Dealing With Delicate Issues in Continuous Deep Sedation

Varying Practices Among Dutch Medical Specialists, General Practitioners, and Nursing Home Physicians

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Background: This article examines delicate issues in continuous deep sedation (CDS) from the perspectives of different types of physicians. The following sensitive issues involved in CDS were investigated: artificial hydration, sedation for nonphysical discomfort, the relationship between CDS and euthanasia, and patient involvement in decision making for CDS.

Methods: A structured retrospective questionnaire concerning the most recent case of CDS during the past 12 months was sent to a sample of medical specialists (n=727), general practitioners (n=626), and nursing home physicians (n=111).

Results: Response rates were 26.4% for medical specialists, 37.4% for general practitioners, and 59.5% for nursing home physicians. Indications for CDS differed among the types of physicians. General practitioners (25.0%) were most often confronted with a patient request for euthanasia before starting CDS compared with medical specialists (8.9%) and nursing home physicians (6.5%). A decision to forgo artificial hydration in CDS was more often made by nursing home physicians (91.3%) compared with medical specialists (53.7%) and general practitioners (51.2%). Shorter survival was found for patients sedated for nonphysical discomfort (vs other patients) by general practitioners. Among all patients, 74.5% were involved in decision making before the start of CDS.

Conclusions: The present study demonstrates notable differences in CDS practice among various types of physicians. To what extent this is related to different patient populations or to different expertise requires further investigation. The use of CDS for nonphysical discomfort calls for critical examination to avoid ambiguous practice.

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PALLIATIVE SEDATION HAS BEEN defined as "the use of sedative medications to relieve intractable and refractory distress by the reduction in patient consciousness."[1] The definition of palliative sedation includes refractoriness of symptoms, which is the impossibility to timely decrease discomfort using conventional treatment methods. Although this definition includes intermittent and continuous sedation, it is continuous deep sedation (CDS) until death, also called *terminal sedation* or *sedation in the last phase of life*, that has received the most attention[2] and that is addressed in the present article. Continuous deep sedation is mostly applied in patients with end-stage cancer.[3] It was shown for the Netherlands that the frequency of CDS increased between 2001 and 2005.[4] It has been suggested that CDS can be used as a "hidden" or "slow" alternative to euthanasia as it offers physicians the possibility to shorten the life of a patient without reporting it as formal euthanasia.[5] In particular, the withdrawal of artificial hydration and the use of CDS for nonphysical discomfort have been identified as gray areas.[6,7] Others justify an increased risk of life-shortening effects in CDS in terms of the physician's intentions (which should be aimed at symptom relief and not at ending life), in terms of the proportionality of benefits and harms of CDS, and in terms of the patient consent for CDS.[8,9] Finally, it has been argued that CDS does not involve life shortening at all, making a moral justification superfluous.[10]

The practice of CDS is mostly evaluated from the perspective of the hospice palliative care unit, although there is evi-

dence that it is also applied in other settings such as hospitals and home care.[11] In the Netherlands, CDS is applied within the following 3 major medical settings: the hospital, the nursing home or hospice, and the patient's home (under the guidance of a general practitioner).[12] Medical specialists operate in a clinical environment directed at the treatment of acute and specific symptoms and diseases. For general practitioners, terminally ill patients with cancer compose about half of the patients dying at home, indicating the importance of continuity of care at home.[13,14] Contrary to other countries, nursing home physicians in the Netherlands are a separate specialty (distinguished from family practice) and are often on staff in nursing homes or hospices.[15]

The objective of this article is 3-fold. First, symptoms of the patients treated by the 3 types of physicians will be considered. Second, how the different types of physicians deal with the sensitive issues surrounding CDS will be examined. Third, it will be discussed how different ways of dealing with sensitive issues relate to differences in patient populations among the types of physicians. Medication administration in CDS has been addressed elsewhere.[16] The following delicate issues will be addressed in particular: (1) the relationship between CDS and euthanasia, (2) the forgoing of artificial hydration during CDS, (3) nonphysical discomfort as a reason for CDS, and (4) patient involvement in the decision making regarding CDS.

