

# Administering anticipatory medications in end-of-life care: A qualitative study of nursing practice in the community and in nursing homes

*Palliative Medicine*  
2015, Vol. 29(1) 60–70  
© The Author(s) 2014  
Reprints and permissions:  
sagepub.co.uk/journalsPermissions.nav  
DOI: 10.1177/0269216314543042  
pmj.sagepub.com  


Eleanor Wilson<sup>1</sup>, Hazel Morbey<sup>2</sup>, Jayne Brown<sup>3</sup>, Sheila Payne<sup>2</sup>,  
Clive Seale<sup>4</sup> and Jane Seymour<sup>1</sup>

## Abstract

**Background:** In the United Kingdom, an approach to improving end-of-life care has been the introduction of ‘just in case’ or ‘anticipatory’ medications. Nurses are often responsible for deciding when to use anticipatory medications, but little is known about their experiences.

**Aim:** To examine nurses’ decisions, aims and concerns when using anticipatory medications.

**Design:** An ethnographic study in two UK regions, using observations and interviews with nurses working in community and nursing home teams ( $n = 8$ ).

**Findings:** Observations ( $n = 83$ ) and interviews ( $n = 61$ ) with community nurses. Nurses identified four ‘conditions’ that needed to be established before they implemented anticipatory medications: (1) irreversibility; (2) inability to take oral medication; (3) where the patient was able, they should consent and (4) decision had to be independent of demands or requests from patient’s relatives. By using anticipation medications, nurses sought to enable patients to be ‘comfortable and settled’ by provision of gradual relief of symptoms at the lowest dose possible. They aimed to respond quickly to needs, seeking to avoid hospital admission or medical call-out, while adhering to local prescribing policies. Worries included distinguishing between pain and agitation, balancing risks of under- and over-medication and the possibility of hastening death.

**Conclusion:** Nurses take a leading role in the administration of anticipatory medications. Nurses apply consideration and caution to the administration of anticipatory medications but some experience emotional burden. Education, training and experience played a role in the nurses’ confidence and should continue to be central to efforts to improving the quality of palliative care in the community and nursing homes.

## Keywords

Anticipatory medication, end of life, community nursing, nursing homes, decision-making, symptom management, place of death, qualitative, ‘just in case’

### What is already known about the topic?

- Community nurses have a central role in assessing dying patients’ needs for pain and symptom control and enabling their timely access to appropriate medications.
- A key element of the strategic approach to improving end-of-life care in the United Kingdom has been the introduction of ‘anticipatory prescribing’. This involves the writing of prescriptions, usually by GPs, in anticipation of them being needed by a named patient and the development of area wide systems to ensure that medications can be dispensed ‘out-of-hours’.
- Nurses often have limited knowledge and experiences with the relevant medications, lack resources and encounter power differentials between themselves and medical practitioners.

<sup>1</sup>School of Health Sciences, University of Nottingham, Queens Medical Centre, Medical School, Nottingham, UK

<sup>2</sup>Division of Health Research, Lancaster University, Lancaster, UK

<sup>3</sup>School of Nursing and Midwifery, De Montfort University, Leicester, UK

<sup>4</sup>Sociology and Communications, Brunel University, London, UK

### Corresponding author:

Eleanor Wilson, School of Health Sciences, University of Nottingham, Queens Medical Centre, Medical School, Nottingham, NG2 7UH, UK.  
Email: eleanor.wilson@nottingham.ac.uk

**What this paper adds?**

- Once medications had been correctly prescribed and dispensed, nurses identified four conditions which they perceived needed to be met before they could administer anticipatory medications: (1) symptoms that were both irreversible and due to entry into the dying phase; (2) inability to take oral medication; (3) patient consent where possible and (4) decisions made independent of influence from a patient's relatives.
- A key driver perceived by nurses was avoidance of hospital admission or medical call-out.
- Some nurses considered such decisions to be emotionally burdensome. This was a key theme among nurses with less experience, resulting in worries about distinguishing between pain and agitation and concerns about the possibility of hastening death.

**Implications for practice, theory or policy**

- Nurses require education, training and support from the multidisciplinary team to reduce the risk of emotional burden when administering anticipatory medications.
- Nurses in this study reported that establishing that a patient had entered the dying or 'end-of-life' phase was a necessary condition for their use of anticipatory medication. Whether a narrow or broader interpretation of the 'end of life' is employed in practice may restrict the use of anticipatory medications in groups of patients with uncertain prognoses, potentially leaving some with their pain and symptoms under or untreated.
- Nurses must be free to respond to individual patients' needs when making decisions relating to the use of anticipatory medications, rather than feeling the need to take into consideration policy drivers aimed at reducing 'out of hours' calls or hospital admissions.

**Introduction**

Community nurses have a central role in assessing dying patients' needs for pain and symptom control and enabling their timely access to appropriate medications.<sup>1,2</sup> A synthesis of the small body of international research<sup>3</sup> suggests that nurses often face difficulties because of limited knowledge and experience with relevant medications, lack of resources, and differentials in professional power between themselves and medical practitioners. In the United Kingdom, there has been a widespread introduction of 'anticipatory prescribing' especially in community-based palliative care. This involves general practitioners (GPs) writing prescriptions in anticipation of them being needed by a certain patient and the development of systems to ensure that medications can be dispensed 'out-of-hours'. Anticipatory medications (AMs) give considerable responsibility to

community nurses, who must make decisions about their administration,<sup>4</sup> however there is little evidence about nursing practice in this area. This article reports data from an ethnographic study involving 61 nurses working in two regions of England in community-based care, including nursing homes, with a view to addressing this gap.

