

Continuous Deep Sedation Until Death—a Swiss Death Certificate Study

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BACKGROUND: In the last decade, the number of patients continuously deeply sedated until death increased up to fourfold. The reasons for this increase remain unclear.

OBJECTIVE: To identify socio-demographic and clinical characteristics of sedated patients, and concurrent possibly life-shortening medical end-of-life decisions.

DESIGN: Cross-sectional death certificate study in German-speaking Switzerland in 2001 and 2013.

PARTICIPANTS: Non-sudden and expected deaths (2001: N = 2281, 2013: N = 2256) based on a random sample of death certificates and followed by an anonymous survey on end-of-life practices among attending physicians.

MAIN MEASURES: Physicians' reported proportion of patients continuously deeply sedated until death, sociodemographic and clinical characteristics, and possibly life-shortening medical end-of life decisions.

KEY RESULTS: In 2013, physicians sedated four times more patients continuously until death (6.7% in 2001; 24.5.5% in 2013). Four out of five sedated patients died in hospitals, outside specialized palliative care units, or in nursing homes. Sedation was more likely among patients younger than 65 (odds ratio 2.24, 95% CI 1.6 to 3.2) and those dying in specialized palliative care (OR 2.2, 95% CI 1.3 to 3.8) or in hospitals (1.7, 95% CI 1.3 to 2.3). Forgoing life-prolonging treatment with the explicit intention to hasten or not to postpone death combined with intensified alleviation of symptoms was very strongly associated with continuous deep sedation (OR 6.8, 95% CI 4.7 to 9.8).

CONCLUSIONS: In Swiss clinical practice, continuously deeply sedated patients predominantly died outside specialized palliative care. The increasing trend over time appears to be related to changes in medical end-of-life practice rather than to patient's clinical characteristics.

KEY WORDS: deep sedation; primary care; general internal medicine; withholding treatment; symptom alleviation.

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INTRODUCTION

Despite substantial progress in medical care, some patients still experience intractable symptoms and unbearable suffering.¹ As an option of last resort, sedating medications can be used to control refractory symptoms such as pain, dyspnea, or delirium. The level of so-called palliative sedation varies in duration and depth and is used intermittently or continuously until death to induce a mild or deep level of patient's unconsciousness.^{2, 3} In the past decade, continuous deep sedation until death has become a more common medical practice not only in specialized palliative care but also in primary and hospital care. US findings indicate an incidence of 10% of continuous deep sedation until death.⁴ In comparison, European population-wide studies have estimated the overall prevalence to vary between 2.5 and 18.2%, ⁵⁻¹⁰ with an almost fourfold increase between 2001 (4.7%) and 2013 (17.5%) in Switzerland.¹¹ This variance in prevalence is partly due to different practices across jurisdictions,⁸ healthcare settings, physicians' specialties, and patient populations.^{12, 13} Furthermore, there is systematic variation in making end-of-life decision between countries stemming from individual values and concerns that are a function of respective cultural and legal backgrounds.14, 15

With the increasing use of palliative sedation, several US and European recommendations and clinical practice guidelines have been developed.¹⁶⁻¹⁸ Despite striking differences in terminology, they all emphasize its use solely with the intention to relieve a patient's suffering when all standard therapies have failed and no alternative for palliation is available.¹⁶ Therefore, most guidelines, particularly in countries where physician-assisted death is legal.¹⁹ provide clear differentiation of palliative sedation from life-shortening end-of-life decisions such as physician-assisted death. Thus, abuse of palliative sedation occurs when hastening of death is intended.² Physician-assisted death but not euthanasia is legalized in Switzerland, Oregon, Washington, Vermont, Montana, and California.^{20, 21} Continuous administration of sedatives causing unconsciousness until death is indicated only for terminally ill patients with a life expectancy no longer than a few days.²² Benzodiazepines such as midazolam are widely recommended as medications of first choice, whereas sedation induced by opioids is considered inappropriate.^{2, 23, 24}

Guidelines and definitions have been developed and applied within specialized palliative care, but a significant amount of end-of-life practice happens in primary and hospital care.^{25, 26} In everyday clinical practice, non-compliance with clinical guidelines was found in up to 43% of cases in the Netherlands in 2007.^{27, 28} Such deviations are often caused by ongoing ethical discussions around the belief that continuous deep sedation until death is life-shortening.^{29, 30}

