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Palliative sedation in Sweden: specialised palliative care nationwide survey

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ABSTRACT

Objectives The aim of this study was to map the use of palliative sedation (PS) in specialised palliative care (SPC) in Sweden and compare the results with a survey made 20 years ago.

Methods A survey to all SPC units in Sweden was performed during the first quarter of 2025 as add-on questions to the Swedish Register of Palliative Care. The definition of PS was continuous sedation in the final stage of life with the aim of lowering the patient's consciousness due to intractable symptoms. Questions included whether the patient had received PS (yes/no), choice of drug and how long the sedation lasted.

Results Of 2701 deaths in SPC during the study period, 2069 cases had answered the survey (response rate 77%). Of these, 208 had received PS (10%). The majority of patients had received midazolam as the main sedative, n=185 (89%). Other drugs used as main sedatives were levomepromazine, n=14 (7%); propofol, n=5 (2%); and haloperidol, n=2 (1%). The median duration of sedation was 2 days and 4% had sedation longer than 7 days.

Conclusions PS is more common in Sweden today than 20 years ago, 10% compared to 1%. The vast majority received midazolam as a sedative.

WHAT IS ALREADY KNOWN ON THIS TOPIC

⇒ Palliative sedation may be used in end-of-life care as the last resort in case of refractory suffering. Previous studies have shown that palliative sedation is seldom used in specialized palliative care in Sweden.

WHAT THIS STUDY ADDS

⇒ This nation-wide survey showed that palliative sedation is more common in specialized palliative care in Sweden today than 20 years ago, an increase from 1% to 10% of all deaths.

HOW THIS STUDY MIGHT AFFECT RESEARCH, PRACTICE OR POLICY

⇒ This study indicate that palliative sedation has become more used in Sweden during recent years, almost to the same extent as in the rest of Europe.

INTRODUCTION

Palliative sedation (PS) may be used in end-of-life care as the last resort in case of refractory suffering when conventional treatment options have failed.[1–3] During continuous PS, sedatives are given with the aim of lowering the level of consciousness and the goal is neither to shorten nor prolong the dying process.[1 4 5] If a patient becomes tired and unconscious as a side effect of, for example, midazolam given to relieve anxiety, this is not classified as PS.

The most commonly used drug for PS in Europe is midazolam.[1 4 6 7] Other drugs used are propofol, dexmedetomidine, levomepromazine and haloperidol.[1 2 4 6–8]

According to a nationwide study on PS in specialised palliative care (SPC) in Sweden conducted in 2006 (published in 2009), only 1% of all deceased patients had received PS.[9] This is a very low frequency compared with other European countries that report the use of PS in 10%–18% of all deaths in SPC.[1 4] In addition to the nationwide survey from 2006, a smaller study (n=640) performed in the southern part of Sweden was conducted in 2016 showing that 8% of patients in SPC had received PS.[7] This indicates that the use of PS might have increased in Sweden—but also that there might be regional differences within the country.

The aim of this study was to map the use of PS in SPC in Sweden in 2025 in comparison to the survey performed in 2006 with a focus on drugs used and length of sedation.

METHOD

The study was performed within the context of the Swedish Register of

Palliative Care (SRPC) as add-on questions to the regular end-of-life questionnaire (ELQ) during 1 January to 31 March 2025. Only SPC units received the add-on questions. The SRPC is a national quality register that has been running for 20 years, and the items in the ELQ have been validated.[10 11] The total coverage of the register is currently 60% of all deaths in Sweden, with a coverage of over 95% of patients dying in SPC. After the death, healthcare staff answer a web-based questionnaire with 27 questions about care during the last week of life. The add-on questions were:

- Question 1: Did the patient receive continuous PS at the end of life? (Definition: Continuous PS aims to alleviate treatment-resistant suffering at the end of life by administering drugs with the intent to lower the patient's level of consciousness. The treatment is given continuously without waking the patient.)

If the answer to question 1 was 'yes', two additional questions appeared:

- Question 2: Which drug(s) was used? Answer options: midazolam/haloperidol/levomepromazine/dexmedetomidine/propofol/Other.
- Question 3: How many days was the sedative treatment given?

Extraction of data from the register was made on 14 April 2025. In addition to the survey questions, other data extracted from the SRPC were sex, age, place of death, main diagnosis and symptoms during the last week in life. In question 2 it was possible to choose several drugs if applicable. In each case, the study team assessed which was the main sedative.

Statistical analysis was performed in Excel and Graph Pad Prism vs 9.0. Mean age and SD were calculated and statistical differences between patients receiving and not receiving PS were analysed using two-sided t-test. Differences in sex between the groups were calculated using Fisher's exact test.

Use of anonymous data from the SRPC for research is approved by the Swedish Ethical Authority, Dnr 2024-08460-01.

RESULTS

During the study period, 2701 deaths were registered from SPC, of which 2069 answered the survey (response rate 77%). Of the 2069 deaths, including 120 different SPC units, 208 patients received PS (10%) in 53 different SPC units. The use of PS was equally distributed across the country. The patients receiving PS were younger than those not receiving PS, median age 74 years (SD±13) compared with 77 years (SD±12) ($p<0.01$). There were no sex differences between those receiving or not receiving PS, 49% and 50% women ($p=0.82$). Of the 208 patients that received PS, 53 (25%) died at home and 155 (75%) died in a SPC in-patient ward.

