

# Forgoing Treatment at the End of Life in 6 European Countries

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**Background:** Modern medicine provides unprecedented opportunities in diagnostics and treatment. However, in some situations at the end of a patient's life, many physicians refrain from using all possible measures to prolong life. We studied the incidence of different types of treatment withheld or withdrawn in 6 European countries and analyzed the main background characteristics.

**Methods:** Between June 2001 and February 2002, samples were obtained from deaths reported to registries in Belgium, Denmark, Italy, the Netherlands, Sweden, and Switzerland. The reporting physician was then sent a questionnaire about the medical decision-making process that preceded the patient's death.

**Results:** The incidence of nontreatment decisions, whether or not combined with other end-of-life decisions, varied widely from 6% of all deaths studied in Italy to 41% in Switzerland. Most frequently forgone in every country were hydration or nutrition and medication, together representing between 62% (Belgium) and 71%

(Italy) of all treatments withheld or withdrawn. Forgoing treatment estimated to prolong life for more than 1 month was more common in the Netherlands (10%), Belgium (9%), and Switzerland (8%) than in Denmark (5%), Italy (3%), and Sweden (2%). Relevant determinants of treatment being withheld rather than withdrawn were older age (odds ratio [OR], 1.53; 95% confidence interval [CI], 1.31-1.79), death outside the hospital (death in hospital: OR, 0.80; 95% CI, 0.68-0.93), and greater life-shortening effect (OR, 1.75; 95% CI, 1.27-2.39).

**Conclusions:** In all of the participating countries, life-prolonging treatment is withheld or withdrawn at the end of life. Frequencies vary greatly among countries. Low-technology interventions, such as medication or hydration or nutrition, are most frequently forgone. In older patients and outside the hospital, physicians prefer not to initiate life-prolonging treatment at all rather than stop it later.

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**M**ODERN MEDICINE PROVIDES unprecedented opportunities in diagnostics and treatment to save and sustain life, which, in principle, nobody wants to do without. However, confronted with patients in the last stage of disease, the question arises whether it is sometimes justified or even advisable not to use all possible life-sustaining measures. Some studies<sup>1-5</sup> have found that many patients wish particular life-sustaining treatment to be withheld or withdrawn. Other studies<sup>6-9</sup> have shown that physicians dispense with various life-sustaining treatments when faced with terminally ill patients. However, when considering real end-of-life situations, the validity of studies based on hypothetical scenarios is less clear.<sup>3,4</sup> Furthermore, most of these studies are restricted to specific settings (eg, hospital, nursing home, or intensive care unit)<sup>1,4,6-9</sup> or patient groups (eg,

patients with cancer or those with renal failure).<sup>2,5</sup> Given the different patient populations and/or study designs, it is often hard to compare results.

Until recently, comprehensive overviews of end-of-life decisions had been published only for the Netherlands and Belgium.<sup>10-12</sup> Based on the questionnaire and design of these studies, the international European End-of-Life (EURELD) project was established in 2000 to investigate the incidence and background characteristics of end-of-life decisions in 6 European countries: Belgium (Flanders), Denmark, Italy (4 areas), the Netherlands, Sweden, and Switzerland (German-speaking part).<sup>13</sup> This article presents one part of the project, which aims to (1) quantify different types of treatment forgone within each participating country and compare these figures among countries; (2) describe and compare patient characteristics and decision-making processes for different types of treatment for-

**Table 1. Nontreatment Decisions and Treatments Forgone in 6 European Countries\***

Variable	Belgium	Denmark	Italy	The Netherlands	Sweden	Switzerland	All 6 Countries
Annual No. of deaths†	55 793	57 044	22 368	140 377	93 755	44 036	NA
Response, %	59	62	44	75	61	67	NA
Total No. of deaths studied‡	2950	2939	2604	5384	3248	3355	20 480
Nontreatment decisions, No.§	885	732	201	1794	783	1362	5757
Incidence of nontreatment decisions, % (95% CI)	27 (25-28)	23 (22-25)	6 (5-7)	30 (29-32)	22 (21-23)	41 (40-42)	NA
Treatments forgone, No.§	1517	1111	233	3131	1094	2321	9407
Treatments withheld, No. (%)	894 (59)	493 (46)	126 (54)	1829 (57)	731 (66)	1539 (66)	5612 (60)
Treatments withdrawn, No. (%)	623 (41)	618 (54)	107 (46)	1302 (43)	363 (34)	782 (34)	3795 (40)

Abbreviations: CI, confidence interval; NA, not applicable.

