

Original Article

Care and Decision-Making at the End of Life for Patients With a Non-Western Migration Background Living in The Netherlands: A Nationwide Mortality Follow-Back Study



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Abstract

Context. Migrant populations across Europe are aging and will increasingly need end-of-life care.

Objective. The objectives of this study were to gain insight into end-of-life care and decision-making for patients with a non-western migration background and assess differences compared to patients with a Dutch or western migration background.

Methods. A mortality follow-back study was conducted using a stratified sample of death certificates of persons who died between August and December 2015, obtained from the central death registry of Statistics Netherlands. Questionnaires were sent to the attending physician ($n = 9351$; response 78%). Patients aged ≥ 18 years who died a nonsudden death were included in this study ($n = 5327$).

Results. Patients with a non-western migration background are more likely than patients with a Dutch or western migration background to be admitted to and die in hospital (51.6% vs. 33.9% [OR 1.74; 95% CI 1.26–2.41]; 39.1% vs. 20.1% [OR 1.96; 95% CI 1.39–2.78]); less likely to receive morphine or morphine-like medication and continuous deep sedation (72.8% vs. 80.1% [OR 0.62; 95% CI 0.43–0.89]; 16.8% vs. 25.2% [OR 0.52; 95% CI 0.34–0.80]); and more likely to receive end-of-life care that, according to physicians, is directed at cure for too long (6.8% vs. 1.7% [OR 3.61; 95% CI 1.83–7.12]). End-of-life decisions are made less frequently for patients with a non-western migration background (71.6% vs. 79.2% [OR 0.64; 95% CI 0.45–0.91]). Characteristics of decision-making are similar.

Conclusion. End-of-life care for patients with a non-western migration background focuses more, or longer on maximum, curative treatment and end-of-life decisions are made less often. *J Pain Symptom Manage* 2020;59:990–1000. © 2019 American Academy of Hospice and Palliative Medicine. Published by Elsevier Inc. All rights reserved.

Key Words

End-of-life care, end-of-life decision-making, migrant patients

Key Message

This article describes a nationwide mortality follow-back study into end-of-life care and decision-making for patients with a non-western migration background.

The results indicate end-of-life care, compared to patients with a Dutch or western migration background, focuses more or longer on maximum, curative treatment, and end-of-life decisions are made less often.

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Accepted for publication: November 26, 2019.

Introduction

Migrant populations across Europe are aging. In The Netherlands, adults with a non-western migration background make up 4% of the population aged 65 years and older. Their number is expected to increase to 17% in 2060.¹ As populations age, the pattern of diseases people suffer and die from changes; more people die from chronic disease and the people needing care are much older. Societies are confronted with the challenge of taking care of frail and older people and guaranteeing them a good quality of life.² Palliative care is an approach that improves the quality of life of patients and their families facing the problems associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems—physical, psychosocial, and spiritual.³ In The Netherlands, palliative care is delivered by generalists, who are supported by health care professionals specialized in palliative care, for example, from palliative care units, consultation teams, or hospices, when required.⁴ The costs of palliative care are covered by either the general health insurance or the long-term care act.

To ensure good care at the end of life, quality indicators, for example, proportion of home deaths on population level or documentation of treatment preferences, have been established.⁵ What is perceived as good care, however, may vary based on cultural values. In The Netherlands, patients with a Turkish and Moroccan background were found to have contrasting ideas regarding end-of-life care compared to their Dutch providers; they preferred not to have negative prognosis disclosed, preferred maximum and curative treatment, and strongly preferred care by their families.⁶ Whether actual differences in end-of-life care and decision-making exist is less evident. Available studies often focus on access to and use of specific services, whereas population based studies—focusing on all types and settings of end-of-life care and all patients—needed to assess actual differences are scarce.^{7–10}

A population-based study on place of death found first-generation migrants in London were more likely to die in hospital and less likely to die in hospice or at home than those born in the U.K.¹¹ A nationwide study from The Netherlands, in 2005, similarly found patients with a non-western migration background more often died in hospital.¹² It furthermore found slight variation in end-of-life decisions (ELDs), for example, decisions to withhold or withdraw treatment or to alleviate pain or symptoms taking into account potential hastening of death, compared to patients with a Dutch or western migration background; the ELD to intensify symptom alleviation taking into account potential hastening of death was made less

often for patients with a non-western migration background.¹² Over the years, there has been an increase in attention for palliative care, and the percentage of persons for whom an end-of-life decision preceded death increased from 43% in 2005 to 58% in 2015.^{13–15} The objective of this study was to gain insight into current end-of-life care and decision-making practices for patients with a non-western migration background living in The Netherlands. This leads to the following research questions:

1. What are end-of-life care practices for patients with a non-western migration background living in The Netherlands?
2. What end-of-life decisions are made, and what are the characteristics of decision-making for patients with a non-western migration background living in The Netherlands?
3. What are the differences in end-of-life care and decision-making for deceased patients with a non-western migration background compared to deceased patients with a Dutch or western migration background living in The Netherlands?

Methods

Design

We performed a mortality follow-back study in 2015, which was largely similar to studies in 1990, 1995, 2001, 2005, and 2010.^{13,16–18} A stratified sample of 9351 death certificates of persons who died between August and December was obtained from the central death registry of Statistics Netherlands, which receives death certificates for all deaths in The Netherlands. All deaths were assigned to one of 10 strata, allowing for oversampling of persons with a higher likelihood of an end-of-life decision having been made and persons with a non-western migration background (see [Appendix Table 1](#) for a description of all strata). Questionnaires were sent to the physician listed on the death certificate. Physicians were asked to forward the questionnaire to the attending physician, in the case they themselves were not the attending physician. The anonymity of both physicians and patients was guaranteed; returned questionnaires were opened only after information about the identities of the patient and physician had been removed. The questionnaire was first developed for the mortality follow-back study performed in 1991. Validation studies were performed in 1991 and 1995.^{19,20} In subsequent years, the questionnaire was altered as little as possible (see [Appendix II](#) for the questionnaire used in this study). Further details on the study design are described elsewhere.¹³

Ethics

Ethical approval for the posthumous collection of anonymous patient data was not required under the Dutch Medical Research Involving Human Subjects Act.²¹ Informed consent of the physicians was assumed on return of the questionnaire.

Population

Out of the 9351 sampled death certificates, 7277 questionnaires were returned, resulting in a response rate of 78%. In this study, we included data of patients aged ≥ 18 years who died a nonsudden and expected death, from here on referred to as “nonsudden.” We included 5327 cases; 605 were patients with a non-western migration background, 4277 were patients with a Dutch or western migration background.

Data Collection

Questionnaire. The written questionnaire sent to the attending physicians contained questions on care and decision-making at the end of life. With regards to care, there were questions regarding hospital admission in the last month, caregivers involved in the last month, morphine administration in the last 24 hours, continuous deep sedation until death, appropriateness of end-of-life care according to the physician, and place of death. With regards to decision-making, there were four key questions on end-of-life decisions, inquiring whether the responding physician had withheld or withdrawn medical treatment taking into account possible hastening of death; had intensified measures to alleviate pain or other symptoms taking into account possible hastening of death; had withheld or withdrawn medical treatment with the explicit intention of hastening death; or had administered, supplied, or prescribed drugs with the explicit intention of hastening death, resulting in the patient's death. If the last question was answered affirmatively and the act was done in response to an explicit request from the patient, this classified as euthanasia or assisted suicide (depending on whether the patient had taken the drugs themselves). If more than one of the key questions was answered affirmatively, the act that involved the most explicit intention was used to classify the case. These key questions were followed by questions about the decision-making process and the degree to which death had been hastened, as estimated by the physician. In the questionnaire, we additionally asked whether the patient had suffered from a psychiatric illness, dementia, or an accumulation of health problems related to old age.