**Background**

In the United Kingdom, the trend towards 'anticipatory prescribing' (see Box 1) has been actively encouraged to try to minimise the risk of patients suffering uncontrolled symptoms and distress, a key reason why terminally ill patients are admitted to hospital in contradiction of most people's preferences.<sup>8</sup>

**Box 1. What is anticipatory prescribing?**

- Anticipatory prescribing in the community is designed to 'ensure that there is a supply of drugs in the patient's home, combined with the apparatus needed to administer them, with the intention that they are available to an attending clinician for use after an appropriate clinical assessment'. (p. 1)<sup>5</sup>
- A standard anticipatory prescription would include medication to treat pain, anxiety, nausea and respiratory secretions. The specific drugs prescribed may vary according to local area.
- The Palliative Care Formulary recommends that these medications be provided in 'just in case boxes' also containing syringes and needles, local prescribing algorithms, permissions for medication use and patient information.<sup>6</sup>
- Anticipatory medications are normally administered as an 'as required' or PRN dose injected into the subcutaneous tissue, although a 'just in case box' may also include medication for rectal administration such as diazepam or lorazepam.<sup>6</sup>
- Practice guidance proposes that if a patient then requires regular doses, it is more effective and less intrusive to administer medication slowly and continuously over a 24 h period via a syringe driver pump.<sup>7</sup>
- In order to set up a syringe driver, a separate prescription is required.
- Anticipatory medications may be kept in the home to be used 'as required' for breakthrough symptoms until the medication in the syringe driver can be assessed and the dose adjusted as necessary.

A UK study of community health professionals involved in home-based palliative care identified anticipatory prescribing to be a three-stage process: (1) prescription writing, (2) dispensing and (3) administration.<sup>9</sup> In the third 'administration' stage, a nurse will commonly be the attending clinician who is responsible for deciding whether or not to administer the medications prescribed. Little is known about how nurses perceive or manage these responsibilities or what challenges they face.<sup>10,11</sup>

Existing research shows that nurses working in palliative and end-of-life care contexts including care homes often experience stress, sometimes reporting a lack of confidence in and knowledge about managing pain and controlling symptoms in spite of their significant responsibilities in this area of patient care.<sup>1,12,13</sup> In addition, nurses sometimes feel they have too much responsibility without the necessary professional status or power to execute this effectively.<sup>3</sup> International community-based research shows that nurses sometimes perceive that GPs lack experience and expertise in care of the dying.<sup>14-16</sup> Research in care homes has shown a lack of collaboration and communication between care home staff and GPs about patient care,<sup>13,17</sup> which impedes the quality of end-of-life care.

Authors of many studies recognise the need for proactive care planning at the end of life<sup>14,15,18</sup> supporting the aims of anticipatory prescribing to respond to symptoms promptly and prevent hospital admissions that are unwanted by patients.<sup>19</sup> However, until now, the evidence base has primarily been descriptive reports of localised pilots,<sup>20</sup> audits<sup>21-23</sup> or guidance and feasibility of use studies.<sup>24,25</sup>

This study examined community and nursing home nurses' decisions to administer medications prescribed and dispensed in anticipation of anxiety, delirium and other difficult symptoms patients may experience at the end of life. In this article, we report the conditions that nurses identified were necessary before they used AMs, their aims in using these and what concerns they expressed about this area of practice.

## Methods

### Study design

The larger study from which this article is drawn comprised an ethnography of community nursing practice in two areas of England and a survey of community nurses in the same localities. In this article, we report findings from the ethnography. Ethnography demands that the researcher becomes involved in the daily activities of the particular group under study (in this case, community nurses). The researcher then records, according to specified research objectives, aspects of the group's work and experiences in a detailed way, before making analytical interpretations that allow consideration of the broader implications.<sup>26</sup>

### Setting

The study took place in two regions in England. The first, Lancaster and South Cumbria, covered a large semi-rural area serving a largely dispersed population. The second, the Midlands, was a socio-demographically varied area with a dense and varied population in urban districts, as well as a more dispersed population in rural areas. In each of the two geographic areas, two community nursing teams, involving district nurses and specialist palliative care nurses, and two care homes for older people registered to provide nursing care (i.e. nursing homes) were invited to take part using a convenience sampling approach. We employed a recruitment approach used successfully in a previous study of end-of-life care in care homes,<sup>17</sup> namely, working with key local end-of-life care stakeholders to publicise the study, identify potentially participating sites and then invite participation via the team leader or care home senior nurse.

### Participants

Study participants included registered nurses providing end-of-life care in each of the study sites, GPs responsible for anticipatory prescribing and community pharmacists responsible for dispensing. At the majority of sites, we continued to recruit study participants until data saturation for each site was achieved. At one nursing home site, this was not possible within the time constraints of the study. This article reports the findings from interviews and observations with nurses.

### Data collection

Data collection took place between December 2011 and May 2012 and was conducted by two researchers (E.W. and H.M.).

