU countries

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**Background:** Transitions between care settings may be related to poor quality in end-of-life care. Yet there is a lack of cross-national population-based data on transitions at the end of life. **Method:** International mortality follow-back study with data collection in Belgium, Netherlands, Italy and Spain (2009–11) via existing representative epidemiological surveillance networks of general practitioners (GPs). All general practitioners reported weekly, on a standardized registration form, every deceased patient ( $\geq 18$  years) in their practice and identified those who died 'non-suddenly'. **Results:** Among 4791 non-sudden deaths in Belgium, Netherlands, Italy and Spain, 59%, 55%, 60% and 58%, respectively, were transferred between care settings at least once in the final 3 months of life (10%, 8%, 10% and 13% in final 3 days of life); 10%, 5%, 8% and 12% were transferred three times or more ( $P < 0.001$  in multivariate analyses adjusting for country differences in age, sex, cause of death, presence of dementia). In all countries, transitions were more frequent among patients residing at home (61–73%) than among patients residing in a care home (33–40%). Three months before death 5–7% of patients were in hospital, and this rose to 27–39% on the day of death. Patient wishes were cited as the reason for the last transition before death in 27%, 39%, 9% and 6% of cases in Belgium, Netherlands, Italy and Spain, respectively ( $P < 0.001$ ). **Conclusion:** End-of-life transitions between health care settings are common across EU countries, in particular late hospitalizations for people residing at home. Frequency, type and reasons for terminal hospitalizations vary between countries.

### Introduction

Transitions between health care settings can be burdensome for patients with life-threatening illnesses and their families, particularly if they occur at the end of life and involve admissions to acute care settings.<sup>1–3</sup> There is consistent evidence that people prefer to die in their own home or home-replacing environments<sup>4–6</sup> and that being moved between settings increases the risk of fragmented care from multiple caregivers and medical errors<sup>2,3,7,8</sup> that impede the provision of high-quality palliative care.

Only a few studies have been conducted on place of care and transitions between care settings in the final 3 months of life, and none have compared different countries using analogous methodologies.<sup>1,9–14</sup> The extent to which patient or family preferences play a role when a patient moves between settings has not been well studied. Place of death as registered on death certificates—often used to compare countries<sup>13,14</sup>—does not report on the length of stay in care settings or the reasons for transitions, and often cannot differentiate between hospitals and palliative care units/hospices. However, to develop an effective public health policy on end-of-life care on a national and international level, there is a high need for standardized and cross-national monitoring of the place of care and changes in the place of care over the last months of life for all people suffering from life-limiting diseases. Cross-national comparative research has the potential to provide a better understanding of country-specific issues and issues that are shared across countries and to highlight where changes may be possible. In this context, comparisons across countries with different approaches to

long-term care and family care, such as Northern and Southern European countries, can highlight potential effects of cultural influences in the organization of end-of-life care.

The objective of this study was to use existing nationwide representative networks of general practitioners (GPs) in Belgium, the Netherlands, Spain and Italy to investigate the places of care in the final 3 months of life, the frequency of transitions between care settings and the most frequently occurring final transitions and the reasons for these transitions.

### Methods

#### Study design

Data were collected through nationwide representative networks of GPs as part of the EURO-SENTIMELC ('European Sentinel Networks Monitoring End-of-Life Care') study that was performed over 2 years, in 2009 and 2010 in Belgium, the Netherlands and Italy, and in 2010 and 2011 in Spain.<sup>15</sup>

Within Europe, general practice is highly accessible and GPs have a central coordinating role in the countries' health care systems with almost all of the population having a GP who they consult regularly. The networks of GPs are existing networks of practices/community-based physicians who monitor health problems on a continuous basis and who provide information not captured by other databases or disease registries.<sup>16,17</sup> Earlier studies have shown the added value of these primary care networks for the systematic monitoring of death and dying from a societal perspective in

