General practitioners’ and nurses’ descriptions of their collaboration, roles and responsibilities during the process of continuous sedation until death at home in three European countries

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**Background and aims**

- Continuous sedation until death requires a multidisciplinary team approach, with adequate collaboration and communication.

- It is unknown how general practitioners and home care nurses experience being involved in the use of sedation at home.

- We present case-based GP and nurse descriptions of their collaboration, roles and responsibilities during the process of continuous sedation until death at home in Belgium, the Netherlands and the UK.
Methods

- Study population: 25 GPs and 26 nurses closely involved in the care of 29 adult cancer patients who received CSUD at home in Belgium, the Netherlands and the UK.

<table>
<thead>
<tr>
<th>Country</th>
<th>Patients (n=29)</th>
<th>Physicians (n=25)</th>
<th>Nurses (n-26)</th>
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<tbody>
<tr>
<td>BE</td>
<td>11</td>
<td>9</td>
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<tr>
<td>NL</td>
<td>10</td>
<td>10</td>
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<td>UK</td>
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- Design and methods: Qualitative case study design, based on face-to-face interviews.
- The interviews were transcribed verbatim and analyzed with the help of qualitative analysis software (NVIVO 9).
Results

- In the three countries, GPs and nurses said that nurses often coordinated care at home. They also described how nurses supported the patient and the patient’s family when there were emotional issues towards the end of the patient’s life.

  GP, Be: Those nurses played a very, shall I say, covering role, a coaching role. They took over a lot [of the tasks].

- The nurses in the studied countries also often explained that they had an explanatory role, informing the patient and the family about what one can expect towards the end of life.
Results

- In Belgium and the Netherlands it was the GP who typically took the decision to use continuous sedation.

  Nurse, NI: The doctor really made the decision, we only suggested that the patient had told us that he could not bear it anymore and we just supported him. We see it, but it is not like we tell the doctor: ‘you should do this or that now’, because we are not doctors, it doesn’t work like that.

- In the UK it was predominantly the nurse who both encouraged the GP to prescribe anticipatory medication and decided when to use the prescription.

  Nurse, UK: I think the district nurses have really got to terms with the use of anticipatory drugs. Whereas I used to have conversations with GPs where I would recommend that they prescribe anticipatory drugs and then they would say to me, ‘What do you recommend I prescribe?’.
Results

- Nurses in the three countries reported that they commonly perform and monitor CSUD in the absence of the GP.

Interviewer: Is it also usually the doctor who starts the sedation, or is that left to the nurse?

Nurse, BE, case 1: Yes, the nurse usually does that with someone from the palliative home care team.

Interviewer: And administering the medication in the pump – is that also done by the nurse?

Nurse, BE, case 1: Yes. We know what should go in there and we do that. The doctors don’t start up the syringe driver. They actually don’t really know that driver. And if there is a problem at night then we are also the ones who go because doctors usually don’t know that.

- Some experienced this responsibility to be burdensome

Nurse n°2, UK, case 1 and 5: Actually, once the doctors have written the medication up, it’s up to the nurses to decide when it’s given and to monitor it and contact the doctor if it’s not working or if the patients are needing it frequently. And I remember a very sort of difficult situation with someone with terminal agitation who was very near to death, and that dilemma: ‘Will this sedation actually kill them?’ But they need it because they’re not settled and they’re a danger to themselves, but it’s still that sort of emotional burden on the nurse, sort of like, ‘Do I give it?’ And I suppose in doubt you ask the doctor but we’re trusted enough to make the decision.
Conclusions

- We have found variety between the countries studied regarding the decision making about CSUD and provision of CSUD at home.

- These differences may among others be due to different cultures and responsibilities in the three countries, e.g. re the use of anticipatory medication.
This work was supported by funding from the Economic and Social Research Council (UK) (grant no: RES-062-23-2078), Research Foundation Flanders (BE), the Flemish Cancer Association (BE), the Research Council of Ghent University (BE), the Netherlands Organisation for Scientific Research (NL) and the Netherlands Organisation for Health Research and Development (NL).