### Observations

Approximately 4 weeks was spent with each nursing team and in each nursing home to observe incidences of when prescriptions were written in advance of symptoms, as well as how, when and in what circumstances the prescriptions were activated (for example, see Box 2). Each staff member gave written consent at the start of their involvement in the study, and verbal consent was gained from those in the field of observation at any particular time. Patients and their family carers were provided with information about the study and asked to verbally consent to or 'opt out' of aspects of their care being included in the observations. A record of this decision was placed in the patient's notes. These observations allowed the study team to understand how the process of prescribing and using AMs unfolded in situ. The resultant data provided important contextual information for the subsequent

**Box 2.** Examples of observations.

Shadowing nursing staff involved in prescription decisions by attending

- Home visits;
- Meetings relating to prescribing;
- Drug rounds;
- Discussions between staff about patient care, including communication with family carers.

No intimate nursing care was observed.

qualitative interviews, helped to guide the interview process and enabled data triangulation.

**Interviews**

Nurses were invited to take part in interviews both to complement the observational data and to gain their perceptions of the practical, organisational, ethical and communication issues they experienced. The aim was to recruit, at each site, up to 15 participants for interview from a range of professionals, with particular focus on nurses. At each site, this was achieved, apart from one nursing home where AMs were not used during the study period. We chose to include specialist palliative care nurses in the study, as well as non-specialist community and nursing home nurses since we

were aware that specialist palliative care nurses often took the lead in supporting community and nursing home nurses, as well as GPs, in the use of AMs. Sampling was dependent upon who was involved in writing, dispensing and using AMs at the study sites. We used a flexible interview schedule, adapted on the basis of the observations and informed by a literature review. Box 3 shows the aide-memoire employed. Interviews took place at the participant's place of work and lasted between 10 min and 2 h. In addition to single interviews, six small group interviews were held: four with two nurses, one with three nurses and one with six nurses. Two interviews were conducted over the telephone with nurses working out-of-hours for the convenience of the participants. Of the 61 nurses interviewed, 5 were interviewed twice as directed by observations.

**Box 3.** Overview of interview aide-memoire.

- Just to get started, can you tell me a bit about your role and your work with the community/nursing home team?
  - What does your work involve on a daily basis?
  - How long have you work in this field?
  - How long have you worked with this team?
- As you know, in this project we are interested in anticipatory prescribing for patients receiving end-of-life care. When you think of this issue, what comes to mind for you?
- Can you tell me about your role in (making, dispensing or using) anticipatory prescriptions?
- Do you feel you have enough knowledge of anticipatory prescribing?
- I would like you to try to recall a patient with whom you were involved who needed anticipatory prescriptions
  - Can you tell me how you worked with other professionals involved in that person's care?
  - Were there any other non-professionals involved?
  - Did you face any difficulties or challenges in the care of this patient? (and follow up more generally)
  - What worked well?
  - Is there anything that you would have liked to see done differently? (and follow up more generally)
- Thinking more generally, and from your experience, how does medication management affect the quality of end-of-life care that patients receive? (follow up on any issues about place of care)
- Are there any things that you thought we would talk about that we have not covered?

**Data recording and analysis**

Hand written field notes were used to record observations. Field notes were typed up and anonymised. Interviews were digitally recorded and transcribed verbatim. A preliminary coding framework was developed through discussion at project meetings and on the basis of a preliminary literature review.<sup>3</sup> This was adapted as data collection proceeded. Each data source was coded by E.W. and J.S. separately. Codes were then compared and discussed in order

to group into themes and then further distilled into categories. The validity of the categories was checked with clinical project advisors and an expert stakeholder group.

**Findings**

Across the eight study sites, 83 episodes of observation were conducted and interviews undertaken with 61 nursing participants (see Table 1). Table 2 provides a breakdown of the nurse participants by their professional role.

In this study, Specialist Palliative Care Nurses were defined as nurses who had received additional training in palliative care (see Box 4).

Three overarching themes emerged from the data: (1) conditions that must be met before nurses would administer AMs; (2) what nurses aimed to achieve by using the medication; and (3) nurses' concerns about use. These themes and sub-themes are summarised in Table 3.

### *Necessary conditions identified by nurses in order to administer AM*

Nurses identified four conditions, all of which needed to be met before they felt able to administer the medication:

**Table 1.** Breakdown of data collection from nurses per site.

Site	Interviews	Observations
The Midlands	38	42
• Community nursing teams × 2	23	14
• Care home teams × 2	15	28
Lancaster and Cumbria	23	41
• Community nursing teams × 2	19	29
• Care home teams × 2	4	12
Total	61	83

**Table 2.** Number of interviews with nurses by professional group.

Professions	Interviews conducted
Nursing home nurses	16
District/community nurses	27
Specialist palliative care nurses	18
Total	61

### **Box 4.** Types of community nurse in the United Kingdom.

*Community nurses* – for the purposes of this article, this includes those qualified as district nurses.

*Nursing home nurses* – qualified nurses working in care home environments registered to provide nursing care.

*Specialist palliative care nurses* – those working at a Band 6 or 7\* level with additional training in palliative care. These may include

Clinical Nurse Specialists – these nurses provide advice and support to patients and families as well as having expertise in the management of symptoms. They may be assigned to work in patients' homes or directly with care homes.