Europe.<sup>6,9,10,18–22</sup> In Belgium and the Netherlands, the networks are representative for age, sex and the geographical distribution of GPs in the country. The Spanish networks cover the centre and east of Spain (Castile and Leon and the Valencian Community). In Italy, we used a new GP network that only performed registrations on end-of-life care and that was representative for all GPs in the country. The Italian physicians were stratified by health district and by age and sex of the GPs in each district. The GP networks in Belgium and the Netherlands were nationwide, covering a population of 1.8% and 0.8% in 2009 and 1.5% and 0.8% in 2010, respectively. The Italian network covered 4.3% (2009) and 2.7% (2010) of the population of nine health districts spread across the country. The population coverage of the Spanish GP network in the Valencian Community was 2.2% of the population aged 18 years or older in 2010 and 2.1% in 2011; in Castile and Leon, the respective figures were 3.8% in 2010 and 3.4% in 2011. Further information on the characteristics and operating procedures of the GP networks was reported in previous publications.<sup>15,23</sup>

### Study population

The GPs reported every deceased patient who was part of their practice (deaths certified by themselves and deaths of which they were informed afterwards) and who was aged 18 years or older at the time of death. To identify patients with life-limiting diseases or patients eligible for palliative care, we excluded all deaths that had occurred ‘suddenly and totally unexpectedly’ as judged by the GPs, following the example of other research designs.<sup>24,25</sup>

In the Netherlands, we excluded patients who died in specialist nursing homes, where residents are treated by specialist elderly care physicians and not by GPs. Previous Dutch studies showed that few nursing home residents are transferred at the end of life.<sup>11</sup> However, people in homes for elderly people in the Netherlands are treated by GPs and were therefore included in the study. Nursing home residents are cared for by an elderly care physician and nursing staff, whereas homes for elderly people are assisted living facilities without nursing care where care is primarily provided by GPs.<sup>26</sup>

A previous analysis showed no large differences between the deaths registered by the GP networks for the EURO-SENTIMELC study and representative reference populations in the four countries, with the exception of nursing home deaths in the Netherlands.<sup>15</sup> GPs can identify deaths due to cancer and non-cancer as well as dying at home and in institutional settings. GPs underreport a small number of non-sudden hospital deaths in Belgium and the Netherlands, deaths of people younger than 65 years in Belgium and deaths of women in the Netherlands. GPs in Italy and Spain presumably also underreport some sudden hospital deaths, but this assumption could not be tested due to the absence of place of death information in Spanish and Italian death certificates.<sup>15</sup>

### Data collection

GPs registered deaths continuously and on a weekly basis via a standardized registration form, over 2 consecutive years, from 1 January until 31 December (in 2009 and 2010 in Belgium, the Netherlands and Italy, and in 2010 and 2011 in Spain). In Italy and Valencia (Spain), GPs registered electronically, whereas the other networks used paper and pencil. To limit recall bias, physicians were instructed to register all deaths immediately after being informed of them. The GPs used patient records and information coming from hospitals when filling in the forms. The usual operating procedures followed by the networks were also applied to the end-of-life care registrations.<sup>15</sup>

### Measurements

The place of death and (maximally three) previous places of care up to 90 days before death were registered, as was the duration of stay (in days) in each location. We distinguished the locations home (or

with relatives), care home (including homes for older people in all four countries and nursing homes in Belgium, Italy and Spain), hospital and palliative care unit or hospice.

Transitions between health care settings were defined as moves or changes in the location of care during the last 3 months of life. If a patient was transferred to another setting at least once, the GP registered the reason for the final transition (options: wish of patient, wish of family, patient needed palliative care/treatment, patient needed curative/life-prolonging treatment, patient did not need further treatment in that setting, other (specified)); multiple responses could be indicated per patient). The individual characteristics registered for each death were date of birth, date of death, sex, cause of death and presence of dementia.

The items of the registration form were developed in Dutch and translated into French and English via forward–backward translation. The Italian and Spanish versions were developed from the English version through the same procedure. The specifics of the translations and pilot testing were reported previously.<sup>15</sup>

### Ethical approval

The study protocol was approved by the Ethical Review Board of Brussels University Hospital of the Vrije Universiteit Brussel, Belgium and by the Local Ethical Committee ‘Comitato Etico della Azienda U.S.L. n. 9 di Grosseto’ in Tuscany, Italy. As the data collection was retrospective and anonymous, no ethical approval was needed in the Netherlands or Spain according to these countries’ data protection legislation.