METHODS

A structured retrospective questionnaire concerning the most recent case of CDS during the past 12 months was sent to 1464 Dutch physicians. The target group included medical specialists (n=727), general practitioners (n=626), and nursing home physicians (n=111). The sample of medical specialists consisted of all the respiratory and geriatric specialists registered in the Netherlands and all the internal medicine specialists (including oncologists) registered in the southeastern part of the Netherlands. All general practitioners and nursing home physicians in the southeastern part of the Netherlands were included. The questionnaire contained 61 questions, and a subset of these questions is reported on in the present study. The questionnaire was mailed to the physicians from February 2003 to May 2005, but the study was completed before the introduction of the national guideline for palliative sedation by the Royal Dutch Medical Association in December 2005.[17] A response reminder was sent after 1 month. A definition of CDS was provided with the questionnaire, indicating that CDS was restricted to sedation, with the expectation that the sedation would last until the patient dies. Decisions concerning artificial hydration and nutrition were not part of the definition.

The primary questions concerned (1) the indicating symptoms for CDS, (2) the perceived difference between CDS and euthanasia, (3) ungranted requests for euthanasia before CDS, (4) decisions about forgoing artificial hydration, and (5) patient involvement in decisions for CDS. The survival of patients was reported in categories referring to the number of days (ie, 1, 2, 3, 4-7, 8-14, 15-21, or >21 days). Nonphysical discomfort was defined as the presence of anxiety, existential discomfort, or loss of dignity. Forgoing artificial hydration was defined as a decision not to supply artificial hydration (stopping or not starting). Finally, the availability of technological support was addressed.

Data were analyzed using commercially available software (SPSS 12.0; SPSS Inc, Chicago, Illinois). χ^2 Tests and 95% confidence intervals (CIs) were used to identify statistically significant differences among the different types of physicians. Grouped median and nonparametric tests (Mann-Whitney test and Kruskal-Wallis test) were used to test differences in survival. In all tests, α=.05 was used.

RESULTS

Of 1464 physicians invited to respond, 525 (35.9%) returned the questionnaire. The response rates varied across types of physicians (**Table 1**). A limited nonresponse analysis showed that most of the nonrespondents lacked the time needed to complete the questionnaire or thought that they had too little experience with CDS to provide useful information. Of 525 respondents, 312 (59.4%) reported a case of CDS within the past 12 months. Eight of these questionnaires had to be excluded from the analyses because the respondent was not a medical specialist, general practitioner, or nursing home physician (eg, nurses). Therefore, 304 cases of CDS were included in the final analyses (Table 1). Most of these respondents were male (65.8%), and the mean age was 46 years. Frequent decisions regarding the undertaking of CDS (ie, consideration on >5 occasions during the past year) seemed to occur less often for general practitioners (0.8%) than for nursing home physicians (22.2%) and medical specialists (38.7%) ($P<.001$).

REASONS TO START CDS

Continuous deep sedation was initiated for different reasons (**Table 2**). Pain was frequently a reason to start CDS for general practitioners (60.2%), medical specialists (55.2%), and nursing home physicians (52.2%). Dyspnea was a reason to start CDS for 80.0% of medical specialists, 37.0% of nursing home physicians, and 30.8% of general practitioners ($P<.001$). Anxiety was an indication for CDS among 36.0% of medical specialists, 40.6% of general practitioners, and 65.2% of nursing home physicians ($P=.002$). Additional analysis showed that CDS was initiated for 1 symptom (48 cases [15.8%]), 2 symptoms (116 cases [38.2%]), and 3 symptoms or more (139 cases [45.7%]), without statistically significant differences among types of physicians ($P=.35$). In their written comments, some of the physicians further explained their reasons for CDS. Among others, aphasia, ileus, restlessness, myoclonus, rectal loss of blood, and uncontrollable screaming in end-stage dementia were reported. Hastening of death and the desires of the patient were also mentioned by a few physicians. Patients were fully conscious before the start of CDS in 53.2%, 47.4%, and 37.0% of the cases seen by medical specialists, general practitioners, and nursing home physicians, respectively.

