EVIDENCE-BASED PUBLIC HEALTH POLICY AND PRACTICE

End-of-life decision-making in Belgium, Denmark, Sweden and Switzerland: does place of death make a difference?

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Objective: To examine differences in end-of-life decision-making in patients dying at home, in a hospital or in a care home.

Design: A death certificate study: certifying physicians from representative samples of death certificates, taken between June 2001 and February 2002, were sent questionnaires on the end-of-life decision-making preceding the patient's death.

Setting: Four European countries: Belgium (Flanders), Denmark, Sweden, and Switzerland (German-speaking part).

Main outcome measures: The incidence of and communication in different end-of-life decisions: physician-assisted death, alleviation of pain/symptoms with a possible life-shortening effect, and non-treatment decisions.

Results: Response rates ranged from 59% in Belgium to 69% in Switzerland. The total number of deaths studied was 12 492. Among all non-sudden deaths the incidence of several end-of-life decisions varied by place of death. Physician-assisted death occurred relatively more often at home (0.3–5.1%); non-treatment decisions generally occurred more often in hospitals (22.4–41.3%), although they were also frequently taken in care homes in Belgium (26.0%) and Switzerland (43.1%). Continuous deep sedation, in particular without the administration of food and fluids, was more likely to occur in hospitals. At home, end-of-life decisions were usually more often discussed with patients. The incidence of discussion with other caregivers was generally relatively low at home compared with in hospitals or care homes.

Conclusion: The results suggest the possibility that end-of-life decision-making is related to the care setting where people die. The study results seem to call for the development of good end-of-life care options and end-of-life communication guidelines in all settings.

The place of death has, for some time now, been an issue of interest to public health policy and in particular to palliative care. Interest in this issue has increased with the observation that patients often prefer to die at home, whereas only a small number actually does so.[1–6] More recently, economic motives have also attracted attention concerning the place of death.[7 8] The subject has clearly also received attention in healthcare research because of an association between the place of dying and the type and quality of end-of-life care;[9–18] the setting of end-of-life care seems to involve a particular 'care culture'.[9–15] From this perspective it is possible that the place of dying also influences end-of-life decision-making. Empirical evidence is, however, lacking. Although studies on the practice of end-of-life decisions have occasionally been undertaken,[19–25] few or none of those studies have conducted focussed evaluations on the different settings of care (hospital, care home, home).

The research questions in this paper are therefore: first, are there differences in the incidence and type of end-of-life decisions in patients dying at home, in a hospital or in a care home; second, are there differences according to these settings in the discussion between the physician and the patient, relatives, or other healthcare professionals preceding these end-of-life decisions; and third, do these differences occur in all the countries studied?

METHODS

Study design

Data used in this work are from the European study of end-of-life decisions (EURELD), covering six European countries: Belgium (Flanders), Denmark, Italy (four areas), the Netherlands, Sweden, and Switzerland (German-speaking part). The main results of the study were presented in 2003.[22] Because it was not possible to distinguish between home, hospital or care home as the place of death in the Netherlands and Italy, these countries were not included in our analyses.

In every participating country or region, random samples of death certificates were taken, stratified for cause of death (indicating the likelihood that an end-of-life decision had preceded the death).[22 26] The stratification procedure, applied to make more reliable estimates of end-of-life decisions, was not possible in Switzerland because of its delay in cause of death registration.

Questionnaires were sent to the physicians certifying the deaths sampled. In case they were not the treating physician, they were asked to pass the questionnaire to the treating physician.[22 26] Follow-up mailings were used to optimise the response rate.[22 26] In each country, specific information from the death certificate was linked to the information in the corresponding questionnaire, after complex anonymity procedures to preclude the identification of any of the doctors or patients. All country-specific databases were integrated into one common file. Depending on the sampling procedure and the representativeness of the national or regional sample obtained, a weight factor correcting for stratification and for patient characteristics (e.g. sex, age, cause of death) was added in order to make reliable estimates of end-of-life decisions.

