Family centered end-of-life care? 
Experiences of relatives with palliative sedation

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1. Literature review
Bruinsma et al. 
J Pain Symptom Manage, 1 June 2012 (Epub)

2. A focus group study
Bruinsma et al, submitted.

Four themes
Information and communication
Decision making
Sedation process (involvement and support)
Evaluation

To guide caregivers, several international, national and local guidelines for the use of palliative sedation have been published

These guidelines typically include recommendations involving relatives, on
- information and communication
- involvement in decision-making
- role in care giving process
- support

1. Literature review

- 39 published papers
- 28 quantitative studies, six qualitative and five mixed methods
- 17 countries
- 3 studies concerned relatives’ reports, 26 studies physicians’ and nurses’ reports, seven studies medical records and three studies combined different sources

2. Focus groups

Relatives
- 5x patient’s partner, 3x patient’s child, 1x patients grandchild, 1x patient’s daughter in law

Patients
- Age at which patients died: 43-89
- Primary diagnosis: 8x cancer, 1x Alzheimer, 1x no specific diagnosis (high age)
- Setting where patient received sedation: 5x home, 3x hospice, 1x nursing home, 1x geriatric institution
- Duration patients’ illness: 4 weeks-2.5 years

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Information and communication

5 quantitative studies
  * 60-100% of relatives received adequate information (n=5)
  * 89-100% of relatives understood information (n=2)
  * 75% of relatives satisfied about information (n=1)

3 qualitative studies
  * relatives have different information needs (n=3)

Focus groups

‘Everything was lumped under one heading – pain relief. The word palliative sedation was never mentioned.’

‘They didn’t say “we are going to start morphine now and we are going to add some midazolam and then you can expect ….” because they just don’t think that way … it’s not what they do.’

Almost all participants referred to euthanasia

‘Yes, if you stop sedation, then they wake up again. In that respect it has nothing to do with euthanasia.’

‘Actually I think.. to me palliative sedation is also a form of euthanasia. You send someone to sleep, and then instead of it all being over in five minutes like it would be with euthanasia, it takes two days.’

‘Beforehand we had already decided that if it got really bad, well, we didn’t want to go through that, we wanted euthanasia (…). And then, during the intake interview they said “we don’t do euthanasia, but we do palliative sedation”.’

Involvement in decision-making process

27 quantitative papers
  * 81-100% of relatives involved in decision-making (n=6)
  * 69-100% relatives gave consent (n=10)
  * 90-93% decision was discussed with relatives (n=4)
  * 95-100% relatives were informed (n=2)
  * 9-41% sedation was requested by family (n=4)
  * 12-33% wellbeing relatives was indication for use of sedation (n=2)

3 qualitative papers
  * Patient is central (1 study)
  * Wellbeing relatives may play a role (1 study)
  * Relatives should decide (1 study)

Focus groups

* Physicians always made final decision
* Sometimes relatives played an active part in decision making
* In some cases physician did not involve relatives in the decision making

‘He (the patient) made the choice himself, and we had talked about it a few times. I supported his decision, well rationally I did, but emotionally I would rather it had gone differently.’

‘We assumed that if sedation was going to be given, then it would be the patient who made the decision. But in reality … we left on Sunday morning, change of shift, and we came back in the evening and we heard that she had been given an injection that had knocked her out. What on earth had happened?’
Involvement in care

- 2 quantitative studies
  - 42% of relatives were involved in monitoring patient (n=1)
  - 17% of relatives were involved in care for patient (n=1)
- No qualitative studies

Support for relatives

- No studies

Focus groups

- ‘On the Friday she was provided with morphine (…), and I think received midazolam too, at some point in time (…), and she died on the Wednesday. We thought that it really took a very long time (…), it really was a very difficult time’.

- ‘As a family, we just weren’t taken seriously. Our information about him and the care and so on, it really wasn’t taken seriously. (…) After all who knows the person better than those who are with them all the time? The nurses took us seriously, but the others didn’t.’

Emotions and evaluation

- 9 quantitative studies
  - 78-93% satisfied with use of sedation (n=3)
  - 88% felt that sedation helped to alleviate patient’s symptoms (n=1)
  - 93% sedation ethically acceptable (n=1)
  - 5% dissatisfaction (n=1)
  - 25-51% distress/concerns (n=2)
- 5 qualitative studies
  - Anger, frustration, disappointment, concerns, struggles, guilt, helplessness, and physical and emotional exhaustion

Focus groups: positive evaluations

- Otherwise it would have been unbearable for him. ... And this is a wonderful way of doing it.’

- ‘I think it is a good process in that you actually allow your body to go its own way, that you are no longer interfering with the natural process. (…) from the patient’s point of view it can be a relief, but also for us.’

Focus groups: negative evaluations

- ‘The time finally came to start sedation, with a pump. That meant she would no longer regain consciousness. (…). We had embraced each other for the last and were waiting for her to fall asleep. (…). We expected that she would indeed go peacefully. But, she woke up twice, oh how horrible that was. And when she had to go back to sleep it didn’t work. (…). She was in so much pain.’

Conclusions

- Majority of relatives are adequately involved in the decision-making process
- Majority of relatives is satisfied about the use of sedation
- Distress / concerns are not uncommon
- Information and communication could be improved
- More studies needed about adequate involvement of relatives in sedation process and about support for relatives
**Discussion**

- Assessment of patient’s suffering (whose suffering?)
- Relatives may request palliative sedation (for whom?)
- Burden of involvement in decision making
- Why is providing adequate information so difficult, how to improve it?

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