Macmillan Nurses – some specialist palliative care nurses are badged under the brand of 'Macmillan Cancer Support', a national cancer charity. These nurses focus on providing advice for the management of complex symptoms and/or psychological distress.

Advanced Nurse Practitioners – those participating in this study were based with general practitioner (GP) practices and had advanced training and prescribing skills. Their focus is on identifying indicators of comorbidities by undertaking basic medical tasks. They often liaise with care homes to try to manage patients' symptoms proactively.

\*In the United Kingdom, qualified nurses start at Band 5 and go up to Band 8. Nurses at Band 6 have advanced training, skills and experience; those at Band 7 have managerial roles in addition. For further information, see <http://www.nhs.uk/explore-by-career/nursing/pay-for-nurses/>

For information about advanced nurse practitioners, see [http://www.rcn.org.uk/\\_data/assets/pdf\\_file/0003/146478/003207.pdf](http://www.rcn.org.uk/_data/assets/pdf_file/0003/146478/003207.pdf)

symptoms that were both irreversible and due to entry into the dying phase; inability to take oral medication; patient consent where possible and decisions made independent of influence from a patient's relatives. These are discussed in turn below.

First, nurses described how they needed to be satisfied that the patient had irreversible symptoms due to the dying phase:

97 year old woman, lives with daughter ... had a call from daughter to say patient had fallen out of bed and taken to A&E. Patient returned home. Request from daughter for [community nurses] to visit to give her mother something for pain. Nurse R visited but asked for a GP review of pain medication because she did not feel it was appropriate to use one of the [anticipatory] drugs in these circumstances – it was not why they had been prescribed and was not an end of life care need. (Observation field notes of community nurse team, 1 March 2012)

Second, given that AMs were usually injectable drugs for subcutaneous use, nurses reported that they needed to be satisfied that the patient was unable to take oral medication. Third, nurses needed to be sure, where patients were alert and competent, that they consented to being given the medication. In the extract from observational field notes below, the patient's wife had asked the nurse to go to see her husband as he had been struggling to take his oral medication and appeared uncomfortable. When the nurse arrived, she assessed the patient and identified that he was in pain, with increasing anxiety. The nurse contacted a colleague for assistance and together they reassessed the patient. They determined that he would benefit from the use of the AMs he had in place and then sought his consent to administer these to him:

Nurse B says 'We have something that can make you less anxious, we can give you a little dose of something for the pain and something to help you settle'. [Patient] says 'Whatever

**Table 3.** Summary of presented themes.

Theme	Sub-theme
Necessary conditions identified by nurses in order to administer AMs	<ul style="list-style-type: none"> <li>• Irreversible symptoms due to the dying phase</li> <li>• Inability to take oral medication</li> <li>• Where possible gain the patients' consent</li> </ul>
Nurses' aims in using AMs	<ul style="list-style-type: none"> <li>• Decisions are independent of demands or requests from relatives</li> <li>• Comfort and settle</li> <li>• Prevent transfers to hospital and avoid medical call-out</li> <li>• Start at the lowest dose and work within guidelines</li> </ul>
Nurses' concerns when using AMs	<ul style="list-style-type: none"> <li>• Using the most appropriate drug for the presenting symptom</li> <li>• Used at the most appropriate time</li> <li>• Under medicating</li> <li>• Over medicating</li> <li>• Hastening death</li> </ul>

AM: anticipatory medications.

you think is best' Nurse B says 'No it is only if you want it'. [Patient] says 'If I am comfortable in the bed then I am ok'. ... Nurse B explains (to the researcher) that Nurse D has assessed him and identified [additional] pain and agitation; they have now reassessed him together and get his consent to give him morphine and midazolam. (Observation field notes of a home visit with community nurses, 10 May 2012)

The extract above also illustrates the fourth condition that any decision taken by nurses to administer medications had to be independent of an instruction or request from the patient's relatives. Nurses acknowledged that although relatives often provided the majority of personal care to patients and had considerable insight into their needs, they took great care not to be 'unduly' swayed by relatives' judgements or requests:

I'll say to the family do you mind just going in the other room so I can assess Mr so and so, because they greet you at the door say he's in pain, he's in pain and it's very easy to have that autosuggestion and [then] you're rushing and give them a big injection of diamorphine when actually he just needs a pee or something ... [so] go and spend some time with the patient first and find out what's going on, rather than just rushing and give an injection because the family are demanding on it, because I mean it is big pressure really and you've got to be confident enough to do that. (Specialist palliative care nurse, 23 February 2012)

Nurses reported that what enabled them to establish whether these four conditions were in place was reflection on their prior experience and training, as well as knowledge or familiarity with the particular patient and knowledge of the patient's condition.