The increasing trends of continuous deep sedation are in line with previous developments of other end-of-life decisions such as intensified alleviation of symptoms or forgoing life-prolonging treatments, but contrast with physicians' perception that this is a rare clinical practice.^{10, 11} There is little evidence specifically clarifying whether in everyday clinical practice, continuous deep sedation is performed according to the aforementioned guidelines. Therefore, we aimed to identify specific patients' socio-demographics, clinical characteristics, and possibly life-shortening end-of-life decisions associated with the use of continuous deep sedation in Switzerland, a country with an especially high increase. Furthermore, we aimed to evaluate changes in sedation practice since 2001 to identify potential explanations for its fourfold increase within the last decade.

METHODS

Study Design

We conducted a cross-sectional death certificate study in Switzerland. This study built upon the large death certificate end-of-life decision-making in six European countries (EURELD) study in 2001.³¹ Between August 2013 and February 2014, the Swiss Federal Statistical Office drew a continuous random sample of death certificates of residents (aged ≥ 1 year) on a weekly basis in German-speaking Switzerland. Investigators of the Epidemiology, Biostatistics and Prevention Institute of the University of Zurich (EBPI) sent 4998 questionnaires to certifying physicians who completed the death certificates. Non-respondents received at most two reminders per death certificate, last on April 15, 2014. In order to guarantee physicians' anonymity, the questionnaires had to be returned to the Swiss Academy of Medical Science (SAMS) and were forwarded only to the investigators at EBPI after deletion of the connection code to the physician's address. The study was approved by the Zurich Cantonal Ethics Board (KEK-StV-Nr. 23/13).

End-of-life decision questionnaire

In order to assess trends in possibly life-shortening medical end-of-life decisions (MELDs) and continuous deep sedation, the 2013 questionnaire was designed to keep maximal comparability with that used in the international EURELD study in 2001.³² In 2013, a question was added on physician-patient relationship and categories for place of death (assisted-living facility; hospice/palliative care unit) and cause of death (accident/violence/suicide) were supplemented. Full details of sampling methods, the questions, and the first results have previously been reported.^{11, 15, 32}

Physicians answered general questions about patient demographics and clinical characteristics including sex, age, marital status, place of death, and cause of death. For the purposes of this study, we asked physicians to self-identify either as medical specialist or medical generalist including primary care physicians and hospitalists.

Furthermore, they were asked whether a patient's death occurred suddenly and unexpectedly. All non-sudden and expected deaths were regarded as eligible for MELDs and for these cases, physicians had to report on three key decisions¹: withholding or withdrawing a life-prolonging medical treatment taking into account hastening of death or explicitly intending to hasten or not to postpone death²; intensifying the alleviation of symptoms taking into account or partly intending hastening of death; or³ prescribing or administering a drug with the explicit intention of ending the patient's life (physician-assisted death).

Aside from MELDs, we asked physicians if their patient received drugs, such as benzodiazepines and/or other sedative substances, to keep him or her in deep sedation or coma until death. We differentiated this question from the three key questions of possibly life-shortening MELDs, as to date, there is no empirical evidence for shortened survival times among patients continuously deeply sedated until death.^{33, 34}

Analysis

We restricted our study population to non-sudden and expected deaths, as only these were eligible for end-of-life decisions and administration of continuous deep sedation. To adjust for age- and sex-related differences in response rates, we weighted all data and standardized them to the age distribution of Swiss residents at death in 2013. We calculated univariate associations between socio-demographics, clinical characteristics, and combined MELDs of patients continuously deeply sedated in 2001 and 2013 using the Pearson χ^2 test for two-way contingency tables, two-sample t test for mean comparison and one-way ANOVA. Binary logistic regressions were used to analyze the administration of continuous deep sedation until death (yes/no) conditional on patients' socio-demographic and clinical characteristics, and MELDs. We included the following covariates in the regression model: patient's sex, age, marital status, place of death, and cause of death, physician's specialization, physician-patient relationship, and MELDs. For our analysis, we grouped patients who died of accidents/violence/suicide with others as well as those dying in assisted-living facilities with patients dying in nursing homes. Missing data was present for continuous deep sedation (2001: n = 112, 4.9%; 2013: n = 89, 3.9%), place of death (2001: n = 4, 0.1%; 2013: n = 2, 0.2%), physician's specialization (2001: n = 27, 2.6%; 2013: n = 62, 0.1%), and for physician-patient relationship (2013: n = 91, 4.0%). For binary logistic regressions, we excluded all patients with missing data in the outcome variable of continuous deep sedation. For missing data in the covariates, we performed multiple imputation. To evaluate independence across covariates, we calculated Pearson's correlation and Cramer's V. Post hoc sensitivity analyses were used to assess the effects of interactions in order to identify significant differences between specific patient demographics, clinical settings, and MELDs. We reported % confidence intervals (CIs) for odds ratios (ORs), and results were considered statistically significant at p < 0.05. All analyses were