Additional Sources. The cause of death was derived from the death certificate. Data on the deceased persons' migration background, age, sex, and marital

status were derived from the municipal administration registers. In Dutch, the term “persons” with a migration background is used to refer to both migrants and their descendants. According to the definition by Statistics Netherlands, someone has a migration background if that person or at least one of their parents was born outside The Netherlands. In case they or at least one of their parents were born in Europe (excluding Turkey), North America or Oceania, Indonesia or Japan, the person has a western migration background. Someone has a non-western migration background if they or at least one of their parents were born in any other country.²² The grouping of countries in the category western is based on assumed similarities with regard to socioeconomic and cultural position.²³ In this study, the population is grouped into two categories: “non-western migration background” and “Dutch or western migration background.” Owing to privacy rules of Statistics Netherlands, it was not possible to specify migration background in more detail. In 2015, 56% of all persons with a migration background had a non-western migration background, most commonly a Turkish (19.5%), Moroccan (18.7%), or Surinamese (17.1%) background.²⁴

Data Analysis

Statistical analyses were carried out using IBM SPSS Statistics Version 22 (IBM Corp., Armonk, NY). All cases were weighted to adjust for the sampling fractions and differences in response rates in relation to age, sex, marital status, region of residence, and cause and place of death. As a result of this weighting procedure, the percentages presented cannot be derived from the absolute unweighted numbers presented. We performed χ^2 tests to assess the significance of differences in background characteristics between patients with a non-western migration background and patients with a Dutch or western migration background. We performed logistic regression analyses to assess the difference in end-of-life care and decision-making between these patient groups. We used migration background as the independent variable, whereby the category Dutch or western migration background was used as the reference group, and care and decision-making characteristics as dependent variables. We calculated odds ratios for migration background, univariable and multivariable, adjusting for age, sex, and cause of death.

Results

Population Characteristics

Table 1 portrays characteristics of both the general and study population. There is a difference in age structure in the general population, with a smaller

Table 1
Background Characteristics of Deceased Persons With a Non-Western Migration Background and Dutch & Western Migration Background (for All Deaths and Nonsudden Deaths)

Patient Characteristics	General Population ²⁴		All Deaths		<i>P</i>	Nonsudden Deaths		<i>P</i>
	Non-Western Migr. Background	Dutch & Western Migr. Background	Non-Western Migr. Background	Dutch & Western Migr. Background		Non-Western Migr. Background	Dutch & Western Migr. Background	
	Total <i>N</i> = 2,038,509	Total <i>N</i> = 14,862,217	Total <i>N</i> = 891	Total <i>N</i> = 6,107		Total <i>N</i> = 605	Total <i>N</i> = 4,722	
	%	%	<i>n</i> (%) ^a	<i>n</i> (%) ^a		<i>n</i> (%) ^a	<i>n</i> (%) ^a	
Age					<0.001			<0.001
17–64	92.3 ^b	75.1 ^b	354 (39.1)	1,061 (13.5)		200 (32.1)	802 (12.0)	
65–79	6.8	18.7	320 (35.7)	2,181 (30.7)		239 (39.5)	1,692 (30.4)	
80+	0.9	6.2	217 (25.2)	2,865 (55.8)		166 (28.4)	2,228 (57.7)	
Gender					0.001			0.030
Male	50.1	49.5	523 (58.6)	3,054 (47.6)		332 (54.3)	2,318 (45.7)	
Female	49.9	50.5	368 (41.4)	3,053 (52.4)		273 (45.7)	2,404 (54.3)	
Marital status								
Married or partnership	30.5	41.3	383 (43.0)	2,708 (40.3)	<0.001	281 (45.4)	2,249 (41.6)	<0.001
Unmarried	59.8	45.8	171 (19.0)	617 (9.6)		100 (16.6)	382 (8.0)	
Divorced	8.3	7.3	203 (22.4)	637 (9.7)		128 (21.5)	461 (9.3)	
Widowed	1.4	5.6	134 (15.6)	2,145 (40.3)		96 (16.6)	1,630 (41.1)	
Cause of death					0.007			0.331
Cancer			296 (28.7)	3,116 (30.6)		267 (37.0)	2,861 (37.1)	
Cardiovascular disorder			173 (17.7)	821 (20.6)		80 (12.3)	460 (15.0)	
Pulmonary disorder			40 (5.5)	338 (8.9)		31 (6.2)	254 (8.6)	
Neurological disorder			102 (9.7)	550 (12.0)		76 (11.1)	442 (12.6)	
Other			280 (38.4)	1,282 (27.9)		151 (33.3)	705 (26.8)	
Conditions ^{c,d}								
Psychiatric disorder			62 (7.6)	193 (4.2)	0.012	27 (4.3)	133 (3.5)	0.572
Dementia			97 (11.4)	894 (22.2)	<0.001	74 (13.0)	729 (24.0)	0.001
Accumulations of health problems related to old age			132 (16.1)	1,050 (24.3)	0.004	87 (16.0)	829 (25.0)	0.009
Sudden and unexpected death					0.029			
Yes			286 (31.6)	1,385 (25.4)				
No			605 (68.4)	4,722 (74.6)				

^aWeighted column percentage.

^bOwing to different age groups used by the central bureau for statistics, these numbers refer to the age group 20–65.

^cDeceased patients could have had a combination of psychiatric disorder, dementia, and/or an accumulation of health problems.

^dMissing *n* = 374 (This value refers to the patients for whom it was clear that death was sudden and unexpected, and therefore, no questionnaire had been sent out to the attending physician).

percentage of adults aged ≥ 65 years among the population with a non-western migration background (67.9%) compared to the population with a Dutch and western migration background (88.1%).²⁴ Of all deaths, 68.4% of deaths of patients with a non-western migration background and 74.6% of deaths of patients with a Dutch or western migration background were nonsudden. Among nonsudden deaths, we found no significant differences in cause of death; compared to other patients, patients with a non-western migration background suffered less often from dementia (13% compared to 24%) and an accumulation of health problems associated with old age (16% compared to 25%).

Care at the End of Life

Of patients with a non-western migration background who died a nonsudden death, 51.6% had been admitted to the hospital in the last month and 39.1% died in the hospital (see Table 2). They were more likely than patients with a Dutch or western migration background to be admitted to the hospital (adjusted OR 1.74; 95% CI 1.26–2.41) and die in the hospital (adjusted OR 1.96; 95% CI 1.39–2.78). There were no differences in the type of caregivers involved between patients with a non-western migration background and other patients; a palliative care team was consulted in 14.2% and 12.9% and a spiritual counselor in 13.6% and 13.1%, respectively.

Morphine or morphine-like medication was administered in the last 24 hours of life to 72.8% of the patients with a non-western migration background. This was less often than it was administered to patients with a Dutch or western migration background (adjusted OR 0.62; 95% CI 0.43–0.89). Patients with a non-western migration background also received continuous deep sedation less often (16.8% vs. 25.2%; adjusted OR 0.52; 95% CI 0.34–0.80). And during continuous deep sedation, they received artificial nutrition or hydration more often than other patients (29.6% vs. 8.6%, adjusted OR 3.20; 95% CI 1.23–8.33).