CDS AND EUTHANASIA

Among all physicians, 1.7% (95% CI, 0%-3.2%) regarded CDS as equivalent to euthanasia, while 81.6% (95% CI, 77.1%-86.0%) of the physicians believed that CDS is not aimed at patient death. Medical specialists (81.8%),

Table 1. Physician Experience With End-of-Life Care and Continuous Deep Sedation (CDS)[a]

Variable	Medical Specialists	General Practitioners	Nursing Home Physicians
Respondents, % (No. of respondents/total No. of sample)[b]	26.4 (192/727)	37.4 (234/626)	59.5 (66/111)
Physicians reporting case of CDS during the past 12 mo, % (No. of respondents/total No. of sample)	65.1 (125/192)	56.8 (133/234)	70.0 (46/66)
Experience With End-of-Life Care			
Involved in the dying process of a patient on >5 occasions during the past 12 mo[c]	74.1 (66.5-81.9) [99/124]	30.0 (22.1-37.9) [39/130]	91.1 (82.8-99.4) [41/45]
Experience With CDS			
Decided to start CDS on >5 occasions during the past 12 mo with the expectation that the patient would die under CDS[c,d]	38.7 (30.1-47.3) [48/124]	0.8 (0-2.3) [1/131]	22.2 (10.1-34.4) [10/45]
Availability of technological support (eg, pumps) for palliative sedation[c,e]			
Very adequate	67.7 (59.5-76.0) [84/124]	30.1 (22.0-38.2) [37/123]	26.1 (13.4-38.8) [12/46]
More or less adequate	25.8 (18.1-33.5) [32/124]	55.3 (46.5-64.1) [68/123]	52.2 (37.7-66.6) [24/46]
Poor	6.5 (2.1-10.8) [8/124]	11.4 (5.8-17.0) [14/123]	19.6 (8.1-31.0) [9/46]
Very poor	0	3.3 (0.1-6.4) [4/123]	2.2 (0.0-6.4) [1/46]

[a] Data are given as percentage (95% confidence interval) [number of the respondents/total number surveyed] unless otherwise indicated.
[b] Thirty-three physicians were excluded because they could not be categorized in one of these 3 categories of physicians.
[c] $P < .001$.
[d] Data missing for 4 physicians.
[e] Data missing for 11 physicians.

Table 2. Demographics of Patients Starting Continuous Deep Sedation (CDS): Last Case Past 12 Months[a]