Most patients receiving PS suffered from cancer, 175 (84%) (table 1). Patients without cancer died from cardiovascular diseases including stroke, n=13 (6.5%), pulmonary disease, n=4 (2%), dementia, n=1 (0.5%) or other conditions, n=15 (7%).

Most of the patients receiving PS had several distressing symptoms in the last week of life. The most common symptoms reported were pain, n=181 (87%). and anxiety, n=167 (80%). Delirium during the last week of life was reported in 73 cases (35%), dyspnoea in 50 cases (24%) and nausea in 36 cases (17%).

Table 1 Data on patients receiving palliative sedation (PS) in specialised palliative care (SPC) in Sweden during January–March 2025

	Number of patients (n=208)	Proportion of all patients receiving PS
Main diagnosis		
Cancer	175	84%
Cardiovascular disease and stroke	13	6.5%
Pulmonary disease	4	2%
Dementia	1	0.5%
Other conditions	15	7%
Place of death		
SPC in-patient ward	155	75%
At home with SPC home-care team	53	25%
Symptoms the last week before death		
Pain	181	87%
Anxiety	167	80%
Delirium	73	35%
Dyspnoea	50	24%
Nausea	36	17%
Sedatives used		
Midazolam	200	96%
Levomepromazine	14	7%
Propofol	5	2%
Haloperidol	38	18%
Hydromorphone	1	0.5%
Dexmedetomidine	0	0%
Unknown	1	0.5%
Main sedative used		
Midazolam	185	89%
Levomepromazine	14	7%
Propofol	5	2%
Haloperidol	2	1%
Hydromorphone	1	0.5%
Unknown	1	0.5%
Duration of PS		
< 1 day	19	9%
1 day	48	23%
2 days	55	26%
3 days	43	21%
4 days	15	7%
5–7 days	19	9 %
> 7 days	8	4%
unknown	1	0.5%

The vast majority of patients received midazolam, n=200 (96%), sometimes together with other drugs (table 1). Levomepromazine was used in 14 patients (7%), of which 13 received it together with midazolam. Propofol was used in five patients (2%), of which two received it along with midazolam. Haloperidol was used in 38 patients (18%), of which 36 received it with midazolam. In one case, hydromorphone was used without any other drug. In one case, no drug was registered. Dexmedetomidine was never used. Propofol was only used in patients that died in SPC in-patient wards. Levomepromazine was used in SPC in-patient wards in 11 cases and three cases at home by SPC home care teams.

Midazolam was assessed as being the main sedative in 185 cases (89%). Levomepromazine was assessed as the main sedative in 14 cases (7%) and propofol in five cases (2 %). Haloperidol as the only sedative was used in two cases (1%). The median duration of sedation was 2 days, and 80% had received PS for 3 days or less. Only 4% had PS longer than 7 days.

DISCUSSION

In this nationwide study, we show that PS is more common in Sweden today than 20 years ago, 10% compared with 1%. The vast majority received midazolam as sedative, and propofol and levomepromazine were more seldom used. The size of the study cohort was equal to that in the previous national study, 2069 compared with 2021.[9]

Various studies have shown that PS is used to a significantly higher extent in the rest of Europe compared with Sweden.[1 4 6] The European countries that have reported the highest use of PS are the Netherlands and Switzerland, where the frequency is reported to be 17%–18% of all deaths in SPC units.[1] However, the differences between studies may partly depend on how PS is defined.

Our results are in line with previous results showing that midazolam is the most commonly used sedative in PS.[1 4 6 7] The use of levomepromazine as a sedative was unexpectedly high (7%). This drug was not presented in any of the previous studies performed in Sweden.[7 9] Notably, in Sweden, levomepromazine is no longer available on the common market and can only be prescribed if the unit has a special licence from the Swedish Medical Drug Authority to use this drug.

One case had registered hydromorphone as the only sedative. The use of opioids as the main sedative in PS has been questioned since sedation is a secondary effect of opioids, rather than the primary effect.[12] However, also other studies have reported the use of opioids for PS.[6]

Sedation was generally started very close to death, more than half of the patients died within 2 days after PS was started. This is in line with the current guidelines in Sweden for PS, which recommend that the remaining lifetime should be assessed as very short, days to maximum 2 weeks.[13] In contrast, according to a recent Delphi study, there is generally no specific recommendation of remaining lifetime expectancy when starting PS in other European countries.[3] Instead, the decision should be based on the need for relief from unbearable and refractory suffering.[3]

The strength of this study is the nation-wide approach, covering all regions in Sweden. However, there are several limitations that need to be addressed. First, although the response rate was high (77%)—still data on 23% of all deaths in SPC was missing in the survey. Moreover, the quality of the registered data may vary, and sometimes healthcare staff who have not been involved in the care of the patient have filled in the register. Also, even if the definition of PS was stated in the question, it cannot be ruled out that PS was registered also in cases where the patient became unconscious as a side effect of, for example, anxiolytic treatment. Finally, the assessment of the main sedative was performed by the study team. Since no doses were available, it is uncertain if the assessment of main sedative was correct in each case.

To conclude, PS is more common in SPC in Sweden today than 20 years ago, 10% compared with 1%, and most of the patients received midazolam.

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Competing interests None declared.

Patient consent for publication Not applicable.

Ethics approval This study involves human participants and was approved by Swedish Ethical Authority, Dnr 2024-08460-01.Anonymized data was extracted from the Swedish Register of Palliative Care where almost all deceased patients in Swedish specialized palliative care are registerd. Use of this data was approved by the Swedish Ethical Authority, Dnr 2024-08460-01.

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