conducted by using STATA IC for Macintosh (version 13.1, College Station, TX, USA).

Data Availability. No additional data available.

RESULTS

Characteristics of the Study Population

In total, physicians returned 3355 out of 4991 questionnaires mailed in 2001 (67.2%) and 3173 questionnaires out of 4998 mailed in 2013 (63.5%). Of all certified deaths, 69.9% in 2001 and 71.4% in 2013 were non-sudden and expected and therefore eligible for MELDs and continuous deep sedation until death.

As shown in Table 1, in both years, patients had a mean age between 79 and 80 (2001, 79.0; 2013, 79.9), were slightly

Table 1 Socio-Demographics and Clinical Characteristics of All Patients Dying Non-suddenly and Patients Continuously Deeply Sedated Until
Death

	2001		2013	
Characteristics	Total	Sedated patients*	Total	Sedated patients*
Total % (n)	100 (2281)	6.7 (160)	100 (2256)	24.5 (557)
Age (years)				
Mean (SD)	79.0 (13.2)	74.9 (14.0)	79.9 (13.1)	76.5 (14.3)
Age groups (years)				
1–64	10.2 (294)	10.4 (32)	11.7 (269)	38.8 (105)
65–79	23.8 (643)	8.3 (53)	25.0 (600)	27.4 (165)
≥ 80	66.1 (1344)	5.5 (75)	63.4 (1387)	20.7 (287)
Sex				
Female	55.7 (1226)	6.3 (80)	54.9 (1209)	23.4 (286)
Male	44.3 (1055)	7.0 (80)	45.1 (1047)	25.7 (271)
Marital status				
Married	36.2 (889)	8.0 (74)	39.5 (909)	27.8 (254)
Not married	63.8 (1392)	5.9 (86)	60.5 (1347)	22.3 (303)
Place of death [†]				
Home	15.5 (370)	7.0 (23)	13.0 (297)	14.4 (43)
Nursing/retirement home	41.5 (866)	5.1 (45)	44.4 (982)	19.2 (190)
Hospice and palliative care unit	N/A	N/A	5.3 (121)	35.8 (43)
Hospital	42.9 (1043)	8.2 (92)	37.3 (852)	32.7 (281)
Cause of death	12.9 (1013)	0.2 (92)	57.5 (052)	52.7 (201)
Cancer	29.3 (727)	10.2 (74)	27.2 (627)	28.1 (177)
Cardiovascular diseases	30.6 (655)	4.4 (30)	26.9 (599)	23.2 (140)
Neurological diseases	13.4 (301)	7.5 (23)	18.6 (414)	22.3 (93)
Pulmonary diseases	10.6 (235)	4.4 (10)	9.8 (220)	25.9 (58)
Other	16.1 (363)	5.8 (23)	17.6 (396)	22.3 (89)
Physicians' specialization [†]	10.1 (303)	3.8 (23)	17.0 (390)	22.3 (89)
	71 1 (1576)	5 2 (94)	(5.0 (1476)	21.4(210)
Medical generalist:	71.1 (1576)	5.3 (84)	65.9 (1476)	21.4 (319)
Medical specialist	26.3 (643)	10.7 (73)	32.9 (753)	30.4 (231)
Physician-patient relationship†	NT/A	NT/A	(0, 2, (1550))	25.2 (280)
Responsible physician	N/A	N/A	69.3 (1558)	25.3 (389)
Not my patient	N/A	N/A	26.7 (607)	24.0 (147)
Medical end-of-life decisions (MELD)			1 - 0 (100)	0.0.000
No MELD	25.5 (577)	5.1 (31)	17.8 (400)	9.2 (38)
At least one MELD	74.5 (1704)	7.2 (129)	82.3 (1856)	27.7 (519)
Forgoing life-prolonging treatment only	22.4 (500)	5.0 (26)	17.3 (389)	11.0 (44)
Forgoing life-prolonging treatment intended to hasten/not	18.7 (430)	9.6 (44)	32.0 (723)	41.6 (302)
to postpone death combined with intensified alleviation of symptoms				
Intensified alleviation of symptoms only	14.1 (327)	7.5 (25)	10.7 (242)	18.5 (46)
Intensified alleviation of symptoms combined with forgoing	17.9 (412)	6.7 (29)	19.1 (430)	25.4 (110)
life-prolonging treatment taking into account to hasten death				
Physician-assisted death	1.4 (35)	14.5 (5)	3.1 (72)	24.0 (17)