Physicians regarded the provided end-of-life care as appropriate in 89.4% of the cases for patients with a non-western migration background; this was less often than for patients with a Dutch or western migration background (adjusted OR 0.39; 95% CI 0.21–0.70). When physicians regarded care as not appropriate, for patients with a non-western migration background, this was more likely because, according to physicians, care was directed at curation for too long (adjusted OR 3.61; 95% CI 1.83–7.12).

End-of-Life Decision-Making

In 71.6% of cases of patients with a non-western migration background who died a nonsudden death,

an ELD had been made (see Table 3). Intensified pain and symptom alleviation was the most common ELD (43.2%), followed by foregoing life-prolonging treatment (25.9%) and euthanasia or physician-assisted suicide (1.9%). ELDs were made less frequently than for patients with a Dutch or western migration background (adjusted OR 0.64; 95% CI 0.45–0.91) (Table 3). In the case an ELD was made, euthanasia and physician-assisted suicide was less common for patients with a non-western migration background (adjusted OR 0.24; 95% CI 0.09–0.77).

Characteristics of End-of-Life Decision-Making

In the case an ELD was made, the possible hastening of death was discussed with patients with a non-western migration background in 41.9% of the cases (see Table 4). When consequences of the decision were discussed with others, these were most often the patient's partner or family (49.5%), other physicians (46.2%), a nurse or other formal caregiver (28.2%). When a discussion took place, patients with a non-western migration background were more often not fully competent at the time of discussion (adjusted OR 2.19; 95% CI 1.01–4.79). Furthermore, when a discussion did not take place, physicians reported the fact that the patient was subconscious or unconscious as the most important reason not to discuss the consequences of the ELD with the patient (44.3%). There was mostly either no shortening of life due to the ELD (58.1%), or one of less than 24 h (19.0%). None of this was significantly different compared to patients with a Dutch or western migration background.

For patients with a non-western migration background, 27.9% of ELDs, were made at the explicit request of the patient. This was less frequent than for patients with a Dutch or western migration background (adjusted OR 0.44; 95% CI 0.28–0.70). If ELDs were made at the explicit request of the patient, patients with a non-western migration background less often had a verbal and written request (adjusted OR 0.31; 95% CI 0.11–0.83). Of patients with a non-western migration background, 16.3% had ever expressed a wish to forego treatment (clearly or unclearly). This was also less frequent than patients with a Dutch or western migration background (adjusted OR 0.30; 95% CI 0.17–0.51). No perspective on improvement was physicians' most important reason for ELDs in all patients. Physicians less often mentioned patient's request, severe symptoms, and loss of dignity as the most important reason for the treatment decision for patients with a non-western migration background (adjusted OR 0.41, 95% CI 0.23–0.73; adjusted OR 0.63, 95% CI 0.42–0.94; adjusted OR 0.44, 95% CI 0.22–0.89, respectively).

Table 2
Care Received at the End of Life of Patients With a Non-Western Migration Background and Dutch & Western Migration Background (for Nonsudden Deaths)

	Non-Western Migration Background	Dutch & Western Migration Background	Odds Ratio ^a			
	Total N = 605	Total N = 4722				
Care at the end of life	n (%) ^b	n (%) ^b	Unadjusted	CI (95%)	Adjusted ^c	CI (95%)
Hospital admission in the last month ^d						
Yes	298 (51.6)	1619 (33.9)	2.09	1.53–2.86	1.74	1.26–2.41
If yes, duration of hospital admission: ^e	n = 298	n = 1619				
≥1 week	130 (45.5)	863 (54.9)	0.69	0.44–1.10	0.73	0.46–1.17
<1 week	146 (54.5)	597 (45.1)	1.44	0.91–2.28	1.37	0.86–2.19
Place of death ^d						
Home	220 (31.3)	2279 (33.2)	0.90	0.65–1.27	0.75	0.52–1.10
Hospital	208 (39.1)	663 (20.1)	2.58	1.87–3.56	1.96	1.39–2.78
Care home	16 (2.5)	357 (10.0)	0.25	0.10–0.65	0.41	0.16–1.10
Nursing home	96 (16.8)	824 (25.8)	0.57	0.38–0.87	0.75	0.47–1.20
Hospice or palliative care unit	59 (9.9)	564 (10.1)	0.96	0.57–1.63	0.99	0.57–1.71
Other	3 (0.6)	23 (0.6)	0.74	0.08–7.20	0.61	0.06–6.07
Caregivers involved in the last month ^f	n = 605	n = 4722				
Palliative care consultant/team	92 (14.2)	795 (12.9)	1.12	0.71–1.75	1.05	0.66–1.67
Specialist pain control	26 (4.3)	167 (2.4)	1.71	0.77–3.80	1.18	0.52–2.67
Psychiatrist/psychologist	37 (6.8)	250 (6.0)	1.10	0.58–2.07	0.97	0.51–1.85
Spiritual counselor	81 (13.6)	580 (13.1)	1.03	0.65–1.63	1.15	0.72–1.82
Morphine or morphine-like medication administered in the last 24 h ^d						
Yes	446 (72.8)	3754 (80.1)	0.67	0.47–0.95	0.62	0.43–0.89
Continuous deep sedation ^d						
Yes	98 (16.8)	1173 (25.2)	0.59	0.39–0.90	0.52	0.34–0.80
If yes, artificial nutrition or hydration during sedation	n = 98	n = 1173				
Yes	26 (29.6)	66 (8.6)	4.75	2.05–11.03	3.20	1.23–8.33
If yes, amount of time between start of sedation and death	n = 98	n = 1173				
0–24 hours	39 (38.5)	446 (38.5)	1.02	0.46–2.23	1.02	0.46–2.23
1–7 days	50 (51.9)	661 (56.3)	0.81	0.38–1.74	0.80	0.37–1.75
<1 week	8 (7.7)	32 (3.0)	3.26	0.85–12.59	2.90	0.72–11.64
Appropriateness of end-of-life care according to physician ^{d,f}						
Appropriate care	540 (89.4)	4542 (95.3)	0.30	0.17–0.53	0.39	0.21–0.70
Not appropriate						
Directed at curation for too long	39 (6.8)	66 (1.7)	4.21	2.19–8.09	3.61	1.83–7.12
Too little symptom alleviation	6 (1.2)	15 (0.4)	2.42	0.51–11.35	1.41	0.29–6.87
Too little psychosocial or spiritual care	6 (1.2)	13 (0.2)	5.49	1.18–25.48	3.81	0.79–18.42
Not specified	4 (0.6)	34 (0.8)	0.92	0.14–6.23	0.68	0.10–4.73

Bold values indicate a *P*-value < 0.05.

^aOdds ratio is for migration background (reference group Dutch or western migration background).

^bWeighted column percentage.

^cAdjusted for age, sex, and cause of death.

^dMissing values between 1 (0.2%) and 15 (2.5%) for patients with a non-western migration background and between 3 (0.1%) and 67 (1.4%) for patients of Dutch and western background.

^eMissing *n* = 181 (about 9% but rates are comparable for patients with non-western migration background (7.4%) and patients with a Dutch and western migration background (9.8%).

^fMore than one answer possible.