\*Belgium includes the Flanders region; Italy, the areas of Emilia-Romagna, Trento, Tuscany, and Veneto; and Switzerland, the German-speaking part.

†Belgium, the Netherlands, Sweden, and Switzerland, data from the year 2001; Denmark, data from 2000; and Italy, data from 1999.

‡Deaths of infants younger than 1 year (for Italy, all deaths of children <18 years) were excluded from the sample.

§All cases in which at least 1 treatment was forgone, taking into account or explicitly intending to hasten the patient's death, whether or not combined with other end-of-life decisions.

||Percentages are weighted for stratification (except Swiss data, which were not stratified) and nonresponse.

¶"Forgone" indicates withheld plus withdrawn. More than 1 treatment forgone could be mentioned for each death.

gone; and (3) describe specific characteristics of withholding and withdrawing treatment.

## METHODS

### DATA COLLECTION

Between June 2001 and February 2002, random samples of death certificates were obtained from central registries in each participating country or region. Deaths of infants younger than 1 year were excluded (deaths of children <18 years had to be excluded for Italy). All deaths reported during the sampling period were stratified for the likelihood that an end-of-life decision had preceded death. The sampling fractions were higher for strata in which the cause of death made an end-of-life decision more likely (eg, cancer as opposed to a car crash). This procedure enhances the proportion of end-of-life decisions among the studied cases and gives smaller confidence intervals (CIs) around estimates; it has been described in detail elsewhere.<sup>13</sup> Stratification of Swiss data was not possible because of the delay in registering cause of death.

The highest priority when collecting data was to ensure anonymity for the responding physicians. A clearing house (usually a notary's office) was interposed in each participating country. No envelope that contained a returned questionnaire reached the researchers before all identifying information had been removed from the data set using a separate code system.

### QUESTIONNAIRE

A 4-page questionnaire was sent to the attending physician for each death included in the sample. If death was not sudden and unexpected, the physician was asked whether he or she had made any decision that might have hastened death (or not prolonged the patient's life). A case was counted as a nontreatment decision if the physician answered "yes" to either part of the following question: "Did you (1) withhold or (2) withdraw medical treatment while taking into account the possibility or certainty that this would hasten the patient's death?" The physician was then asked to specify the type of treatment forgone, detail the decision-making process, and estimate life shortening that resulted from the most important end-of-life decision. A nontreatment decision was deemed the most important end-of-life decision if it was the only such decision or the only one with the explicit intention of hastening death.

## DATA ANALYSIS

The results were weighted for stratification and response by sex, age, and place and cause of death to make them as representative as possible of all deaths in each country during the period studied. Weighting was not possible for place and cause of death in Switzerland or for cause of death in Denmark. The country-specific data sets were combined into a common database. To calculate estimates for all countries together, an additional country-specific weighting factor (the inverse of the weighted number of deaths studied in each country) was applied. Possible determinants for a treatment being withheld or withdrawn were analyzed by multiple logistic regression. We used SPSS statistical software, version 10 (SPSS Inc, Chicago, Ill), and StatXact statistical software, version 6 (Cytel Software Corp, Cambridge, Mass), for statistical analyses.