Numbers are unweighted

MELD possibly life-shortening medical end-of-life decisions, N/A data not accessed in 2001

*Figures are row percentages and (numbers). Percentages are weighted according to the age 2013. Missing data were omitted for percentages †Missing data 2001/2013: 2/4 for place of death, 62/27 for physician's specialization, NA/91 for physician-patient relationship

†Medical generalists included primary care physicians and hospitalists

	Continuous deep se	P value	
Characteristics	2001 (<i>n</i> = 160)	2013 (<i>n</i> = 557)	
Age in years			
1-64	15.8 (32)	18.5 (105)	
65–79	29.6 (53)	28.0 (165)	
≥ 80	54.6 (75)	53.5 (287)	
Sex			
Female	52.5 (80)	52.6 (286)	0.99‡
Male	47.5 (80)	47.4 (271)	
Marital status			
Married	43.6 (74)	44.8 (254)	0.78‡
Not married	56.4 (86)	55.2 (303)	
Place of death			
Home	15.6 (23)	7.7 (43)	N/A
Nursing/retirement home	31.6 (45)	34.8 (190)	
Hospice and palliative care unit	N/A	7.7 (43)	
Hospital	52.8 (92)	49.8 (281)	
Cause of death			
Cancer	44.6 (74)	31.3 (177)	0.95§
Cardiovascular diseases	20.1 (30)	25.4 (140)	
Neurological diseases	14.9 (23)	16.9 (93)	
Pulmonary diseases	6.3 (10)	10.3 (58)	
Other	14.1 (23)	16.0 (89)	
Physicians' specialization*			
Medical generalist ⁺	56.0 (84)	58.6 (319)	0.74‡
Medical specialist	42.2 (73)	41.4 (231)	•
Physician-patient relationship*			
Responsible physician	N/A	73.2 (398)	N/A
Not my patient	N/A	26.8 (147)	
Medical end-of-life decisions (MELD)			
No MELD	19.5 (31)	6.7 (38)	0.009§
At least one MELD	80.5 (129)	93.0 (519)	
Forgoing life-prolonging treatment only	16.8 (26)	7.8 (44)	
Forgoing life-prolonging treatment intended to hasten/not	26.7 (44)	54.5 (302)	
to postpone death combined with intensified alleviation of symptoms			
Intensified alleviation of symptoms only	15.8 (25)	8.1 (46)	
Intensified alleviation of symptoms combined with forgoing life-	17.9 (29)	19.9 (110)	
prolonging treatment taking into account to hasten death			
Physician-assisted death	3.0 (5)	3.1 (17)	

Table 2 Socio-Demographics and Clinical Characteristics of Patients Continuous	v Deeply Sedated Until Death

Figures are column percentages and (numbers). Percentages are weighted according to the age 2013. Missing data were omitted for percentages. N are unweighted

MELD possibly life-shortening end-of-life decisions, N/A data not accessed in 2001

*Missing data 2001/2013: 3/7 for physician's specialization, NA/12 for physician-patient relationship

