Coming home to go...
Heest, Flora Bastiana van

IMPORTANT NOTE: You are advised to consult the publisher's version (publisher's PDF) if you wish to cite from it. Please check the document version below.

Document Version
Publisher's PDF, also known as Version of record

Publication date:
2009

Link to publication in University of Groningen/UMCG research database

Citation for published version (APA):

Copyright
Other than for strictly personal use, it is not permitted to download or to forward/distribute the text or part of it without the consent of the author(s) and/or copyright holder(s), unless the work is under an open content license (like Creative Commons).

Take-down policy
If you believe that this document breaches copyright please contact us providing details, and we will remove access to the work immediately and investigate your claim.

Downloaded from the University of Groningen/UMCG research database (Pure): http://www.rug.nl/research/portal. For technical reasons the number of authors shown on this cover page is limited to 10 maximum.
Chapter 8

Telephone consultations on palliative sedation therapy and euthanasia in general practice in the Netherlands 2003: a report from inside

FB. van Heest\textsuperscript{a}, I. Finlay\textsuperscript{b}, J.J.E. Kramer\textsuperscript{c}, R. Otter\textsuperscript{d}, B. Meyboom-de Jong\textsuperscript{e}

\textsuperscript{a} GP, MSc Palliative Medicine, GP advisor in Palliative Medicine for Drenthe, Integraal Kankercentrum Noord Oost, Groningen, the Netherlands
\textsuperscript{b} Professor the Baroness Finlay of Llandaff, Cardiff University, UK, and Honorary Professor in Palliative Medicine University Medical Centre of Groningen, the Netherlands and member of the House of Lords
\textsuperscript{c} in 2003 final year medical student, department of General Practice, University Medical Centre Groningen, the Netherlands
\textsuperscript{d} M.D., Ph.D, oncologist, University Medical Centre of Groningen, director of the Comprehensive Cancer Centre North-Netherlands (CCCN), Groningen, the Netherlands
\textsuperscript{e} M.D., Ph.D., Professor of General Practice, University Medical Centre Groningen, the Netherlands

Accepted for publication in Family Practice

Introduction

Setting: the project

The region covered by the Integraal Kanker Centrum Noord-Oost, is a predominantly rural area with a population of 2.1 million, about 1000 GPs, 17 hospitals (1 university hospital) and 5500 cancer deaths per year. In 1998-1999 in this area 61% of all deaths occurred at home (1).

Palliative care advice became available to all GPs caring for patients dying at home in our region when four GP-advisors in palliative care were appointed in September 1999, one in each of the four different sub regions, in addition to their normal activities as a GP.
Any GP in the region could telephone the GP advisor at any time of the day or night, any day of the year (24/7) to discuss a palliative care problem encountered in routine clinical primary care. All telephone advice calls were documented; the consultation service was evaluated by sending a standard questionnaire to the GP after 2-6 weeks, as described elsewhere (2).

Setting: end of life care in the Netherlands

End of life care and dying has its own tradition in the Netherlands, which is reflected in the way the practice of voluntary euthanasia, palliative care and the concept of palliative sedation as a therapy have developed (2-9). Awareness of palliative care as a domain of medical knowledge was encouraged by the funding of the Centres for Development of Palliative Care by the Dutch government in 1999. Prior to that time, any palliative care given was part of (general) medical and nursing care. Awareness of the psychological impact of dying was high amongst GPs as many had been taught about Kubler-Ross’s work, but knowledge of symptom management was poor. Palliative medicine is not a recognised specialty in the Netherlands. A tradition of dying at home has also resulted in few inpatient hospice beds with hospital or nursing home providing the alternative to home care at the end of life.

Euthanasia has a protocol which can take some days to work through. It involves specific criteria, including a second opinion from an independent doctor; this is usually a SCEN (“Support and Consultation for Euthanasia in the Netherlands”) doctor who is specially selected, trained (in three days) and participates in an ongoing group to review, share and discuss experiences (10). In 2003, 1815 cases (1.3% of all deaths) were reported nationally as euthanasia or physician assisted suicide (11).