### *Nurses' aims in using AMs*

The predominant aim expressed by nurses when using AMs was to 'comfort' and 'settle' dying patients:

It just settled her well ... she'd been quite agitated, [her son] had gone out because he got upset, and then we gave her the injection and when he came back in she was just sleeping really peacefully. (Nursing home nurse, 1 February 2012)

... I just want them to be comfortable ... because if they're getting to that stage where they're dying, it's all about comfort, that's what we're trying to be there for. (Community nurse, 13 March 2012)

Another key aim was to enable management of symptoms in the patient's home or care home to prevent patients' transfer to hospital. In addition, nurses felt that AMs meant they often were able to avoid calling 'out-of-hours' doctors whom they perceived were highly likely to admit patients to hospital:

[for example] today, we've been able to, instead of having to phone someone, we've got medication here, we can use what we've got, ... before having to call out a doctor to say this is happening or, God forbid, having to send someone in to hospital who is end of life ... and I mean that is one of our fears, sending someone in [to hospital] who doesn't [want to go]. There's nothing they can do in hospital that we can't do, and then having them pass away on a trolley in a busy A&E department ... that's not the type of environment the families want. (Nursing home nurse, 9 December 2011)

A third aim described by nurses in the use of AMs was to start at the lowest prescribed dose and work within local and national guidance; this was described as doing it 'by the book'. At some sites, drug doses were prescribed within a narrow range allowing nurses some discretion. All nurses reported they would always start with the lowest dose, but that a range allowed them to increase the dose if necessary without calling the GP. However, not all were comfortable with using a range, with some seeing this as a difficult additional responsibility. Nurses expressed particular caution with those patients considered to be 'opiate naïve' or frail:

Interviewer: So your stance is to err on the side of caution?

Nurse: *Side of caution yeah, it's not always the answer when somebody's needing relief from something, but I do think people absorb obviously drugs at a different rate, and it's no good bombarding them. It's better to give a small dose and then go back a bit later and you can always give them another small dose and just see. (Community nurse, 20 April 2012)*

Observational data showed how time was spent checking the prescriptions and preparing the necessary drugs. Nurses often worked in pairs to make additional checks and provide support during decision-making:

Nurse B and Nurse Y check the notes and look for the grey box under the bed ... They agree to give 5 mg of Midazolam and 10 mg of Morphine Sulphate. ... Nurse B explains to the patient: 'the reason we are talking to each other is that we have to check everything'. They check the dates on the vials, and write on the lilac form. ... Both nurses sign the administration sheet. They both check the dosage in the syringe. ... They check the dose again with each other and give the midazolam first ... then the morphine. ... Nurse B then checks the left over vials and puts them in the sharps bin. Nurse B checks he has enough [medication] for the weekend. (Observation field notes, visit to patient's home, 10 May 2012)

### Nurses' concerns when using AMs

Administering the medication raised a number of concerns for nurses. First, they were keen to distinguish between pain and agitation so as to administer the most appropriate drug but sometimes found this difficult:

It is a bit of a grey area, and you just have to use your clinical judgement. It depends on how well you know the patient and how they've been before, because you might have seen them in lots of pain but now they're trying to climb out of bed and don't know what they're doing, in which case you put that down to agitation as well. I think, anecdotally, I've got no proof of this, but I think people would normally start on morphine and then add something a bit more sedating afterwards, just to see if it's just the pain ... (Community nurse, 13 March 2012)

In addition, nurses were keen to ensure AMs were used at the most appropriate time. AMs were welcomed because they offered nurses the opportunity to provide timely relief to a dying patient. However, some nurses expressed concerns about using the prescribed medications 'too soon', that is, prior to recognising the patient as entering the dying phase:

It is up to us to know when to administer them. ...

Interviewer: is there a point when it is a difficult decision?

I do think sometimes, because you do just question is it the right time? You know, although you know they're in pain, are they in pain because this is it? Or have they just got a pain? And I think you have to differentiate. I think from experience you do know when. (Nursing home nurse, 12 December 2011)

Third, nurses noted that on some occasions starting at the lowest dose meant that it could take time to manage the patient's symptoms; community nurses in particular were concerned about leaving patients under medicated:

I do sometimes worry about decisions that I've made and run through over in my head after I've made the decisions, which I suppose is only natural really. ... Really it is not giving something when I should have done and having somebody in pain or in distress and I could have done something about it. So it's probably that I find more fearful if that's the right word [than over medicating someone]. (Community nurse, 17 February 2012)

Despite all participants stating that they would always start on the lowest prescribed dose of the medication, some raised a fourth area of concern about *over* medicating patients and this resulting in unwanted side effects:

We don't want to give them stuff that's going to knock them out, we want to give them stuff to control the symptoms, and there's a fine line between the symptoms and completely sedating them. ... And I know nurses worry about that, about giving that last injection and families accusing them. ... because [the nurse] rang me and she said oh god he's gone really sleepy, we've given him some Midazolam. And I was just trying to reassure her really because it was a small dose, he was obviously really angst and uptight, you don't want to see anybody like that. You see the other thing was he could have been exhausted from being in that state, so it could have had nothing to do with the Midazolam, it might have just relaxed him and at the end of the day these are small doses ... (Community nurse, 14 May 2012)

In some instances, nurses recalled and echoed relatives' concerns that if patients were sedated they would be unable to take oral hydration or nutrition, thus potentially hastening death. In addition, some expressed concerns about whether medication to control pain and symptoms hastened death. This worry was particularly associated with opioids and tended to be expressed by nurses who had less experience and training:

Diamorphine, because whenever they get it you think they're not going to be here much longer now, now they've had that. So I think now I think I don't want to give them too much because am I hastening things. It's quite scary but you're on

your own when you're making those decisions. (Nursing home nurse, 12 December 2011)