†Medical generalists included primary care physicians and hospitalists

 $\ddagger p$ value using Pearson χ^2 test for two-way contingency table

§p value using one-way ANOVA

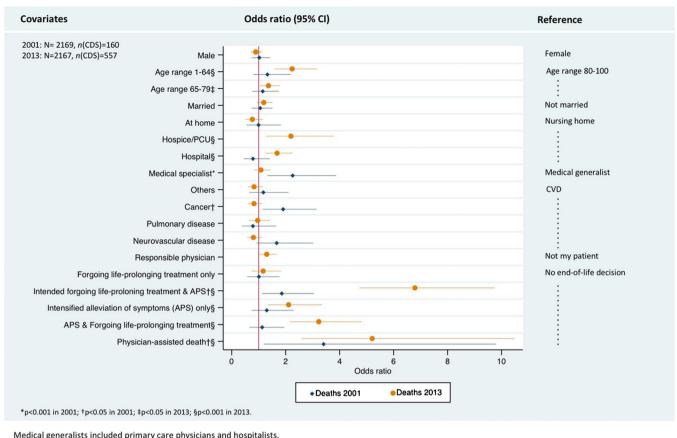
more often female (2001, 56%; 2013, 55%) and predominantly not married (2001, 64%; 2013, 61%). Eligible decedents typically died in a nursing home or hospital and roughly three out of ten were diagnosed with cancer (2001, 29%; 2013, 27%) or cardiovascular disease (2001, 31%; 2013, 27%).

The vast majority of patients died after at least one MELD (2001, 75%; 2013, 82%). In 2001, forgoing life-prolonging treatment decisions, including withholding and/or withdrawing medical treatments, accounted for the most frequent decisions (22%, n = 500). In 2013, the prevalence of MELDs was higher for combined decisions and highest when physicians intended to hasten or not to postpone death. This increasing trend was particularly visible for patients with a decision to forgo life-prolonging treatment explicitly intending to hasten or not to postpone death combined with intensified alleviation of symptoms (2001, 19%; 2013, 32%).

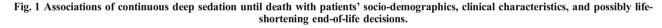
Irrespective of MELDs, the prevalence of patients continuously deeply sedated until death increased fourfold since 2001 from 6.7 to 24.5% of all non-sudden deaths. This fourfold increase was consistent across men and women, and all age groups. The prevalence of continuous deep sedation was highest among those < 65 years of age (2001, 10%; 2013, 39%), treated by a medical specialist (2001, 11%; 2013, 30%) and dying in hospital (2001, 8%; 2013, 33%) or hospice/palliative care unit (2013, 36%). In 2013, continuous deep sedation occurred more frequently among patients with preceded MELDs. Compared to 2001, we found highest proportional increases among patients with a decision to forgo life-prolonging treatment explicitly intending to hasten or not to postpone death combined with intensified alleviation of symptoms (10 to 42%).

Characteristics of Patients Continuously Deeply Sedated Until Death

Patients continuously deeply sedated until death in 2001 and 2013 were comparable with regard to their socio-demographic



CI = confidence interval. CDS = continuous deep sedation until death. PCU = palliative care unit. CVD = cardiovascular disease. APS = intensified alleviation of symptoms.



characteristics. As shown in Table 2, in both years, more than 50% of patients continuously deeply sedated were aged \geq 80 years, diagnosed with cancer or cardiovascular disease, and more than 80% died in hospitals or nursing homes. Only a minority of sedated patients died at home (2001, 16%; 2013, 8%) or in specialized palliative care (2013, 8%). In line with these findings, sedated patients were slightly more often women, not currently married and treated by a medical generalist.

Continuous deep sedation predominantly occurred together with at least one MELD (2001, 81%; 2013, 93%). Among the sedated patients in 2013, physicians reported twice as many decisions to forgo treatment explicitly intending to hasten or not to postpone death combined with intensified alleviation of symptoms (2001, 27%; 2013, 55%).