Approval for the study was given in all countries by the relevant institutions (e.g. research ethics committees).[26]

Table 1 Characteristics of the deaths sampled in Belgium, Denmark, Sweden and Switzerland

	Belgium	Denmark	Sweden	Switzerland
Total number	2950	2939	3248	3355
Response percentage	59	62	61	67
Sex				
Male	50.5	48.0	47.5	49.3
Female	49.5	52.0	52.5	50.7
Age (years)				
1–17	0.3	0.3	0.2	0.4
18–64	17.0	19.1	11.8	17.3
65–79	33.9	34.3	31.8	29.3
80+	48.8	46.3	56.3	53.0
Cause of death				
Cardiovascular diseases	30.1	26.2	50.6*	36.1
Malignant neoplasms	26.5	27.0	27.2	24.5
Respiratory diseases	10.4	11.7	4.3	8.4
Diseases of the nervous system	11.2	10.2	1.0*	10.7
Other/unknown	21.8	24.9	16.8	20.2
Place of death				
Hospital	50.0	39.8	43.9	37.3
Home	26.5	25.4	21.2	22.7
Care home†	21.0	30.6	33.6	33.7
Other	2.5	4.1	1.4	6.3

*In Sweden stroke was not categorised under diseases of the nervous system, but under cardiovascular diseases.
†Care homes include nursing homes and residential homes for older people.

Measures

Place of death and patient characteristics

Place of death, cause of death (aggregated into five major categories: cardiovascular diseases; malignant neoplasms; neurological diseases; respiratory diseases; and other diseases), sex, and age (aggregated into four categories: less than 18, 18–64, 65–79, 80 years or older) of the deceased were available from the death certificate.

End-of-life decisions

On the basis of a combination of answers to the questions (that only needed to be answered when the death was not totally sudden and unexpected) end-of-life decisions were classified as indicated in box 1.

Box 1. Classification of end-of-life decisions

- Physician-assisted death: the administration, prescription or supply of drugs with the explicit intention of hastening the patient's death, further subdivided into:
  - Euthanasia or physician-assisted suicide if drugs were respectively administered or prescribed or supplied at the patient's explicit request.
  - Life-ending acts without the patient's explicit request if drugs were administered without an explicit request of the patient.
- Possibly life-shortening alleviation of pain and symptoms by using drugs (e.g. morphine), taking into account the possibility of hastening the patient's death, or partly with the intention of hastening the patient's death.
- Non-treatment decisions: the withholding or withdrawing of (potentially life-prolonging) treatment, taking into account the possibility of hastening the patient's death or explicitly intending to hasten the patient's death.

To describe the end-of-life decision (if any) preceding each death, a decision with an explicit life-shortening intention prevailed over a decision with a partly life-shortening intention, which in its turn prevailed over a decision taking into account the life-shortening possibility. More information on the classification of end-of-life decisions can be found elsewhere.[22]

Continuous deep sedation until death was measured by asking the physician to indicate whether the patient received drugs, such as barbiturates or benzodiazepines, to keep him/her continuously in deep sedation or coma until death. A distinction is made between cases with or without the administration of artificial nutrition or hydration. More information can be found elsewhere.[27]

Next to these questions, the questionnaire enquired about whether or not the patient was competent (i.e. capable of making a decision) when the decision was made, and whether or not the end-of-life decision had been discussed with the patient, with the patient's relatives, and with other caregivers (i.e. one or more physicians, nursing staff, or other caregivers).

Statistical analyses

For the different places of death (hospital, home, care home), the percentage of deaths preceded by different types of end-of-life decisions were presented and Fisher's exact tests were used to test for statistically significant differences. Because the probability of dying suddenly and unexpectedly varies strongly between the three settings, the analyses were limited to non-sudden deaths, in which an end-of-life decision was possible.

A multivariate logistic regression was performed on all non-sudden deaths to test the relationship between all end-of-life decisions and the place of death, controlling for age and cause of death.

Finally, Fisher's exact tests were used to examine differences between the three places of dying as to whether or not (the life-shortening potential of) the end-of-life decision had been discussed with the patient, relatives and other caregivers.