Some nurses, with a variable range of experience, recognised the continued influence of the infamous Shipman case<sup>27</sup> not only on their own perceptions of morphine but also on those of prescribing GPs, other nurses and the public:

Well part of confidence and experience as well and the ripples of Shipman go very, very deep. ... some people are very anxious or do have anxieties about giving them to very poorly patients. (Specialist palliative care nurse, 10 May 2012)

Nurses reported that their emotional burden in this area of practice was likely to be diminished by experience of working autonomously and/or higher levels of training. Where possible, nurses reported working in pairs or liaising with a team to gain support from colleagues and talk through decisions. Nurses generally sought support from other nursing colleagues and rarely mentioned contacting GPs other than to inform them that medication had been given or to request further prescriptions. However, all were aware of sources of specialist palliative care support such as Macmillan nurses, the local hospice or a palliative care consultant, and they all reported that they would call for advice if needed. However, the pace of the working environment, especially for community nurses, meant that there was little time to reflect on decisions made 'in the field' and made at some speed. This added to the feeling of burden that some nurses expressed as the following observational notes captures:

Seemingly not a moment for reflection on the circumstances and events around dying patients, or as on my visit last week, when a patient had died. Maybe this happens in a different setting, but my general impression is that this is the pace of work for them all, *all* of the time – weekdays and weekends. Is this the pace at which nurses consider and make decisions about AM? (Observation field notes, visit to community nursing team, 6 December 2011)

## Discussion

The study reported here sheds detailed light on community and nursing home nurses' experiences and roles in the use of AMs prescribed to relieve symptoms and distress at the end of life. This study builds on the research by Faull et al.<sup>5</sup> who described anticipatory prescribing as a process from prescription writing, to dispensing and administration. We have highlighted the necessary conditions identified by nurses for them to administer AMs, what they sought to achieve by the use of the medication and the concerns and challenges they encountered.

Nurses identified four 'conditions' that needed to be established before they would administer AMs: symptoms

needed to be irreversible and due to entry into the dying phase; the patient should be unable to take oral medication to relieve the symptoms; where able, patient consent should be sought; finally, the decisions to administer medications from an anticipatory prescription needed to be made independent of demands or request from patient's relatives. By administering the AMs, nurses sought to enable patients to be 'comfortable' and 'settled' by provision of relief of symptoms. They aimed to respond quickly to needs, seeking to avoid hospital admission or medical call-out. In addition, nurses endeavoured to adhere to local prescribing policies and guidelines by starting at the lowest dose and supporting colleagues through the processes of 'double checking'. Concerns were raised about distinguishing between pain and agitation, balancing risks of under- and over-medication and the possibility of hastening death.

In general, nurses working in community teams and in nursing homes in both regions had similar views about the use of AMs. The key differences related to their levels of experience and the availability of peer support. Those working in patients' own homes had the support of large community nursing teams and reported being able to work in pairs to support junior staff. For nurses working in nursing homes, high staff turnover<sup>28</sup> and the presence of only one or two qualified nurses on each shift meant that they lacked support, as well as confidence and experience in using AMs. The specialist palliative care nurses in the study often acted in an advisory and supportive role for those community and nursing home nurses who needed to use AMs.

Nurses in this study relied on their clinical skills and knowledge of the patient to assess the need to use AMs.<sup>11</sup> Our findings echo those of Eisenhauer et al.<sup>10</sup> in a study of nurses' critical thinking in relation to drug administration in North American hospitals. These authors suggest that although administration of medication can appear to be a 'technical task', it entails considerable complex decision-making skills and needs to be underpinned by sound knowledge to prevent harm and achieve good outcomes for patients. The complexity of this multifaceted aspect of nursing is intensified when nurses are working autonomously and in relative isolation from medical support available in acute settings.

In accounts reported here, some nurses advocated the use of prescriptions that allowed drugs to be administered within a small range. Yet many did not want or feel it was appropriate for them to have decision-making responsibilities about dose ranges. Some considered such decisions to be emotionally burdensome, especially those with less training and experience. A number of other UK studies have illustrated the emotional strain felt by district nurses providing palliative and end-of-life care. This burden can be heightened by communication issues, limited knowledge, experience of some conditions, a lack of support and



time pressures.<sup>1,12,15,29-31</sup> Nurses working in care homes can often face similar barriers to providing good quality end-of-life care.<sup>13,17,32</sup> There is now increasing evidence that symptoms are often undertreated, especially in older patients and in those with conditions other than cancer.<sup>33</sup> The effects of the murders committed by Shipman continue to influence public and professional attitudes.<sup>15,34,35</sup>

In this study, experience of dealing with dying patients, as well as having a clear understanding of the medications and their side effects, was considered by participating nurses to increase their confidence in administering medications. This echoes McIlfattrick and Curran's<sup>31</sup> observations of district nurses' educational needs relating to the management of pain and symptoms, disease progression and drug therapies. Those in this study who reported working autonomously, such as those attached to 'out-of-hours' nursing teams, perceived themselves to be more confident than those with less experience; the latter tended to be nurses working in nursing homes where the use of AMs was a more recent phenomena.

