

Original Article

Descriptions by General Practitioners and Nurses of Their Collaboration in Continuous Sedation Until Death at Home: In-Depth Qualitative Interviews in Three European Countries

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Abstract

Context. One palliative care approach that is increasingly being used at home for relieving intolerable suffering in terminally ill patients is continuous sedation until death. Its provision requires a multidisciplinary team approach, with adequate collaboration and communication. However, it is unknown how general practitioners (GPs) and home care nurses experience being involved in the use of sedation at home.

Objectives. To 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 U.K.

Methods. We held in-depth qualitative interviews with 25 GPs and 26 nurses closely involved in the care of 29 adult cancer patients who received continuous sedation until death at home.

Results. We found that, in Belgium and The Netherlands, it was the GP who typically made the final decision to use sedation, whereas in the U.K., it was predominantly the nurse who both encouraged the GP to prescribe anticipatory medication and decided when to use the prescription. Nurses in the three countries reported that they commonly perform and monitor sedation in the absence of the GP, which they reported to experience as “emotionally burdensome.”

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Conclusion. We found variety among the countries studied regarding the decision making and provision of continuous sedation until death at home. These differences, among others, may be the result of different organizational contexts in the three countries such as the use of anticipatory medication in the U.K. *J Pain Symptom Manage* 2015;49:98–109. © 2015 The Authors. Published by Elsevier Inc. on behalf of American Academy of Hospice and Palliative Medicine. This is an open access article under the CC BY license (<http://creativecommons.org/licenses/by/4.0/>).

Key Words

Palliative sedation, continuous sedation until death, general practitioners, nurses, collaboration, home

Introduction

Continuous sedation until death (from here onward referred to as sedation) is often used as a last resort option for relieving intolerable refractory (i.e., untreatable) symptoms of terminally ill patients in which the patient's consciousness is lowered until the time of death.^{1–4} Previous international research has shown that sedation is commonly used in different countries and that systematic differences occur in its practice among countries.^{5–8} Guidelines on sedation were developed in The Netherlands in 2005 and in Belgium in 2010.^{2,3} In 2009, the European Association for Palliative Care (EAPC) published a framework of recommendations for the use of sedation.⁴ No sedation guidelines exist in the U.K.

Although these guidelines have been primarily developed for supporting physicians in their practice of sedation, recommendations also may have consequences for tasks performed by nurses involved in the care for the patient.⁹ Thus, guidelines recommend that GPs should bear final responsibility for the performance of sedation, but studies have shown that nurses are also important participants in the decision-making process and the implementation of sedation.^{2–4} As palliative care requires a team approach according to the World Health Organization,¹⁰ it is surprising that studies have been either focused on physicians' or nurses' practices and attitudes regarding the complex realities of the performance of sedation, and have not studied these issues in-depth from a double perspective.

For instance, a British study suggested that U.K. nurses have a key role in activating

anticipatory prescriptions, although research into this issue is scarce.¹¹ In the U.K., these anticipatory prescriptions are written by the GPs for patients who wish to remain at home in the last few days or weeks to ensure that there is no delay in responding to a symptom if it occurs.¹² The anticipatory medication that is prescribed in advance consists of sedatives alongside other commonly used drugs at the end of life. These are often referred to as the “just in case” medications and are kept in the patient's home.¹³

Furthermore, recent Belgian and Dutch studies found that home care nurses were less often involved by GPs in the decision-making process of sedation than nurses working in institutions.^{9,14–16} However, they were frequently involved in the performance and monitoring of sedation at home in the absence of the GP in a substantial number of cases.^{9,14,15} Another substantial number of Dutch nurses made independent decisions concerning the dosage of medication.¹⁴ The authors of these studies, therefore, have raised questions regarding the autonomy and responsibilities of nurses at home, and their collaboration with the GPs during sedation.^{9,14,15}

