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## Original Study

# Continuous Palliative Sedation in Nursing Home Residents With Dementia and Refractory Neuropsychiatric Symptoms



Annelies E. Veldwijk-Rouwenhorst MD<sup>a,b,\*</sup>, Martin Smalbrugge MD, PhD<sup>c</sup>,  
Sytse U. Zuidema MD, PhD<sup>d</sup>, Suzan A.J. Hanssen MD<sup>a,b</sup>,  
Raymond T.C.M. Koopmans MD, PhD<sup>a,b,e</sup>, Debby L. Gerritsen PhD<sup>a,b,\*</sup>

<sup>a</sup> Department of Primary and Community Care, Radboud Institute for Health Sciences, Radboud University Medical Center, Nijmegen, the Netherlands

<sup>b</sup> Radboudumc Alzheimer Center, Nijmegen, the Netherlands

<sup>c</sup> Department of General Practice and Elderly Care Medicine, Amsterdam Public Health Research Institute, Amsterdam University Medical Centers Location VUmc, Amsterdam, the Netherlands

<sup>d</sup> Department of General Practice and Elderly Care Medicine, University of Groningen, University Medical Center Groningen, Groningen, the Netherlands

<sup>e</sup> De Waalboog "Joachim en Anna," Center for Specialized Geriatric Care, Nijmegen, the Netherlands

## A B S T R A C T

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**Keywords:**

Continuous palliative sedation  
neuropsychiatric symptoms  
dementia  
nursing home

**Objectives:** Extreme neuropsychiatric symptoms can be a heavy burden for nursing home (NH) residents, relatives, and caregivers. Sometimes, when extreme neuropsychiatric symptoms are considered refractory, continuous palliative sedation is administered. The aim of this study was to explore the trajectory leading to continuous palliative sedation and its administration in NH residents with dementia and refractory neuropsychiatric symptoms.

**Design:** A qualitative interview and explorative study was performed.

**Setting and Participants:** Relatives, elderly care physicians, and other staff members involved with 3 NH residents with dementia and extreme refractory neuropsychiatric symptoms who received continuous palliative sedation were interviewed. These NH residents lived on dementia special care units of 3 NHs in the Netherlands.

**Methods:** Consecutive sampling was used to select participants. Medical files were studied. Semi-structured interviews were conducted. Transcriptions were analyzed with thematic analysis, including directed content analysis.

**Results:** Nine in-depth interviews with 13 participants were held. Analysis resulted in 6 main themes, with several subthemes reflecting phases of the continuous palliative sedation trajectory: (1) run-up, describing an unbearable struggle of the resident; (2) turning point, at which hope was lost; (3) considering continuous palliative sedation and administration of intermittent sedation; (4) decision to start continuous palliative sedation based on 1 decisive trigger; (5) administration of continuous palliative sedation with stakeholders experiencing relief; and (6) evaluation.

**Conclusions and Implications:** The trajectory leading up to continuous palliative sedation in NH residents with dementia and extreme refractory neuropsychiatric symptoms was complex and burdensome, but the initiation led to relief and contentment for all those involved. This study highlights that continuous palliative sedation can be a valuable treatment option among these residents. A recommendation is to include external consultation in the decision process and to administer intermittent sedation as a preceding step when continuous palliative sedation is considered.

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\* Address correspondence to Annelies E. Veldwijk-Rouwenhorst, MD, Radboud University Medical Center, Radboud Institute for Health Sciences, P.O. Box 9101, 6500 HB Nijmegen, the Netherlands; or Debby L. Gerritsen, PhD, MSc, Department of Primary and Community Care, Radboud Institute for Health Sciences, Radboud University Medical Center, P.O. Box 9101, 6500 HB Nijmegen, the Netherlands.

E-mail addresses: [annelies.veldwijk-rouwenhorst@radboudumc.nl](mailto:annelies.veldwijk-rouwenhorst@radboudumc.nl) (A.E. Veldwijk-Rouwenhorst), [debby.gerritsen@radboudumc.nl](mailto:debby.gerritsen@radboudumc.nl) (D.L. Gerritsen).

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Palliative sedation is a way to reduce unbearable suffering in patients with dementia. According to the Dutch practice guideline, palliative sedation is defined as “the deliberate lowering of a person’s level of consciousness in the last stages of life.”<sup>1</sup> Palliative sedation encompasses 2 distinct types of interventions: brief or intermittent sedation and continuous palliative sedation. The Dutch guideline states that continuous palliative sedation can only be administered if the patient’s life expectancy is less than 2 weeks and if 1 or more refractory symptoms cause unbearable suffering.<sup>1</sup> A symptom is refractory if “none of the conventional treatments are effective or fast-acting enough and/or if these treatments are accompanied by unacceptable side-effects.”<sup>1–3</sup> In the Netherlands, 21% of nursing home (NH) residents with dementia received continuous palliative sedation on their day of dying. The most common reasons for starting continuous palliative sedation were physical symptoms, that is, pain, exhaustion, or dyspnea.<sup>4</sup>

Neuropsychiatric symptoms, such as anxiety, aggression, or agitation, occur in 82% of NH residents with dementia.<sup>5</sup> At times, these symptoms become extreme and even refractory. Guidelines on palliative sedation do not specify neuropsychiatric symptoms as potential refractory symptoms.<sup>1,6,7</sup> However, from clinical practice we know that in exceptional cases, continuous palliative sedation is sometimes administered in NH residents with dementia and refractory neuropsychiatric symptoms,<sup>8</sup> but exact numbers are missing. Little is known about this exceptional practice; more specifically, there is a lack of clarity surrounding the process of decision making that leads to continuous palliative sedation. Therefore, the aim of this study was to explore this process of decision making, the trajectory of continuous palliative sedation, and the experiences of those involved.