### Analyses

Each GP network applied its standard control measures to ensure data quality and to limit the amount of missing data. Descriptive statistics (percentages and confidence intervals) were used to describe the main outcome measures. We calculated the proportion of patients who were in a particular setting on a particular day for each of the last 90 days before death.

Differences between countries in the outcome measures were analysed using bivariate and multivariate logistic regression models, adjusted for differences in sex and age, as well as cause of death and presence of dementia, to take into account certain courses of disease that may affect patterns of transitions between care settings. All analyses were conducted with a significance level of  $\alpha = 0.05$  in IBM SPSS Statistics 20.

## Results

### Patient characteristics

In total, GPs registered 7411 deceased patients of whom 4877 (65.8%) died non-suddenly. Following the exclusion of patients whose place of death was not known or ‘elsewhere’, we studied 1596 non-sudden deaths in Belgium, 633 in the Netherlands, 1827 in Italy and 735 in Spain. Between 32% and 45% were aged 85 years or older and between 46% and 54% were female (Table 1). Cancer was the cause of death in 37–53% of cases.

### Places of care in the final 3 months of life

Figure 1a–d (Supplementary Material) depict the places of care in the last 90 days of life. In Belgium, the percentage of patients at home at 3 months before death was 57% and dropped to 23% on the day of death (34% point decrease). In the Netherlands, it decreased from 75 to 44% (31% point decrease), in Italy from 86 to 47% (39% point decrease) and in Spain from 79 to 44% (35% point decrease).

The percentage of patients in hospitals in Belgium increased from 6% at 3 months before death to 36% on the day of death. In the

**Table 1** Characteristics of the sample of people who died non-suddenly

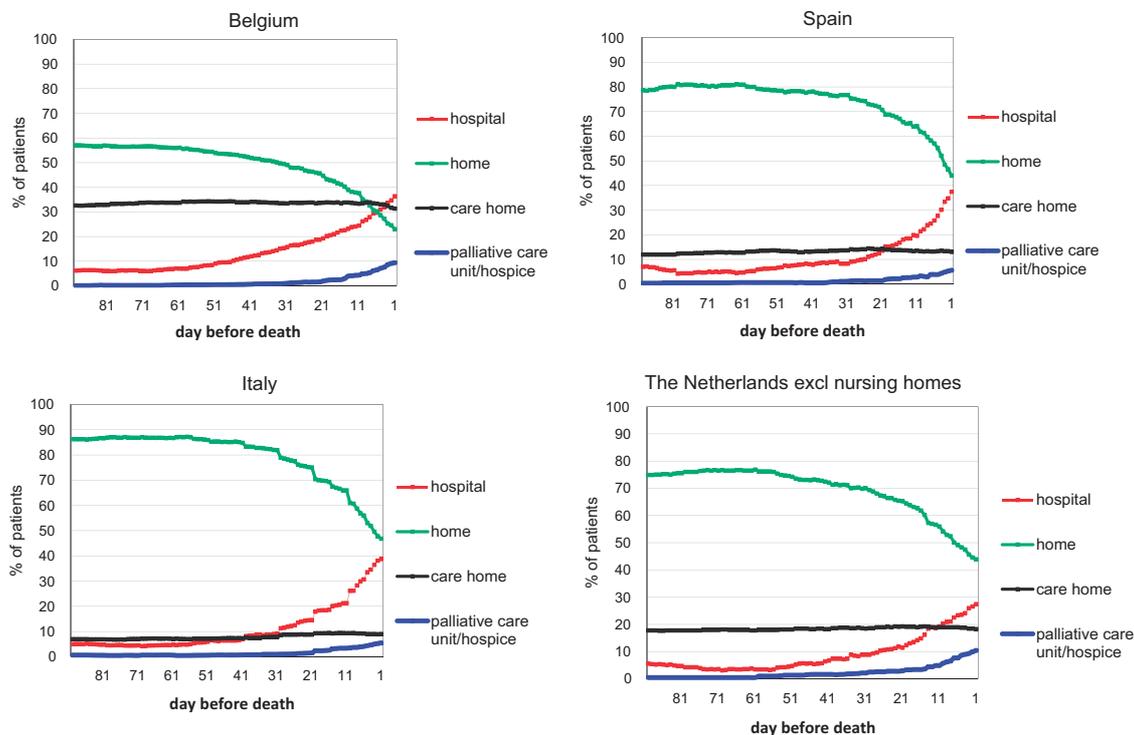
Sample characteristics <sup>a</sup>	BE (n = 1596)		NL (n = 633)		IT (n = 1827)		ES (n = 735)		P
	n	%	n	%	n	%	n	%	
Female sex	864	54.3	331	52.9	973	53.3	333	45.7	0.001 <sup>c</sup>
Age (years)									
Median (IQR)	82	73–88	79	68–87	82	73–88	84	76–89	<0.001 <sup>b</sup>
18–64	217	13.7	117	18.5	229	12.5	74	10.1	<0.001 <sup>c</sup>
65–84	750	47.3	316	49.9	857	46.9	331	45.0	
85 or more	617	39.0	200	31.6	741	40.6	330	44.9	
Cause of death									<0.001 <sup>c</sup>
Cancer	590	37.0	334	52.9	824	46.2	272	37.8	
Cardiovascular diseases	236	14.8	93	14.7	374	21.0	145	20.1	
Respiratory diseases	170	10.7	49	7.8	130	7.3	83	11.5	
Diseases of the nervous system	113	7.1	19	3.0	105	5.9	36	5.0	
Stroke	109	6.8	24	3.8	180	10.1	62	8.6	
Other	376	23.6	112	17.7	170	9.5	122	16.9	
Place of death									<0.001 <sup>c</sup>
Home	367	23.0	276	43.6	846	46.3	338	46.0	
Care home	499	31.3	114	18.0	164	9.0	86	11.7	
Hospital	580	36.3	177	28.0	716	39.2	274	37.3	
Palliative care unit/hospice	150	9.4	66	10.4	101	5.5	37	5.0	
Presence of dementia									<0.001 <sup>c</sup>
Yes, severe dementia	292	18.6	29	4.7	255	14.2	105	14.8	
Yes, mild dementia	200	12.7	50	8.2	266	14.8	110	15.5	
No	1078	68.7	532	87.1	1280	71.1	495	69.7	