Especially in the home care setting, the practice of sedation can be challenging for the GPs and the nurses.^{17–20} Barriers surrounding the adequate performance of this practice at home as experienced by the GPs and nurses include a lack of knowledge of GPs about this practice; obstacles regarding the availability of medications, medical equipment, and clinical staff at all times; and a lack of time, coordination of the patient's care at home,

and collaboration with other health care professionals.^{9,21–24} Another qualitative study in the U.K. reported additional challenges such as resourcing concerns, professional expertise/experience, professionals' relationships with patients, and professionals' relationships with other professionals.²⁵

To explore qualitatively and to seek to explain differences in reported practices of sedation among different countries, the U.K. Netherlands Belgium International Sedation Study (UNBIASED study) has been set up in Belgium, The Netherlands, and the U.K.²⁵ The present study is part of the UNBIASED study and focuses on the reports of physicians and nurses in the home setting regarding the decision-making processes, performance, and monitoring of sedation.

The goal of our qualitative in-depth interview study was to investigate descriptions by the GPs and nurses of their collaboration, roles, and responsibilities during the process of sedation at home in Belgium, The Netherlands, and the U.K.

Methods

In the larger UNBIASED study, in-depth interviews were held with physicians, nurses, and decedents' relatives in Belgium, The Netherlands, and the U.K. in 2011–2012 in hospitals (oncology wards), palliative care units (in Belgium) or hospices (in the U.K. and The Netherlands), and at home. We refer to the published UNBIASED study protocol for a full description of the methods used.²⁵ The protocol and the aide-memoires (or “interview guides”) used in qualitative data collection were developed in close collaboration among the countries to ensure comparability of research conduct, especially with regard to inclusion criteria of patient cases.

Ethical Approval

The study was approved in the U.K. by the Leicestershire, Northampton, and the Rutland Research Ethics Committee 1, reference number 10/H0406/57; in Belgium by the Ghent University Hospital Ethics Committee, reference number B670201010174; and in The Netherlands by the Erasmus MC Medical Ethical Research Committee, reference

number NL33327.078.10, V03. Each participant gave written informed consent before participating.

Study Design, Setting, and Participants

A qualitative in-depth retrospective case study design was used to enable exploration of the practice of sedation from a variety of perspectives and in terms that relate to “real-world” practice. By using a case study design, it is possible to explore practically and ethically complex situations, as is the practice of sedation until death. Detailed insights from well-constructed case studies also have an explanatory potential.²⁵ Herein, we report perspectives from the GPs and nurses in the home care setting in the three countries. The GPs and nurses were invited to take part in a face-to-face interview if they had recently taken a key role in the care of a patient older than 18 years, who had died of cancer, and who had been continuously sedated until death. Patients who had only received opioids were excluded. The GP practitioners were asked to identify patients who before death had received continuous sedation. If the case was judged by the GP as suitable for our study, the GP practitioners sent out the invitations for interviews to the decedents as well as the staff most associated with the case. The GPs and nurses in the three countries were interviewed about no more than three patients.

Procedures

The interviews were held by trained interviewers in private meeting rooms and lasted approximately 30 minutes. All participants signed a consent form and consented to the interview being audiotaped. At the beginning of each interview, sociodemographic information was obtained through a short questionnaire about the interviewee and the patient (via the GP in the three countries or the nurse in the U.K.). The interviewer explained that he/she did not know the details of the patient's case, for reasons of anonymity. Participants could use the patient records if necessary to support them in their recollection but were asked to provide relevant information about the case in an anonymous manner. The interviews were semistructured and supported with the use of aide-memoires. Before the interview study, the aide-memoires had

been piloted in focus groups and several interviews. The aide-memoires focused on participants' recollections of the decedent's care and the use of sedation in particular. Interviewees were asked to describe the reasons for the use of sedation, how the decision-making process evolved, and how sedation was performed. Finally, the participants were asked about their general ideas and attitudes regarding the use of sedation.