There are no reliable national figures on the use of “palliative sedation” in the Netherlands from 2003 as no agreed definition, and therefore no coding system, existed to collect this data. In 2005, 2 years after the period studied, a national protocol was introduced for “palliative sedation therapy”, defined as ‘the intentional lowering of consciousness of a patient in the last phase of his or her life’, since then euthanasia deaths have stopped rising (12, 13, 14). Deep sedation appears to be used in the Netherlands to relieve suffering in the terminal phase, which is very different to the light sedation achieved by titration in the UK.

Our telephone advice project aimed to support GPs in delivering end of life care.

In this study we wanted to ascertain how often palliative sedation and/or euthanasia were a reason for seeking advice or brought up during discussion in the telephone consultation, whether GPs seeking such advice differed from GPs asking other questions and whether the patients for whom consultation was sought differed from other patients. We were also interested in the content of the discussions, the complexity of the problems
facing the GP in routine practice in the Netherlands and the role and value of the GP advisor.

Method

We undertook a retrospective analysis of our database and the consultation record forms from 2003. Every consultation had been documented on a standardised form, which consisted of a tick box section for electronic use (quantitative, no information on sedation or euthanasia) and an open section for free text. To ascertain how often sedation and/or euthanasia were discussed and what information could be gained from the registration forms, a data collection proforma was piloted by an independent analyst (JJMK) using 20 forms from one of the GP advisors (FvH), following which all forms from this GP advisor were examined. To widen the sample, the forms of the other three GP advisors were examined, initially reviewing every fourth form. This revealed that two of the GP advisors consistently had recorded qualitative and detailed information, including completion of the free text area; the other two advisors had only documented quantitative (tick box) data and as their forms provided no information on sedation or euthanasia they were excluded from the analysis.

The data collection proforma was used by JJMK to score systematically whether the registration of the consultation covered sedation and/or euthanasia, the core details of the GP, the patient and medication. Data from the service evaluation forms were also analysed.

Definition of terms

The consultation was defined as covering sedation/euthanasia if the following terms were used: “Euthanasia”, “SCEN doctor”, “palliative sedation”, “sedation”, “parenteral medication to sleep”, “wants to sleep” and consultations in which a dose of midazolam >30mg/24hr or higher (i.e. sedative dose) was advised.

All consultation records containing one or more of the operationalised expressions were then reviewed by three independent observers (final year medical students) to classify them. This resulted in the forms being classified by the presenting problem, by the outcome of the discussion and then by type of advice finally given. Only one of the evaluation forms mentioned the operationalised expressions, so further categorisation of these was not feasible.

SPSS v 11.5 was used for the analysis. The characteristics of the doctors and the patients in the different groups were compared using Chi square in nominal variables and one way ANOVA in continuous variables. The Kruskal Wallis test was used for unequal variances; the Shapiro-Wilk was performed to assess normality.
Results

Quantitative analysis
Characteristics of the doctors seeking advice from the service in 2003: A total of 415 consultation calls were received by two GP advisors in 2003; in 87 of these either euthanasia and/or sedation were discussed. In 89% (370) of cases the person seeking advice was a GP, the target population of the service. The other 11% were nurses, pharmacists or medical specialists.

Doctors asking for advice about euthanasia had worked in their practice on average 9.6 years, compared to an average of 13 years overall amongst those using the telephone advisory service; this difference was not significant.

There were no differences in age distribution, gender, place of work or type of practice between GPs seeking advice for euthanasia and/or sedation, and GPs seeking advice on other problems.

Characteristics of the patients Mean overall age of the patients on whom advice was sought was 64.5 years (18-100), and did not differ significantly when the presenting problem related to euthanasia (63.1 years; range 41-96 years), sedation (65.6 years; range 24-99) or both (68.3 years; range 48-96).