## Methods

### *Study Aim, Design, Setting, and Participants*

This qualitative explorative study is part of the WAALBED (WAAL-Behavior-in-Dementia)-III study that focuses on NH residents with dementia and extreme neuropsychiatric symptoms.<sup>9</sup> The aim of the current qualitative study was to explore the process of decision making, the trajectory of continuous palliative sedation, and the experiences of those involved. We conducted and reported this study according to the Consolidated criteria for Reporting Qualitative studies (COREQ) checklist (see [Supplementary Table 1](#)).<sup>10</sup> For this explorative study, we intended to include 3 cases of deceased NH residents with dementia and extreme refractory neuropsychiatric symptoms in whom continuous palliative sedation had been administered. Our sample size was determined using the model of information power of Malterud et al.<sup>11</sup> Following this model, (1) a narrow study aim and a specific combination of participants was applied; (2) a longitudinal in-depth exploration of narratives was performed; and (3) the interviewer had relevant background knowledge because she was an elderly care physician in training.<sup>11</sup> To recruit cases, we used consecutive sampling (see [Supplementary Table 1](#)), where the participants were selected in order of sign-up according to their appropriateness for inclusion.<sup>12</sup> Cases were assessed by AV and RK based on whether (a) they occurred recently, preferably less than 3 months ago; (b) continuous palliative sedation was administered because of extreme neuropsychiatric symptoms; (c) the NH resident had no acute life-threatening disease; and (d) they had been staying in the NH for at least 4 weeks. Three interviews per case were performed to explore the perspective of different stakeholders: 1 with the involved elderly care physician, 1 with an involved staff member, and 1 with a relative. Participants were not involved in the setting up of the study. The study was assessed by the local Medical Ethics Review Committee (CMO

Regio Arnhem-Nijmegen [number 2015-1723]), which stated that the study did not require medical ethical approval under the legislation in medical trials. In accordance with the Declaration of Helsinki and the applicable Dutch legislation,<sup>13</sup> all participants provided written informed consent for participation and audio recording of the interviews. Before starting the interview, participants were assured that the transcripts would be anonymized and that only the researchers would have access to the original interviews.

### *Data Collection*

Resident’s characteristics, reason for admission, medical history, drug prescriptions, and course of neuropsychiatric symptoms were extracted from their medical files. A topic list for the interviews was prepared by AV and discussed with the coauthors (see [Supplementary Table 2](#)). A separate topic list was developed for the interviews with the relatives (see [Supplementary Table 3](#)). Topics were as follows: course of and interventions for reducing the neuropsychiatric symptoms, process of decision making leading to continuous palliative sedation and its administration, and the impact on those involved. Face-to-face, semistructured, in-depth interviews were conducted and audio-taped. During the analysis process, an additional telephone interview was held with each elderly care physician to obtain more information.

### *Data Analysis*

All interviews were transcribed verbatim, eliminating any private information. Thematic analysis was used including directed content analysis.<sup>14–16</sup> This concerned an iterative process involving several steps. Based on the aims of our study and topic list, deductive coding was used, with the identification of potential categories and sub-categories as codes (SH, AV, DG).<sup>14</sup> Inductive coding (deriving codes from the data, modifying them throughout the coding process, and moving to an explanation of the data) was also applied.<sup>14</sup> New codes were grouped into categories and combined with existing codes and categories into a coding tree (SH). In weekly consensus meetings (SH, DG, AV), codes, categories, and the coding tree were discussed. All authors performed individual critical appraisals of the coding tree and of 1 or more coded interviews, which were discussed as a group. Relevant elements of the additional telephone interviews were highlighted in the transcripts of these interviews and added to the results of the other analyses. Categories were refined into definitive themes and subthemes during consensus meetings (SH, DG, AV). For within-case analysis, mind maps were made per case, which are “visual, non-linear representations of themes and sub-themes and their relationships.”<sup>17,18</sup> These 3 mind maps covered the range of themes, subthemes, and their connections. Group discussions about the mind maps were held with all authors. The mind maps were combined into 1 mind map for a cross-case analysis (SH). After having analyzed the interview fragments that pertained to the codes that were included in the mind map and having had several group discussions, a final graphic representation of the themes, subthemes, and connections was made.

## Results

Three cases from dementia special care units of 3 NHs in the Netherlands were included. We conducted 9 interviews with a total of 13 participants. Participants were 3 elderly care physicians (1 per case), an elderly care physician in training (case 1), 2 nurses (case 1 and 2), a vocational nurse specifically assigned to the resident (case 3),

1 psychologist (case 3), and 5 relatives (two each in case 1 and 2, and one in case 3, respectively). Four of the interviews had 2 interviewees.

The background information of each case is described in [Table 1](#). The neuropsychiatric symptoms were unpredictable and extreme in all 3 cases. Also, 2 residents had a history of psychiatric disorders. Furthermore, several interventions had been applied since the beginning of the neuropsychiatric symptoms, such as psychosocial interventions (eg, playing music and guidance from the psychologist on how to cope with the behaviors), prescription of several psychotropic drugs, and an external consultation by a (geriatric) psychiatrist ([Table 1](#)). All of these interventions failed in reducing the neuropsychiatric symptoms. Analysis of the interview data resulted in the identification of 6 main themes. Retrospectively, these can be described according to phases ([Figure 1](#)). To improve readability, the results are mainly formulated from the perspective of the elderly care physician, as they lead the process of decision making and the administration of continuous palliative sedation. The themes are summarized below, illustrated by a selection of quotes that were translated into English. We display additional quotes for all described themes in [Supplementary Table 4](#).

### Phase 1: Run-up

In the run-up to continuous palliative sedation, relatives and members of staff mentioned that the neuropsychiatric symptoms were detrimental to the quality of life of the NH resident. They described it as an unbearable suffering and dubbed the experience of the NH resident as an inner struggle.

Hanging in the chair like a battered human, yes that was just horrible. And to that effect, it was clear enough to me: this is unbearable suffering

(Elderly care physician, case 1)

Elderly care physicians termed suffering of the NH resident as unbearable based on (non)verbal expressions (having a disconcerted appearance and body posture or constant screamed wishes to sleep and to have rest). However, they stated that they found this very difficult to determine, because of the subjective character of this judgment. Furthermore, hope played an important role for all participants. This included hope in reducing the neuropsychiatric symptoms and the unbearable suffering of the NH resident, as well as for creating a manageable situation for all of those involved, particularly the nursing staff.

Still you hope that you will find something which turns it [the suffering] around and that someone feels better ... every change of medication, every new approach you keep hoping that you invented Columbus' egg.