Data Analysis

All recordings of the interviews were transcribed verbatim and safeguards were taken to reduce the risk of breach of confidentiality. Identifiers were stripped from the transcripts. The Belgian and Dutch interviews were translated into English by a professional translation bureau and checked for accuracy. All interviews were read in-depth by L. A. and J. A. R., and the main themes concerning GPs' and nurses' collaboration, roles, and responsibilities during the process of sedation at home were identified based on Straus and Corbin's constant comparative method.²⁶ This involved labeling small extracts of data with a descriptive code and then grouping similar codes together into a theme. The transcripts were coded exhaustively. Based on these themes regarding the GPs' and nurses' collaboration, roles, and responsibilities during the process of sedation at home, a coding tree was developed by L. A. and J. A. R. and agreed by all the authors. The interviews were reread and quotes were selected and classified under the matching main and subthemes. The selection and classification was done by L. A. and checked by J. A. R. The development of the analysis was discussed with all co-authors in telephone meetings. Finally, quotes per main theme were selected by L. A. and J. A. R. for publication and approved by all researchers. For the questions addressed in this article, we were able to continue identification of eligible deaths and recruitment of physicians and nurses until data saturation occurred (i.e., no new issues emerging).²⁷ Where possible, we compared the GPs' and nurses' comments on the same sedation case.

Results

We explored 29 cases of patients with cancer (11 BE, 10 NL, and 8 U.K.) who had been

continuously sedated until death at home with 25 GPs (9 BE, 10 NL, and 6 U.K.) and 26 nurses (11 BE, 8 NL, and 7 U.K.). In 28 cases, both a GP and a nurse had been involved in the patient's care at home (11 BE, 9 NL, and 8 U.K.). In one Dutch case, no nurse had been involved according to the GP because the patient's family took care of the patient until the patient's death. In 24 (9 BE, 9 NL, and 6 U.K.) of these 28 cases, we were able to interview both the GP and the nurse most involved. Characteristics of the deceased patients, GPs, and nurses may be found in [Table 1](#).

A home care team had been involved in 24 cases (10 BE, 6 NL, and 8 U.K.) and a specialist palliative home care team in 20 cases (7 BE, 9 NL, and 4 U.K.). In two Belgian cases, the GPs reported that a specialist palliative home care team had not been involved but that they themselves were specialized in palliative care.

In the interviews, the GPs and nurses in the three countries reported on their collaboration, roles, and responsibilities during the decision-making process, performance, and monitoring of sedation at home.

Decision-Making Process of the Use of Sedation Until Death

We found differences across countries in the decision-making process, who discusses sedation with the family, who is involved in the final decision and how, and who makes the final decision.

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

GP, BE, Case 7: Those nurses played a very, shall I say yes covering role, a coaching role. They take over a lot [of the tasks].

Nurse no. 2, U.K., Case 1: I remember my role being more related to the emotional side of things. I didn't have much contact with the patient or the district nurses towards the end of his/her life because they were coordinating things by then and the patient had a syringe driver in situ so they were going in every day and, as a specialist nurse, unless there are specific emotional or symptom issues, I would

Table 1
 Characteristics of Patients, Physicians, and Nurses

Characteristics	Patients, <i>n</i> = 29	Physicians ^a , <i>n</i> = 25	Nurses ^a , <i>n</i> = 26	Cases With Both Perspectives, <i>n</i> = 24
Country				
Belgium	11	9	11	9
The Netherlands	10	10	8	9
U.K.	8	6	7	6
Age				
≤40	2	2	6	n/a
41–50	1	6	8	
51–60	3	9	7	
61–70	8	2	0	
71–80	10	0	0	
>80	5	0	0	
Not stated	0	6	5	
Gender				
Male	12	14	2	n/a
Female	17	11	23	
Not stated	0	0	1	
Diagnosis				
Abdominal/stomach	1	n/a	n/a	n/a
Bladder/renal	1			
Colorectal	2			
Brain/glioblastoma	1			
Breast	4			
Gynecological	1			
Facial maxillary/esophageal	1			
Gallbladder/pancreatic	3			
Leukemia/myelofibrosis/myeloma	2			
Lung/mesothelioma	8			
Melanoma	1			
Peritoneal	2			
Prostate	2			

^aMore than one could have been interviewed.

liaise with the community team and they know they can contact me for advice but I wouldn't necessarily be visiting regularly because the district nurses were going in daily and things were controlled.

