Exploration of Concerns of Relatives During Continuous Palliative Sedation of Their Family Members with Cancer

Presented by: Dr. Woon-Chai Yong, 6th October 2009, at the Grey Nuns Palliative Care Unit


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Background: Data on the experiences of relatives during continuous palliative sedation are scarce. Because these relatives may be the ones most closely involved with the patient, it is important to evaluate the possible burdens that they experience.

Aim: We aimed to explore and evaluate concerns of relatives during continuous palliative sedation of their family members admitted to an acute palliative care unit.

Methods: Through retrospective multidisciplinary record research, we obtained data on concerns of the relatives during the period that continuous palliative sedation took place. From October 2001 to October 2004, 45 patients died after starting continuous palliative sedation.

Results: In 51% of the cases, the relatives expressed concerns after starting the therapy.

Concerns could be distinguished into three main themes: concerns about the aim of continuous palliative sedation (27%), concerns related to the well-being of the patient (29%), and concerns related to the well-being of relatives themselves (18%).

Patient and sedation characteristics did not differ significantly between sedations in which relatives did and did not express concerns, except for the duration of the sedation. The median duration of the continuous palliative sedation when concerns were expressed was 46 hours, compared with 19.5 hours when this was not the case ($P < 0.05$).

Conclusions: Both the nature and extent of the concerns suggest that relatives are in need of continuous information and professional guidance during continuous palliative sedation of their family members. Availability of caregiver guidance and clear process documentation are crucial and indispensable in providing this.

Patient and Sedation Characteristics (n45)

<table>
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<tr>
<th>Male/Female</th>
<th>22/23</th>
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<tr>
<td>Age (median &amp; range)</td>
<td>57 (27 – 89)</td>
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<tr>
<td>Duration of continuous sedation (median &amp; range)</td>
<td>21 hours (2-114 hours)</td>
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| Reasons for sedation | - Terminal restlessness - 29/45 (64%)  
- Dyspnea - 20/45 (44%)  
- Pain - 15/45 (33%) |
Use of midazolam | 41 (91%)
Increase of dose of midazolam | 2 times
(median & range) | (0 – 6 times)

Strengths:

- First study examining impact of palliative sedation on family during the process of sedation
- Able to bring forward the discussions of various concerns
- Systematic documentations

Weaknesses:

- Retrospective study
- May not have complete documentations
- Information gathered not per relative but per patient
- Small sample size
- Did not produce the detailed of the patients from 2 groups

Applications:

- Similar population as compared to our unit
- The number of patients on our unit with palliative sedation & concerns of the family
- Address the importance of the process
- To give extra attention to the family members of patient, who required a prolonged period of palliative sedations