(Nurse, case 2)

### Phase 2: Turning Point

At a certain moment, the elderly care physicians and other staff members lost hope and became convinced that they had tried all possible treatment options. They were convinced that no further improvement of the neuropsychiatric symptoms could be expected and that these were considered refractory.

In my view we had tried everything, we had a lot of patience and we used several interventions, which just didn't help.... Crudely stated, this [continuous palliative sedation] was the last intervention which we could apply.

(Nurse, case 1)

Elderly care physicians and the other staff experienced feelings of powerlessness and failure, especially as they could not relieve the suffering of the NH resident.

**Table 1**  
Background Information of Each Case

|   | Case 1  | Case 2  | Case 3  |
|---|---|---|---|
| Gender, age   | Man, 82 y   | Woman, 80 y   | Woman, 78 y   |
| Duration of institutionalization  | 4 mo  | 30 mo   | 18 mo   |
| Department  | Psychogeriatric unit  | Psychogeriatric unit  | Psychogeriatric unit, specialized in neuropsychiatric symptoms  |
| Medical problems  | Alzheimer's disease<br>Hypertension<br>Cataract<br>Osteoarthritis hip   | Dementia<br>Bipolar disorder, depressive disorder<br>Hereditary spastic paraparesis   | Alzheimer's disease<br>Alcohol abuse, osteoarthritic knee<br>Suspicion of borderline personality disorder   |
| Interventions   | Visits from family with dog<br>Behavior management<br>Advice to cope with behavior (psychologist)<br>External consultation psychiatrist | Family conversations<br>Playing music<br>Looking at photo albums<br>Advice to cope with behavior (psychologist)<br>Crisis intervention plan (psychologist)<br>External consultation geriatric psychiatrist, psychiatric nurse | Dimming the lights<br>Warm and indulging care<br>Advice to cope with behavior (psychologist)<br>External consultation psychiatrist  |
| Medication applied (less than 3 mo before continuous palliative sedation) | Haloperidol, midazolam, temazepam, quetiapine, oxazepam, clozapine, lorazepam, valproic acid  | Analgesics, oxazepam, lithium, nortriptyline, citalopram (Cipramil), haloperidol, lorazepam, clozapine, midazolam, levopromazine  | Trazodone, haloperidol, zuclopenthixol, midazolam, valproic acid, quetiapine, lorazepam   |
| Medications applied during continuous palliative sedation                 | Midazolam (60 mg/d, sc)<br>Morphine (60 mg/d, sc)   | Midazolam (240 mg/d, sc)<br>Levopromazine (150 mg/d, sc)<br>Fentanyl (600 µg/d, transdermal)  | Midazolam (up to 165 mg/d, infusion pump)<br>Midazolam (30 mg before care)<br>Midazolam (prn, max 180 mg/d, sc)<br>Morphine (up to 60 mg/d, infusion pump)<br>Morphine (15 mg before care)<br>Morphine (prn, max 60 mg/d, sc)<br>Haloperidol (up to 2.5 mg/d, infusion pump)<br>Levopromazine (up to 25 mg/d, infusion pump)<br>Levopromazine (prn, max 100 mg/d, sc) |

prn, as needed (pro re nata); sc, subcutaneously.

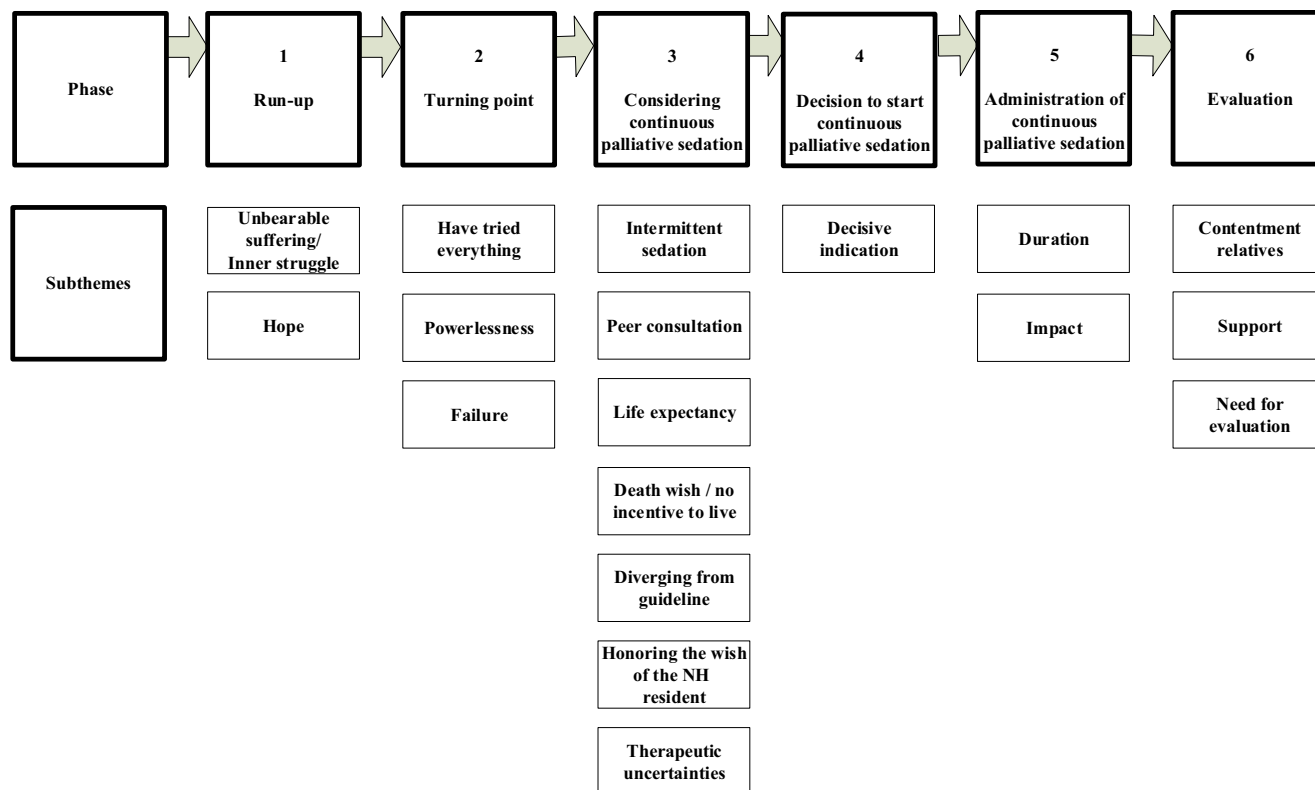


Fig. 1. Phases in the trajectory of continuous palliative sedation with corresponding subthemes.