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 toward the end of life. Nurses reported that they informed patients and their families about the possibilities at the end of life, such as sedation and euthanasia in Belgium and The Netherlands, and the use of anticipatory medication in the U.K.

Nurse no. 2, UK, Case 1: I do a lot of explanation with the family as to what they [anticipatory medication] are and when they're used.

Although some nurses in Belgium and The Netherlands reported that they discussed the option of sedation with patients and families,

several respondents in these countries stated that the option of sedation was mostly discussed by the GP. The GP also discussed it sometimes with the home care nurses or the palliative team. In Belgium and The Netherlands, it was usually the GP who made the final decision to use sedation and reported themselves as having overall responsibility, even where the nurses suggested when sedation should be begun or increased the sedative medication within prescribed parameters.

GP, NL, Case 1: The decision [to sedate] lies with me because you cannot just perform palliative sedation in any situation.

Interviewer: And who else was involved in the decision making?

GP, NL, Case 1: If you take a decision about dying, I want to have the conversation in the first instance only with the patient. Then I have a second conversation with the most involved relative. What I also always say is that the decision [to sedate] is never

my own decision. I also involve the palliative care team, and I also let them decide.

Nurse, NL, Case 1: It [sedation] is not our decision, it is really a decision between the GP and the patient, who [the GP] then decides to start with it.

Interviewer: And you yourself were present at that conversation?

Nurse, NL, Case 1: At the moment when the GP discussed sedation with the patient today, I was present. Not before.

Interviewer: And who else was present during that conversation?

Nurse, NL, Case 1: The patient's wife.

Nurse, BE, Case 7: I think that the indication of that decision often lies with the nurse. But the GP always decides. The GP is the one who says "the syringe driver will or will not be placed," but I think we indicate the moment. Especially the nurses, because we are the ones who are most often with the patient day by day.

Nurse, BE, Case 9: The doctor is still the one responsible, that's good because in the end it is the nurse who puts in the pump and increases the medication.

The role of the nurses in the decision-making process was, according to most of them, to advocate the patient's perspective and needs and affirm the GP's decision to sedate.

Nurse, NL, Case 1: The doctor really takes the decision, we only suggested that the patient also had told us that he/she can't take it anymore and we just supported him/her. We see it as well, not that I'm saying to the doctor "you should do that now" because we are not doctors, it doesn't work like that.

Nurses and GPs from the U.K. described a rather different decision-making process about the use of sedation compared with those from Belgium and The Netherlands, as well as differences in the GP and nurse roles. The GPs and nurses from the U.K. described that first it was necessary to decide to prescribe the anticipatory medication and second, it was necessary for a decision to be made to implement the prescription and use the medication.

Several British GPs and nurses reported that it is often the nurse who both encourages the GP to prescribe the anticipatory medication and then takes the responsibility for deciding when to use prescribed medication for the patient.

Interviewer: And what about the district nurses - do they come sometimes and say to you, "I think ..."

GP, U.K., Case 5: Yeah, they're generally quite good and they generally will suggest if they think that somebody's at the stage of needing a syringe driver, and they probably deal with it a lot more than we [GPs] do really.

Nurse no. 2, U.K., Case 5: I think the district nurses have really got to terms with the use of anticipatory drugs and, whereas I used to have conversations with GPs where I would recommend that they prescribe anticipatory drugs and they would then say to me, "What do you recommend I prescribe?"