Discussion

Statement of Principal Findings

Our study shows that patients with a non-western migration background compared to patients with a Dutch or western migration background, in the case of a nonsudden death, are more likely to be admitted

to, and die in the hospital, less likely to receive morphine or morphine-like medication and continuous deep sedation, and more likely to receive end-of-life care that, according to physicians, is directed at curation too long. Involvement of caregivers, such as a palliative care consultant, does not differ.

Table 3
Decision-Making at the End of Life for Patients With a Non-Western Migration Background and Dutch & Western Migration Background (for Nonsudden Deaths)

	Non-Western Migr. Background	Dutch & Western Migr. Background	Odds Ratio ^a			
	Total N = 605	Total N = 4722				
End-of-life decision-making	n (%) ^b	n (%) ^b	Unadjusted	CI (95%)	Adjusted ^c	CI (95%)
Yes	434 (71.6)	3828 (79.2)	0.67	0.47–0.95	0.64	0.45–0.91
Most important end-of-life decision						
Euthanasia and assisted suicide	15 (1.9)	830 (6.4)	0.32	0.11–0.93	0.26	0.09–0.77
Ending of life without explicit patient request	3 (0.6)	15 (0.4)	1.40	0.17–11.63	1.10	0.13–9.36
Intensified alleviation of pain and symptoms	271 (43.2)	2158 (48.9)	0.80	0.58–1.09	0.84	0.61–1.16
Foregoing life-prolonging treatment	144 (25.9)	825 (23.4)	1.14	0.80–1.63	1.09	0.75–1.57

Bold values indicate a *P*-value < 0.05.

^aOdds ratio is for migration background (reference group Dutch or western migration background).

^bWeighted column percentage.

^cAdjusted for age, sex, and cause of death.

Our study shows that ELDs are made less frequently for patients with a non-western migration background; and that, if an ELD is made, the decision for euthanasia and physician-assisted suicide is less common. Our findings suggest decision-making characteristics do not differ greatly. However, patients with a non-western migration background less frequently explicitly request for an ELD; less frequently express a wish to forego treatment, and patient request is less often physicians' most important reason for a treatment decision.

Strengths and Weaknesses

Major strengths of our study are the large sample, representative of all deaths in The Netherlands in 2015, and the high response rate. When interpreting the results, some limitations need to be considered. First, our results are based on a survey among physicians. Consequently, our study does not include the patient or caregiver/family perspective and cannot fully explain found differences in end-of-life care and decision-making, for example, when physicians regard care as not appropriate, we do not have information on the patient or caregiver/family perspective on the appropriateness of care. Second, the use of the country-of-origin system in health research has been challenged for reifying contested ethnic and racial concepts, divisions, and hierarchies.²⁵ Owing to the nature of our data, it was unavoidable to use standardized categories. However, we realize these categories represent patients of various migration backgrounds who differ in their level of Dutch language proficiency, health literacy, religion, and so on. When comparing our findings to other studies, it is furthermore important to note race and ethnicity are operationalized in different ways in different studies.

Comparison With Other Studies

The higher likelihood of patients with a non-western migration background to be admitted to and die in the hospital reflects findings from population-based studies in the U.K. and Canada.^{11,26} Our findings confirm end-of-life care for patients with a migration background focuses more, or longer on maximum, curative treatment.^{6,26} In Canada and the U.S., patients with a migration or ethnic minority background were also found to undergo more intensive procedures, such as mechanical ventilation, feeding tube placement, and tracheostomy.^{26,27} Our findings furthermore confirm disparities in pain treatment reported in the U.S., where ethnic minority patients were found to be less likely to receive opioid analgesics and more likely to have pain untreated compared to white patients.²⁸ We found no studies reporting on sedation. Studies on differences in involvement of caregivers are scarce; one hospital-based study found ethnic minority patients were more likely to have had an in patient palliative care consultation.⁹ Several studies demonstrate favorable outcomes after such consultation, that is, increases in satisfaction, documentation of treatment preferences, and proportion of home deaths.^{29–31}

Hardly any studies report on differences in end-of-life decisions. Lower incidence of euthanasia and physician-assisted suicide for patients with a non-western migration background was recently related to a lower likelihood of requesting euthanasia and is not due to a difference in granting rate.³² A review of data from the U.S. indicated the typical patient receiving physician-assisted suicide is "older, white, and well-educated."³³ Studies reporting on differences in characteristics of decision-making consistently show a lower likelihood of discussion and documentation of

Table 4

Characteristics of the Decision-Making Process of End-of-Life Decisions for Patients With a Non-Western Migration Background and Dutch & Western Migration Background (for Nonsudden Deaths, Selection of Cases in Which an End-of-Life Decision Was Made)

