

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

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Introduction

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.

Aim

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.

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. 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) and heart rate variability (HRV)
- 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, synchronized with the NeuroSENSE and HRV recordings
- Background information based on the patient's medical file and interviews with caregivers and relatives
- open semi-structured interviews will be conducted with the relatives and caregivers after the death of the patient

Conclusions: not yet available

Publications: not yet available