Sometimes, British nurses and GPs reported that GPs were very wary and afraid of prescribing or administering medication because of possible implications for themselves.

GP, U.K., Case 5: I don't think sedation is over-used. Perhaps in occasions, as doctors, we maybe should have thought about putting drivers in sooner than later.

Interviewer: And why do you think that we tend to wait and hang on a little bit?

GP, U.K., Case 5: Sometimes I think it's just worrying about being too aggressive and making somebody too sedated and how the family might react to that. You always worry about, you give that dose of morphine and then they stop breathing that second and then it just looks like you've done it. If there was no family you might do things a bit differently if you felt that you wouldn't have eyes scrutinizing you.

Nurse no. 2, U.K., Cases 1 and 5: I think it's very difficult to sort of marry up the GP's responsibility for prescribing that sedation with the patient's wishes, as in the case of the patient who wanted to be sedated. It is difficult to go back to the patient and say, "I know you don't want to be awake ... but

you've got to be." I mean, obviously I would never say, "the doctor won't prescribe it ... because he/she's worried about the implications on him/her."

British nurses described how they sometimes suggested what medication should be used for sedation, although several of them reported this should be a team decision.

Nurse no. 2, U.K., Cases 1 and 5: It's often the district nurse making that decision and going to see the GP and saying, "time for a syringe driver." And it depends on the GP and their knowledge and experience, but quite often we're suggesting what they put in it as well.

Nurse, U.K., Case 3: I've noted that sometimes nurses will go their own way, which I think is a huge thing. I strongly believe it should be a double-up nursing situation. If you're making that decision and you feel that it's appropriate to start a syringe driver, I would still always ring the out-of-hours GP, even though it's written up, and discuss it. I think it's got to be a team decision.

In the U.K., the decision to administer anticipatory medication was sometimes described as a joint decision between the nurse and the GP, with the final responsibility lying with the GP.

GP, U.K., Case 6: So it [administering medication] is always a collaborative decision-making in some respect. The final sort of responsibility probably lies with me, but in fact the actual decision's been made with nursing input, and in fact the patients and staff and the relatives' wishes as well.

Interviewer: Who made that decision?

Nurse, U.K., Case 6: We make it together with the GPs. There's a basic set of drugs written up that cover the base symptoms. It's just deciding when to or if you need to start them.

Interviewer: And was that a nursing decision to start them?

Nurse, U.K., Case 6: Well, it's a joint decision between the nurses and the GP.

Performance of Sedation Until Death

After the decision was made to use (anticipatory) medication, respondents in the three countries described how it was mainly the

nurse who started the syringe driver and administered the medication, mostly in the absence of the GP.

Interviewer: Was the GP also present at the time of the connection of the pump?

Nurse, NL, Case 5: Well here in [place] that is almost never the case. I worked in [another place] before and there it was a must; we would say to the GP "if you are not there then we won't start the sedation." But that is not common here.

According to some Belgian and Dutch nurses, the GPs lack knowledge about placing a syringe driver. Also, starting sedation is a technical act and several nurses said that they are more skilled at it than GPs.

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.

In a Dutch case, the GP said that he/she did not find his/her presence necessary at the start of sedation because the nurse had plenty of experience. The nurse from that same case said that he/she found the presence of the GP desirable, although the GP was mostly not present.

Interviewer: Have you been present at the start of sedation?

GP, NL, Case 6: No, I've discussed it with the nurse who was going to administer it, and whether s/he wanted me to be there. But well, I think it's not necessary, because they have plenty of experience and everything was said and done and discussed. So yeah, I don't need to be present at the start of sedation I think.

Interviewer: And you were there yourself, at the start of the sedation, you connected the pump.

Nurse, NL, Case 6: Yes.

Interviewer: How does that exactly work? Is there for example a doctor always present as well?

Nurse, NL, Case 6: No a doctor isn't always present, it is desirable that the GP is there, but that's usually not the case. No, there is usually no doctor present.