Percentages are rounded and therefore may not add up to 100. BE, Belgium; NL, the Netherlands; IT, Italy; ES, Spain; IQR, inter-quartile range.

a: Missing data: age  $n = 12$  (0.3%), sex  $n = 19$  (0.4%), cause of death  $n = 63$  (1.3%), presence of dementia  $n = 99$  (2.1%).

b: Kruskal–Wallis test.

c: Pearson's chi-squared test.

**Figure 1** Places of care in the final 3 months of life of non-sudden deaths per country

Netherlands, the respective percentages increased from 6 to 27%, in Italy from 5 to 39% and in Spain from 7 to 37%.

Care homes were used over the final 3 months of life by 31–34% of patients in Belgium compared with 18–19% in the Netherlands, 7–9% in Italy and 12–14% in Spain. Stays in palliative care units/hospices occurred primarily in the final 2 weeks of life.

### Transitions between health care settings

In Belgium, the Netherlands, Italy and Spain, respectively, 59%, 55%, 60% and 58% of patients were transferred to other care settings at least once in the final 3 months of life and, respectively, 10%, 5%, 8% and 12% of patients were transferred three times or more in that period (Table 2) ( $P < 0.001$  in multivariate analyses).

**Table 2** Prevalence of transitions between health care settings in the last 3 months and days of life of non-sudden deaths per country