Multivariate Analyses

The administration of continuous deep sedation until death was very strongly associated with MELDs whereas sociodemographics and clinical characteristics were moderately associated with continuous deep sedation until death (Fig. 1). In 2013, patients were more likely to be continuously deeply sedated when MELDs preceded death if they were younger than 65 (OR 2.2, 95% CI 1.3 to 3.8, p < 0.001) or death occurred in hospital (OR 1.7, 95% CI 1.3 to 2.3, p < 0.001) or in a specialized palliative care setting (OR 2.2, 95% CI 1.6 to 3.2, p < 0.001) (Table 3). We found strong associations with forgoing treatment decisions combined with intensified alleviation of symptoms, and strongest associations when decisions were made with the intention to hasten or not to postpone death (OR 6.8, 95% CI 4.7 to 9.8, p < 0.001). We identified significant interaction terms between MELDs and physician's clinical specialization (p < 0.001) indicating that for all patients with combined decisions, the odds of being continuously deeply sedated were significantly higher when the attending physician was a medical generalist such as a primary care physician or a hospitalist. In turn, for patients with only one reported MELD, the associations were smaller for medical specialists (Online appendix Table 1).

DISCUSSION

To our knowledge, this is the first study investigating the administration of continuous deep sedation until death in relation to combined MELDs. In Swiss clinical practice in 2013, patients continuously deeply sedated predominantly died in hospitals outside specialized palliative care units or in nursing homes. Multivariate analyses revealed that continuous deep sedation was most likely for patients aged younger 65, for patients dying in

Table 3 Associations Between the Administration of Continuous Deep Sedation Until Death, Patient's Characteristics, and Possibly Life-
Shortening Medical End-of-Life Decision 2013. $N = 2167$

Covariate* [reference]	Odds ratio	[95% CI]	P valu
Age [age range ≥ 80]			
Age range 1–64	2.24	[1.59,3.16]	< 0.001
Age range 65–79	1.36	[1.04,1.77]	0.020
Sex [female]			
Male	0.89	[0.71,1.12]	0.32
Marital status [not married]			
Married	1.19	[0.93,1.51]	0.170
Place of death [nursing home]			
At home including others	0.76	[0.51,1.15]	0.20
Hospice/palliative care unit	2.20	[1.28,3.77]	< 0.001
Hospital	1.68	[1.25,2.25]	< 0.001
Cause of death [cardiovascular disease]			
Others	0.83	[0.60,1.14]	0.25
Cancer	0.82	[0.60,1.13]	0.23
Pulmonary disease	0.96	[0.65,1.42]	0.84
Neurological disease	0.80	[0.58,1.12]	0.19
Physicians' specialization [medical generalist] ⁺		[]	,
Medical specialist	1.08	[0.83,1.42]	0.57
Physician-patient relationship [not my patient]	1100	[0:00,11:2]	0107
Responsible physician	1.30	[1.00,1.68]	0.050
Medical end-of-life decision [no end-of-life decision]	1.50	[1.00,1.00]	0.050
Forgoing life-prolonging treatment only	1.16	[0.74,1.83]	0.51
Forgoing life-prolonging treatment intended to hasten/	6.79	[4.73,9.75]	< 0.001
not to postpone death combined with intensified	0.17	[1.73,9.75]	20.001
alleviation of symptoms			
Intensified alleviation of symptoms only	2.11	[1.33,3.34]	< 0.001
Intensified alleviation of symptoms combined with	3.23	[2.16,4.81]	< 0.001
forgoing life-prolonging treatment taking into account	5.25	[2.10, 1.01]	< 0.001
to hasten death			
Physician-assisted death	5.21	[2.59,10.47]	< 0.001

Eighty-nine missing for continuous deep sedation excluded

CI confidence interval

*Data are weighted to the age distribution of 2013. Missing data imputed for place of death, physicians' specialization and physician-patient relationship †Medical generalists included primary care physicians and hospitalists

hospital or specialized palliative care, and among those with reported MELDs. We found strong associations with forgoing life-prolonging treatment decisions combined with intensified alleviation of symptoms, and strongest associations when this combination was made with the intention to hasten or not to postpone death. Compared to 2001, the probability of dying continuously deeply sedated in 2013 was more strongly related to end-of-life practices, but less strongly associated with cancer or being treated by a medical specialist.