RESULTS

A response rate ranging from 59% in Belgium to 67% in Switzerland resulted in a total of 2950 deaths in Belgium; 2939 in Denmark; 3248 in Sweden and 3355 in Switzerland.

Table 2 Incidence of end-of-life decisions by place of death in non-sudden deaths in Belgium, Denmark, Sweden and Switzerland*

	Hospital	Home	Care home	p Value†	Total‡
Belgium, no. of non-sudden deaths§ (% of all deaths)	1054 (71.5%)	417 (53.3%)	457 (73.8%)	<0.001	1938 (65.7%)
Physician-assisted death	2.6	4.3**	2.0	0.101	2.8
Euthanasia or physician-assisted suicide	0.3	1.4**	0.0	0.005	0.5
Life-ending without explicit patient request	2.3	2.6	2.0	0.804	2.3
Alleviation of pain/symptoms	34.4	38.3	26.0	<0.001	33.3
Taking into account life-shortening	30.0	32.5	23.2	0.005	28.9
Partly intending life-shortening	4.5	5.8	2.8	0.099	4.3
Non-treatment decision	22.4	17.7**	26.0	0.012	22.2
Taking into account life-shortening	9.9	6.5**	10.7	0.060	9.3
Explicitly intending life-shortening	12.5	11.3	15.3	0.179	12.9
Denmark, no. of non-sudden deaths§ (% of all deaths)	736 (63.9%)	413 (56.2%)	762 (86.0%)	<0.001	1954 (66.5%)
Physician-assisted death	0.7	2.7**	0.9	0.015	1.2
Euthanasia or physician-assisted suicide	0.0	0.7	0.1	0.034	0.2
Life-ending without explicit patient request	0.7	1.9	0.9	0.131	1.0
Alleviation of pain/symptoms	37.1	46.2	37.5	0.005	39.0
Taking into account life-shortening	33.3	42.1**	35.3**	0.011	35.7
Partly intending life-shortening	3.8	4.1	2.2	0.110	3.3
Non-treatment decision	27.0	14.5**	18.9**	<0.001	20.9
Taking into account life-shortening	11.7	6.1**	9.4**	0.007	9.5
Explicitly intending life-shortening	15.4	8.5**	9.4**	<0.001	11.4
Sweden, no. of non-sudden deaths§ (% of all deaths)	948 (67.9%)	315 (46.7%)	842 (78.8%)	<0.001	2145 (66.0%)
Physician-assisted death	0.4	0.3	0.4	0.999	0.4
Euthanasia or physician-assisted suicide	0.0	0.0	0.0	–	0.0
Life-ending without explicit patient request	0.4	0.3	0.4	0.999	0.4
Alleviation of pain/symptoms	29.2	29.8	33.3	0.168	30.8
Taking into account life-shortening	28.6	29.8	32.5	0.189	30.2
Partly intending life-shortening	0.6	0.0	0.7	0.387	0.6
Non-treatment decision	27.2	17.5**	16.0**	<0.001	21.4
Taking into account life-shortening	8.6	5.4	6.3**	0.069	7.3
Explicitly intending life-shortening	18.5	12.1**	9.7**	<0.001	14.1
Switzerland, no. of non-sudden deaths§ (% of all deaths)	1044 (83.7%)	354 (46.6%)	867 (77.0%)	<0.001	2283 (68.0%)
Physician-assisted death	0.4	5.1**	1.2**	<0.001	1.5
Euthanasia or physician-assisted suicide	0.1	3.4**	0.6**	<0.001	0.9
Life-ending without explicit patient request	0.3	1.7**	0.6	0.018	0.6
Alleviation of pain/symptoms	34.3	33.3	30.3	0.158	32.4
Taking into account life-shortening	31.1	28.0	26.6	0.081	28.7
Partly intending life-shortening	3.2	5.4	3.7	0.170	3.7
Non-treatment decision	41.3	32.8**	43.1	0.003	40.8
Taking into account life-shortening	8.8	7.3	13.2	0.001	10.3
Explicitly intending life-shortening	32.6	25.4**	29.9	0.038	30.5