Another Dutch nurse explicitly said that he/she had appreciated the GP's presence while he/she had started the sedation.

Nurse, NL, Case 4: Well I'm the one who connected the pumps, inserted the needles. What I found very positive by the way, was that the GP was present when connecting the pump. This is very desirable but it's actually almost never done.

Interviewer: Oh I think that is special to hear, that it wasn't, let's say, that standard that the GP stayed?

Nurse, NL, Case 4: Yes, I have said it to the GP as well, that his/her presence is very nice. For the family too, because they have been so long with the GP. It's just closing a piece of care, I think it's very neat.

In a few cases studied in Belgium and The Netherlands, the GP had started the sedation.

Interviewer: Were you actually present yourself at the start of the sedation?

GP, NL, Case 8: Yes I have been present, but I can imagine there might be situations where it'll be different, I don't know.

Interviewer: Okay, but in any case, you were present for this patient.

GP, NL, Case 8: Yes.

Nurse, NL, Case 8: The GP just gave the injection.

Interviewer: And does it always go like that, or do you as a nurse do that too?

Nurse, NL, Case 8: We do it as well, but that first injection is usually done by the doctor, yes always actually.

Monitoring of Sedation Until Death

In general, the monitoring of sedation until the patient's death was not often discussed by physicians and nurses during the interview in any of the countries. According to some GPs and nurses in all countries, this was mostly the nurse's task.

Interviewer: So obviously you're saying that the Macmillan nurses were involved ... I presume the district nurses were involved as well?

GP, UK, Case 4: Yeah, district nurses obviously. The syringe driver was being looked after by the district nurses.

Several Belgian, Dutch, and British nurses in our study talked about the responsibility that they, and colleagues with less experience with syringe drivers, experienced during sedation. A British nurse said that although they are trusted by GPs to make decisions regarding giving anticipatory medication, nurses also may struggle with the dilemma of actually administering the medication; some reported an emotional burden relating to uncertainty about whether the medication had hastened the patient's death.

Nurse no. 2, U.K., Cases 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.

Nurses perceived responsibility especially when the GP lacked sufficient knowledge and left the start up and monitoring of sedation to the nurse.

Nurse no. 1, U.K., Case 1: GPs rely on us virtually for all the information because they just don't know the patients or the families. I

wish that GPs had more education. They often do not even know how to write a prescription and we have to tell them. They tend to write up the largest doses straight away and we will say “no, I think we should start with a small dose.” They should go out and visit the patient before prescribing. Not all of them do that, and this is a big responsibility on us, especially nurses with less experience of syringe drivers. It all comes from experience.

Discussion

Our study provides insight into GPs' and nurses' views and descriptions of their collaboration, roles, and responsibilities during the decision-making process, performance, and monitoring of end-of-life sedation at home. We found that it was the GP who primarily made the final decision to use sedation in Belgium and The Netherlands, whereas in the U.K., many nurses reported that they encouraged the GP to prescribe the anticipatory medication and then decided themselves when to use the prescription for the patient. Nurses in Belgium and The Netherlands seemed to take on a relatively subordinate role compared with the U.K., where the use of sedation was more a team decision. Most nurses in all three countries reported that they had themselves performed and monitored sedation until death, often in the absence of the GP. Several nurses reported that they felt burdened by the responsibility of performing and monitoring sedation in cases where the GP was not present or lacked knowledge about sedation.

Strengths and Weaknesses

By conducting interviews with GPs and nurses in three European countries, we were able to obtain detailed, diverse, and in-depth knowledge on the collaboration between health care professionals during the practice of sedation at home. A major strength of our qualitative study is the cross-national comparison among Belgium, The Netherlands, and the U.K., which enabled us to identify and explain possible differences in the practice of sedation in these countries. Another strength is that we combined the perspectives of both GPs and nurses involved in care for the same

patient during sedation at home. This allowed us to compare how they had experienced their collaboration during this medical practice. A strength of our data analysis process is that two data analysts were involved encoding the transcripts, with input from the whole research team. Although our results cannot be generalized to the whole population of GPs and nurses because of the relatively small numbers of cases and interviews, we believe that our findings may provide new insights that may be extrapolated to similar clinical situations.