## RESULTS

Questionnaire response rates were as follows: Belgium, 59%; Denmark, 62%; Italy, 44%; the Netherlands, 75%; Sweden, 61%; and Switzerland, 67%; with 20 480 deaths being studied in total (**Table 1**). There were marked differences in the incidence of nontreatment decisions: 41% of all deaths in Switzerland, 30% in the Netherlands, 27% in Belgium, 23% in Denmark, 22% in Sweden, and 6% in Italy were preceded by a nontreatment decision (total of 5757 cases studied) whether or not combined with other end-of-life decisions. In all 6 countries, half to two thirds of these percentages were also the most important end-of-life decisions.<sup>13</sup>

Multiple treatments forgone were often reported for a single nontreatment decision, resulting in a total of 9407 treatments forgone. The ratio of treatments withheld to treatments withdrawn showed minor differences between countries. Except in Denmark, more treatments were not started at all than were stopped later. Overall, the ratio of treatments withheld to treatments withdrawn was 60% to 40%.

Medication was the most frequent life-sustaining treatment forgone in all countries except Italy, ranging from 33% for Italy to 54% for Denmark; the mean for all coun-

**Table 2. Different Types of Treatment Forgone in 6 European Countries\***

Treatment Type	Belgium (n = 1517)	Denmark (n = 1111)	Italy (n = 233)	The Netherlands (n = 3131)	Sweden (n = 1094)	Switzerland (n = 2321)	All 6 Countries (n = 9407)
Medication	42 (16 + 26)	54 (11 + 43)	33 (14 + 19)	38 (13 + 25)	37 (20 + 18)	48 (23 + 24)	44 (17 + 26)
Hydration or nutrition	20 (14 + 6)	14 (9 + 5)	38 (22 + 16)	25 (18 + 7)	30 (22 + 8)	18 (15 + 3)	22 (16 + 6)
Respiration	9 (7 + 2)	6 (4 + 1)	3 (2 + 0.8)	7 (3 + 4)	7 (5 + 2)	4 (3 + 1)	6 (4 + 2)
Oncotherapy	10 (6 + 3)	2 (1 + 0.7)	5 (2 + 3)	4 (2 + 1)	4 (3 + 1)	7 (5 + 3)	6 (4 + 2)
Surgery	6 (5 + 0.4)	5 (4 + 0.2)	2 (2 + 0.0)	4 (4 + 0.1)	7 (6 + 0.9)	7 (6 + 0.4)	6 (5 + 0.4)
Dialysis	3 (2 + 1)	2 (1 + 0.8)	3 (0.8 + 2)	2 (1 + 1)	4 (3 + 1)	2 (2 + 0.5)	3 (2 + 0.9)
General	11 (9 + 2)	18 (15 + 3)	16 (11 + 5)	19 (15 + 4)	10 (8 + 2)	14 (12 + 2)	15 (12 + 3)

\*"Forgone" indicates withheld plus withdrawn. Data are weighted column percentages rounded to whole numbers. Where the percentage is less than 1, numbers are given to 1 decimal place.

**Table 3. Different Types of Treatment Forgone According to Patient Characteristics (All 6 Countries)\***

Characteristic	Treatment Type							Total Treatments
	Medication	Hydration or Nutrition	Respiration	Oncotherapy	Surgery	Dialysis	General	
Age range, y (n = 9370)†								
1-64	12	10	24	<b>30</b>	16	19	13	14
65-79	31	29	41	40	31	<b>43</b>	30	32
≥80	57	<b>61</b>	35	31	53	38	57	54
Sex (n = 9373)‡								
Male	42	39	<b>53</b>	<b>53</b>	47	49	45	44
Female	58	<b>61</b>	47	47	53	51	55	56
Place of death (n = 9390)§								
Hospital	43	34	<b>88</b>	51	69	83	47	47
Other	57	<b>66</b>	12	49	31	17	53	53
Cause of death (n = 9406)¶								
Malignancy	26	31	16	<b>93</b>	35	16	28	31
Cardiovascular	26	20	28	4	<b>29</b>	26	25	24
Respiratory	13	7	<b>21</b>	0.3	4	6	9	10
Nervous system	14	<b>18</b>	14	1	9	4	11	13
Other or unknown	21	24	20	2	23	<b>49</b>	27	22

\*Data are weighted column percentages rounded to whole numbers. Where the percentage is less than 1, numbers are given to 1 decimal place. Row maxima are in bold.