Characteristics of end-of-life decision-making	Non-Western Migr. Background	Dutch & Western Migr. Background	Odds Ratio ^a			
	Total N = 433 <i>n</i> (%) ^b	Total N = 3828 <i>n</i> (%) ^b	Unadjusted	CI (95%)	Adjusted ^c	CI (95%)
Discussion of possible hastening of death with patient ^d						
Yes	165 (41.9)	2026 (45.5)	0.88	0.61–1.28	0.80	0.54–1.71
At the time of decision-making	75 (19.0)	636 (17.4)	1.12	0.69–1.82	1.19	0.72–1.95
Some time before	90 (22.9)	1390 (28.1)	0.76	0.48–1.20	0.65	0.41–1.04
Discussion took place						
Competence at time of discussion ^d	<i>n</i> = 165	<i>n</i> = 2,026				
Fully competent	115 (68.2)	1747 (76.5)	0.64	0.34–1.21	0.62	0.31–1.23
Not fully competent	33 (20.5)	151 (11.2)	1.95	0.92–4.15	2.19	1.01–4.79
Incompetent	17 (11.4)	130 (12.3)	0.96	0.38–2.42	0.85	0.32–2.25
Discussion did not take place						
Competence at the time of discussion ^d	<i>n</i> = 228	<i>n</i> = 1475				
Fully competent	46 (18.3)	491 (24.0)	0.70	0.36–1.35	0.53	0.25–1.11
Not fully competent	49 (21.7)	229 (14.9)	1.55	0.83–2.90	1.75	0.92–3.31
Incompetent	128 (60.0)	748 (61.1)	0.92	0.55–1.54	0.96	0.53–1.74
Reason(s) not to discuss with patient ^e						
Patient was subconscious or unconscious	98 (44.3)	481 (36.4)	1.43	0.86–2.39	1.14	0.67–1.95
Other	101 (42.6)	655 (37.5)	1.23	0.73–2.06	1.30	0.75–2.25
Dementia	36 (18.0)	371 (31.8)	0.45	0.23–0.88	0.65	0.31–1.36
The EoL practice was clearly the best option	23 (9.8)	201 (11.8)	0.87	0.38–2.00	0.93	0.40–2.16
Intellectual disability	7 (3.3)	14 (1.2)	2.65	0.58–12.11	0.97	0.20–4.82
Discussion would harm the patient	4 (1.6)	12 (0.8)	2.45	0.36–16.50	2.08	0.28–15.26
Psychiatric disorder	4 (1.6)	24 (1.8)	0.82	0.10–6.60	0.80	0.10–6.64
Discussion of possible hastening of death with others ^{d,e}						
With one or more physicians	168 (46.2)	1653 (38.9)	1.35	0.91–1.99	1.07	0.72–1.60
With one or more nurses or formal caregivers	103 (28.2)	733 (24.6)	1.21	0.79–1.87	1.17	0.75–1.83
With patient's partner or family	188 (49.5)	1839 (53.4)	0.87	0.59–1.28	0.84	0.56–1.24
With others	11 (2.9)	94 (2.7)	1.14	0.36–3.55	1.00	0.32–3.18
No	141 (34.6)	1052 (33.8)	1.04	0.69–1.57	1.16	0.77–1.76
Estimated shortening of life due to the treatment decision ^d						
No shortening of life	233 (58.1)	1706 (56.1)	1.06	0.73–1.53	1.17	0.80–1.70
<24 h	71 (19.0)	452 (15.1)	1.29	0.79–2.10	1.13	0.68–1.86
1–7 days	58 (15.2)	620 (16.5)	0.87	0.51–1.50	0.90	0.52–1.55
1–4 weeks	20 (4.8)	423 (7.3)	0.67	0.28–1.62	0.63	0.26–1.53
1–6 months	5 (1.0)	231 (3.6)	0.34	0.06–1.89	0.32	0.06–1.81
>6 months	7 (1.9)	91 (1.3)	1.50	0.36–6.17	1.10	0.26–4.70
ELD at the explicit patient request ^d	<i>n</i> = 433	<i>n</i> = 3828				
Yes	114 (27.9)	1972 (41.8)	0.54	0.35–0.83	0.44	0.28–0.70
Verbal request	93 (23.1)	1105 (30.4)	0.69	0.44–1.09	0.68	0.42–1.08
Written request	3 (1.0)	73 (1.4)	0.42	0.04–5.06	0.38	0.03–4.53
Verbal and written request	18 (3.8)	794 (10.0)	0.37	0.14–1.00	0.31	0.11–0.83
Competence at the time of request ^d	<i>n</i> = 114	<i>n</i> = 1972				
Fully competent	105 (96.3)	1883 (93.2)	0.81	0.21–3.03	0.68	0.17–2.67
Not fully competent	5 (3.7)	66 (4.7)	1.09	0.20–5.82	1.25	0.23–6.89
Incompetent	2 (0.0)	22 (2.2)	0.71	0.04–14.17	0.90	0.04–18.78
Had patient ever expressed a wish to forgo treatment(s)? ^d	<i>n</i> = 433	<i>n</i> = 3828				
Yes	69 (16.3)	1716 (35.8)	0.36	0.21–0.60	0.30	0.17–0.51
Yes, clearly	50 (11.5)	1466 (27.5)	0.34	0.19–0.63	0.29	0.16–0.54
Yes, unclearly	19 (4.8)	250 (8.3)	0.60	0.25–1.43	0.57	0.24–1.38
Physician's most important reason for the treatment decision ^{d,e}						
No perspectives on improvement	217 (57.5)	2054 (56.7)	1.03	0.70–1.53	0.94	0.63–1.41

(Continued)

Table 4
Continued

Characteristics of end-of-life decision-making	Non-Western Migr. Background	Dutch & Western Migr. Background	Odds Ratio ^a			
	Total N = 433 n (%) ^b	Total N = 3828 n (%) ^b	Unadjusted	CI (95%)	Adjusted ^c	CI (95%)
Severe pain	164 (40.0)	1559 (39.9)	1.00	0.67–1.49	1.03	0.68–1.57
Severe symptoms	161 (40.0)	1897 (51.6)	0.62	0.42–0.93	0.63	0.42–0.94
Expected suffering of the patient	103 (26.7)	1122 (28.9)	0.89	0.57–1.38	0.90	0.58–1.41
Further/other treatment was too burdensome	63 (16.3)	501 (15.5)	1.09	0.65–1.84	1.14	0.67–1.94
Other	61 (16.3)	502 (15.9)	1.03	0.61–1.75	0.96	0.56–1.64
Patient's request	59 (13.5)	1331 (26.6)	0.44	0.25–0.78	0.41	0.23–0.73
Family's request	35 (9.5)	474 (16.6)	0.51	0.26–0.99	0.56	0.28–1.10
Loss of dignity	37 (8.7)	848 (15.9)	0.49	0.25–0.98	0.44	0.22–0.89

Bold values indicate a *P*-value < 0.05.

^aOdds ratio is for migration background (reference group Dutch or western migration background).

^bWeighted column percentage.

^cAdjusted for age, sex, and cause of death.

^dMissing values between 1 (0.6%) and 47 (10.9%) for patients with a non-western migration background and between 2 (0.1%) and 340 (8.9%) for patients of Dutch and western background.

^eMore than one answer possible.

preferences in advanced directives for patients with an ethnic minority or migration background.^{34–37} This is reflected in our study by the lower likelihood that an ELD was made; ELD was at the explicit request of the patient; or patients expressing a wish to forego treatment. Patients with a non-western migration background are generally known to have a stronger preference for physician-directed or family-based decision-making, which may explain some of these findings.^{38,39} Our study, however, did not show a higher likelihood of discussion of ELDs with patient's partner or family. We do not know whether this affected decision-making or satisfaction with care.

Possible Explanations and Implications

Differences in care and decision-making may be explained by patient factors (e.g., preferences related to culture and religion, language proficiency, health literacy) as well as provider factors (e.g., responsiveness, cultural competence). Generally, patients have a preference to die at home.^{40,41} However, the strong preference for—and pursuit of—curative care of patients with a non-western migration background may contribute to their higher likelihood to be admitted to and die in hospital.^{6,26,41} Religious beliefs influence preferences for life-sustaining treatment and may have a restrictive influence on advance care planning as well as end-of-life decision-making concerning morphine, sedation, and the active ending of life through euthanasia and assisted suicide.^{6,42,43} Patient preferences for curative care may become reflected in the care provided at the end of life as shared decision-making, in which there is information exchange between physicians and patients and involvement of both parties in decision-making, is increasingly implemented in The Netherlands.⁴⁴ Linguistic and cultural barriers,

however, may complicate shared decision-making with patients with a non-western migration background and their families.⁴⁵

Limited understanding of end-of-life care as a consequence of low health literacy contributes to disparities. Low socioeconomic status, and particularly educational attainment, is the most important determinant of health literacy.⁴⁶ Studies have shown low socioeconomic status explains low awareness of palliative care among ethnic minorities; educational attainment explains lower likelihood ethnic minority patients want potentially life-shortening palliative drugs; health literacy explains the relationship between race and the preference for aggressive care; and health literacy reduces the influence of race on possession of advance directives.^{34,41,47,48}

The ability of palliative care providers to respond to preferences and needs of patients affects care and decision-making. Previous studies indicate insufficiency in responsiveness: caregivers were more likely to overestimate ethnic minority patients' survival time, which presents a barrier to treatment in accordance to preferences; and differing care values hampered communication between patients with a non-western migration background, their families, and providers, negatively affecting decision-making and satisfaction with end-of-life care.^{39,49} Although our study does not provide clear signs of (in)sufficiency in responsiveness, physicians more often regarding care for patients with a non-western migration background not appropriate as it was directed at curation for too long is interesting in this respect. It suggests a challenge to providing care in line with patient and family preferences. Increasing physicians' understanding for the complexity of communication in decision-making and their ability to provide

patient-centered, culturally competent care may help overcome such challenges and contribute responsive end-of-life care.^{39,45,50}

Conclusion

The evaluation of differences in preferences, needs, and care received by dying patients and their families is vital as demographic changes like the aging of migrant populations ask for an approach to palliative care that ensures a good end of life for all patients.² Our study demonstrates differences in end-of-life care and decision-making for patients with a non-western migration background living in The Netherlands. It suggests these may relate to variation in patient preferences, understanding of palliative care, and limited responsiveness of physicians to differing preferences and needs. Future research may look at interventions to increase physician responsiveness, by focusing on improved communication, person-centered, and cultural competent care.