	BE (n=1596)		NL (n=633)		IT (n=1827)		ES (n=735)		Adjusted P value <sup>c</sup>
	%	95% CI	%	95% CI	%	95% CI	%	95% CI	
No. of transitions in the last 3 months of life <sup>a</sup>									
Across all care settings									0.001
0	40.7	38.3–43.1	44.9	41.1–48.7	40.1	37.8–42.4	41.6	37.8–45.4	
1	34.3	32.0–36.6	32.3	28.7–35.9	36.3	34.0–38.6	34.5	30.8–38.2	
2	15.4	13.6–17.2	18.1	15.2–21.0	16.0	14.3–17.7	11.5	9.0–14.0	
3 or more	9.7	8.2–11.2	4.7	3.1–6.3	7.6	6.4–8.8	12.4	9.9–14.9	
By longest place of residence in the last year of life <sup>b</sup>									
Home/with family	n=1041		n=490		n=1691		n=637		<0.001
0	27.1	24.4–29.8	38.9	34.5–43.3	39.0	36.6–41.4	39.1	35.0–43.2	
1	43.3	40.3–46.3	35.3	31.0–39.6	36.6	34.3–38.9	36.2	32.2–40.2	
2	16.6	14.3–18.9	20.0	16.4–23.6	16.6	14.8–18.4	11.3	8.7–13.9	
3 or more	13.0	10.9–15.1	5.9	3.8–8.0	7.8	6.5–9.1	13.5	10.6–16.4	
Care home	n=507		n=134		n=111		n=78		0.182
0	67.0	62.9–71.1	67.2	59.1–75.3	60.0	50.8–69.2	63.6	52.9–74.3	
1	16.9	13.6–20.2	20.3	13.3–27.3	28.2	19.8–36.6	24.7	15.1–34.3	
2	13.1	10.2–16.0	11.7	6.1–17.3	8.2	3.1–13.3	9.1	2.7–15.5	
3 or more	3.0	1.5–4.5	0.8	0.0–2.3	3.6	0.1–7.1	2.6	0.0–6.2	
No. of transitions in the last 3 days of life <sup>a</sup>									
Across all care settings	9.7	8.2–11.2	8.3	6.1–10.5	10.1	8.7–11.5	12.6	10.1–15.1	0.107

Percentages are rounded and therefore may not add up to 100. BE, Belgium; NL, Netherlands; IT, Italy; ES, Spain; CI, confidence interval. a: Missing data for number of transitions are due to uncompleted parts of the care trajectory in the last 3 months of life: BE: n=22 (1.4%); NL: n=20 (3.2%); IT: n=73 (4.0%); ES: n=91 (12.4%).

b: Missing data: longest place of residence in the last year of life: n=28 (0.6%).

c: P-value based on bivariate logistic regression analysis (dependent variable: 0 vs. 1 or more transitions) adjusted for sex, age, cause of death and presence of dementia.

Two cases in Belgium and Italy and one case in Spain had three or more hospitalizations in the last 3 months of life (not shown in Table). In all countries, transitions were more frequent for patients residing at home (between 61% and 73%) than for patients residing in a care home (between 33% and 40%).

Respectively, 10%, 8%, 10% and 13% of patients in Belgium, the Netherlands, Italy and Spain ( $P=0.1$  in multivariate analysis) experienced a transition in the last 3 days of life (Table 2). For patients residing at home 3 months before death, respectively, 12%, 8%, 10% and 14% of patients in Belgium, the Netherlands, Italy and Spain had a transition in the final 3 days of life ( $P=0.04$ ) and for patients residing in care homes figures ranged between 3% and 8% ( $P=0.45$ ) (not shown in Table).

### Final transitions to place of death

The most frequently occurring final transition in all countries was from home to hospital where the patient died and concerned 46%, 42%, 60% and 55% of patients who had at least 1 transition in Belgium, the Netherlands, Italy and Spain, respectively (Supplementary Table). Death at home following a transfer from a hospital occurred in 12%, 22%, 16% and 18% of cases who had at least one transition in Belgium, the Netherlands, Italy and Spain, respectively, and dying in a care home coming from a hospital occurred in 12%, 6%, 4% and 4% of patients with at least one transition. A transfer from a care home followed by a death in hospital was a frequent final transition in Belgium (11% of cases) but less frequent in the other countries (3–7%). Dying in a palliative care unit/hospice after a transition from home or hospital occurred in 15–17% of cases in Belgium/the Netherlands and in 9% of cases in Italy/Spain.

### Reasons for final transitions

In 20% of the cases in Belgium and the Netherlands, the reason for a final transition to the hospital for patients coming from home or care home was a wish of the patient, compared with 7% and 3.5% in Italy and Spain (Table 3). Family wishes were cited most frequently in Belgium (22.5%) compared with the other countries (between

7.5% and 13%). The most frequently cited reason for a terminal hospital admission was that the patient needed curative/life-prolonging treatment (between 49% and 88%) ( $P<0.001$ ).