†Information missing for 37 treatments forgone.

‡Information missing for 34 treatments forgone.

§Information missing for 17 treatments forgone.

¶Information missing for 1 treatment forgone. Cerebrovascular diseases were classified as diseases of the nervous system in Belgium, Denmark, the Netherlands, and Switzerland and as cardiovascular diseases in Italy and Sweden.

tries was 44% (**Table 2**). Forgoing hydration or nutrition was also common (18% in Switzerland to 38% in Italy; 22% on average). Measures less commonly forgone were respiration therapy (6% on average), oncotherapy (6%), surgery (6%), and dialysis (3%). In all, the distribution of treatments forgone was similar everywhere. Medication was forgone relatively often in Denmark, whereas forgoing oncotherapy and hydration or nutrition were uncommon. Among the few cases in Italy, hydration or nutrition was frequently forgone but surgery and medication only rarely. Throughout the study areas, virtually all treatments were more often withheld than withdrawn. Medications were the exception, being withdrawn rather than withheld, except in Sweden.

The distribution of age, sex, and cause and place of death of patients for whom nontreatment decisions were made was similar in all countries.<sup>13</sup> Further analysis according to patient characteristics showed that hydra-

tion or nutrition was forgone in older patients (61%) more frequently than average (54%), whereas respiration therapy (35%) or oncotherapy (31%) were comparatively seldom forgone in such patients (**Table 3**). On average, 56% of treatments forgone were in women. The percentage of women was higher in categories with a high proportion of older patients, especially hydration or nutrition (61%) and medication (58%). Forty-seven percent of all treatments forgone were for patients dying in the hospital, mainly respiration therapy, dialysis, and surgery (88%, 83%, and 69%, respectively).

Information on the life-shortening and decision-making process was available only if a nontreatment decision was the most important end-of-life decision (**Table 4**). The estimated shortening of life could therefore be attributed only to a single type of treatment in cases in which this was the only treatment forgone. The extent to which life was shortened (or not prolonged)

**Table 4. Different Types of Treatment Forgone According to Estimated Shortening of Life and Discussion With Patient or Relatives in 6 European Countries\***

Treatment Type	Belgium	Denmark	Italy	The Netherlands	Sweden	Switzerland	All 6 Countries
<b>Shortening of Life Estimated &gt;1 Month (n = 1976)†</b>							
Medication	5	4	2	7	0	9	6
Hydration or nutrition	7	8	0	10	0	2	5
Respiration	8	0	...	3	0	0	2
Oncotherapy	20	...	...	10	21	12	14
Surgery	22	13	...	19	0	9	12
Dialysis	18	...	...	38	22	25	25
General	7	1	3	11	3	9	6
Total treatments	9	5	3	10	2	8	7
<b>Treatment Forgone Discussed With Patient or Relatives (n = 5661)‡</b>							
Medication	85	66	57	95	67	82	80
Hydration or nutrition	85	81	75	94	70	82	83
Respiration	77	80	...	94	79	73	81
Oncotherapy	88	74	...	99	84	90	89
Surgery	91	86	...	90	66	85	84
Dialysis	100	91	...	97	80	97	93
General	82	71	74	95	54	78	79
Total treatments	85	72	68	95	69	82	82

\*Data are weighted percentages rounded to whole numbers. Ellipses indicate no separate percentages were calculated owing to the small number of cases (fewer than 10 unweighted cases).

†Information available only for cases in which a nontreatment decision was the most important end-of-life decision. Among these, numbers include cases only in which shortening of life was the result of 1 treatment forgone. Information missing for 128 treatments forgone.