Variable	% (95% Confidence Interval)			*P* Value
	Medical Specialists	General Practitioners	Nursing Home Physicians	
General Features[b]				
Male sex	51.7 (42.7-60.6) [62/120]	56.1 (47.6-64.5) [74/132]	35.6 (21.6-49.5) [16/45]	.60
Age, y				
≤40	3.3 (0.1-6.4) [4/123]	5.3 (1.5-9.1) [7/133]	2.2 (0-6.4) [1/46]	.57
41-70	31.7 (23.5-39.9) [39/123]	48.1 (39.6-56.6) [64/133]	10.9 (1.9-19.9) [5/46]	<.001
≥71	65.0 (56.6-73.5) [80/123]	46.6 (38.1-55.1) [62/133]	87.0 (77.2-96.7) [40/46]	<.001
Consciousness Before CDS[c]				
Patient was fully conscious	53.2 (44.4-62.0) [66/124]	47.4 (38.9-55.9) [63/133]	37.0 (23.0-50.9) [17/46]	.44
Patient was slumbering	35.5 (27.1-43.9) [44/124]	40.6 (32.3-48.9) [54/133]	50.0 (35.6-64.4) [23/46]	
Patient was sleeping, with intact pain and care reflexes	11.3 (5.7-16.9) [14/124]	12.0 (6.5-17.6) [16/133]	13.0 (3.3-22.8) [6/46]	
Indication for CDS, With >1 Answer Possible				
Pain	55.2 (46.5-63.9) [69/125]	60.2 (51.8-68.5) [80/133]	52.2 (37.7-66.6) [24/46]	.57
Dyspnea	80.0 (73.0-87.0) [100/125]	30.8 (23.0-38.7) [41/133]	37.0 (23.0-50.9) [17/46]	<.001
Anxiety	36.0 (27.6-44.4) [45/125]	40.6 (32.3-48.9) [54/133]	65.2 (51.5-79.0) [30/46]	.002
Delirium	11.2 (5.7-16.7) [14/125]	26.3 (18.8-33.8) [35/133]	23.9 (11.6-36.2) [11/46]	.007
Vomiting	2.4 (0-5.1) [3/125]	12.0 (6.5-17.6) [16/133]	4.3 (0-10.2) [2/46]	.007
Nausea	2.4 (0-5.1) [3/125]	9.8 (4.7-14.8) [13/133]	8.7 (0.1-16.8) [4/46]	.047
Exhaustion	30.4 (22.3-38.5) [38/125]	43.6 (35.2-52.0) [58/133]	13.0 (3.3-22.8) [6/46]	<.001
Existential suffering	12.0 (6.3-17.7) [15/125]	21.1 (14.1-28.0) [28/133]	21.7 (9.8-33.7) [10/46]	.11
Loss of dignity	11.2 (5.7-16.7) [14/125]	28.6 (20.9-36.2) [38/133]	6.5 (0-13.7) [3/46]	<.001

[a] Data are given as percentage (95% confidence interval) [number of the respondents/total number surveyed] unless otherwise indicated.
[b] Data missing for sex (7 patients) and age (2 patients).
[c] Data missing for 1 patient.

general practitioners (66.4%), and nursing home physicians (84.1%) differed in their views about whether CDS is symptom control ($P = .007$) (**Table 3**). General practitioners (25.0%) received a request for euthanasia from the patient in advance of CDS statistically significantly more often than medical specialists (8.9%) and nursing home physicians (6.5%) ($P < .001$).

ARTIFICIAL HYDRATION

A decision to forgo artificial hydration in CDS was more often made by nursing home physicians (91.3%) than by medical specialists (53.7%) or general practitioners (51.2%) ($P < .001$) (Table 3). The decision was also made more often for patients who were given a deeper level of

Table 3. Continuous Deep Sedation (CDS), Euthanasia (EUT), Artificial Hydration, and Nonphysical Discomfort[a]