Comparison With Existing Literature

Belgian and Dutch interviewees in our study reported that it was mostly the GP who made the final decision for the use of sedation. This is in agreement with sedation guidelines that state that the GP most involved in the patient's care bears responsibility for determining the indications and the decision making for sedation.²⁻⁴ Nurses reported, however, that they were not always involved in this process by the GP. This finding is consistent with several quantitative studies that found that home care nurses are less often involved in decision making than their colleagues in institutions.^{9,16,28} Unlike institutions where physicians and nurses work within the same teams and attend daily multidisciplinary team meetings to review patient cases, the GPs and nurses at home usually work separately and do not often see one another at the patient's bedside.^{16,29,30} In contrast, we found that in the U.K., nurses reported how they encouraged the GPs to prescribe anticipatory medication and often made the decision about when to use the prescription. This proactive and leading role of nurses in decision making about the administration of anticipatory medication for symptom control has been described in other qualitative British studies.^{31,32} Nurses in the three countries reported that they initiated and monitored sedation until the patient's death, often in absence of the GP. These practices seem not to be uncommon as they are also reported in other quantitative studies among nurses on sedation at home.^{9,14} Several respondents in our study suggested that GPs often lack knowledge about the technical performance of sedation and sometimes about the dosages of medication that should be used. This is consistent with qualitative and quantitative studies

reporting that GPs perceived their own lack of knowledge and technical competence about symptom control as barriers to providing good palliative care and were less aware of the drugs used in syringe drivers.^{21,31} As GPs are confronted with patients with unbearable symptoms needing sedation less often than are specialists in a hospital, they may not have adequate knowledge about its use and its performance.^{5,33} Also, nurses may have greater experience with drugs and syringe drivers, and GPs in our study, therefore, may have left the administration of sedation to them.³⁴

Several quantitative and qualitative studies, however, have raised questions with respect to nurses' responsibilities and emotional distress when administering sedation on their own.^{9,14,31,35} In these studies, "emotional distress" was understood to mean, among other things, having ambivalent feelings, ethical dilemmas, concerns, and struggles regarding this practice.^{35,36} Our findings add to the literature that some nurses find performing sedation "burdensome" and feel responsible, especially when GPs leave its initiation and monitoring to them and lack sufficient knowledge regarding its use. Nurses said that they sometimes struggle with the dilemma of actually administering the medication and the emotional burden of wondering whether the medication has hastened the patient's death. As nurses may find it challenging to question the GP's decisions openly or to discuss their feelings, it may be possible that GPs are not always aware of the responsibility and burden perceived by nurses when complying with the GP orders.^{31,37}

Implications for Policy, Practice, and Research

We believe that open communication between GPs and nurses regarding their roles and responsibilities during the use of sedation, combined with increased multidisciplinary teamwork, may further improve this practice at home. Further in-depth research is needed on the unique roles and responsibilities of nurses regarding the decision to use sedation (in the U.K., by using the anticipatory prescriptions) and the performance and monitoring of sedation. When formulating suggestions for policy regarding the use of sedation, we suggest keeping in mind that cultural, legal, and

organizational differences may exist between countries and may affect end-of-life care.

Conclusion

Our study reveals how respondents perceived that the final decision on the use of sedation in Belgium and The Netherlands was often made by the GP, whereas in the U.K., it was often the nurse who made the decision to use an anticipatory prescription. These differences may be the result of different organizational contexts in the three countries. Furthermore, nurses in all three countries reported that they had often initiated and monitored sedation until death in absence of the GP and that they often experienced this as burdensome.

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