Towards a better understanding of what palliative sedated patients experience. Linking numbers to experiences. (Research protocol)

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Towards a better understanding of what palliative sedated patients experience. Linking numbers to experiences.

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Introduction

BACKGROUND

Once death is imminent, a major concern is to assure maximal comfort. In case of untreatable suffering, palliative sedation may be chosen. In such cases comfort is sought by reducing the patient's level of consciousness. An important principle is that 'sedation should not be deeper than necessary to assure comfort'. A straightforward way to know if a patient suffers would be to ask him. However, in case of (deep) palliative sedation communication is usually impossible. Caregivers then have to assess the patient's comfort by observing him/her. Recently, more sophisticated techniques from the neurosciences have been used and found out that sometimes consciousness and pain is undetectable with the traditional behavioral methods.

RELEVANCE

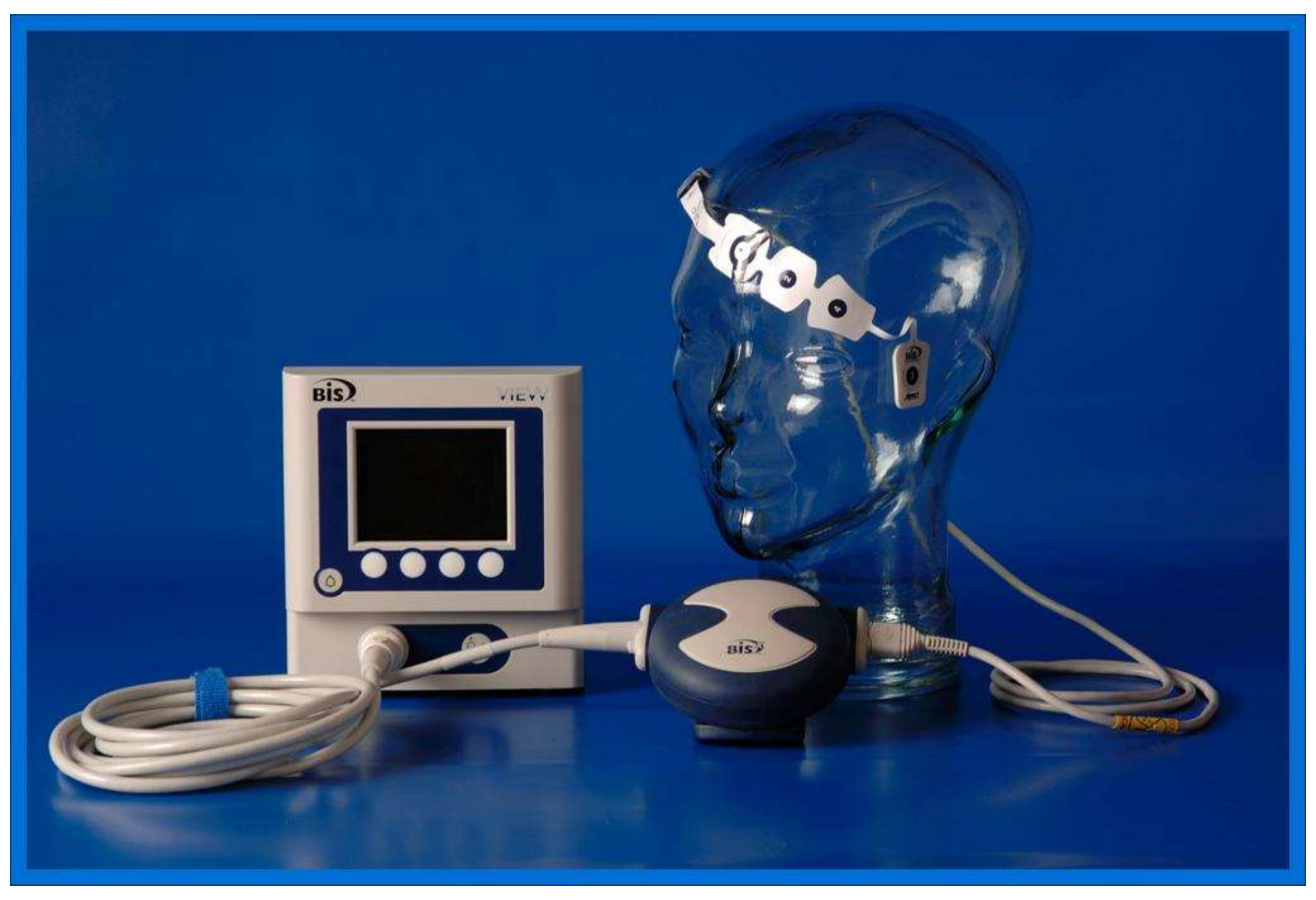
The aim of this study is to better understand what palliative sedated patients experience in the last days of their life and to find out if they are really free of pain. In this study we want to observe 40 patients from the moment that palliative sedation has been initiated until death. We will evaluate to what degree assessments of comfort based on behavioural observations are in line with the results from a brain function monitor that is often used in operating theatre. Additionally we want to find out if changes in the measured depth of sedation can be experienced by the patient, caregivers and relatives, especially in the last moments of life when unexpected changes can be measured.

RESEARCH QUESTIONS

- **With regard to SEDATION**
  1. What methods do caregivers routinely use to assess the depth of sedation and what do they conclude from it?
  2. How adequately are palliative sedated patients sedated according to:
     the treating physician | the involved nurses | the relatives of the patient ?
  3. Do these findings correspond with assessments based on brain function monitors (e.g. BIS monitors or comparable monitors)?
- **With regard to COMFORT of palliative sedated patients**
  4. How do caregivers assess comfort in palliative sedated patients?
  5. To what degree do caregivers and relatives believe that these patients are comfortable?
- **With regard to AWARENESS and COMMUNICATION**
  6. What is, according to the caregivers and relatives, the level of awareness of the patient?
  7. To what degree do caregivers and relatives believe communication with the patient is possible?
- **With regard to FLUCTUATIONS**
  8. Are there changes in depth of sedation, level of comfort, awareness and communication during the period of palliative sedation
     - as measured by a brain function monitor (BIS-monitor or comparable monitors)?
     - according to the perceptions of relatives?
  9. Are changes in these brain function monitors reflected in changes in assessments by caregivers and relatives about the depth of sedation, awareness, comfort or any other kind of perceptions (for instance that "something happened")?

Methods

- **An innovative and challenging aspect of this study is its qualitative approach, implicating that all the different types of data will be used to link 'objective' and 'subjective' data to achieve a holistic understanding of the study topics.**
- 40 participants will be recruited in nursing homes in Flanders
- For each patient the following data will be collected:
  - Assessment by the patients themselves (if possible) by scoring a VAS pain scale
  - Brain function monitoring (NeuroSENSE)
  - Assessment by caregivers (physicians and nurses) on 3 VAS scales (daily)
  - Relatives' perception of the quality of the dying process on 3 VAS scales (daily)
  - Assessment by 2 trained investigators using:
    - RASS (Richmond Agitation-Sedation Scale)
    - CCPOT (Critical Care Pain Observational Tool)
    - Doloplus 2 scale developed for elderly non-communicative patients
    - BPS (Behavioral Pain Scale)
  - Observation: video and audio registrations every day for 90 min, synchronized with the NeuroSENSE recordings
  - Background information based on the patient's medical file and interviews with caregivers and relatives
- open semi-structured interview will be conducted with the relatives and caregivers after the death of the patient



Results

- No results available at this point, study is at starting phase

Conclusions

- N.A.

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