Once AMs had been prescribed and were in place, most nurses reported that they perceived little need to contact the GP before initiating their use. AMs were welcomed because they offered nurses the opportunity to provide timely relief to a dying patient without the need for GP call-out. Nurses with little experience and clinical support who were involved in the use of AMs, such as those in nursing homes, reported greater readiness to contact the GP or sought support from specialist palliative care nurses.

### *Implications for practice*

Findings from this study point to four central recommendations for practice.

**Level of decision-making.** Nurses applied consideration and caution to the assessment of patients and making decisions to administer AMs, with the expressed aim of relieving symptoms and distress. It is important that the responsibility of such decisions be recognised by those providing and dispensing prescriptions in order for nurses to feel supported in the decisions that they make.

**Multidisciplinary team (MDT) support and communication.** Throughout this study, nurses reported working in pairs or liaising with colleagues during the decision-making and administration process. It was clear that the weight of the decision whether or not to give AM, and the subsequent complexities of making sure the administration of the drug was correct, resulted in emotional burden for some nurses. Education, training and experience played a role in the nurses' confidence and therefore should continue to be central to the provision of quality palliative care. Clear access to, and good communication with,

nursing colleagues/managers, GPs, disease-specific and specialist palliative care services should be encouraged in order to sustain multidisciplinary relationships and sources of advice and support.

**Policy versus clinical assessment.** Nurses respected the serious nature of using AMs and wanted to make sure that they not only did what was best for the patient but also complied with local guidance and national regulations.<sup>5,6,24</sup> Concerns were expressed by some nurses about the possible under medication of patients' symptoms due to the limited doses of drugs being prescribed and adherence to the recommendations to always start at the lowest dose. In addition, a policy emphasis on preventing medical call-out may also have contributed to nurses continuing with inappropriate doses to control symptoms rather than contacting a doctor to increase the dose when the doses prescribed had not been effective. It is therefore essential that nurses are free to respond to the patients' needs as they present rather than making decisions based on perceived policy drivers.

**Examining the 'end-of-life' label.** Nurses in this study cited establishing that a patient had entered the dying or 'end-of-life' phase was a necessary condition for their use of AM. However, both nurses and other health professionals are challenged by prognostication, particularly for conditions with uncertain trajectories of decline such as heart failure, chronic obstructive pulmonary disease (COPD) or frailty. Nor is there consensus about what the 'end-of-life' phase means and whether or not it is narrowly confined to dying. Faull et al.<sup>36</sup> define the 'end of life' as 'a focus on the last 6-12 months of life' (p. 3). Whether a narrow or broader interpretation of the 'end of life' is employed in practice may restrict the use of AMs in groups of patients with uncertain prognoses, potentially leaving some with their pain and symptoms under or untreated.

### *Limitations*

This article has presented findings from interviews and observations with nurses. We used a convenience sampling approach, potentially limiting the generalisability of the findings. GPs and pharmacists were also included in the study, and both play a key role in anticipatory prescribing. These data are presented elsewhere. Patients and relatives were not included in this study, so we cannot be sure how they felt their contributions were perceived when decisions were made to administer AMs or how they viewed nursing practice in this area. However, a strength of our approach was the provision of data on the views and opinions of nurses who used AMs, alongside complementary observational data on the processes of decision-making and associated discussions that took place when the medications were administered.

## Declaration of conflicting interests

The authors declare that there is no conflict of interest.

## Funding

This work was supported by Marie Curie Cancer Care (C30627/A12557).