Drugs which you could try, had all failed and that makes it powerless again. We became more powerless by the look of that man. And by the intense grief of the wife and especially the kids. (Elderly care physician, case 1)

### Phase 3: Considering Continuous Palliative Sedation

Several considerations played a role in phase 3. During this phase, elderly care physicians involved relatives and staff intensively. First, all 3 elderly care physicians applied intermittent sedation to relieve symptoms such as sleeping problems, agitation, and anxiety. Thereby, they hoped to achieve comfort for the resident and to create a period of ease. To receive additional support, 2 elderly care physicians employed peer consultation (a colleague in case 3, and a geriatric psychiatrist and psychiatric nurse in case 2). Because intermittent sedation had only a temporary and limited effect, and because the unbearable suffering of the NH resident persisted, the option of continuous palliative sedation was considered. Several factors influenced this consideration. A first influencing factor was life expectancy. All elderly care physicians estimated the life expectancy of the NH residents as less than 2 weeks, but estimating the life expectancy was difficult for them. For example, the elderly care physician of case 3 questioned whether the criterion of a life expectancy of less than 2 weeks is appropriate in an NH resident with extreme neuropsychiatric symptoms.

Well, in my opinion those 2 weeks are not a real critical boundary; it can be something more and something less, but it's the idea of the approaching death anyway, so that plays a role. (Elderly care physician, case 3)

A second influencing factor was whether there had been a death wish of the NH resident. In all cases, relatives mentioned that the NH

resident had expressed a wish to die before admission and/or during the stay in the NH. Before admission to the NH, the NH resident case 1 had asked his relatives for a rope to commit suicide, and during his stay in the NH he expressed several times that he did not want to live anymore. The NH resident case 2 repeatedly asked people to kill her during her stay in the NH, saying that this was no life for her. The NH resident case 3 had repeatedly expressed a wish to die in the last 15 years, including during the stay in the NH. The elderly care physicians of cases 2 and 3 included these expressions in their considerations for continuous palliative sedation but did not regard this as a main issue. In case 1, the elderly care physicians did not include the resident's expressed wish to die in his consideration for continuous palliative sedation, as he had never heard this wish from the NH resident himself.

A third influencing factor in the consideration for continuous palliative sedation were thoughts about diverging from the Dutch practice guideline regarding palliative sedation.<sup>1</sup> Although they could rationalize their actions, elderly care physicians regarded administering continuous palliative sedation to NH residents with dementia and extreme neuropsychiatric symptoms as "acting on the edge." Relatives understood the struggle of the elderly care physicians and wished that the criteria for administering continuous palliative sedation could be more flexible for exceptional cases.

It's good that there are laws and rules but sometimes it [continuous palliative sedation] is good for the exceptional cases. And then it is always the question when is it an exception and when may you ease that rule, true or not? That's difficult and I think this remains a very difficult thing.

(Relative, case 1)

A fourth influencing factor concerned honoring the wish of the NH resident. For example, the relative of case 1 wondered how long the suffering of the NH resident should continue, because being in the

current situation would have been unacceptable for the NH resident himself. Furthermore, the decision for continuous palliative sedation was experienced as a great responsibility for the elderly care physician.

The final influencing factor in considering continuous palliative sedation were therapeutic uncertainties. Namely, elderly care physicians mentioned that it was difficult to determine the moment at which they could decide to start continuous palliative sedation. Moreover, they wondered if they had followed “the right way” in managing the neuropsychiatric symptoms.

#### *Phase 4: Decision to Start Continuous Palliative Sedation*

The initiation of continuous palliative sedation was regarded as a medical decision by the elderly care physicians. All relatives consented with the decision. Influencing factors for this decision were the accumulation of refractory neuropsychiatric symptoms, a short estimated life expectancy, and unbearable suffering. However, in each case, 1 specific aspect was considered as being the decisive trigger for the ultimate decision to initiate continuous palliative sedation. These were a complete loss of dignity (case 1), severe anxiety (case 2), and severe agitation in combination with a repeatedly expressed wish to die that already existed before the onset of dementia (case 3).

The huge anxiety, I think that prevailed ... and that hallucinations, all those bad events, I think that prevailed together with the fact that she just had a death wish. So, fears, that was really the reason why we actually just wanted her to sleep continuously.

(Elderly care physician in training, case 2)

#### *Phase 5: Administration of Continuous Palliative Sedation*

Finally, continuous palliative sedation was administered with the administered drugs displayed in Table 1. As a result of continuous palliative sedation, in all cases the NH resident became more relaxed and comfortable and his or her consciousness was lowered until death. The duration of continuous palliative sedation was 77 hours in case 1, 7 hours in case 2, and 92 hours in case 3. Staff and relatives previously had expected that this trajectory would take longer. Feelings of relief, gratefulness, relaxation, and contentment after the start of continuous palliative sedation were expressed by all those involved.

Especially rest and gratefulness that the fighting was finally over, because he was fighting and the others were victim, but actually he of course was the biggest victim.

(Elderly care physician, case 1)

#### *Phase 6: Evaluation*

After the residents died, relatives were content and felt to have been properly involved in the decision trajectory leading to continuous palliative sedation and its administration.

I was really okay with it, I had a lot of good conversations in advance. Everything was explained very clearly to me, what, and how it could go.... No, I really liked it, before and during the sedation. Questions, treatment staff who were very thoughtful, came to me and asked if I would like to know something or were also caring to my mother.... No, I don't know if I wished it had happened differently.

(Relative, case 1)

Different opinions were expressed among the participants about the support received. Relatives had experienced enough support from

the elderly care physician and their own social network. However, the elderly care physician of case 3 said that she had not received enough emotional support from colleagues, partly because she had not expressed her needs clearly. In case 2, the elderly care physician considered the assistance and support of the consulted mental health care organizations as unsatisfactory.