Disclosures and Acknowledgments

All authors have completed the ICMJE uniform disclosure form at www.icmje.org/coi_disclosure.pdf and declare no support from any organization for the submitted work; no financial relationships with any organizations that might have an interest in the submitted work in the previous three years; no other relationships or activities that could appear to have influenced the submitted work.

This work was supported by The Netherlands Organization for Health Research and Development (ZonMw project number 3400.8003).

References

1. StatLine C. Prognose bevolking; geslacht, leeftijd en migratieachtergrond, 2018-2060. CBS StatLine, 2017. Available from <https://opendata.cbs.nl/statline/#/CBS/nl/dataset/83784NED/table?fromstatweb>.
2. Cohen J, Deliens L. A public health perspective on end of life care. Oxford: Oxford University Press, 2012.
3. National Cancer Control Programmes. Policies and managerial guidelines, 2nd ed. Geneva: World Health Organization, 2002.
4. Boddaert M, Douma J, Dijkhoorn F, Bijkerk M. Netherlands Quality Framework for Palliative Care. IKNL/Palliatief, 2017.
5. De Roo ML, Leemans K, Claessen SJ, et al. Quality indicators for palliative care: update of a systematic review. *J Pain Symptom Manage* 2013;46:556–572.
6. de Graaff FM, Francke AL, van den Muijsenbergh ME, van der Geest S. 'Palliative care': a contradiction in terms? A qualitative study of cancer patients with a Turkish or Moroccan background, their relatives and care providers. *BMC Palliat Care* 2010;9:19.
7. Chuang E, Hope AA, Allyn K, Szalkiewicz E, Gary B, Gong MN. Gaps in provision of primary and specialty palliative care in the acute care setting by race and ethnicity. *J Pain Symptom Manage* 2017;54:645–653.e1.
8. Henke A, Thuss-Patience P, Behzadi A, Henke O. End-of-life care for immigrants in Germany. An epidemiological appraisal of Berlin. *PLoS One* 2017;12:e0182033.
9. Sharma RK, Cameron KA, Chmiel JS, et al. Racial/ethnic differences in inpatient palliative care consultation for patients with advanced cancer. *J Clin Oncol* 2015;33:3802.
10. Johnson KS. Racial and ethnic disparities in palliative care. *J Palliat Med* 2013;16:1329–1334.
11. Koffman J, Ho YK, Davies J, Gao W, Higginson IJ. Does ethnicity affect where people with cancer die? A population-based 10 year study. *PLoS One* 2014;9:e95052.
12. Buiting HM, Rietjens JA, Onwuteaka-Philipsen BD, van der Maas PJ, van Delden JJ, van der Heide A. A comparison of physicians' end-of-life decision making for non-western migrants and Dutch natives in The Netherlands. *Eur J Public Health* 2008;18:681–687.
13. van der Heide A, van Delden JJM, Onwuteaka-Philipsen BD. End-of-life decisions in The Netherlands over 25 years. *N Engl J Med* 2017;377:492–494.
14. Centeno C, Lynch T, Garralda E, Carrasco JM, Guillen-Grima F, Clark D. Coverage and development of specialist palliative care services across the World Health Organization European region (2005–2012): results from a European Association for Palliative Care Task Force Survey of 53 countries. *Palliat Med* 2016;30:351–362.
15. Chambaere K, Bernheim JL. Does legal physician-assisted dying impede development of palliative care? The Belgian and Benelux experience. *J Med Ethics* 2015;41:657–660.
16. Onwuteaka-Philipsen BD, Brinkman-Stoppelenburg A, Penning C, de Jong-Krul GJ, van Delden JJ, van der Heide A. Trends in end-of-life practices before and after the enactment of the euthanasia law in The Netherlands from 1990 to 2010: a repeated cross-sectional survey. *Lancet* 2012;380:908–915.
17. Onwuteaka-Philipsen BD, van der Heide A, Koper D, et al. Euthanasia and other end-of-life decisions in The Netherlands in 1990, 1995, and 2001. *Lancet* 2003;362:395–399.
18. van der Heide A, Onwuteaka-Philipsen BD, Rurup ML, et al. End-of-life practices in The Netherlands under the euthanasia act. *N Engl J Med* 2007;356:1957–1965.
19. Van Der Maas PJ, Van Delden JJ, Pijnenborg L. Medische beslissingen rond het levenseinde. The Hague: SDU Uitgeverij, 1991.
20. Van Der Maas PJ, van der Wal G. Euthanasia and other medical decisions concerning the end of life. The Hague: SDU Uitgeverij, 1996.
21. Wet bescherming persoonsgegevens (personal data Protection act) [statute on the internet]. Available from <https://wetten.overheid.nl/BWBR0011468/2018-05-01#Hoofdstuk1>.
22. CBS. Annual Report on Integration. The Hague: Statistics Netherlands, 2016.
23. Keij I. Standaarddefinitie allochtonen. Hoe doet het CBS dat nou. *Index* 2000;10:24–25.