‡Information available only for cases in which a nontreatment decision was the most important end-of-life decision. Information missing for 296 treatments forgone.

as a result of forgoing treatment was found to differ for each type of treatment and also from country to country. Overall, an estimated shortening of life by more than 1 month was rare in the respiration (2%), hydration or nutrition (5%), and medication categories (6%) but comparatively frequent when surgery (12%), oncotherapy (14%), and in particular dialysis were forgone (25%). Although these tendencies were similar in all countries, the percentages of forgone treatments estimated to have shortened life by more than 1 month were systematically higher in the Netherlands (10%), Belgium (9%), and Switzerland (8%) than in Denmark (5%), Italy (3%), and Sweden (2%). These figures hold when only a single treatment was forgone. Further analysis showed that the percentage of cases in which life was shortened by more than 1 month (the additive effect of all treatments forgone) decreased with increasing numbers of treatments forgone: 7% for 1 treatment, 5% for 2 treatments, and 4% when 3 treatments were mentioned.

In all countries, treatment forgone was discussed with the patient or relatives in more than 50% of cases. Dialysis was discussed most often (93%), followed by oncotherapy (89%) and surgery (84%). Discussion of such decisions with patients or relatives was found to be systematically more common in the Netherlands (95%), Belgium (85%), and Switzerland (82%) than in Denmark (72%), Sweden (69%), or Italy (68%).

Taking all countries together, approximately half (49%) of the nontreatment decisions were to withhold medical treatment; the remainder included decisions to withdraw and decisions to withhold and withdraw treatment (**Table 5**). The percentage of decisions to withhold was higher in patients 80 years/or older (54%), in

those dying outside the hospital (53%), and when the estimated shortening of life exceeded 1 month (62%). Multiple logistic regression analysis revealed that old age (odds ratio [OR], 1.53; 95% CI, 1.31-1.79), death outside the hospital (OR, 0.80; 95% CI, 0.68-0.93 for in the hospital), and greater life-shortening effect (OR, 1.75; 95% CI, 1.27-2.39) contributed independently to the likelihood that a decision would be made to withhold a possible life-sustaining treatment (instead of withdrawing it). No significant association with withholding or withdrawing treatment was found for sex, cause of death, or discussion with the patient or relatives.

#### COMMENT

The EURELD project is the first study on end-of-life decisions based on large representative samples of deaths from whole populations of different countries or regions across Europe. The data provide a comprehensive overview of the practice of deciding to forgo potentially life-prolonging treatment. Some aspects of this study (types of treatment forgone as well as factors of age, sex, and place and cause of death) have so far been the subject of similar investigations only in the Netherlands.<sup>14,15</sup> Other issues, such as the effect of the decision to shorten life by forgoing different treatments and the relationship between treatments withheld and treatments withdrawn, have never previously been investigated in this way.

Studies of such sensitive areas call for the utmost care. In all countries, after seeking the support of professional medical organizations or other authorities, the study

was announced in national or regional medical journals. Physicians were informed about the special procedure of interposing a notary's office to guarantee anonymity. All questions were formulated as neutrally as possible, avoiding terms such as *nontreatment decision*, *euthanasia*, or *physician-assisted suicide*. As with all surveys, nonresponse could have biased the results: this holds true especially for Italy, where the response rate was less than 50%. In addition, the possibility cannot be ruled out that some answers were influenced by considerations of social acceptability (which might vary considerably from country to country). This may be reflected in the answers not only to questions on decisions made or not made but also to questions on discussions with patients and relatives and on estimated shortening of life. Finally, different concepts of futility may have affected perceptions of when the nonapplication of a therapeutic option is a nontreatment decision.<sup>16</sup>

Nontreatment decisions are influenced by both cultural and medical factors. Important cultural differences can be expected to have country-specific effects on end-of-life practices. A recent international study on neonatal end-of-life decision making showed that country is the most important predictor of a physician's attitudes and practices.<sup>17</sup> On the other hand, because all regions participating in this study enjoy high medical standards, medical factors can be expected to affect end-of-life decisions similarly in all 6 countries.