There was no significant difference in time since diagnosis or type of primary diagnosis (mostly cancers).

The predicted prognosis was shorter for patients on whom advice about sedation was sought (hours 3% days 73%, weeks 13.5%) compared to patients for advice on euthanasia. (hours none, days 50%, weeks 34.4%). The nursing input was greater in patients for advice on sedation (65%) compared to patients for advice on euthanasia (47%).

Palliative sedation therapy and euthanasia in the advice calls
In 87 (21%) of the 415 analysed consultations sedation and/or euthanasia was discussed either in the presenting question or during discussion (table 8.1). In 37 cases euthanasia came up as a presenting problem, in 26 cases sedation and in 10 cases both. During consultation about other problems, sedation came up in 11 cases and euthanasia in 3 cases.

Euthanasia apparently was problematic in 25 consultations (see qualitative discussion). It remained an option in only 12 cases; both euthanasia and sedation were considered options in 5 cases.
Advice on sedation was given in a total of 43 cases: 20 of the 26 presenting a question about sedation, in 5 of the 37 seeking euthanasia advice, in 7 of the 10 consultations about both euthanasia and sedation and in 11 of 342 consultations that initially sought neither sedation nor euthanasia advice.

In four cases technical difficulties with performing euthanasia were the main reason for asking advice: one concerned venous access (performing euthanasia requires venous access to administer the large volumes of barbiturate and muscle relaxant) and three concerned contacting a SCEN doctor.

Technical pharmacological aspects of sedation (table 8.2) arose in 48 calls: in 38 cases midazolam by subcutaneous infusion was advised, twice supplemented with sublingual lorazepam; in a further 10 cases (categorised as “sedation” or “sedation and euthanasia”) sedation was mentioned but no dosage of midazolam was documented. Documented midazolam dosage ranged from 30 to 120 milligrams/24 hours with a mean of 60mg midazolam/24 hrs. In 22 cases midazolam was combined with morphine (10-300 mg/24 hr). Midazolam was combined with a neuroleptic: haloperidol in 12 cases and levomepromazine in 10 cases.

<table>
<thead>
<tr>
<th>Presenting problem</th>
<th>No of Cases</th>
<th>Category after Discussion</th>
<th>No of cases</th>
<th>Outcome after advice</th>
<th>No of cases</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. Sedation</td>
<td>26</td>
<td>Sedation</td>
<td>20</td>
<td>Sedation</td>
<td>43</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Euthanasia</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td>Sedation and euthanasia</td>
<td>1</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td>No sedation/ euthanasia</td>
<td>5</td>
<td></td>
<td></td>
</tr>
<tr>
<td>2. Euthanasia</td>
<td>37</td>
<td>Euthanasia</td>
<td>9</td>
<td>Euthanasia</td>
<td>12</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Sedation</td>
<td>5</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td>Sedation and euthanasia</td>
<td>4</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td>No sedation/ euthanasia</td>
<td>19</td>
<td></td>
<td></td>
</tr>
<tr>
<td>3. Sedation and euthanasia</td>
<td>10</td>
<td>Sedation</td>
<td>7</td>
<td>Both</td>
<td>5</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Euthanasia</td>
<td>0</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td>No sedation/ euthanasia</td>
<td>3</td>
<td></td>
<td></td>
</tr>
<tr>
<td>4. No sedation or euthanasia</td>
<td>342</td>
<td>Sedation</td>
<td>11</td>
<td>No sedation/</td>
<td>355</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Euthanasia</td>
<td>3</td>
<td>euthanasia</td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td>No sedation/ euthanasia</td>
<td>328</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

Table 8.1 Advice calls
Evaluation
The response rate for the evaluation of all consultations was 65% (n=272). Overall 85% of GPs (n=232) stated that the advice had been of value for the patient; however, for all (n=53) of the consultations that had discussed euthanasia/sedation, the GP stated the advice had been valuable.