*All data are weighted (i.e. adjusted for stratification and sociodemographic characteristics).
†Fisher's exact test for differences between home, hospital and care home.
‡This includes a small number of deaths in other places. Totals might not add up.
§Number of deaths (and percentage within total number of deaths in hospital, at home, etc.) in which an end-of-life decision was possible (i.e. not sudden or unexpected, and when the physician first saw the patient before the the patient's death).
**The probability remained statistically higher or lower than for hospitals (reference category) in a logistic regression controlling for age, sex and cause of death.

Place of death

The proportion of people dying in a hospital varied from 37.3% in Switzerland to 50.0% in Belgium, at home from 21.2% in Sweden to 26.5% in Belgium, and in a care home from 21% in Belgium to 33.7% in Switzerland (table 1).

Place of death and end-of-life decisions

Of all deaths, 65.7–68.0% were not sudden and unexpected. Of these non-sudden deaths, 0.4% in Sweden to 2.8% in Belgium were preceded by physician-assisted death, 21.4% in Sweden to 39.0% in Denmark were preceded by possibly life-shortening pain and symptom alleviation, and 20.9% in Denmark to 40.8% in Switzerland were preceded by non-treatment decisions (table 2).

The probability that a death was not sudden and unexpected, and thus the possibility that death was preceded by an end-of-life decision, varied between the settings. The proportion of non-sudden deaths was generally lower at home (46.6–56.2%) and higher in hospitals (63.9–83.7%) and care homes (73.8–86.0%).

Among the non-sudden deaths, the incidence of several end-of-life decisions varied by the place of death. In Denmark and Switzerland, the incidence of physician-assisted death was higher at home than in a hospital or care home. In these countries as well as in Belgium, euthanasia or physician-assisted suicide in particular more often occurred at home. In Switzerland, a quarter of all assisted suicides occurred in the apartments of a right-to-die organisation (other place of death). The incidence of life-ending acts without an explicit request from the patient also tended to be higher at home, but only significantly in Switzerland. Small setting differences were found in the incidence of the alleviation of pain and symptoms with a possible life-shortening effect. It tended to be higher at home in Denmark and lower in care homes in Belgium. No significant differences were found, however, for the incidence of these decisions with a partly life-shortening intention. Non-treatment decisions generally occurred less frequently at home, and in Denmark and Sweden also less frequently in care homes. In Belgium and Switzerland the incidence of non-treatment decisions in which life-shortening was not the explicit intention was even higher in care homes.

Multivariate logistic regression confirmed several differences between the three settings in the probability of end-of-life decisions, independent of (confounding) differences in age, sex and cause of death. A higher probability of physician-assisted death at home was confirmed in Denmark, Belgium, and

Table 3 Incidence of continuous deep sedation by place of death in non-sudden deaths in Belgium, Denmark, Sweden and Switzerland

	Hospital	Home	Care home	p Value*	Total
Belgium					
Continuous deep sedation (total)	18.9	7.1†	4.3†	<0.001	12.8
Without ANH	5.6	5.7	2.9	0.078	4.9
With ANH	13.4	1.5†	1.3†	<0.001	7.9
Denmark					
Continuous deep sedation (total)	4.7	4.7	2.6	0.063	3.9
Without ANH	1.4	4.5†	2.6	0.007	2.6
With ANH	3.3	0.2†	0.0	<0.001	1.3
Sweden					
Continuous deep sedation (total)	7.9	2.1†	3.0†	<0.001	5.2
Without ANH	3.8	0.7†	3.0	0.028	3.0
With ANH	4.1	1.4†	0.1†	<0.001	2.2
Switzerland					
Continuous deep sedation (total)	9.2	7.0	5.4	0.009	7.4
Without ANH	4.1	6.1	4.2	0.289	4.4
With ANH	5.1	0.9†	1.2†	<0.001	3.0

ANH, Administration of (artificial) nutrition and hydration.
All data are weighted (i.e. adjusted for stratification and sociodemographic characteristics).
*Fisher's exact test for differences between home, hospital and care home.
†The probability remained statistically higher or lower than for hospitals (reference category) in a logistic regression controlling for age, sex and cause of death.