## Discussion

This international study showed that transitions between health care settings were prevalent in the final 3 months of life among people who died non-suddenly in Belgium, the Netherlands, Italy and Spain. Transitions in the last 3 days of life occurred in 1 in 10 patients. Hospitalizations increased considerably when patients were closer to death and were in some cases requested by the patient/family. Patients most at likely to experience terminal hospitalizations were those residing at home.

This is the first international study monitoring transitions between care settings at the end of life on a population-based level, using the same methodology across several countries. Strengths include the use of established GP networks that were not chosen based on a particular interest in end-of-life care and that are representative for the GPs in the countries studied. Limitations concern the reliance on GPs to describe transitions retrospectively—since this information is not routinely available in patient records—and the lack of an objective evaluation of whether transitions were avoidable.

Palliative care policies in all the countries studied aim to reduce the frequency of transitions and deaths in acute hospitals, but transitions, and particularly hospitalizations towards the end of life, are common challenges despite variations in health care systems. Although it is reassuring that most patients did not experience a transition in the last 3 days of life, more than half in all countries were moved at least once in the last 3 months of life. This poses important challenges to the continuity and quality of care at the end of life.<sup>1–3,7,8</sup> The fact that 1 in 10 patients who died non-suddenly experienced a transition in the final 3 days of life also suggests room for improvement in end-of-life care provision in all countries. The provision of good end-of-life care takes some time to organize well and its effect may not be maximal for patients who are in transition between settings. A recent US study showed that these late-stage

**Table 3** Reasons for final transition overall and per type of final transition among non-sudden deaths per country

Reason for final transition <sup>a,b</sup>	Deceased who had at least one transition in the last 3 months of life								Adjusted P value <sup>c</sup>
	BE (n = 943)		NL (n = 348)		IT (n = 1090)		ES (n = 392)		
	%	95% CI	%	95% CI	%	95% CI	%	95% CI	
Reason for final transition <sup>a,b</sup>									
Wish of patient	26.8	24.0–29.6	38.6	33.5–43.7	9.4	7.7–11.1	6.1	3.7–8.5	<0.001
Wish of family	28.0	25.1–30.9	18.9	14.8–23.0	19.7	17.3–22.1	17.3	13.6–21.0	<0.001
Patient needed palliative care/treatment	55.1	51.9–58.3	35.4	30.4–40.4	16.8	14.6–19.0	34.4	29.7–39.1	<0.001
Patient needed curative/life-prolonging treatment	81.0	78.5–83.5	53.2	48.0–58.4	44.1	41.2–47.0	34.4	29.7–39.1	<0.001
Patient did not need further treatment in that setting	5.9	4.4–7.4	11.8	8.4–15.2	8.1	6.5–9.7	5.6	3.3–7.9	0.031
In case of final transition to hospital (coming from home or care home)	n = 537		n = 170		n = 689		n = 230		
Wish of patient	20.1	16.6–23.6	20.8	13.5–28.1	7.1	5.2–9.0	3.5	1.1–5.9	<0.001
Wish of family	22.5	18.9–26.1	7.5	2.8–12.2	12.8	10.3–15.3	12.6	8.3–16.9	<0.001
Patient needed palliative care/treatment	36.7	32.5–40.9	19.2	12.2–26.2	12.6	10.1–15.1	34.8	28.6–41.0	<0.001
Patient needed curative/life-prolonging treatment	88.3	85.5–91.1	70.8	62.7–78.9	55.7	52.0–59.4	49.1	42.6–55.6	<0.001
Patient did not need further treatment in that setting	1.0	0.1–1.9	2.5	0.0–5.3	3.6	2.2–5.0	0.9	0.0–2.1	0.015
In case of final transition to home or care home (coming from hospital)	n = 223		n = 97		n = 221		n = 84		
Wish of patient	40.0	33.5–46.5	53.1	42.2–64.0	16.3	11.4–21.2	14.3	6.8–21.8	<0.001
Wish of family	32.7	26.5–38.9	17.3	9.1–25.5	26.7	20.9–32.5	21.4	12.6–30.2	0.096
Patient needed palliative care/treatment	75.9	70.2–81.6	34.6	24.2–45.0	12.7	8.3–17.1	17.9	9.7–26.1	<0.001
Patient needed curative/life-prolonging treatment	91.4	87.7–95.1	49.4	38.5–60.3	27.1	21.2–33.0	11.9	5.0–18.8	<0.001
Patient did not need further treatment in that setting	19.5	14.3–24.7	28.4	18.6–38.2	24.9	19.2–30.6	21.4	12.6–30.2	0.331