Our data show systematic differences among the countries with respect to incidence, decision making, and estimated shortening of life. Swiss and Dutch physicians report distinctly more nontreatment decisions than physicians from the other countries, whereas Italian physicians report markedly fewer. In the Netherlands, Switzerland, and Belgium, forgoing treatment is discussed more often than in Denmark or, to an even greater extent, Sweden and Italy. Finally, estimated shortening of life because of a treatment forgone is clearly higher in the Netherlands, Switzerland, and Belgium than in Denmark, Italy, or Sweden. These findings can be interpreted that physicians in the first 3 countries are more willing to distance themselves from an absolute duty to sustain life to comply with their patients' wishes, thus reflecting cultural differences in end-of-life attitudes. Such an interpretation is consistent with earlier reports from this study that showed the incidence of end-of-life decisions is highest overall in Switzerland, that active forms (physician-assisted death) are highest in the Netherlands and Belgium, and that in these 3 countries end-of-life decisions are discussed with patients and relatives more frequently than in Denmark, Sweden, or Italy.<sup>13</sup> Moreover, these findings agree with several recent European studies on physicians' attitudes and practices. Studying end-of-life decisions in neonatal intensive care from physicians' self-reported practices in 7 European countries (including Italy, the Netherlands, and Sweden), Cuttini et al<sup>18</sup> showed that most physicians from Sweden and the Netherlands, but fewer from Italy, reported having at least once limited the intensive care of infants with incurable conditions or poor neurologic prognosis. In a prospective observational study of 37 European intensive care units, Sprung et al<sup>8</sup> found forgoing

**Table 5. Determinants of Decisions to Withhold or Withdraw Treatment (All 6 Countries)\***

Characteristic	Decision to Withhold (n = 1556), %	Decision to Withdraw (n = 1637), %†	Determinant for Withholding, OR (95% CI)‡
All cases	49	51	NA
Age range, y			1.53 (1.31-1.79)§
1-64	38	62	
65-79	44	56	
≥80	54	46	
Sex			0.88 (0.76-1.02)¶
Male	49	51	
Female	49	51	
Place of death			0.80 (0.68-0.93)¶¶
Hospital	45	55	
Other	53	47	
Cause of death			1.13 (0.95-1.34)#
Malignancy	49	51	
Cardiovascular	47	53	
Respiratory	55	45	
Nervous system	46	54	
Other or unknown	50	50	
Shortening of life			1.75 (1.27-2.39)**
≤1 mo	48	52	
>1 mo	62	38	
Discussion with patient or relatives			0.90 (0.76-1.08)††
Yes	49	51	
No	50	50	

\*Data in columns 1 and 2 are weighted row percentages. All percentages are rounded to whole numbers. Information available only for cases in which the nontreatment decision was the most important end-of-life decision (284 cases missing overall).

†Includes cases in which treatments were both withheld and withdrawn.

‡Determined using multiple logistic regression analysis with dichotomized variables.

§For age ≥80 (reference category is ages 1-79).

¶For female (not significant).

¶¶For hospital.

#For malignancy (reference category is cause of death other than cancer [not significant]).

\*\*For shortening of life more than 1 month.

††For no discussion (not significant).

treatment to be more common in northern (86%) and central (68%) than in southern Europe (57%), whereas active shortening of the dying process was most common in central European countries (7%) but markedly less common in the north (1%) and south (0%).

The differences described herein contrast with the relative similarities of the individual countries regarding the distribution of the different types of treatment; sociodemographic factors such as age, sex, and place and cause of death; and the ratio of treatments withheld and withdrawn. These parameters seem to be medically influenced to a high degree. In all 6 countries, low-technology interventions, such as medication or hydration or nutrition, were the therapies most frequently forgone, mainly in older patients and comparatively often in nursing homes. Earlier Dutch studies<sup>14,15</sup> that investigated treatments forgone and sociodemographic parameters yielded similar results.