I feel myself standing lonely at the top sometimes.... That you support the care staff very much as a doctor and always answer the questions, but you wouldn't be so quick to say like well, this is how it affects me, that's difficult to me.

(Elderly care physician, case 3)

Two elderly care physicians (case 2 and 3) indicated having a need for evaluation after the resident's death, both regarding the process and the impact of continuous palliative sedation on all those involved. The elderly care physician in training of case 2 suggested learning by reflecting on personal experiences with colleagues as a point for improvement.

## **Discussion**

As far as we know, this is a first exploration of administering continuous palliative sedation to NH residents with extreme refractory neuropsychiatric symptoms. In all 3 cases, the neuropsychiatric symptoms were described as unpredictable and difficult to manage. Analysis showed that the unbearable suffering of the NH resident and the hope for improvement were important key points in the run-up to continuous palliative sedation. Participants were convinced they had tried everything and experienced feelings of powerlessness and failure. Several considerations played a role before continuous palliative sedation was initiated (which was based on 1 decisive indicator). In retrospect, relatives were content and felt to have been properly involved.

These important insights in the process and evaluation of continuous palliative sedation in NH residents with dementia and neuropsychiatric symptoms give rise to several reflections. To begin with, this study shows that the behavior of the NH resident and the trajectory up to and the initiation of continuous palliative sedation had a great impact on care and treatment staff. These findings are in line with a Dutch study by Zwijssen et al, which demonstrates that the presence of neuropsychiatric symptoms is a strong predictor of distress of care staff.<sup>19</sup> The study emphasizes the importance of supporting care staff in coping with neuropsychiatric symptoms in NH residents with dementia.<sup>19</sup> Therefore, we think it might be helpful if elderly care physicians and psychologists take the time to share emotions and experiences with care staff and other stakeholders and evaluate the steps taken in the decision-making process and the trajectory of continuous palliative sedation in NH residents with dementia and refractory neuropsychiatric symptoms. Future research should investigate how this can be provided optimally.

A second reflection concerns estimating the life expectancy of the NH resident. According to the Dutch guideline, continuous palliative sedation can only be administered if the patient's life expectancy is less than 2 weeks.<sup>1</sup> Although the elderly care physicians in this study estimated the life expectancy of the 3 NH residents as less than 2 weeks, they found determining life expectancy difficult in these residents, which is supported by previous research in terminally ill patients with and without dementia.<sup>20–22</sup> Estimating imminent death or the terminal status is more difficult in these residents, and the terminal status may last longer than exactly 2 weeks, raising doubts about the applicability of the 2-week life expectancy criterion for use of continuous palliative sedation. It may be conceivable to apply the criterion of a life expectancy of less than 2 weeks less strict in NH residents with dementia and extreme refractory neuropsychiatric symptoms.

Unbearable suffering is a third point to discuss. All participants in our study mentioned that the NH residents were suffering unbearably. They based their judgment on (non)verbal expressions and aggravation of the neuropsychiatric symptoms. Especially in NH residents with dementia, it is difficult to judge and assess the degree and bearableness of suffering. These residents are not able to describe and reflect on their own situation, thus requiring the judgment of an elderly care physician in agreement with a relative. The Dutch guideline for palliative sedation states that “in practice, it is frequently a nonlinear combination of diverse dimensions of one or more symptoms that leads to a situation that constitutes unbearable suffering for the patient.”<sup>4,3</sup> In line with our study, Dees et al<sup>23</sup> state that medical and social elements may cause suffering, but that especially when accompanied by psychoemotional and existential problems suffering will become unbearable. Because it is not yet known how to determine and how to diagnose unbearable suffering in NH residents with extreme refractory neuropsychiatric symptoms and a terminal status, this should be a subject for further investigation, for example, with a Delphi study among clinical experts. The possibility of mandatory external consultation (eg, by a geriatric psychiatrist) to overcome the subjectivity of determining unbearable suffering of the NH resident could also be examined in further studies.

Fourth, the refractoriness of the neuropsychiatric symptoms gives reason for discussion. Although in our study refractoriness of neuropsychiatric symptoms were the most important reason for starting continuous palliative sedation, guidelines on palliative sedation do not include these symptoms as potentially refractory.<sup>1,6,7</sup> Nevertheless, a previous study among patients who had recently received continuous palliative sedation (including NH residents) showed that administering this sedation tends to follow from a situation in which not only physical, but also psychological, symptoms together produce a “refractory state.”<sup>3</sup> Not being able to relieve the state of the patient establishes the need for continuous palliative sedation.<sup>3</sup>

In our opinion, refractoriness of neuropsychiatric symptoms should be taken into account when guidelines on palliative sedation are revised or developed.

A final reflection includes the recurrent death wish of the NH resident with dementia and refractory neuropsychiatric symptoms before and during admission. In our study, this death wish was considered relevant by the involved elderly care physicians in the decision-making process. However, it is difficult to determine if these uttered wishes are manifestations of an underlying depressive disorder or of the unbearable suffering as a result of the refractory neuropsychiatric symptoms. An accurate diagnostic process with analysis of depression could be of added value in these cases.

The results of this study were incorporated into a recently published Dutch practice guideline from the occupational group of elderly care physicians (Verenso) about palliative sedation among people with dementia and refractory neuropsychiatric symptoms.<sup>24</sup> It provides elderly care physicians with tools in the administration of intermittent sedation and continuous palliative sedation for refractory neuropsychiatric symptoms in NH residents with dementia. The guideline describes that continuous palliative sedation can be a final treatment option in NH residents with dementia and refractory neuropsychiatric symptoms when intermittent palliative sedation has not resulted in an acceptable situation. It states that thorough multidisciplinary analysis, decision-making process, and treatment must have taken place beforehand as well as external consultation by, for example, a geriatric psychiatrist.

