**Annex 1: Semi-structured interview guide**

**PART 1
SCREENING QUESTIONS**

**1.1. Did you conduct palliative sedation for existential suffering in the last 12 months?**

**YES**

1.1.1 What were the conditions that were applied to these cases?

 a) Were these conditions sufficient for you?

 b) Were there any alternatives?

**NO**

1.1.2 Have you been confronted with the request for palliative sedation for existential suffering?

**YES**

a) Why did you not conduct palliative sedation for existential suffering?

b) Under what conditions would you consider it necessary?

c) What alternatives did you consider?

**NO – next question**

**1.2. Can you describe in your own words your understanding of existential suffering?**

 1.2.1. In what ways is it different/or not from other kinds of suffering?

 1.2.2. How would you assess it?

 1.2.3. Do you believe existential suffering be refractory?

 a) If yes, how should refractory existential suffering be relieved?

 b) If no, how should existential suffering be relieved?

**1.3. Can you describe in your own words your opinions about the use of palliative sedation for existential suffering?**

1.3.1. **If positive attitude**
a) What do you believe – based on your experience – are strong arguments for the use of palliative sedation for existential suffering?

 b) Which ethical values are important for you to support your opinion? (dignity, patient’s autonomy, compassion, etc…)

1.3.2. **If negative attitude**
a) What do you believe are strong arguments against the use of palliative sedation for existential suffering?

 b) Which ethical values are important for you to support your opinion? (nonmaleficence, dignity, etc…)

**PART 2
QUESTIONS AROUND A CLINICAL CASE (VIGNETTE)**

We will now present you with a vignette of a clinical case regarding the request for palliative sedation for existential suffering by a patient with short term prognosis.

**Clinical vignette [16]**

*Claire Germain is a 55-year-old lawyer and divorcee with no children. However, her family network is large and she has many friends. Ovarian cancer was diagnosed 15 months ago. She underwent surgery: hysterectomy, oophorectomy, bilateral salpingectomy, and cytoreduction of neoplastic implants found at the peritoneal level. Last year, the cancer progressed in spite of many cycles of different types of chemotherapy.*

*Claire has, therefore, been admitted to the palliative care unit because the situation at home was becoming too difficult. She has multiple hepatic metastases and major peritoneal carcinomatosis with no intestinal obstruction. She also presents large ascites that were tapped twice in the past 10 days. She suffers from diffuse pain in the abdomen and the right lower part of the thorax. Analgesic medication makes her comfortable.*

 *Examination shows that the patient has lost weight but is not jaundiced. She is lucid, but has slower motor skills. She needs help with all her activities. Pulmonary auscultation shows a decreased vesicular murmur by one-third on the lower right lung, which is evidence of pleural effusion. The patient is not, however, dyspneic. The abdomen has been supple since the last ascites puncture; the multiple hepatic and peritoneal nodules can be felt.*

 *She is deteriorating quickly and one can reasonably assume the prognosis is less than 10 days.*

 *Physical pain is well alleviated and the patient feels comfortable, however, she needs help with all her activities. She is grateful for the help given, but Claire says she can no longer stand this deterioration, which she finds degrading. Despite the psychosocial support she receives from the social worker and the joint follow up by her physician, she constantly repeats that her life no longer “makes sense”.*

**2.1. What do you think of this situation?**

**2.2. Would you conduct PS-ES in this case? Why or why not?**

**2.3. What conditions should be met?**

**2.4. Do you see alternatives to PS-ES in this case? Which ones?**

**PART 3 - IN-DEPTH EXPLORATION**

**3.1. How would you describe your perspective with regard to palliative sedation for existential suffering?**

**3.2. What are the most important reasons for your position?**

3.2.1. On which ethical values or principles is your position based? (dignity, patient’s autonomy, beneficence, respect of life, compassion, etc…)

**3.3. Do you think your perspective is influenced by your worldviews (religious affiliation, philosophical convictions, values, etc…)?**

3.3.1. What do you think makes a human being?

 3.3.2. How does this view affect your decisions regarding PS-ES?

**3.4. Is your perspective regarding palliative sedation for existential suffering different from your perspective on PS for physical suffering? Why?**

**3.5. If you conduct palliative sedation for existential suffering, what conditions should be met?**

**3.6. What alternatives do you see for palliative sedation for existential suffering?**

 *3.6.1.* If all other alternatives fail, would you consider palliative sedation for existential suffering?