Switzerland. Euthanasia or physician-assisted suicide was also more likely to take place at home in Belgium and Switzerland, and a life-ending act without an explicit request from the patient was more likely to take place at home in Switzerland. No significant differences were found between the settings of care for the probability of the alleviation of pain and symptoms, except in Denmark where the probability of these kinds of decisions with only a foreseen life-shortening was lower in hospitals. The lower probability of death being preceded by a non-treatment decision (and in particular one in which hastening death was the explicit intention) was confirmed for home deaths in Switzerland, and for home deaths as well as care home deaths in Sweden and Denmark.

Continuous deep sedation until death occurred in 3.9–12.8% of all non-sudden deaths and was more likely to be found in hospital deaths in Belgium and Sweden (table 3). There was, however, a varying picture depending on whether or not artificial nutrition/hydration was withdrawn. In all countries continuous deep sedation with artificial nutrition/hydration was (also after controlling for age, sex and cause of death) more likely in hospitals than in care homes or at home. Continuous deep sedation without artificial nutrition/hydration was more likely in Denmark and less likely in Sweden to precede a death at home.

Place of death and communication of end-of-life decisions

In Switzerland and Belgium physician-assisted death was most often discussed with other caregivers in hospitals (100%), and least often at home (42.9–73.0%). This tendency was also found in the other countries but was, because of a limited number of cases, not statistically significant (table 4).

Table 4 Discussion of end-of-life decisions by place of death in Belgium, Denmark, Sweden and Switzerland

	Physician-assisted death			Alleviation of pain/symptoms			Non-treatment decision		
	Hospital	Home	Care home	Hospital	Home	Care home	Hospital	Home	Care home
Belguim, no. of cases	26	38	10	374	324	144	202	106	121
Not discussed with patient, patient incompetent	50.0	26.3	90.0*	50.5	44.4	65.3*	66.3	63.4	67.2
Discussed with patient	50.0	65.8	0.0*	34.0	36.5	19.8*	27.5	26.7	20.7
Discussed with relatives	92.3	94.7	90.0	70.2	72.5	66.9	82.0	93.0	77.4*
Discussed with other professionals	100.0	73.0	80.0*	81.8	59.5	84.2*	92.2	70.4	92.9*
Denmark, no. of cases	6	17	8	342	273	281	200	76	123
Not discussed with patient, patient incompetent	16.7	29.4	62.5	60.5	44.8	67.0*	68.8	41.1	68.7*
Discussed with patient	50.0	58.8	37.5	19.6	25.1	12.9*	23.7	47.9	27.0*
Discussed with relatives	83.3	88.2	62.5	39.9	50.8	39.3*	62.5	74.0	58.3†
Discussed with other professionals	80.0	62.5	71.4	41.0	32.8	55.9*	76.0	56.9	71.4*
Sweden, no. of cases	5	1	2	370	111	336	280	58	144
Not discussed with patient, patient incompetent	75.0	0.0	100.0	62.4	52.1	73.3*	67.7	66.1	80.3*
Discussed with patient	0.0	0.0	0.0	10.0	9.6	4.7†	22.3	19.6	14.4
Discussed with relatives	75.0	0.0	100.0	25.7	22.2	16.5*	65.1	58.9	51.1*
Discussed with other professionals	75.0	0.0	100.0	28.1	27.8	18.8*	70.4	66.1	61.1
Switzerland, no. of cases	4	18	10	358	118	262	431	116	373
Not discussed with patient, patient incompetent	25.0	26.7	30.0	46.9	30.7	57.8*	54.6	35.4	58.4*
Discussed with patient	50.0	66.7	70.0	40.0	41.6	27.0*	38.1	55.8	29.9*
Discussed with relatives	75.0	86.7	70.0	68.6	65.0	53.2*	79.7	80.5	65.6*
Discussed with other professionals	100.0	42.9	90.0*	77.2	49.5	74.0*	87.2	53.1	87.3*

*$p<0.05$ (Fisher's exact test); †$p<0.1$ (Fisher's exact test).