Like the present study, these Dutch projects focused on information about medical treatment in cases in which such treatment was forgone. Because the data did not include any information about treatment continued until the

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end of life, no relative withdrawal percentages could be calculated for all patients who received a particular treatment. These percentages would clearly be higher for interventions that are considered less often (eg, dialysis).<sup>1,2</sup>

Despite differences among individual countries, little overall effect on the estimated shortening of life resulted from forgoing low-technology interventions. In other words, with respect to prolonging life, many physicians seem to consider such interventions almost futile, which could explain the comparatively low rate of discussion with patients and/or relatives. A few authors have stated that health care professionals may or should forgo futile measures without informing the patient, although a growing majority agree that the patient should at least be informed even if not involved in joint decision making.<sup>16,19</sup>

High-technology treatments, such as respiration therapy, oncology, surgical interventions, and dialysis, are associated with a greater burden of treatment for patients. When dialysis, oncology, and surgical interventions were forgone in our study patients, a substantial decrease in survival time often resulted, and this could explain why precisely these treatments were more often discussed with patients and relatives. Dispensing with treatment that has substantial effects on expected survival time clearly needs the patient's explicit consent.

In many cases, forgoing one particular treatment does not mean that death is either imminent or inevitable, resulting in a stepwise retreat.<sup>1,9</sup> The estimated shortening of life can then be difficult to attribute to a single category. Our analysis was therefore restricted to cases in which death occurred after forgoing a single treatment (ie, when in retrospect death was judged to be the possible or inevitable consequence of forgoing one specific treatment). These results show a remarkable correlation with the mean ranks for forgoing specific interventions in hospitalized patients, as reported by Faber-Langendoen.<sup>1</sup> In that study, surgery and dialysis were among treatments forgone early, whereas intravenous fluids, medication, nutrition, and mechanical ventilation were forgone later (there was no separate oncology category). That the estimated shortening of life was lower, not higher, when more than 1 treatment was forgone is a further indication that stepwise retreats may also have played an important role in our study population.

Research that directly compares withholding and withdrawing of treatment is scarce. In a study of hospitalized patients who developed renal failure, physicians pre-

ferred not to start potentially life-sustaining treatment in older patients rather than stopping it later.<sup>2</sup> Possible reasons may be that physicians do not want to encumber elderly patients with the associated extra burden of treatment or the patients themselves do not wish for this. Furthermore, increasing comorbidity with age may mean that an intervention is seen from the start as less favorable than in younger patients. It has nevertheless been shown that even after adjustment for prognosis and patients' care preferences, seriously ill older patients are treated less aggressively than younger patients.<sup>20</sup> The accumulation of treatment forgone outside the hospital found in our study may be due to certain therapies being available only in hospitals. Withholding treatment may be chosen to allow patients to remain in their customary surroundings. The association of marked life-shortening effects and withholding treatment may to some extent be a result of a stepwise retreat, in which withholding is typically decided on early but withdrawal only somewhat later.<sup>1</sup>

The work presented herein is one part of a series of studies that are improving our knowledge of medical non-treatment decisions by quantifying medical case records and questioning physicians. Further research should place greater emphasis on the patient's viewpoint and consider subjective parameters such as quality of life.<sup>21</sup> In this context, Battin<sup>22</sup> showed more than 20 years ago that many patients' belief that treatment refusal leads to a "natural" and dignified (rather than medically prolonged) death can in fact be a misconception. It is still an open question whether the relationship between old age and less aggressive treatment is better explained by the withholding of life-prolonging treatment from older patients or excessive provision of nearly ineffective treatment to younger patients.<sup>20</sup> An important future task must therefore be to obtain evidence of the circumstances in which nontreatment decisions help the patient achieve the peaceful death that is considered an explicit goal of modern medicine.<sup>23</sup>

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## REFERENCES

1. Faber-Langendoen K. A multi-institutional study of care given to patients dying in hospitals. *Arch Intern Med.* 1996;156:2130-2136.
2. Wenger NS, Lynn J, Oye RK, et al. Withholding versus withdrawing life-sustaining treatment: patient factors and documentation associated with dialysis decisions. *J Am Geriatr Soc.* 2000;48:S75-S83.
3. Sullivan M, Ormel J, Kempen GI, Tymstra T. Beliefs concerning death, dying, and