Qualitative analysis
Sedation and euthanasia raised different issues in the consultation, including discussion, exploring treatment options and wanting to know more about either sedation and/or euthanasia. Examples of typical consultation are given in boxes 1-4.

Some GPs consulted the GP advisor prior to visiting the patient when intending to discuss end of life issues. Sometimes - as in the case in box 1 - experience played a role. Doctor-centred problems included a need to exchange ideas with an expert to validate a proposed clinical action (e.g. when a difference of opinion about euthanasia arose between the treating doctor and the independent "SCEN" doctor). Difficulties for the doctor also arose through a lack of communication between professional caregivers. In one case the patient was discharged from hospital to have euthanasia at home, but the GP had not been involved in this decision and, as the doctor responsible for care at home, he found himself under enormous pressure.
One GP needed clarification of the difference between stopping treatments and performing euthanasia.

In the case in box 2, differences of opinion between the patient and the patient’s partner about euthanasia complicated the situation. Actually in retrospect the patient was dying at the time the GP asked advice. Problems arose more often when euthanasia was not a legal option; for example when patients lacked capacity to express their wish due to delirium. Some families then pressurised the GP to perform euthanasia, claiming that the patient had always said that he or she wanted euthanasia. Two times the patient had asked for euthanasia but the

**Box 1 Doctor-centered problems**

A 34 yr old female doctor phoned at 1.30 pm about a 70 yr old male patient with a colorectal carcinoma diagnosed 3 months previously at surgery. He was at home, cared for by his family. Medication: oral morphine slow release 100 mg 12 hourly, morphine tablets 10 mg 5-6 per day, amitriptyline 25 mg increased to 100 mg once daily.

Presenting problem: pain relief was not effective. The patient and family wanted euthanasia but the doctor wanted good palliation first. There was a large tumour mass in the pelvis, the stoma was not working well, patient drank sips, was sometimes restless, had a urinary catheter.

So there was a difficult pain problem with a substantial neuropathic component, some delirium of the patient and pressure on the doctor to perform euthanasia as a solution. The doctor admitted that she had never yet performed euthanasia and felt reluctant as she thought that palliative options remained. After discussion, admission to hospital for an epidural for better pain relief was suggested; the evaluation form indicated the advice was followed and was appropriate.

**Box 2 Patient not meeting the criteria for euthanasia**

At 3 pm a 51 yr old doctor working as GP for 16 yrs called about a 48 yr old male patient with metastatic lung cancer diagnosed 10 months previously. He had a sudden deafness as a paraneoplastic symptom, he suffered from anxiety and pain, he had difficulty accepting his condition. He had wanted euthanasia, but his wife did not agree with that.

Medication: fentanyl 50µ patch, fluconazole, an oral benzodiazepine had been replaced by rectal because he could no longer swallow. His prognosis was estimated to be days, he was at home cared for by his family. He was extremely cachectic. The GP wanted to sedate the patient to relieve his suffering due to anxiety and asked advice about the dosage. Based on the previous use of benzodiazepine doses, 120 mg of midazalam combined with 25 mg levopromazine/24 hours as a continuous subcutaneous infusion was advised. The disadvantages of sedation were discussed. On evaluation, it turned out that the patient died some hours after the advice call (after 15 mg of midazolam given as sc injection). The GP valued the advice.
disease process “went too fast” so the procedure could not be followed; however advice was given on the management of haematemeses and of faeculent vomiting.

Once a nurse called about a patient who wanted euthanasia but the doctor refused; she wanted to know what rights a patient has, and how she could support the patient yet remain professionally loyal to the doctor.

Sometimes patients wanted to stop living but were not in a final stage of disease or still had palliative options. These patients wanted the doctor to intervene to bring death forward but the doctor considered neither euthanasia nor sedation as an option as yet and wanted to discuss alternatives to relieve suffering. Once admission to a nursing home was advised because the caregivers were exhausted.