Cases of the alleviation of pain and symptoms and non-treatment decisions were generally also more discussed with other caregivers in a hospital or in a care home than at home (except in Sweden).

Relatives tended to be more involved in discussions about (the life-shortening potential of) the alleviation of pain and symptoms or a non-treatment decision at home than in a hospital or care home (in Belgium and in Denmark), and more at home or in a hospital than in a care home (in Sweden and Switzerland).

The incidence of discussion with the patient about the alleviation of pain and symptoms or non-treatment decisions was relatively low (4.7% of alleviation of pain and symptoms in care homes in Sweden to 55.8% of non-treatment decisions at home in Switzerland), but was generally higher at home than in a hospital (except for Sweden), and lower in care homes. A physician-assisted death tended to be discussed more often with the patient at home than in a hospital (or a care home), but this was only statistically significant in Belgium. The reason why the end-of-life decision was not discussed with the patient was mostly, especially in hospitals and in care homes, that the patient was no longer capable of participating in end-of-life decision-making. Further exploration of the end-of-life decisions discussed with the patient learned that in home deaths the discussion was (except in Sweden) significantly more often initiated by the patient and/or (except in Switzerland) by the patient's relatives than in hospital deaths, in which the discussion was more often initiated by the physician (not shown in tables).

DISCUSSION

Our study revealed some clear differences in end-of-life decisions and in the communication about these decisions according to the place of dying. End-of-life decision-making differed by where patients died, even after controlling for the cause of death, sex, and age of the patient, factors found to be correlated with end-of-life decisions in several previous studies.[19 22 27]

This study compares, probably for the first time, the end-of-life decisions that are made in hospital, at home, or in care homes, using a large-scale cross-national death certificate study. It thereby contributes to the knowledge of how people die. The death certificate method used allowed reliable epidemiological estimates to be made by setting. Other methodological strengths are the large and representative nation or region-wide sample sizes and relatively good response percentages. Next to a possible bias by non-response, however, it is uncertain whether the results can be extrapolated to the other regions in Belgium and Switzerland. Possible bias might also occur in the self-reported end-of-life decision-making of physicians, for example as a result of the fear of legal consequences. A more important limitation is that we did not take into account all relevant patient information, which would have allowed us to control for all possible confounders. For example, we cannot exclude the possibility that differences in decision-making between settings might be the result of differences in patient characteristics such as symptom severity.

Physician-assisted death was rare, but although at the time of the study physician-assisted suicide was only legal in Switzerland and euthanasia was illegal in all countries (it became legal in the Netherlands and Belgium in 2002), it occurred in all four countries. Physician-assisted death more often took place at home than in the other settings in Belgium, Denmark and Switzerland. This difference results especially from the higher incidence of euthanasia or physician-assisted suicide at home. Next to the Swiss ''Exit'' association[28] usually offering assistance in suicide in the domestic setting of the patient as a partial explanation for the findings in Switzerland, possible explanations for the higher incidence of euthanasia/physician-assisted suicide at home than in other settings might be the degree of intimacy, privacy and concealment, characteristics of the relationship with the professional caregiver, different (palliative) care and treatment options, or institutional policies to restrict euthanasia.[29] An explanation might also be that both dying at home and dying by euthanasia/physician-assisted suicide characterises those patients (and their families) with (a desire for) a higher degree of autonomy.

Apart from Belgium, non-treatment decisions were more often taken in hospitals, possibly as a result of the fact that the greater availability of possible (technically advanced) treatments that are part of (standard) medical practice in hospitals also contributes to more decisions to withhold or withdraw such treatments.