- hastening death among older, functionally impaired Dutch adults: a one-year longitudinal study. *J Am Geriatr Soc.* 1998;46:1252-1257.
4. Vincent JL. Forgoing life support in western European intensive care units: the results of an ethical questionnaire. *Crit Care Med.* 1999;27:1626-1633.
5. McCarthy EP, Phillips RS, Zhong Z, Drews RE, Lynn J. Dying with cancer: patients' function, symptoms, and care preferences as death approaches. *J Am Geriatr Soc.* 2000;48(suppl 5):S110-S121.
6. Prendergast TJ, Claessens MT, Luce JM. A national survey of end-of-life care for critically ill patients. *Am J Respir Crit Care Med.* 1998;158:1163-1167.
7. Onwuteaka-Philipsen BD, Pasman HRW, Kruit A, van der Heide A, Ribbe MW, van der Wal G. Withholding or withdrawing artificial administration of food and fluids in nursing-home patients. *Age Ageing.* 2001;30:459-465.
8. Sprung CL, Cohen SL, Sjøkvist P, et al. End-of-life practices in European intensive care units. *JAMA.* 2003;290:790-797.
9. Asch DA, Faber-Langendoen K, Shea JA, Christakis NA. The sequence of withdrawing life-sustaining treatment from patients. *Am J Med.* 1999;107:153-156.
10. van der Maas PJ, van Delden JJM, Pijnenborg L, Looman CWN. Euthanasia and other medical decisions concerning the end of life. *Lancet.* 1991;338:669-674.
11. van der Maas PJ, van der Wal G, Haverkate I, et al. Euthanasia, physician-assisted suicide, and other medical practices involving the end of life in the Netherlands, 1990-1995. *N Engl J Med.* 1996;335:1699-1705.
12. Deliens L, Mortier F, Bilsen J, et al. End-of-life decisions in medical practice in Flanders, Belgium: a nationwide survey. *Lancet.* 2000;356:1806-1811.
13. van der Heide A, Deliens L, Faisst K, et al. End-of-life decision-making in six European countries: descriptive study. *Lancet.* 2003;362:345-350.
14. Pijnenborg L, van der Maas PJ, Kardaun JWPF, Glerum JJ, van Delden JJM, Looman CW. Withdrawal or withholding of treatment at the end of life. *Arch Intern Med.* 1995;155:286-292.
15. Groenewoud JH, van der Heide A, Kester JGC, de Graaff CLM, van der Wal G, van der Maas PJ. A nationwide study of decisions to forego life-prolonging treatment in Dutch medical practice. *Arch Intern Med.* 2000;160:357-363.
16. Lofmark R, Nilstun T. Conditions and consequences of medical futility: from a literature review to a clinical model. *J Med Ethics.* 2002;28:115-119.
17. Rebagliato M, Cuttini M, Broggin L, et al. Neonatal end-of-life decision making: physicians' attitudes and relationship with self-reported practices in 10 European countries. *JAMA.* 2000;284:2451-2459.
18. Cuttini M, Nadai M, Kaminski M, et al. End-of-life decisions in neonatal intensive care: physicians' self-reported practices in seven European countries. *Lancet.* 2000;355:2112-2118.
19. van Delden JJ, van der Maas PJ, Pijnenborg L, Looman CWN. Deciding not to resuscitate in Dutch hospitals. *J Med Ethics.* 1993;19:200-205.
20. Hamel MB, Lynn J, Teno JM, et al. Age-related differences in care preferences, treatment decisions, and clinical outcomes of seriously ill hospitalized adults: lessons from SUPPORT. *J Am Geriatr Soc.* 2000;48(suppl 5):S176-S182.
21. Paci E, Miccinesi G, Toscani F, et al. Quality of life assessment and outcome of palliative care. *J Pain Symptom Manage.* 2001;21:179-188.
22. Battin M. The least worst death. *Hastings Cent Rep.* 1983;13:13-16.
23. The goals of medicine: setting new priorities. *Hastings Cent Rep.* 1996;26(6):S1-S27.