 *(For those who would not consider palliative sedation for existential suffering)*

**3.7. Is there anything else you would add to make your opinion on PS-ES clear?**

**THANK YOU FOR YOUR COLLABORATION!**

**Annex 2: Example of a conceptual scheme**

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| --- |
| **Research Question** |

*What are palliative care physicians’ perceptions on ES and arguments regarding the ethics of palliative sedation for existential suffering?*

|  |
| --- |
| **Central Theme** |

Worldview

* **Roman Catholic**

Human person

* **Relational** being: always linked with relatives & society
* Has **internal & external resources** through society
* Has **interacting dimensions** [not specified which dimensions]
* **Mystery**
* **Complexity**

Existential suffering

* Relates to **psychological suffering**
	+ Sometimes **anxiety** prevails
* Relates to **relational suffering**
	+ Combination of suffering and lack of relations, **solitude in suffering**
* ES is a **global** suffering: locked up in ES
* **Hopelessness** and **meaninglessness**
	+ **Unmoved** by beautiful things in life
* Can become **refractory**
* ES **has to be relieved**
	+ By entire **society**, not only by medicine
	+ Solitude of suffering should be diminished in society

PS-ES

* **Relationship with nurses remains** although no communication

Conditions

* **No PS-ES** oronly in very **extreme situations**
* **Other symptom is required** (e.g. delirium) or **not required**
* **End of life** <15 days
* **Refractory ES**
	+ Refractoriness has a **relational aspect**: patients are never alone in their position that ES is refractory
* **No alternatives** or refusing alternatives

Decision making

* **No scales**
* **Interdisciplinary evaluation**
	+ By nurses, physiotherapists, psychologist, no psychiatrist
	+ Having same impression
	+ Evaluating all arguments of team members
* **Looking at patient’s suffering**
	+ Living a bit with patient
	+ Looking at relatives’ suffering because of patient’s suffering (to evaluate patient’s suffering)

Alternatives

* **Accompaniment**
	+ Not leaving patient alone nor flying
	+ Showing meaning of life to patient
* **Psychological** support (inevitably)
* **Social** support
* **Spiritual support**, without being religious
* Support of & reconnecting with **relatives**
* **Medication**: which can result in sedation
	+ anxiolysis & analgesics
* **Creative ideas** from interdisciplinary team
* **Intermittent PS** (may be more appropriate than profound PS)
* **No PS-ES**
* **No psychiatrist**
* **No euthanasia**: never a solution for ES

PS-ES v. PS PP

* **PS for pure PP is not necessary**: many treatment options for PP
* **Different intention** in PS for PP and PS-ES
	+ PP: reducing pain ↔ ES: lowering consciousness

PS-ES v. euthanasia

* Same intention of PS-ES and euthanasia: **cutting off relationships**
* **Difficult to match** euthanasia with palliative care
	+ Fear of influencing patients by performing euthanasia
* **Argument against euthanasia**: although demand of patient, unconscious influences

***No argumentation in favour***

*Argumentation against*

* Clinical arguments
	+ **Unsure if patient is well** when profound PS-ES
	+ **Unsure if dosages** are right if no dialogue
	+ If not at very end: question of **hydration and nutrition**
	+ **Problem with consent**
		- Demand of the patient while in great suffering
		- PS-ES as a disguised euthanasia
* Personal beliefs
	+ **Vulnerability** has meaning ↔ **fragile place of patients** in society ‘*I am too expensive for society’*
	+ **Medication** might not be an answer to ES
	+ ES might be **too complex for doctors** to solve
	+ Doctor personally **doesn’t allow herself to have an answer** to ES
	+ **Worrying** on patients’ wellbeing during PS
	+ PS-ES as **failure** [no further explanation]
	+ PS-ES as **worsening** the situation: solving ES by something even more terrible than ES, i.e. rupture of relationships
* Ethical arguments
	+ **Ruptures any progress**: no way to show life still has meaning
	+ **Non-maleficence**
		- Giving medication to reduce consciousness is not good
		- Intention to end relationships is not good
	+ **Ethical/legal inconsistency**: aid in suicide is prohibited, but euthanasia & PS are allowed
	+ **No autonomy**: in PS-ES there is no autonomy at all
	+ PS-ES can be performed as a **disguised euthanasia** for patients who can’t take the responsibility to decide for euthanasia