Continuous deep sedation occurs less at home or in care homes than in hospitals, possibly because of differences in (technical) palliative medicine possibilities (e.g. constant monitoring of doses). Whether this can be attributed to hospital policies, considering continuous deep sedation an acceptable ''palliative filter''[29] for euthanasia, still needs to be researched further.

The probability of similar patients receiving alleviation of pain and symptoms with a possible life-shortening effect was basically the same at home, in hospital, or in care homes. The use of analgesics is thus probably part of the standard practice of specialists in hospitals as well as of general practitioners at home, and is less influenced by the surrounding (setting-specific) ''care culture''.

Another important finding is that communication about and involvement of others in the decision-making process are, as indicated in previous studies,[24 30] far from perfect. Decisions that may involve the shortening of life, such as the

What is already known on this topic

- Hospitals, home, and care homes involve a different (quality of) end-of-life care
- Many deaths are preceded by medical end-of-life decisions with a possible or certain life-shortening effect
- Empirical evidence on differences in end-of-life decision-making in hospitals, at home, or in care homes is lacking

What this study adds

- The likelihood that physician-assisted death, intensification of pain/symptom alleviation with a possible life-shortening effect, and non-treatment decisions are made differs depending on the place of end-of-life care
- The end-of-life decision-making process involves more communication with other caregivers in institutional settings, but less with patients than at home
- There is a need for organising good palliative care options and developing clear (communication) guidelines for different kinds of end-of-life decisions in all settings for different circumstances

intensification of pain and symptom management and not giving treatment, which were taken in approximately half or more of non-suddenly dying patients, were discussed with only a minority of such patients. Moreover, this was also determined by the setting of end-of-life care. Discussion with other professional caregivers, which is a safeguard in prudent end-of-life practice, is shown to occur rarely at home. The reason for this is probably that general practitioners operate in a more isolated fashion, whereas physicians in institutions have more formal (and informal) consultations and discussions with other physicians or nurses.

The discussion with patients was, however, in most countries more frequent at home than in institutions. The main explanation from the data is that patients dying in hospital were more often incompetent at the time of decision-making, a finding confirming previous research.[24] This is possibly an indication that specialists wait too long before discussing end-of-life decisions. Many acutely ill patients lose the ability to make medical care decisions around the time of hospital admission, but it often seems that discussion and exploration of patient and family wishes could have been initiated earlier (or by advance directives).[31] Indications of a greater control over care and the situation of patients receiving palliative care at home compared with hospital,[14] and of more paternalistic attitudes among specialists[24 32] (also demonstrated in our finding that discussion was less often initiated by the patient and more often by the physician in hospital deaths) are other possible explanations.

Finally, a marked finding of our study is that the differences in end-of-life decisions between settings are similar in all countries, but that there are at the same time some clear country differences. Whereas previous research demonstrated more discussion with patients and families in northern than in central or southern European countries,[24] our results indicate a strikingly lower patient involvement in end-of-life decisions in Sweden and Denmark than in the other countries. Probably some cultural and country-specific factors (e.g. stronger paternalism among Swedish physicians[32]) play a role. Further research will give more insight into these factors.

In summary, our results do not preclude the possibility that end-of-life decision-making practices are related to the care setting in which people die. Our findings suggest a number of focal points to eradicate some differences between settings, and guarantee good end-of-life care in all settings, based on patient preferences and clinical circumstances.[33 34] At home, especially if we aim to let more people die there, general practitioners might benefit from having the possibility of consulting with other professional caregivers so that they do not need to make difficult decisions on their own. In institutional care settings, physicians should particularly avoid waiting until patients become incompetent before discussing end-of-life decisions. If possible, such discussions should be undertaken at an early stage. Involving the patient in timely discussions with regard to their treatment and care probably not only ameliorates medical decision-making, but also increases the likelihood of their dying where they want.[1]

Further research should examine in depth the factors that explain the differences in end-of-life decision-making between settings. In order to make more qualitative interpretations of the decision-making in each setting, attention should also be paid to information on the course of dying.

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APPENDIX

EURELD CONSORTIUM

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