## References

- Burt J, Shipman C, Addington-Hall J, et al. Nursing the dying within a generalist caseload: a focus group study of district nurses. *Int J Nurs Stud* 2008; 45(10): 1470–1478.
- King N, Melvin J, Ashby J, et al. Community palliative care: role perception. *Br J Community Nurs* 2009; 15: 91–98.
- Wilson E and Seymour J. Understanding the role of nurses in the management of symptoms and distress in the last days of life. In: Sterckx S, Raus K and Mortimer F (eds) *Continuous sedation at the end of life*. Cambridge: Cambridge University Press, 2013, pp. 100–115.
- Department of Health. *Delivering the out-of-hours review: securing proper access to medicines in the out-of-hours period*. London: Department of Health, 2004.
- British Medical Association. *Focus on anticipatory prescribing for end of life care*. GPC Guidance. April 2012. British Medical Association, <http://bma.org.uk/practical-support-at-work/gp-practices/prescribing/focus-on-anticipatory-prescribing-for-end-of-life-care>
- Wilcock A. *Pre-emptive prescribing in the community*. In: Palliative Care Formulary (PCF4). 2011, <http://www.palliativedrugs.com/SamplePDF/PCF4/Chapter17.pdf>; Palliativedrugs.com
- Dickman A, Schneider J and A Varga. *The syringe driver: continuous subcutaneous infusions in palliative care*. Oxford, Oxford University Press, 2005.
- National Audit Office. *End of life care*. London: The Stationary Office, 2008, <http://www.nao.org.uk/report/end-of-life-care/>
- Faull C, Windridge K, Ockleford E, et al. Anticipatory prescribing in terminal care at home: what challenges do community health professionals encounter? *BMJ Support Palliat Care* 2013; 3: 91–97.
- Eisenhauer LA, Hurley AC and Dolan N. Nurses' reported thinking during medication administration. *J Nurs Scholarsh* 2007; 39(1): 82–87.
- Bliss J and While A. Decision-making in palliative and continuing care in the community: an analysis of the published literature with reference to the context of UK care provision. *Int J Nurs Stud* 2003; 40(8): 881–888.
- Dunne K, Sullivan K and Kernohan G. Palliative care for patients with cancer: district nurses' experiences. *J Adv Nurs* 2005; 50(4): 372–380.
- Watson J, Hockley J and Dewar B. Barriers to implementing an integrated care pathway for the last days of life in nursing homes. *Int J Palliat Nurs* 2006; 12(5): 234–240.
- Enes SP and de Vries K. A survey of ethical issues experienced by nurses caring for terminally ill elderly people. *Nurs Ethics* 2004; 11(2): 150–164.
- Griggs C. Community nurses' perceptions of a good death: a qualitative exploratory study. *Int J Palliat Nurs* 2010; 16(3): 140–149.
- Karlsson M, Roxberg A and Berggren I. Community nurses' experiences of ethical dilemmas in palliative care: a Swedish study. *Int J Palliat Nurs* 2010; 16(5): 224–231.
- Seymour J, Kumar A and Froggatt K. Do nursing homes for older people have the support they need to provide end-of-life care? A mixed methods enquiry in England. *Palliat Med* 2011; 25(2): 125–138.
- Cruickshank S, Adamson E, Logan J, et al. Using syringe drivers in palliative care within a rural, community setting: capturing the whole experience. *Int J Palliat Nurs* 2010; 16(3): 126–132.
- Lawton S, Denholm M, Macaulay L, et al. Timely symptom management at end of life using 'just in case' boxes. *Br J Community Nurs* 2012; 17(4): 182–183.
- Amass C and Allen M. How a 'just in care' approach can improve out-of-hours palliative care. *Pharm J* 2005; 275(7356): 22–23.
- Carney J. *Analysis of 'just in care' anticipatory audit forms 1st December 2010–28th February 2011*. Report, May 2011. Inverness: Palliative Care Network and NHS Highland.
- Carney J and MacRobbie A. *Analysis of 'Just in Case' anticipatory prescribing pilot*. Report, June 2008. Inverness: Palliative Care Network and NHS Highland, [http://www.palliativedrugs.com/download/091119\\_AnticipatoryPrescribingJune\\_2008.pdf](http://www.palliativedrugs.com/download/091119_AnticipatoryPrescribingJune_2008.pdf)
- Westwood D, Bagshaw K, Curtis C, et al. Audit of the use of 'just in case' boxes as part of a local enhanced service agreement for end of life care. In: *BMJ Supportive and Palliative Care*, 14–16 March 2012, poster no. 174, Suppl. 1, pp. A72–A73. Gateshead: The Palliative Care Congress.
- Kinley J, Stone L and Hockley J. Anticipatory end-of-life care medication for the symptoms of terminal restlessness, pain and excessive secretions in frail older people in care homes. *End Life J* 2013; 3(3).
- Scott-Aiton A. Creating a tool to improve anticipatory prescribing in palliative care. *Pharm J* 2009; 283(7569): 283–284.
- Seymour J. Ethnography. In: Addington-Hall J, Bruera E, Higginson I, et al. (eds) *Research methods in palliative care*. Oxford: Oxford University Press, 2007, pp. 211–228.
- The Shipman Inquiry. *Sixth report – Shipman: the final report*. 2005. Norwich: Corwn Copyright, <http://webarchive.nationalarchives.gov.uk/20050129173447/the-shipman-inquiry.org.uk/finalreport.asp>
- Tilden V, Thompson SA, Gajewski BJ, et al. End-of-life care in nursing homes: the high cost of staff turnover. *Nurs Econ* 2012; 30(3): 163–166.
- Hatcliffe S, Smith P and Daw R. District nurses' perceptions of palliative care at home. *Nurs Times* 1996; 92(41): 36–37.
- Wilkes L, Beale B, Hall E, et al. Community nurses' descriptions of stress when caring in the home. *Int J Palliat Nurs* 1998; 4(1): 14–20.
- Mellifratric S and Curran CI. District nurses' perceptions of palliative care services: part 2. *Int J Palliat Nurs* 2000; 6(1): 32–38.
- Dobie J. Palliative care provision for older people in care homes. *Br J Community Nurs* 2010; 15(4): 170–176.
- Prommer E and Fickel B. Management of pain in the elderly at the end of life. *Drugs Aging* 2012; 29(4): 285–305.

34. Gardiner C, Gott M, Ingleton C, et al. Attitudes of health care professionals to opioid prescribing in end-of-life care: a qualitative focus group study. *J Pain Symptom Manage* 2012; 44(2): 206–214.
35. McClelland B, Ashton S, Roe B, et al. *End of life care: an evaluation of the implementation of the Gold Standards Framework and The Liverpool Care Pathway for people with dementia in five care settings across Greater Manchester* (Evaluation Report). Liverpool: Liverpool John Moores University, NHS North West and Edge Hill University, 2008.
36. Faull C, de Caestecker S, Nicholson A, et al. *The handbook of palliative care*. 3rd ed. Hoboken, NJ: John Wiley & Sons, 2012.