### Strengths and Limitations

The qualitative design of our study allowed for an in-depth description of this niche area enabling participants to express in their own words how they experienced the process of decision-

making leading to continuous palliative sedation and its trajectory. Moreover, with the inclusion of several participants, additional telephone interviews (data source triangulation), and the combination of analytical techniques (analysis triangulation), we increased the internal validity of our study. Furthermore, by involving multiple researchers (investigator triangulation), we enhanced the reliability.<sup>25</sup>

However, this study also has some possible limitations. To start with, 4 interview sessions concerned interviews with 2 participants. Participants may have influenced each other, leading to different answers than in individual interviews. Furthermore, our results reflect the Dutch cultural, societal, and health care context, which might hamper the generalizability of the findings to other countries. Namely, the Dutch national legislation has a law on euthanasia, and in the Netherlands, a national Guideline for Palliative Sedation exists.<sup>1</sup> Furthermore, Dutch geriatric care has a long history of conducting advance care planning conversations with residents in which the quality of life of a resident is taken into account and elderly care physicians have experience with administering continuous palliative sedation. Administering continuous palliative sedation in NH residents with dementia is not uncommon for them and has become a part of practice. Moreover, the perception of suffering and the choice to administer continuous palliative sedation could be influenced by the Dutch culture, in which autonomy, including autonomy regarding the end of one's life, are held in high regard by many people. Finally, the study was not guided by the principle of saturation, which may imply that our understanding of continuous palliative sedation in the case of refractory neuropsychiatric symptoms is not yet exhaustive.

### Conclusions and Implications

This study offers important insights into the trajectory leading up to continuous palliative sedation, its administration, and evaluation of this trajectory in NH residents with dementia and extreme refractory neuropsychiatric symptoms. It highlights that continuous palliative sedation can be a valuable treatment option among these residents.

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## Supplemental Data

## Supplementary Table 1

Detailed Applied Methodology Following the Consolidated Criteria for Reporting Qualitative Studies (COREQ) 32-Item Checklist

| Item No.                                    | Guide Questions/Description   | In Our Research  |
|---|---|--|
| Domain 1: Research team and reflexivity     |   |  |
| Personal Characteristics                    |   |  |
| 1. Interviewer/facilitator                  | Which authors conducted the interview?  | SH. She was instructed and coached by an experienced interviewer (AV).   |
| 2. Credentials                              | What were the researcher's credentials?   | SH: MD, AV: MD   |
| 3. Occupation                               | What was their occupation at the time of the study?   | SH: academic trainee and older adult care physician in training (in the last months of her education). <sup>*</sup> AV: older adult care physician in training and PhD student   |
| 4. Gender                                   | Was the researcher male or female?  | Female   |
| 5. Experience and training                  | What experience or training did the researcher have?  | SH: medicine, AV: medicine, entry-level course in Atlas.ti, basic course qualitative health research<br>Research team:<br>Medical (SZ, MS, RK) and psychological (DG) and are all specialized in older adult care.   |
| Relationship with participants              |   |  |
| 6. Relationship established                 | Was a relationship established prior to study commencement?   | SH was not acquainted with study participants before the interview.  |
| 7. Participant knowledge of the interviewer | What did the participants know about the researcher? Eg, personal goals, reasons for doing the research   | An information letter about the purpose of the study and practical information about the interview was sent to the participants of the eligible cases. This letter also mentioned that the interviewer was an older adult care physician in training (SH).   |
| 8. Interviewer characteristics              | What characteristics were reported about the interviewer/facilitator? Eg, bias, assumptions, reasons, and interests in the research topic               | The occupation of the interviewer was written in the information letter.   |
| Domain 2: study design                      |   |  |
| Theoretical framework                       |   |  |
| 9. Methodological orientation and theory    | What methodological orientation was stated to underpin the study? Eg, grounded theory, discourse analysis, ethnography, phenomenology, content analysis | Thematic analysis was used (both inductive and deductive), including directed content analysis. <sup>1,2,3</sup>   |
| Participant selection                       |   |  |
| 10. Sampling                                | How were participants selected? Eg, purposive, convenience, consecutive, snowball   | We used consecutive sampling to select participants. Cases were assessed for inclusion by AV and RK based on whether (a) these occurred recently, preferably less than 3 mo ago; (b) continuous palliative sedation was administered because of extreme neuropsychiatric symptoms; (c) the NH resident had no acute life-threatening disease; and (d) had been staying in the NH for at least 4 wk. We explored the perspectives of different stakeholders. To recruit cases, an advertisement was placed (January 2017) in the online newsletters of the Dutch association of older adult care physicians (Verenso), <sup>  </sup> the university network of older adult care Nijmegen (UKON), <sup>**</sup> and the Centre for Consultation and Expertise (CCE). <sup>††</sup> |
| 11. Method of approach                      | How were participants approached? Eg, face-to-face, telephone, mail, and e-mail   | AV telephoned the notifying party and the relatives of the NH resident within a week and sent them an information letter by post or by e-mail. They were contacted again by AV within 2 wk by telephone or e-mail to ask for consent. After agreement with participation in the study, appointments were scheduled for the interviews.   |
| 12. Sample size                             | How many participants were in the study?  | Of the 6 applied cases, 3 were assessed as eligible according to the inclusion criteria. The other 3 cases were excluded, because (a) the resident had died more than 3 mo ago; (b) intermittent sedation but not continuous palliative sedation was applied; (c) continuous palliative sedation was considered but not applied yet.   |
| 13. Nonparticipation                        | How many people refused to participate or dropped out? Reasons?   | None of the approached people refused to participate.  |
| Setting                                     |   |  |
| 14. Setting of data collection              | Where was the data collected? Eg, home, clinic, and workplace   | The interviews with professionals were held in March 2017 in the NH of the resident, those with relatives at their own home (n = 1), the NH (n = 1) or in a quiet public place (preference of the participant, n = 1)  |

(continued on next page)