24. StatLine C. Bevolking; kerncijfers CBS StatLine 2018. Available from <https://opendata.cbs.nl/statline/#/CBS/nl/dataset/37296ned/table?ts=1563269809865>.
25. Helberg-Proctor A, Meershoek A, Krumeich A, Horstman K. Ethnicity in Dutch health research: situating scientific practice. *Ethn Health* 2016;21:480–497.
26. Yarnell CJ, Fu L, Manuel D, et al. Association between immigrant status and end-of-life care in Ontario, Canada. *JAMA* 2017;318:1479–1488.
27. Barnato AE, Chang C-CH, Saynina O, Garber AM. Influence of race on inpatient treatment intensity at the end of life. *J Gen Intern Med* 2007;22:338–345.
28. Cintron A, Morrison RS. Pain and ethnicity in the United States: a systematic review. *J Palliat Med* 2006;9:1454–1473.
29. Zaide GB, Pekmezaris R, Nouryan CN, et al. Ethnicity, race, and advance directives in an inpatient palliative care consultation service. *Palliat Support Care* 2013;11:5–11.
30. Bell CL, Kuriya M, Fischberg D. Hospice referrals and code status: outcomes of inpatient palliative care consultations among Asian Americans and Pacific Islanders with cancer. *J Pain Symptom Manage* 2011;42:557–564.
31. Reyes-Gibby CC, Anderson KO, Shete S, Bruera E, Yennurajalingam S. Early referral to supportive care specialists for symptom burden in lung cancer patients: a Comparison of Non-Hispanic Whites, Hispanics, and Non-Hispanic Blacks. *Cancer* 2012;118:856–863.
32. Evenblij K, Pasman HRW, van der Heide A, Hoekstra T, Onwuteaka-Philipsen BD. Factors associated with requesting and receiving euthanasia: a nationwide mortality follow-back study with a focus on patients with psychiatric disorders, dementia, or an accumulation of health problems related to old age. *BMC Med* 2019;17:39.
33. Emanuel EJ, Onwuteaka-Philipsen BD, Urwin JW, Cohen J. Attitudes and practices of euthanasia and physician-assisted suicide in the United States, Canada, and Europe. *JAMA* 2016;316:79–90.
34. Waite KR, Federman AD, McCarthy DM, et al. Literacy and race as risk factors for low rates of advance directives in older adults. *J Am Geriatr Soc* 2013;61:403–406.
35. Kwak J, Haley WE. Current research findings on end-of-life decision making among racially or ethnically diverse groups. *Gerontologist* 2005;45:634–641.
36. Henke O, Behzadi A, Henke A. P-70 Utilisation of advanced care planning among migrants in Berlin. British Medical Journal Publishing Group, 2015.
37. Koss CS, Baker TA. Race differences in advance directive completion: the narrowing gap between white and African American older adults. *J Aging Health* 2017;29:324–342.
38. Mead EL, Doorenbos AZ, Javid SH, et al. Shared decision-making for cancer care among racial and ethnic minorities: a systematic review. *Am J Public Health* 2013;103:e15–e29.
39. de Graaff FM, Francke AL, van den Muijsenbergh ME, van der Geest S. Understanding and improving communication and decision-making in palliative care for Turkish and Moroccan immigrants: a multiperspective study. *Ethn Health* 2012;17:363–384.
40. Gomes B, Calanzani N, Gysels M, Hall S, Higginson IJ. Heterogeneity and changes in preferences for dying at home: a systematic review. *BMC Palliat Care* 2013;12:7.
41. Barnato AE, Anthony DL, Skinner J, Gallagher PM, Fisher ES. Racial and ethnic differences in preferences for end-of-life treatment. *J Gen Intern Med* 2009;24:695–701.
42. Rietjens JA, van der Heide A, Onwuteaka-Philipsen BD, van der Maas PJ, van der Wal G. A comparison of attitudes towards end-of-life decisions: survey among the Dutch general public and physicians. *Soc Sci Med* 2005;61:1723–1732.
43. Johnson KS, Elbert-Avila KI, Tulskey JA. The influence of spiritual beliefs and practices on the treatment preferences of African Americans: a review of the literature. *J Am Geriatr Soc* 2005;53:711–719.
44. van der Weijden T, Post H, Brand PL, van Veenendaal H, Drenthen T, van Mierlo LA, et al. Shared decision making, a buzz-word in The Netherlands, the pace quickens towards nationwide implementation.... *Z Evid Fortbild Qual Gesundheitswes* 2017;123:69–74.
45. Suurmond J, Seeleman C. Shared decision-making in an intercultural context: barriers in the interaction between physicians and immigrant patients. *Patient Educ Couns* 2006;60:253–259.
46. Stormacq C, Van den Broucke S, Wosinski J. Does health literacy mediate the relationship between socioeconomic status and health disparities? Integrative review. *Health Promot Int* 2019;34:e1–e17.
47. Koffman J, Burke G, Dias A, et al. Demographic factors and awareness of palliative care and related services. *Palliat Med* 2007;21:145–153.
48. Volandes AE, Paasche-Orlow M, Gillick MR, et al. Health literacy not race predicts end-of-life care preferences. *J Palliat Med* 2008;11:754–762.
49. Gramling R, Gajary-Coots E, Cimino J, et al. Palliative care clinician overestimation of survival in advanced cancer: disparities and association with end-of-life care. *J Pain Symptom Manage* 2019;57:233–240.
50. Epner DE, Baile WF. Patient-centered care: the key to cultural competence. *Ann Oncol* 2012;23(suppl_3):33–42.

Appendix Table 1
Description of Strata

	Sampling Fraction
1. Medical end-of-life decision impossible, Dutch and western migration background, 17 years and older	1 ^a
2. Medical end-of-life decision unlikely, Dutch and western migration background, 17 years and older	1/12
3. Medical end-of-life decision possible, Dutch and western migration background, 17 years and older	1/8
4. Medical end-of-life decision likely, Dutch and western migration background, 17 years and older	1/4
5. Concrete indication for euthanasia or assisted suicide on death certificate, Dutch and western migration background, 17 years and older	1/2
6. Medical end-of-life decision impossible, Dutch and western migration background, 0–16 yrs	1 ^a
7. Medical end-of-life decision possible, Dutch and western migration background, 0–16 years	1
8. Medical end-of-life decision impossible, non-western migration background, all ages	1 ^a
9. Medical end-of-life decision possible, non-western migration background, all ages	1
10. Suicide	1

^aNo questionnaires were sent out because a medical end-of-life decision was impossible.

Appendix II. Questionnaire Medical End-of-life Decisions

General

-
1. In respect to this death, were you acting as:
- ☐ a general practitioner^a
☐ a medical specialist^a
☐ an elderly care specialist^a
☐ a specialist of a function different to those listed above
2. When was your first contact with the patient?
- ☐ before or at the time of death → go to question 3
☐ after death → go to question 27
3. Did death occur suddenly and totally unexpected?
- ☐ yes → go to question 26
☐ no → go to question 4
-

^aIncluding assistant-medical staff, whether or not in training for the applicable specialty.

Medical End-of-life Decisions

-
4. Did you or another physician carry out (or ensured they were carried out) one or more of the following acts, taking into account the possibility or certainty that this act would hasten the patient's end of life^b? (Please answer 4a, 4b, and 4c)
- 4a. Withholding treatment^b? ☐ yes
☐ no
- If yes, which treatments were withheld? _____
- 4b. Withdrawing treatment^b? ☐ yes
☐ no
- If yes, which treatments were withdrawn? _____
- 4c. Intensifying the alleviation of symptoms using one or multiple drugs? ☐ yes
☐ no → go to question 6
- If yes, which drugs were used? (Please check all answers that apply)
- ☐ morphine or a morphine-derivative
☐ benzodiazepine (s)
☐ other drugs
5. Was hastening the end of life *partly the intention* of the act indicated in question 4c? ☐ yes
☐ no
-

^aEither "hastening the end of life" or "not prolonging life".

^bIn this study, artificial nutrition and/or hydration are considered treatment.

-
6. Was death the consequence of one or more of the following acts, which you or another physician decided to carry out with the explicit intention of hastening the end of life^a? (Please answer both 6a and 6b)
- 6a. Withholding treatment^b? ☐ yes
☐ no
- If yes, which treatments were withheld? _____
- 6b. Withdrawing treatment^b? ☐ yes
☐ no
- If yes, which treatments were withdrawn? _____
-

^aEither "hastening the end of life" or "not prolonging life".

^bIn this study, artificial nutrition and/or hydration are considered treatment.

-
7. Was death the consequence of the use of a drug that was prescribed, supplied, or administered by you or another physician with the explicit intention of hastening the end of life (or of enabling the patient to end his or her own life)? ☐ yes
☐ no → go to question 8
- If yes, who administered this drug (i.e., introduced it into the body)? (Please check all answers that apply)
- ☐ the patient
☐ you or another physician
☐ nursing staff
☐ someone else
☐ neuromuscular relaxant
☐ barbiturate
☐ benzodiazepine
☐ morphine or a morphine-derivative
☐ other drugs
- If yes, which drugs were used? (Please check all answers that apply)
-

Decision-Making Concerning the Last-mentioned Act

Note: If all parts of questions 4, 5, 6, and 7 were answered with “no”, go to question 20. Questions 8 through 19 concern the last-mentioned act, that is, the last “yes” in answer to questions 4 to 7.