**Annex 3 : Overarching conceptual scheme**

**Research Questions:**

1. **What are the perceptions of palliative care physicians on existential suffering at the end of life?**
2. **What ethical arguments palliative care physicians use regarding PS-ES?**

0. View on human person

1 Holistic/personalist approach

 1.1 Complex singularity

 1.2 Relational being

 1.3 Social being

 1.4 Historical being

 1.5 Physical being

 1.6 Thinking being

 1.7 Spiritual being

2 Dualistic approach: body and mind/spirit/soul

1. ES

1.1 Characterization of ES

 1 Loss of meaning

 1.1. Concept of meaning

 1.2 (Inevitably) loss of meaning

 1.3 Loss of reason to live

 2 Fear of death

 2.1 Fear of the unknown

 2.2 Confrontation with death

 2.3 Fear of dying process

 3 No acceptation on loss of control

 3.1 Impression of being a burden/uselessness

 3.2 Loss of dignity and identity

 4 Loneliness

 5 Assessing quality of one’s existence

 6 Refractoriness

 6.1 Concept of refractoriness

6.2 ES can be refractory

6.3 ES is not refractory

1.2 Relation of ES with other types of suffering

 1 Interaction with other types of suffering

 1.1 Resonance of 1 type of suffering on another type

 1.2 ES can be provoked by other (physical/psychological) suffering

 1.3 ES is combined with other (psychological/social) suffering

 1.4 ES can be relieved by relieving other types of suffering

 1.5 ES expresses itself through other types of suffering

 1.6 ES is a (part of) a of a global suffering

 1.7 ES is not a global suffering (pure ES exists)

 2 Psychological nature of ES

 2.1 ES is (/related to) psychological suffering

 2.2 ES is distinct from psychological suffering

 3 Spiritual nature of ES

2 Arguments

2.1 Argumentation in favour

2.1.1 Ethical arguments

 1 Respect for autonomy

 1.1 By providing information on PS-ES

 1.2 Patient’s demand as a condition for PS-ES

 1.3 No paternalism

 1.4 Relational autonomy

 2 Beneficence

 2.1 Beneficence to patient

 2.1.1 Relieving suffering/making suffering stop

 2.1.2 Promoting dignity

 2.1.3 Installing a good death

 2.2 Beneficence to family

 2.3 Beneficence to team

 3 Non-maleficence

 3.1 Non-maleficence to patient

 3.1.1 Avoiding greater evil by PS-ES

 3.2 Non-maleficence to family

 4 Duty to care

 5 Aim of medicine to relieve ES

 6 Equity/Justice

 7 Empathy/compassion for patient

 8 Special ethical principles

 8.1 Double effect

 8.2 Proportionality

 8.3 Golden rule

2.1.2 Personal beliefs

 1 Making abstraction of personal difficulty

 2 Other

2.2 Argumentation against

2.2.1 Clinical arguments

 1 PS-ES is difficult

 1.1 PS-ES is technically difficult

 1.2 Difficulty with sedated body

 1.3 Difficult to decide for PS-ES

 2 No clinical data/uncertainty regarding patients’ wellbeing during PS-ES

2.2.2 Ethical arguments

 1 Respect for autonomy

 1.1 No honest provision of information

 1.2 Concern that patient makes non-autonomous decision

 1.3 If no patient’s demand, no PS-ES

 1.4 PS-ES ends autonomy

 2 Non-maleficence

 2.1 Non-maleficence to patient

 2.1.1 PS-ES doesn’t relieve ES, and thus makes patients die with ES

 2.1.2 Social death is harmful

 2.1.3 If not all conditions are fulfilled, PS-ES is harmful

 2.2 Non-maleficence to relatives

 2.3 Non-maleficence to team

 3 No duty to care

4 Relieving ES is not aim of medicine

 5 Slippery slope

 6 Special ethical principles

 6.1 Misuse of PS-ES, with wrong intention

 6.2 Proportionality

2.2.3 Personal beliefs

1 PS-ES can be meaningless

 2 PS-ES as a failure

3. General attitude

1 In favour of PS-ES
2 Ambiguous position

3 Against PS-ES