Variable	% (95% Confidence Interval)			*P* Value
	Medical Specialists	General Practitioners	Nursing Home Physicians	
Physicians' Opinions on Reported Differences Between CDS and EUT, With >1 Answer Possible[b]				
No difference	2.5 (0-5.2) [3/121]	1.6 (0-3.7) [2/128]	0	.55
Sedation not aimed at patient death	81.8 (74.9-88.7) [99/121]	82.0 (75.4-88.7) [105/128]	79.5 (67.6-91.5) [35/44]	.93
In sedation, the patient dies a natural death	47.9 (39.0-56.8) [58/121]	58.6 (50.1-67.1) [75/128]	70.5 (57.0-83.9) [31/44]	.03
Sedation is symptom control	81.8 (74.9-88.7) [99/121]	66.4 (58.2-74.6) [85/128]	84.1 (73.3-94.9) [37/44]	.007
Medication differs	52.1 (43.2-61.0) [63/121]	58.6 (50.1-67.1) [75/128]	61.4 (47.0-75.8) [27/44]	.45
Decision-making procedure differs	55.4 (46.5-64.2) [67/121]	57.0 (48.5-65.6) [73/128]	45.5 (30.7-60.2) [20/44]	.40
Legal status differs	62.8 (54.2-71.4) [76/121]	63.3 (54.9-71.6) [81/128]	61.4 (47.0-75.8) [27/44]	.98
Presence of a Refused Request for EUT Before CDS (Last Case in Past 12 mo)[c]				
No, request was granted	0	3.1 (0.1-6.1) [4/128]	0	.07
No, no request for EUT was present	82.1 (75.3-88.9) [101/123]	72.7 (64.9-80.4) [93/128]	89.1 (80.1-98.1) [41/46]	.04
Yes, request from patient	8.9 (3.9-14.0) [11/123]	25.0 (17.5-32.5) [32/128]	6.5 (0-13.7) [3/46]	<.001
Yes, request from relatives	6.5 (2.1-10.9) [8/123]	9.4 (4.3-14.4) [12/128]	8.7 (1-16.8) [4/46]	.70
Artificial Hydration (Last Case in Past 12 mo)[d]				
Decision to forgo artificial hydration	53.7 (44.8-62.5) [66/123]	51.2 (42.4-60.0) [64/125]	91.3 (83.2-99.4) [42/46]	<.001
Exclusive Indication for CDS (Last Case in Past 12 mo)[e]				
Nonphysical discomfort[f]	3.2 (0.1-6.3) [4/125]	10.5 (5.3-15.7) [14/133]	17.4 (6.4-28.3) [8/46]	.007
Physical discomfort[g]	52.0 (43.2-60.8) [65/125]	37.6 (29.4-45.8) [50/133]	21.7 (9.8-33.7) [10/46]	<.001
Patient Involvement in CDS (Last Case in Past 12 mo)[h]				
Patient not consulted with before starting CDS	19.7 (12.6-26.7) [24/122]	23.8 (16.5-31.2) [31/130]	45.7 (31.3-60.0) [21/46]	.01
Patient consulted with immediately before CDS	44.3 (35.4-53.1) [54/122]	39.2 (30.8-47.6) [51/130]	32.6 (19.1-46.2) [15/46]	
Patient consulted with some other time before CDS	36.1 (27.5-44.6) [44/122]	36.9 (28.6-45.2) [48/130]	21.7 (9.8-33.7) [10/46]	
% Of patients not consulted with who had proxies involved in decision making	87.5 (74.3-100.0) [21/24]	90.3 (79.9-100.0) [28/31]	95.2 (86.1-100.0) [20/21]	.67

[a] Data are given as percentage (95% confidence interval) [number of the respondents/total number of surveyed] unless otherwise indicated.
[b] Data missing for 11 physicians.
[c] Data missing for 7 physicians.
[d] Data missing for 10 patients.
[e] The category "other symptoms" (n=4) is not included because it can be physical and nonphysical.
[f] Defined as anxiety, existential suffering, or loss of dignity without physical symptoms (pain, dyspnea, delirium, vomiting, or nausea).
[g] Defined as pain, dyspnea, delirium, vomiting, or nausea without other symptoms (anxiety, existential suffering, or loss of dignity).
[h] Data missing for 6 patients.

CDS (*P*=.02, data not shown). Of the patients, 73.3% (95% CI, 68.2%-78.4%) died within 3 days, and 95.8% (95% CI, 93.5%-98.1%) died within 1 week (data not shown). Patients in whom artificial hydration was forgone did not have a shorter survival; for patients of nursing home residents, even longer survival was indicated (*P*=.03) (**Table 4**) although the numbers were small.

NONPHYSICAL DISCOMFORT

Nursing home physicians (17.4%) most often reported CDS for nonphysical symptoms exclusively, followed by general practitioners (10.5%) and medical specialists (3.2%) (*P*=.007) (Table 3). Conversely, physical discomfort as an exclusive reason for CDS was most often reported by medical specialists (52.0%), followed by general practitioners (37.6%) and nursing home physicians (21.7%) (*P*=.001). Thirteen patients sedated for nonphysical symptoms exclusively by general practitioners had a shorter survival after the start of CDS compared with the other patients from general practice (*P*=.01) and compared with patients sedated for nonphysical discomfort by other physicians (*P*=.04) (Table 4). Further analysis showed that most of these 13 patients were fully conscious before CDS and had been consulted with in advance. Three patients had requested euthanasia before CDS. Three general practitioners commented in written text that hastening of death, desires of the patient, and the patient's rejection of euthanasia in favor of CDS were among the main reasons to sedate. Shorter survival was not found for patients sedated for nonphysical discomfort by nursing home physicians and by medical specialists.