Missing data: reasons for final transition  $n = 100$  (3.6% of those who had at least one transition). BE, Belgium; NL, Netherlands; IT, Italy; ES, Spain; CI, confidence interval.

a: More than one reason could be indicated per patient.

b: 'Other' reasons (percentages varying between 1.2% and 10.7%) excluded from comparisons between countries.

c: Adjusted for differences in sample characteristics between countries (sex, age, cause of death, place of death, presence of dementia).

transitions are even more frequent in the United States—twice as frequent in some cases—and that they are related to indicators of poor end-of-life care.<sup>1,2</sup> Additionally, multiple hospitalizations in the final 3 months of life almost did not occur in our study, while they were registered in 1 in 10 cases in the United States.<sup>1,2</sup>

It should be acknowledged that judging the appropriateness of transitions is easier when looking back knowing that the patient died than judging its necessity prospectively. In the current health care systems, some transitions might be unavoidable and sometimes patients or families request them. We found that the wish of the patient and/or family is mentioned in many cases as a reason for final hospitalizations. At first sight, this seems contradictory to most peoples' wish to die at home.<sup>4,6,26</sup> However, the wish for being moved to the hospital may not be a wish to die there but a wish to receive the best possible treatment, perhaps even to prolong life. The patient needing life-prolonging treatment was also often mentioned by GPs as the reason for an admission. The latter might be related to the difficulty of predicting when exactly patients—in particular non-cancer patients<sup>27</sup>—will die but also to limited preparation and communication with patients/families about the (dis)advantages of an admission to acute care settings at the end of life. Other possibly related factors are that patients/families and even GPs see no alternatives because of exacerbating symptoms, high burden on caregivers or that patients or families are not prepared for the dying process.<sup>28,29</sup> These results show the complex situations that physicians encounter when decisions about the place of care need to be made and the large challenge in uniting preferences and expected benefits of hospitalizations. However, if public health policies aim to reduce transitions and particularly hospital deaths, there is an urgent need to further reflect and explore why end-of-life transitions occur and which ones are avoidable, especially in relation to patient and family wishes.

A striking finding applicable to all countries is that patients residing at home seem to have a high probability of experiencing transitions and (late) hospitalizations. This resonates with results of studies among older people.<sup>11,30</sup> Current health care policies are often explicitly aimed at keeping more people at home for a longer time, a policy developed in response to the ageing of the

population, the expected rise in health care costs and debates surrounding active ageing. The perhaps unforeseen consequences of such policies might be that clinical complications in the final phase of life<sup>27</sup> might not always be manageable in primary care settings, which might ultimately lead to a higher number of terminal hospitalizations. Further development and implementation of palliative care in the community therefore seems imperative in all these countries<sup>31</sup> as some studies have shown the potential of palliative home care to influence the place of death.<sup>32–34</sup>

Next to these common challenges, our study revealed considerable country variation, even after correcting for differences in population characteristics. One factor that may have caused the differences between countries is the availability of health and social care resources. The availability of care home beds is relatively low in Italy and Spain, especially when compared with Belgium; hence, more people are living at home in these countries. This might contribute to the higher percentage of home deaths in Italy and Spain when compared with Belgium.<sup>35</sup> On the other hand, Belgium has the highest density of hospital beds of the four countries,<sup>36</sup> and this may have contributed to the relatively high percentage of patients who are in hospital over the last 3 months of life. And yet, if one looks at the last week of life only, the percentage of hospitalized patients in Italy and Spain is similar to that in Belgium. This suggests that even in the Southern European countries, where home care at the end of life is common and the density of hospital beds is lower, patients are hospitalized shortly before they die. The reasons for this may lie in suboptimal communication between patients and physicians regarding diagnosis, prognosis and treatment preferences<sup>21,37,38</sup> and overburden in family carers.<sup>39</sup> The Netherlands differ from the other countries in that they have a relatively low percentage of deaths in hospital, a high number of home deaths and the least frequent transitions compared with the other three countries, which might be a result of the strong focus in policy and practice on primary palliative care and advance care planning in the Netherlands.<sup>18,40,41</sup>