The problem for one doctor was that the legal criteria require the wish for euthanasia to be consistent was not met as the patient was giving conflicting messages, hoping for a “wonder pill” to get better and at the same time asking for euthanasia. Yet the doctor knew that there was no wonder pill, felt that euthanasia could be an appropriate option at a further stage of the disease but wanted to discuss palliative possibilities first.

In most consultations advice to improve symptom control was given like in this case (box 4) where the doctor did not know the patient well. In five cases of advice on sedation the patient was comatose already but appeared uncomfortable, so the advice focussed on additional sedation.

Once, after a long discussion with the GP, it emerged that the patient did not want euthanasia but also did not want a prolonged dying process. The doctor felt pressurised by the patient “to do something” and wanted to discuss whether everything he had done up until now was correct. The role of the GP advisor in such cases was to offer affirmation and support and explore
possibilities in symptom management. In another consultation the patient did not want any further treatments, so the GP was advised to open up discussion about end of life issues.

**Box 4  Symptom control**

A 39 yr old male doctor with 3 years experience as a GP called at 10 in the morning about a 55 year old male patient with mesothelioma, diagnosed 10 months previously. The prognosis of the patient was estimated to be days. He was at home completely dependent on care from his family and professional nursing.

He had an epidural in situ for pain relief (200mg morphine/24 hr). The GP felt he was “really at the end now, had more pain and wanted euthanasia” and was nauseated.

After discussion the GP-advisor suggested starting levopromazine 12.5-25 mg twice daily for nausea, reducing the morphine, starting dexamethasone 5 mg daily for 2-3 days and to start the procedure for euthanasia and add methylfenidate if sleepy.

At evaluation the GP reported that the advice helped the pain, the nausea and the delirium. In the remarks area he wrote: “expert advice, adjusted to the person, accessible, to be continued”.

Sometimes sedation and euthanasia were not the main problem, but appeared to be the opening line for a complex discussion of other issues like symptom control, psychosocial issues or problems with the patient and the family.

**Qualitative analysis of the evaluation of the advisory service**

The free text space on the evaluation forms was often not used. But when it was used, it contained general positive remarks such as “good advice” or “pleasant contact”. Only one evaluation mentioned euthanasia specifically.

**Discussion**

This is the first time that registration forms about the content of advice on end of life decisions from a GP advisory service, run by GPs with additional specialised training, has been analysed.

There is no reason to suppose that the consultations of the two excluded GP-advisors would have revealed a different content. The GPs asking for advice were a self-selected group, which limits the generalisability of the findings; however the value of this report lies in its insights, analogous to “a peek behind the curtain”. Audio recordings of the consultations might have given more detailed information but needs much more input from researchers as well, an idea for future research.
The notes on the GP telephone consultations revealed a rich dialogue in resolving clinical dilemmas and the pressures the GP can face when confronted with demands for euthanasia or end stage sedation. The group of doctors consulting about sedation and/or euthanasia did not seem to differ from the other GPs, suggesting that such decisions are part of normal daily practice in the Netherlands. The prognosis of the patients asking for euthanasia in the consultations was slightly longer than in the sedation group; this is not surprising as the patient needs to be competent for euthanasia, whereas in delirium sedation remains an option.

Consultation questions relating to euthanasia often resulted in other options being suggested, possibly because doctors who experience no problem in performing euthanasia will not seek palliative advice but will call a SCEN doctor for the obligatory consultation.

The advised doses of midazolam to be used for sedation (mean 60 mg/24 hrs) are strikingly high compared to prescribing in the UK (mean 26 mg/24 hrs)(15). This may suggest that in the Netherlands a tradition in delivery of end of life care has developed that encompasses more medication, including overdoses in euthanasia. Other possible explanations include the underlying differences in prescribing practice for benzodiazepines, resulting in Dutch patients needing higher doses to relieve end-stage agitation, or that the intention of the midazolam was to achieve deep sedation rather than being titrated to relieve distress as in UK practice. We had no evidence that these patients prescribed sedation were a more clinically complicated group.