PATIENT INVOLVEMENT IN DECISION MAKING

Among the cases reported herein, involvement of the patient in decision making for CDS occurred in 74.5% (222 of 298) of the cases. The patient was not consulted with before the start of CDS by 19.7% of medi-

Table 4. Patient Survival in Continuous Deep Sedation

Variable	Patient Survival, d (Grouped Median)			*P* Value[a]
	Medical Specialists	General Practitioners	Nursing Home Physicians	
All patients	2.5 (n=118)	2.4 (n=125)	2.7 (n=45)	.47
Nonphysical discomfort exclusively				
No	2.5 (n=115)	2.6 (n=112)	2.6 (n=37)	.83
Yes	2.7 (n=3)	1.5 (n=13)	3.4 (n=8)	.04
P value[b]	.80	.01	.34	
Artificial hydration forgone[c]				
No	2.4 (n=53)	2.5 (n=57)	1.5 (n=4)	.27
Yes	2.3 (n=61)	2.3 (n=61)	2.9 (n=41)	.21
P value[a]	.72	.66	.03	

[a] Kruskal-Wallis test for differences among physicians.
[b] Mann-Whitney test for differences between yes and no.
[c] Data missing for 2 medical specialists and 7 general practitioners.

cal specialists, 23.8% of general practitioners, and 45.7% of nursing home physicians (*P*=.01). The primary reasons reported for noninvolvement of the patient were dementia or delirium (n=42) and unconsciousness (n=21). Patients were consulted with immediately before the start of CDS (32.6%-44.3%) or at some other time before the start of CDS (21.7%-36.9%) (Table 3). Additional analysis showed the latter category of patients to be more often fully aware of their situation than the former (89.2% vs 76.3%, *P*=.01). For patients not consulted with before CDS, proxies had often been involved in the decision making (Table 3).

COMMENT

This study systematically investigated differences in the undertaking of CDS among various types of physicians. Major differences were found in symptoms of their patients starting CDS among medical specialists, general practitioners, and nursing home physicians. In addition, large differences were detected for requests for euthanasia before CDS, decisions to forgo artificial hydration, nonphysical discomfort as a reason to start CDS, and patient involvement in decision making for CDS.

REASONS TO START CDS

The large differences in refractory symptoms as indications for CDS can be partly explained by the various patient populations among the types of physicians. Regarding nursing homes, 1 study[18] showed that two-thirds of residents reported mild or severe pain, which largely correlated with feelings of anxiety. This may explain the large presence of anxiety in patients treated by nursing home physicians in this study. General practitioners in the present study often reported exhaustion, terminal delirium, or loss of dignity among patients as part of the indication for CDS. This corresponds to symptoms that are mentioned frequently in requests for euthanasia and assisted suicide in home care.[19] In contrast, for medical specialists, physical symptoms of patients often served as a reason to start CDS.

CDS AND EUTHANASIA

Virtually none of the physicians regarded CDS as equivalent to euthanasia, which is a positive result. However, concurrently, the physicians did not unanimously agree that "not being aimed at patient death" was a striking difference between CDS and euthanasia. Medical specialists and nursing home physicians regarded CDS as symptom control more frequently than general practitioners. General practitioners were also less familiar with CDS (Tables 1 and 2). Nursing home physicians most frequently regarded CDS as a natural death. A partial explanation may be that in Dutch nursing homes "natural" end points such as cachexia and dehydration in patients with dementia are often confronted and loss of consciousness is common.[20,21] The large number of requests for euthanasia received within the home setting is confirmed in the literature.[22] Only 1.7% of physicians in this study regarded CDS as equivalent to euthanasia, while the finding of euthanasia requests before CDS is mostly restricted to general practitioners. The latter is confirmed in the literature.[22] Nevertheless, now that it has been reported that Dutch physicians increasingly favor CDS over euthanasia,[4] the question of whether CDS is used for purposes of slow euthanasia rather than symptom alleviation gains importance.

