

**Appendix 1 (as supplied by the authors): Semi structured interview: “Proportionate sedation at the end of life: more than a proper balance between drug dose and refractory symptoms”.**

1. a. **Did this case concern mild or deep sedation?**
- b. **What do you in general understand by deep sedation?**

Prompt:

- ❖ Does continuous sedation always takes place like in this case? Or is it sometimes different?

2. **In the questionnaire you have indicated that a symptom was refractory because of ..... What were your most important considerations for considering this symptom to be refractory?**

Prompt:

- ❖ Did it concern a physical symptom or did psychosocial or existential factors also contribute?

3. **In the questionnaire you have not ticked an answer for the question ‘to what extent a symptom was considered refractory’. Was no symptom refractory?**

Prompt:

- ❖ What were your considerations to start continuous sedation?

4. **In this case, who decided about the refractoriness of symptoms?**

Prompt:

- ❖ Did you decide this yourself or was this done by the patient, relatives or other caregivers?

5. **To what extent, in general, gives deciding about the refractoriness of a symptom rise to difficulties?**

Prompts:

- ❖ Does the availability of care- or treatment possibilities regarding the place of care (e.g. at home) play a role?
- ❖ Do differences in opinion of those involved play a role?
- ❖ To what extent does refractoriness concern 1 symptom or a combination of symptoms?

6. **To what extent did the estimated life expectancy of the patient influence the decision to start continuous sedation? Can you elucidate this?**

Prompt:

- ❖ Would a longer life expectancy in this case have led to a different decision?  
Can you elucidate this?

**7. Do you think a short life expectancy is a necessary condition for using continuous sedation until death?**

**Can you elucidate this?**

Prompt:

- ❖ Do you think – in the case of a refractory symptom – that continuous sedation until death can be applied when the patient's life expectancy is more than 2 weeks?

**8. Who, in this case, was the most important person in the decision-making of continuous sedation?**

Prompts:

- ❖ Was it yourself, the patient, relatives, other caregivers?
- ❖ Did opinions differ regarding the decision made?
- ❖ Who made the final decision?

In the questionnaire you have indicated that you felt yes/no to have been put under pressure to start continuous sedation until death.

*If yes:*

**9. What made you feel being put under pressure?**

*Always ask:*

**10. Have you ever felt being put under pressure by patients or relatives to apply continuous sedation until death?**

Prompts:

- ❖ How do you deal with this?
- ❖ How do you experience this pressure?
- ❖ Does this happen often?

**11. What did you discuss with the patient and/or relatives regarding continuous sedation until death?**

Prompt:

- ❖ Depth of sedation
- ❖ Reduced ability to communicate
- ❖ Expected duration of sedation
- ❖ Expected course of sedation (waking up)
- ❖ Nutrition and hydration
- ❖ (possibility of) hastening death

**12. Did you ever experience a patient refusing to be continuously sedated until death, after you had proposed this treatment?**

Prompts:

- ❖ What reasons did the patient have?
- ❖ To what extent was reduced ability to communicate an issue?

**13. Was the dose of the medication in this case determined by the desired depth of the sedation or by the severity of symptoms? Why?**

Prompts:

- ❖ Who decided upon the dose?
- ❖ Who decided upon the severity of symptoms?

**14. To what extent was it in this case important that the patient could communicate as long as possible?**

Prompts:

- ❖ Important for the patient, the relatives, yourself?
- ❖ Did the patient wish to say goodbye?
- ❖ If applicable: How did relatives experience not being able to communicate with the patient?

**15. Do you think, in general, that when using continuous sedation until death the patient's consciousness should be preserved as long as possible? Why?**

Prompts:

- ❖ The capacity to communicate for many people is related to 'being human'
- ❖ Loss of the capacity to communicate is for many people related to loss of dignity

**16. Do you think that physicians should always be present at the start of sedation?**

Prompts:

- ❖ Why yes/no?
- ❖ How do you verify the application of sedation with the nurses?

In the questionnaire you mentioned that the depth of sedation was (yes/no) monitored.

*If yes:*

**17. How was the course of sedation monitored?**

Prompts:

- ❖ When and by whom did observations take place?
- ❖ Observations on specified moments? Following a specified procedure?

*If not:*

**18. Why was the course of sedation not monitored?**

Prompt:

- ❖ Does it always take place like in this case? Or is it sometimes different?

**19. Do you think, in general, that consultation of a palliative care team should be an obligation before continuous sedation until death can be used? Why (not)?**

**20. To what extent do you regard yourself experienced enough to use continuous sedation until death?**

Prompt:

- ❖ Do you think it is important for yourself to follow specific courses on palliative sedation before using it?

**21. If applicable: In the questionnaire you mentioned that continuous sedation until death was used for a patient who had requested euthanasia. Can you further elucidate this?**

If not: **Did you ever propose continuous sedation until death to a patient who requested euthanasia?**

Prompts:

- ❖ What considerations did you have?
- ❖ How did the patient and relatives respond?

**22. In what way does, according to you, continuous sedation until death differ from euthanasia?**

Prompt:

- ❖ How do you discuss the difference with the patient and/or relatives?
- ❖ Do you think continuous sedation until death has a life shortening effect?

In the questionnaire you mentioned that in this case you (yes/no) had used the Royal Dutch Medical Association guideline on palliative sedation.

*If not:*

**23. Why didn't you use this guideline in this case?**

**24. To what extent does the RDMA guideline fit into your practice?**

Prompt:

- ❖ Should adjustments be made to make this guideline more fit into your practice.