In Swiss clinical practice in 2013, continuous deep sedation until death was more likely for patients with combined MELDs of life-prolonging treatment decisions and intensified alleviation of symptoms. These findings are consistent with Dutch results pointing out that the use of opioids at admission to a specialized palliative care setting increased the probability of receiving continuous deep sedation.³⁵ The increasing trend of MELDs in Switzerland is in line with international findings,⁸ except for the Netherlands showing a decrease of forgoing life-prolonging treatment decisions (20.2% in 2001; 18.2% in 2010).^{10, 15} The high proportional increase of forgoing life-prolonging treatment decisions combined with intensified alleviation of symptoms between 2001

and 2013 and the fact that patients continuously deeply sedated until death were most prevalent among those patients, might partly explain the fourfold increase of sedation practice.

We found stronger associations between continuous deep sedation and MELDs when end-of-life decisions were made with the intention to hasten or not to postpone death. According to Abarshi et al. 2017, common guidelines emphasize the use of palliative sedation for refractory symptoms only and clearly differentiate palliative sedation from possibly life-shortening end-of-life decisions.¹⁶ However, the clear distinction between continuous deep sedation and MELDs is a challenge. It seems that many healthcare professionals struggle with the conceptual distinction between continuous deep sedation until death and MELDs,³⁶ as in everyday clinical practice, almost every sedation involves such decisions. To date, there is no empirical evidence for shortened survival times among patients continuously deeply sedat-ed until death.^{33, 34} There is evidence that lessexperienced physicians working in non-specialized settings have difficulties differentiating between continuous deep sedation until death and possibly life-shortening decisions.³⁷ Foley et al. showed that a higher degree of palliative care specialization and sedation experience correlates with a physician's conviction that continuous deep sedation is not life shortening.³⁷

In line with previous studies,^{4, 12, 35} we found a higher probability of receiving continuous deep sedation until death for patients younger than 65 and patients dying in hospital or specialized palliative care. However, only one in ten sedated patients died within specialized palliative care but at least one in three in nursing home and one in two in hospital, outside specialized palliative care units. In the last decade, Swiss palliative care has been increasingly promoted and organized. In 2005, the Swiss Association of Palliative Care released the first national guidelines on palliative sedation.³⁸ These guidelines are published open access and thus freely accessible to everyone. Five years later, the Swiss confederation and cantons promoted palliative care in the context of the "National Strategy for Palliative Care 2010–2015".^{39, 40} This strategy aimed to offer palliative care widely by improving training and education, coordination and synergy at national and cantonal levels. Recently, continuous deep sedation until death has further reached attention through media. These developments in Switzerland might have contributed to the increasing use of continuous deep sedation outside specialized palliative care.

Strengths and Limitations

We had a remarkably high response rate of (67.2% in 2001, 63.5% in 2013) and our study is representative of all deaths across all settings in German-speaking Switzerland.

To our knowledge, our study is the first to analyze the administration of continuous deep sedation until death by taking into account the combinations of MELDs in cases with more than one MELD. Previous studies on MELDs have only reported the most important MELD, defined as the decision with the most explicit intention to hasten death. Including the combinations provides a closer approximation of MELD decision making in everyday clinical practice.

The questionnaire was primarily designed for MELDs, and physician's intention has exclusively been assessed regarding MELDs. Therefore, our results do not allow any conclusions about whether or not physicians intend sedation to hasten death. Furthermore, to account for physician's intention of forgoing life-prolonging treatment decisions, physicians were asked if they explicitly intended to shorten life or whether they explicitly intended not to prolong patient's life. Both intentions were part of a single question; thus, we were not able to differentiate between these two intentions.

Decisions about symptom refractoriness and unbearable suffering require both a physician's and a patient's point of view.⁴¹ Our data provides no information on patient's decision-making of continuous deep sedation until death, the specific drug used, nor if drugs were administered to refractory symptoms as an option of last resort. Therefore, our data do

not allow for final conclusions on whether sedation was performed according to specialized palliative care guidelines.

CONCLUSIONS

In Swiss clinical practice, continuously deeply sedated patients predominantly died outside specialized palliative care. The administration of continuous deep sedation until death seems to be strongly associated with possibly life-shortening medical end-of-life decisions. The increasing trend of sedation practice may be in part a function of changes in medical endof-life practices in primary and hospital care. Therefore, exploring professionals' understanding of sedation and concurrent decision-making processes outside specialized palliative care will be necessary to better understand the variation in sedation practice, and to estimate prevalence and trends over time accurately.

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