ARTIFICIAL HYDRATION

The physicians in the present study differed widely with regard to their policies on the administration of artificial hydration. The issue should be interpreted carefully. In hospitals, artificial hydration in patients with terminal cancer is often discontinued when these patients are discharged. Therefore, it is plausible that there are few patients receiving artificial hydration in the home. For this reason, the general practitioners who did not report a decision to forgo artificial hydration may have wanted to indicate that the issue of hydration was a nonissue rather than that hydration had been supplied. For nursing home physicians, forgoing artificial hydration is often part of explicit advanced care planning, agreed on by the children or proxies of the patient.[23] In contrast to

nursing homes in the United States, Dutch nursing homes more often avoid a curative approach toward patients, resulting in less rehydration therapy and more dehydration in patients with dementia and pneumonia.[24] For palliative sedation, the Dutch national guideline recommends not to continue artificial hydration after the initiation of CDS; moreover, this guideline intends to limit death from dehydration during CDS by restricting its application to the last 1 or 2 weeks of life.[17] The present study shows that most patients died within 3 days after the start of CDS, which may reduce death from dehydration in daily practice.

NONPHYSICAL DISCOMFORT

In the literature, CDS for nonphysical discomfort has only been reported in exceptional cases, as the refractoriness of such symptoms is difficult to measure and death is not necessarily imminent.[7,8,25] Medical specialists in the present study rarely sedated patients for nonphysical discomfort only, while this was much more common among nursing home physicians and general practitioners. Among the latter, CDS for nonphysical symptoms was associated with shorter patient survival. This is not what one would expect given that most of these patients were conscious before CDS and that physical problems were not an indication for CDS. Sedation in conscious patients with primarily nonphysical discomfort requires full anesthesia. It is doubtful whether this can be provided in the average home care setting while maintaining quality standards. Moreover, this study cannot exclude the use of CDS for the purpose of slow euthanasia in at least some cases. The recently established Dutch guideline for palliative sedation considers this problematic.[17] Therefore, the present study confirms the presumption that CDS for nonphysical discomfort can be an ambiguous practice, at least in the home care setting.

PATIENT INVOLVEMENT IN DECISION MAKING

In this study, 80.3% of medical specialists, 76.4% of general practitioners, and 54.3% of nursing home physicians involved their patients in decision making before CDS (Table 3). This seems to be an improvement relative to previous research by Rietjens et al,[12] who reported 65%, 53%, and 55% patient involvement among medical specialists, general practitioners, and nursing home physicians, respectively. Because of the frequent presence of dementia in nursing home residents, it is not surprising that patients in nursing homes were minimally involved in decision making about CDS. However, in most of these cases, proxies were involved in decision making. Our study shows that patients who are consulted with some time before the start of CDS had better awareness than those who are consulted with immediately before the start of CDS. Therefore, practitioners should plan ahead and involve patients in decision making for CDS rather than postpone decision making.[26]

In closing, the results of the present study may be affected by recall bias. In addition, the situation in the Netherlands for end-of-life care and euthanasia is different from that in most other countries. Also, response rate may have been lowered by the unclear juridical status of CDS at the time of this study. Therefore, the present results should be interpreted with caution. Future research should address which reasons are considered proper indications for CDS to maintain quality in palliative care and to avoid the hastening of death. The extent to which variations in practice are related to differences in patient populations rather than to differences in expertise needs further investigation.

To conclude, the present study shows that medical specialists, general practitioners, and nursing home physicians handle the delicate issues associated with CDS in different manners, which seem to be at least partly related to the particular features of the patient population involved. This study found sufficient reasons to call for critical examination of the use of CDS for nonphysical discomfort to avoid ambiguous practice.

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