**Supplementary Table 1** (continued)

| Item No.                               | Guide Questions/Description  | In Our Research  |
|--|--|--|
| 15. Presence of nonparticipants        | Was anyone else present besides the participants and researchers?  | Interviewees had the opportunity to be interviewed together with a second representative of the same perspective. No nonparticipants were present during the interviews.   |
| 16. Description of sample              | What are the important characteristics of the sample? Eg, demographic data and date  | See <a href="#">Table 1</a>  |
| <b>Data collection</b>                 |  |  |
| 17. Interview guide                    | Were questions, prompts, guides provided by the authors? Was it pilot tested?  | For each group of stakeholders, SH used a semistructured interview guide, in which the main questions and subquestions were displayed. This interview guide was also used as an extra check to make sure all topics were discussed. The interview guide was not pilot tested. Planned, informal, and floating prompts were used during the interviews.   |
| 18. Repeat interviews                  | Were repeat interviews carried out? If yes, how many?  | No   |
| 19. Audio/visual recording             | Did the research use audio or visual recording to collect the data?  | All interviews were audio-taped and transcribed ad verbatim by 2 medical students (KE and LB), eliminating any names or privacy-related information. The transcripts were read closely and cross-checked against the tapes for accuracy by SH.   |
| 20. Field notes                        | Were field notes made during and/or after the interview or focus group?  | Field notes were made by SH during and after each interview.   |
| 21. Duration                           | What was the duration of the interviews?   | The interviews lasted between 60 and 90 minutes.   |
| 22. Data saturation                    | Was data saturation discussed?   | All authors discussed the findings and data saturation. We did not include more cases in order to obtain saturation, to keep the analyses manageable. However, during the analysis process, an additional telephone interview was held by SH with each older adult care physician to obtain more detailed information and to answer remaining questions. |
| 23. Transcripts returned               | Were transcripts returned to participants for comment and/or correction?   | A summary of each transcription was made (SH) and returned to the participants as a membercheck. After a few adjustments in some cases, all participants agreed with the summaries.  |
| <b>Domain 3: Analysis and findings</b> |  |  |
| <b>Data analysis</b>                   |  |  |
| 24. Number of data coders              | How many data coders coded the data?   | 2, SH and AV   |
| 25. Description of the coding tree     | Did authors provide a description of the coding tree?  | No, available from the authors on request .  |
| 26. Derivation of themes               | Were themes identified in advance or derived from the data?  | Six themes were derived from the data.   |
| 27. Software                           | What software, if applicable, was used to manage the data?   | Analysis with Atlas.ti version 7.1.4. was conducted during data collection (SH) (Atlas.ti Scientific Software Development, Berlin, Germany).   |
| 28. Participant checking               | Did participants provide feedback on the findings?   | Two participants provided feedback on the summaries of their interview. After a few adjustments, they agreed with the summaries.   |
| <b>Reporting</b>                       |  |  |
| 29. Quotations presented               | Were participant quotations presented to illustrate the themes/findings? Was each quotation identified? Eg, participant number | Yes, see Results section of the article and <a href="#">Supplementary Table 4</a> . Quotes were translated into English by AV and crosschecked by MG, a teacher of English.  |
| 30. Data and findings consistent       | Was there consistency between the data presented and the findings?   | Yes  |
| 31. Clarity of major themes            | Were major themes clearly presented in the findings?   | Yes, see Results section of the manuscript and <a href="#">Supplementary Table 4</a> .   |
| 32. Clarity of minor themes            | Is there a description of diverse cases or discussion of minor themes?   | Yes  |

AV, Annelies Veldwijk; DG, Debby Gerritsen; KE, Kyra Ekker; LB, Leonie Buijsse; MG, Martijn de Groot; MS, Martin Smalbrugge; NH, nursing home; RK, Raymond Koopmans; SH, Suzan Hanssen; SZ, Sytse Zuidema.

\*Koopmans R, Pellegrom M, van der Geer ER. The Dutch Move Beyond the Concept of Nursing Home Physician Specialists. *J Am Med Dir Assoc* 2017;18:746-749.

<sup>1</sup>Braun V, Clarke V. Using thematic analysis in psychology. *Qual Res Psychol* 2006;3:77-101.

<sup>2</sup>Elo S, Kyngas H. The qualitative content analysis process. *J Adv Nurs* 2008;62:107-15.

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<sup>4</sup><https://www.verenso.nl/english>.

<sup>5</sup><https://ukonnetwerk.nl>.

<sup>6</sup><https://www.cce.nl/english>.

**Supplementary Table 2**

## Topic List for Semistructured In-Depth Interview With Participants

| Topic                                     | Interview Questions  | Additional Subquestions  |
|---|--|--|
| Course of neuropsychiatric symptoms       | What does the extreme neuropsychiatric symptoms of the resident consist of?                      | Can you give examples of that?<br>What was the expression of the extreme neuropsychiatric symptoms during the past 3 mo?<br>Which factors influenced the extreme neuropsychiatric symptoms the past 3 mo?  |
| Applied interventions                     | Which interventions were applied for the extreme neuropsychiatric symptoms during the past 3 mo? |  |
| Process of continuous palliative sedation | How did the process of continuous palliative sedation take place?                                | Were you present when the continuous palliative sedation started and how did it go?<br>Did you have to increase the dosage in between?<br>[asked to older adult care physicians (in training)]<br>Would you describe the suffering of this resident as unbearable? If yes, why?<br>How long did it last from the start of the continuous palliative sedation until death?<br>What kind of difficulties did you all experience during this process?<br>Do you experience that starting continuous palliative sedation for extreme neuropsychiatric symptoms as an indicator is different from starting continuous palliative sedation for a physical indicator? If yes, could you explain that?   |
| Impact of continuous palliative sedation  | What was the impact of starting continuous palliative sedation on those involved?                | Which role did other disciplines play in this process? (like social worker, spiritual carer, previous general practitioner)<br>Is there any routine or standing appointment in your nursing home about continuous palliative sedation in neuropsychiatric symptoms?<br>What was your opinion about starting continuous palliative sedation in this resident?<br>What feelings arose with this?<br>To what extent did you discuss this case with your colleagues?<br>Did you feel supported enough by your colleagues?<br>How did the relatives feel about this process?<br>[asked to older adult care physicians (in training), other staff members]<br>How did the communication with the relatives take place?<br>[asked to older adult care physicians (in training), other staff members]<br>What did you notice in the others involved?<br>Is this process evaluated afterward and by whom? |