8. A question about that last-mentioned act: according to your estimate, how much was the patient's life shortened by this act?

- ☐ more than six months
- ☐ one to six months
- ☐ one to four weeks
- ☐ up to one week
- ☐ less than 24 hours

9. Did you or another physician discuss the (possible) hastening of the end of life as a result of the last-mentioned act with the patient?

- ☐ the patient's life was probably not shortened at all
- ☐ yes, at the time of carrying out the act or shortly before
- ☐ yes, some time beforehand

10. At the time of the discussion, did you consider the patient competent to assess his/her situation and to adequately make a decision about it?

- ☐ no → go to question 11
- ☐ yes → go to question 13
- ☐ no, not fully competent → go to question 13
- ☐ no, not competent at all → go to question 13

11. Did you consider the patient competent to assess his/her situation and to adequately make a decision about it?

- ☐ yes
- ☐ no, not fully competent
- ☐ no, not competent at all

12. Why was the (possible) hastening of the end of life as a result of the last-mentioned act not discussed with the patient? (Please check all answers that apply)

- ☐ patient was too young
- ☐ the last-mentioned act was clearly in the best interest of the patient
- ☐ discussion would have done more harm than good
- ☐ patient was sub- or unconscious
- ☐ patient had dementia
- ☐ patient had an intellectual disability
- ☐ patient was suffering from a psychiatric disorder
- ☐ other: _____

13. Was the decision concerning the last-mentioned act made upon an *explicit request* of the patient?

- ☐ yes, upon oral request
- ☐ yes, upon written request
- ☐ yes, upon oral and written request
- ☐ no → go to question 15

14. At the time of this request, did you consider the patient competent to assess his/her situation and to adequately make a decision about it?

- ☐ yes
- ☐ no, not fully competent
- ☐ no, not competent at all

15. To your knowledge, did the patient ever express a wish of hastening of the end of life?

- ☐ yes, clearly
- ☐ yes, unclearly
- ☐ no

16. Did you or another physician discuss the (possible) hastening of the end of life with others previous to the decision about the last-mentioned act? (Please check all answers that apply)

- ☐ yes, with one or more other physicians
- ☐ yes, with nursing staff
- ☐ yes, with patient's partner or relatives
- ☐ yes, with someone else
- ☐ no

In the case a discussion with other physicians took place, did this discussion concern an official consultation as required by the review procedure for the ending of life? (Please check all answers that apply)

- ☐ yes, consultation of a SCEN-physician
- ☐ yes, consultation of another physician
- ☐ no

17. What were the most important reasons to decide on the, in question 4-7, last-mentioned act? (Please check all answers that apply)

- ☐ (severe) pain
- ☐ other (severe) symptoms
- ☐ loss of dignity
- ☐ patient's request
- ☐ family's request
- ☐ expected suffering of the patient
- ☐ no perspectives on improvement
- ☐ further treatment was too burdensome
- ☐ other: _____

18. What do you think would be the *best label* for the last-mentioned act?

- ☐ no-treatment decision
- ☐ symptom alleviation
- ☐ palliative or terminal sedation
- ☐ ending of life
- ☐ euthanasia
- ☐ assisted suicide
- ☐ other: _____

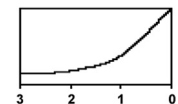
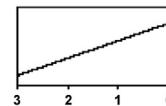
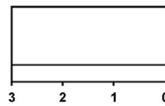
19. Did you or another physician report the last-mentioned act to a regional review committee because of the review procedure for the ending of life upon the request of a patient? (Please check all answers that apply)

- ☐ yes
- ☐ no, because: _____
- ☐ it did not concern a life-ending act
- ☐ reporting is too much of a hassle
- ☐ the requirements for careful practice were potentially (partly) unmet
- ☐ other: _____

Care and Treatment

20. Has the patient been admitted to hospital in the last month of life?
21. Where did the patient die?
22. Which caregivers were involved in the care for the patient in the last month of life? (Please check all answers that apply)
23. Did the patient receive “appropriate care” in the last phase of life? (Please check all answers that apply)
24. Was the patient continuously and deeply sedated until the end of life?
- Which medication was used for sedation? (Please check all answers that apply)
- How long before the end of life did the continuous sedation of the patient start?
- Did the patient receive artificial nutrition or hydration during sedation?
- This way of sedation, whether or not in combination with artificial nutrition or hydration, was performed ...
25. Did the patient receive morphine or a morphine-derivative during the last 24 hours before death?
- Was a higher dose than necessary given to alleviate pain or other symptoms?
- How much time before death was the administration of morphine or a morphine derivative started?
- Which figure best illustrates the dosage of morphine or a morphine derivative doses during the last 3 days before the patient's death?
26. Did the patient make an explicit request to end his or her life which was not granted?
- Why was this request not granted? (Please check all answers that apply)
27. Which of the following statements applies to the patient:
28. Is there any indication that the patient purposely ended his/her life his/herself (without direct help of a physician)?
- Which method was used for this? (Please check all answers that apply)

- ☐ yes, for a duration of ... days
- ☐ no
- ☐ at home
- ☐ care home (but not a palliative unit)
- ☐ nursing home (but not a palliative unit)
- ☐ hospital (but not a palliative unit)
- ☐ palliative unit in institution
- ☐ hospice
- ☐ almost-home-home
- ☐ other: _____
- ☐ palliative consultant of palliative team
- ☐ specialist pain alleviation
- ☐ psychiatrist or psychologist
- ☐ spiritual caregiver
- ☐ other: _____
- ☐ yes
- ☐ no, care was directed at curation for too long
- ☐ no, there was too little symptom alleviation
- ☐ no, there was too little psychosocial or spiritual care
- ☐ yes
- ☐ no → go to question 25
- ☐ midazolam
- ☐ other benzodiazepine
- ☐ morphine or a morphine derivative
- ☐ other type of medication
- ☐ ... hours
- ☐ ... days
- ☐ ... weeks
- ☐ yes
- ☐ no
- ☐ assuming that this would not hasten the end of life
- ☐ taking into account the possible hastening of the end of life
- ☐ with the intention to hasten the end of life
- ☐ yes
- ☐ no → go to question 26
- ☐ yes
- ☐ no
- ☐ ... hours
- ☐ ... days
- ☐ ... weeks
- ☐ No increase ☐ Gradual increase ☐ Strong increase on the last day or start on the last day



- ☐ yes
- ☐ no → go to question 27
- ☐ patient died before request could be granted
- ☐ suffering was not unbearable
- ☐ suffering was not hopeless
- ☐ there was no well-considered request of the patient
- ☐ there was no voluntary request of the patient
- ☐ due to institutional policy
- ☐ due to personal fundamental objections
- ☐ patient withdrew the request
- ☐ other: _____
- ☐ patient had a (severe) somatic disorder
- ☐ patient had a psychiatric disorder
- ☐ patient suffered from an accumulation of health problems associated with old age
- ☐ patient had dementia
- ☐ patient had psychosocial or existential problems
- ☐ other: _____
- ☐ yes
- ☐ no → go to question 29
- ☐ refrained from eating and drinking, whether or not guided by a physician
- ☐ taking (stockpiled) medication
- ☐ other: _____