One striking country difference is that GPs in Italy and Spain mentioned patient wishes as reason for the final transition far less often than GPs in Belgium or the Netherlands. This is congruent with

previous literature on communication about end-of-life issues in these countries.<sup>21,40</sup> That in Italy and Spain family wishes were cited more often than patient wishes, corresponds well with other EU studies showing a strong pattern of family support in the last year of life in Mediterranean countries as opposed to Northern European countries.<sup>42</sup> However, Belgian GPs most frequently indicated family wishes as a reason for the final hospitalization (22.5%) compared with the other countries (7.5–13%), hence a clear picture in terms of differences between northern and southern European countries is probably not present. This study highlights the need for a deeper investigation of the interplay between the organization and provision of health and social care in general and palliative care in particular as well as social and cultural factors in influencing transitions between care settings at the end of life. Countries can use these data to reflect upon their own performance and to identify areas for further improvement. In this context, the influence of individual level characteristics, such as age and cause of death, on transitions between care settings deserves further study.

In conclusion, end-of-life transitions between care settings are prevalent in all countries and many are struggling with high hospitalization rates in the final phase of life, which in some cases follow patient or family wishes. Patients most likely to experience transitions are those residing at home.

## Supplementary data

Supplementary data are available at *EURPUB* online.

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*Conflicts of interest:* None declared.

### Key points

- Literature suggests that transitions between care settings are related to poor quality in end-of-life care. Yet there is a lack of cross-national population-based data on place of care and transitions at the end of life.
- Of 4791 non-sudden deaths in Belgium, the Netherlands, Italy and Spain, 59%, 55%, 60% and 58%, respectively, were transferred between settings at least once in the final 3 months of life (and 8% to 13% were transferred in the final 3 days of life).
- In all countries, transitions were more frequent among patients residing at home (61–73%) than among patients residing in a care home (33–40%).
- Patient or family wishes were an important reason for final transitions to hospital.
- Transitions between care settings are common across all countries, even though current policies are aimed at enabling terminally ill patients to stay in their usual environment for as long as possible.

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## Health literacy and informed decision making regarding colorectal cancer screening: a systematic review

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Making an informed decision about participation in colorectal cancer (CRC) screening may be challenging for invitees with lower health literacy skills. The aim of this systematic review is to explore to what extent the level of a person's health literacy is related to their informed decision making concerning CRC screening. We searched for peer-reviewed studies published between 1950 and May 2013 in MEDLINE, EMBASE, SciSearch and PsycINFO. Studies were included when health literacy was studied in relation to concepts underpinning informed decision making (awareness, risk perception, perceived barriers and benefits, knowledge, attitude, deliberation). The quality of the studies was determined and related to the study results. The search returned 2254 papers. Eight studies in total were included, among which seven focused on knowledge, four focused on attitudes or beliefs concerning CRC screening, and one focused on risk perception. The studies found either no association or a positive association between health literacy and concepts underpinning informed decision making. Some studies showed that higher health literacy was associated with more CRC screening knowledge and a more positive attitude toward CRC screening. The results of studies that obtained a lower quality score were no different than studies that obtained a higher quality score. In order to obtain more insight into the association between health literacy and informed decision making in CRC cancer screening, future research should study the multiple aspects of informed decision making in conjunction instead of single aspects.

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### Introduction

Colorectal cancer (CRC) is one of the most common causes of cancer-related deaths worldwide.<sup>1</sup> As screening for CRC can identify precancerous polyps or cancers in their early stages, and thereby improve the survival rates of CRC, several countries have

implemented national CRC screening programs.<sup>2–4</sup> Building on the idea of individual autonomy when making decisions about screening, it is increasingly being recognized that screening programs should not aim to pursue screening invitees to participate. Instead screening programs should adopt an informed decision-making approach.<sup>5–8</sup> In accordance, invitees should receive