We were unable to access the case notes of the patients for whom advice had been sought, so the ultimate outcome of the consultation could not be independently verified; further research on this is planned. Importantly, there were no negative reports from the evaluation of the telephone consultation service.

The qualitative analysis, including the described cases, demonstrates the complexity of decisions and competing pressures that Dutch GPs face in everyday practice when supporting patients dying at home.

Weighing up the options to relieve suffering appears to provide important support to these GPs who have to deal with patients who can ask for bringing death forward with euthanasia or who may need the therapeutic option of sedation in case of resistant symptoms. Clinical dilemmas are complex, requiring expert support tailored to the situation of the individual patient, rather than relying on protocols. We are concerned that the scarcity of this type of telephone consultation service may force GPs to take decisions in isolation, but a vulnerability of our service is that it is dependent on the constant availability of a GP advisor.

Relevance of the findings to doctors working in other countries
The end of life poses unique challenges to those providing care. The advanced stage of disease means that complex physical symptoms interact with psychological and social concerns as the patient uniquely experiences the impending close of his life. The options in therapy such as euthanasia and
sedation to relieve suffering may at first sight appear valuable, but they raise complex issues that make decision-making no easier for the patient or the doctor. This is particularly evident in euthanasia where the doctor (and the team) treating the patient face a conflict of responsibilities between doing everything possible to improve the quality of patient’s life on one hand, and ending that life as a way to alleviate suffering on the other hand. This demands a great deal, particularly in emotional energy, from the doctor as a fellow human being and can overshadow full consideration of other options in care. Expert telephone advice helped the patient’s GP to find alternative therapeutic options to euthanasia in a significant number of patients.

Competing interests: None declared

Funding body:
This work was supported by grants from the Dutch Ministry of Health

Acknowledgements
Christa Rolf, GP-adviser, for her comments on the paper, the GPs in the area and the fellow GP-advisers of the IKNO for their role in recording the consultations.

I.G. Finlay, R. Otter and B. Meyboom de Jong advised on the organisation of the GP advisor service, on the design of this study and the writing. J.J.M. Kramer undertook independent analysis of the content on the record forms.

References
5 Sheldon T. “Terminal sedation” different from euthanasia, Dutch ministers agree. BMJ 2003; 327:465
8 Rurup M., Muller M.T., Onwuteaka-Philipsen B.D., Heide van der A., Wal van der G., Maas van der P.J., “Requests for euthanasia or physician assisted suicide from older persons who do not have a severe disease: an interview study” Psychological Medicine 2005;35:665-671
12 http://www.pallialine.nl “richtlijn stervensbegeleiding; palliatieve sedatie”
13 Rietjens JAC, Heide van der A, Vrakking AM, Onwuteaka-Philipsen BD, Maas van der P.J, Wal van der G. “Physician reports of terminal sedation without hydration or nutrition for patients nearing death in the Netherlands”. Annals of internal medicine 2004;141:179-185
Abstract

Background
The objective of this study was to identify the general practitioner's perception of educational needs in palliative care. A qualitative study with focus groups was performed.

Method
General practitioners estimate palliative care as an important and valuable part of primary care. Nevertheless, they consider their coordinating role as a course with increasing obstacles. Pain, nausea, dysphagia, delirium, insomnia, anxiety, and depression were mentioned frequently as symptoms difficult to deal with in palliative care. Also, psychosocial issues such as communication, bereavement, and defense mechanisms were subject to discussion in the focus groups. Ethical issues such as euthanasia were mentioned as the most complex subject in palliative care.

Conclusions
In conclusion, general practitioners experience difficulties with their coordinating role in palliative care. With more basic knowledge and skills in communication, but also with consultation, their roles as coordinators of palliative care in primary care will improve. Reflection and deepening of ethical values are necessary conditions for a optimal functioning.