**Supplementary Table 3**

## Topic List for Semistructured In-Depth Interview With Relatives

| Topic   | Interview Questions   | Additional Subquestions  |
|---|---|--|
| Course of neuropsychiatric symptoms                   | What does the extreme neuropsychiatric symptoms of the resident consist of?   | Can you give examples of that?<br>What was the expression of the extreme neuropsychiatric symptoms during the past 3 mo?<br>Which factors influenced the extreme neuropsychiatric symptoms the past 3 mo?  |
| Decision to start with continuous palliative sedation | Finally it was decided to start with palliative sedation. Can you tell me how this went?  | How did you experience this?<br>To what extent did you play a role in this decision?<br>Did you experience this decision as difficult? If yes, why?<br>Who was involved in the decision making and how?<br>How did the communication with the older adult care physician and the vocational nurse specifically assigned to the resident take place?<br>How did the communication with the nursing staff take place?<br>How did the communication with others involved take place?<br>In what way was the decision for continuous palliative sedation discussed with the relatives? |
| Impact of continuous palliative sedation              | What was the impact of the neuropsychiatric symptoms and the process of palliative sedation on the resident and his or her environment? | What impact has this situation and process had on you so far?<br>Which feelings did you experience with starting palliative sedation?<br>Did you feel supported?<br>If yes, by whom?<br>If no, from whom did you miss support?<br>What were the consequences of this process for the residents himself or herself?<br>What were the results of starting palliative sedation for the residents and his or her environment?<br>If you look back on this process, are there things that could have been done differently? If yes, which things?                                       |

**Supplementary Table 4**

Additional Citations for all Described Themes With Subthemes

| Theme  | Additional Quote  |
|--|---|
| Phase 1: Run-up<br>Unbearable suffering/inner struggle                           | “The sight of that man who did his absolute best to fight against this current reality, which he did from admittance, but the real fighting started a month later and became worse, by way of physical aggression, in the price he paid, crashing down, hanging knocked out on the ropes like a damaged boxer, sometimes with wounds of falling or he was stubbed and he only kept on going until he couldn't anymore, that was such a sad image to see that man getting lost in such a way.” (Older adult care physician, case 1)  |
| Hope   | “Well yes, indeed you hope that maybe someone still has the miracle drug.” (Older adult care physician in training, case 2)   |
| Phase 2: Turning point<br>Have tried everything                                  | “And totally no other way left. I mean no way to change the behavior, but in fact we had just tried everything. Everything was applied ... and we didn't have the feeling that we could influence her more in some way that she, how should I say this, would be living in a pleasant way.” (Psychologist, case 2)  |
| Powerlessness  | “In my opinion, unbearable is when just not a single moment is left when you think that you could get someone out or when you think you could still mean something for someone, you can make the suffering more soft, or something like that. There was just nothing left actually which we could do... The last week also the meeting was about the powerlessness everyone felt, like how far should we go with this and to what extent? What do you do to her and what do you do to everyone, to the environment? and Is this not possible in a different way? so to speak.” (Psychologist, case 2) |
| Failure  | “Well I think that every physician sort of feels that at that time, if you don't succeed in something, that you think that you failed. And it was just very miserable that you could not help her.” (Older adult care physician in training, case 2)  |
| Phase 3: Considering continuous palliative sedation<br>Peer consultation         | “I think it is decent to just let someone else take a look at her [NH resident] as well, that we will not all enter some tunnel vision while there may be other options left and while it is maybe actually ethically not as pure as you think yourself... So that is actually the reason to ask her [a colleague].” (Older adult care physician, case 3)   |
| Life expectancy  | “She just did not eat or drink and that was already less for weeks... that few sugar cubes she had, and that, and the renal function which was not very well and which was deteriorating already... then she would not have made it for 2 weeks that way, I think.” (Older adult care physician in training, case 2)  |
| Wish to die  | “I think that she gave up all courage in the last phase and also really had something like, I am done, I don't want to live anymore like this... She also mentioned it very often, this is an inhumane existence, she also said that very often, she could describe that very well and I think for her this was...” (Nurse, case 2)   |
| Diverging from guideline   | “It was definitely cycling on a line but it was truly right.” (Nurse, case 1.)<br>“What do you mean with cycling on a line?” (Interviewer)  |
| Honoring the wish of the NH resident   | “It [continuous palliative sedation] isn't something you just apply, there were really a lot of meetings about this and people discussed a lot about this, like is this the best solution.” (Nurse, case 1)   |
| Therapeutic uncertainties  | “Because how long do you need to let someone suffer while you know he doesn't want to?” (Relative, case 1)<br>“Searching for the real way, that's not always there of course, how far can you just go to treat a man with such a remarkable and extreme behavior... I was waiting for it like when can I do more and when that point is reached?” (Older adult care physician, case 1)  |
| Phase 4: Decision to start continuous palliative sedation<br>Decisive indication | “The most dominant thing was that she was totally done with it and that you had the feeling that there was a high distress in which on the one hand she indeed constantly really wanted to sleep but on the other hand her legs and her arms and the agitation then again gave a lot of restlessness.” (Older adult care physician, case 3)   |
| Phase 5: Administration of continuous palliative sedation<br>Duration            | “We expected that it would take much longer. So that went also pretty fast and with her it was just that her candle shed a light and maybe she did hear us and thought like, fine, now they are gone and now I can sneak out nice and quiet.” (Relative, case 2)  |
| Impact   | “As it started to help for him, that he really received that rest, then I thought like yes it's a relief anyway, not only for us and the other residents, but really especially for him.” (Nurse, case 1)   |
| Phase 5: Evaluation<br>Contentment relatives                                     | “And if you look back to the trajectory of the sedation, could things be done differently?” (Interviewer)<br>“No nothing.” (Relative, case 3)<br>“That was.” (Interviewer)  |
| Support  | “Perfectly, really.” (Relative, case 3)<br>“My trainer also said to me [name nurse case 1] if you want to talk or something like that, it's an intense situation, it has an impact on you, my door is always open, so just come around and you can just talk about it with me, she also asked what you asked me, if I receive support at home.” (Nurse, case 1)   |
| Need for evaluation  | “You can never turn back time, of course you can learn something about it if something went wrong, but yes that's in principle not the aim. I think is just also a bit to vent and look, for other people maybe like, what's the plan? As a learning experience.” (Older adult care physician in training, case 2)  |

NH, nursing home.