

## QUALITATIVE PAPER

# Simultaneously reassuring and unsettling: a longitudinal qualitative study of community anticipatory medication prescribing for older patients

BEN BOWERS<sup>1</sup>, KRISTIAN POLLOCK<sup>2</sup>, STEPHEN BARCLAY<sup>1</sup>

<sup>1</sup>Palliative & End of Life Care Group in Cambridge (PELiCAM), Primary Care Unit, Department of Public Health and Primary Care, University of Cambridge, Cambridge CB2 0SR, UK

<sup>2</sup>Nottingham Centre for the Advancement of Research into Supportive, Palliative and End of Life Care, School of Health Sciences, University of Nottingham, Nottingham NG8 1BB, UK

Address correspondence to: Ben Bowers, Primary Care Unit, Department of Public Health and Primary Care, University of Cambridge, East Forvie Building, Robinson Way, Cambridge CB2 0SR, UK. Tel: +44 1223 763082.

E-mail: [bb527@medschl.cam.ac.uk](mailto:bb527@medschl.cam.ac.uk)

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## Abstract

**Background:** The prescription of injectable anticipatory medications is widely accepted by clinicians to be key in facilitating effective last-days-of-life symptom control. Community end-of-life care and admission avoidance is particularly strongly advocated for older patients. However, patient and informal caregiver views and experiences of anticipatory medication have been little studied to date.

**Objective:** To understand older patients', informal caregivers' and clinicians' views and experiences of the prescribing and use of anticipatory medications.

**Design:** Qualitative study.

**Setting:** Patients' homes and residential care homes.

**Participants:** Purposive sample of six older patients, nine informal caregivers and six clinicians.

**Methods:** Multi-perspective, longitudinal interview study based on 11 patient cases. Semi-structured interviews ( $n = 28$ ) were analysed thematically.

**Results:** Three themes were identified: (i) living in the present whilst making plans: anticipatory medications were used by clinicians as a practical tool in planning for uncertainty, while patients and informal caregivers tried to concentrate on living in the present; (ii) anticipation of dying: it was rare for patients and informal caregivers to discuss explicitly the process and experience of dying with clinicians; and (iii) accessing timely care: the use of anticipatory medications generally helped symptom control. However, informal caregivers reported difficulties in persuading nurses to administer them to patients.

**Conclusions:** Anticipatory medications are simultaneously reassuring and a source of unease to older patients and their informal caregivers. Prescriptions need careful discussion and tailoring to their preferences and experience. Nurses' decisions to administer medication should consider informal caregivers' insights into patient distress, especially when patients can no longer communicate their needs.

**Keywords:** anticipatory prescribing, home palliative care, decision-making, end-of-life care, qualitative methods, older people

## Key Points

- Older patients and their informal caregivers recalled variable and often vague conversations with clinicians about dying and the role of anticipatory medication.
- Anticipatory prescribing is a nuanced complex intervention, which needs tailored and honest discussion.
- The medications may also be a source of concern and distress, especially when they are not used in a timely fashion.

- Informal caregivers carry out considerable hidden work to ensure anticipatory medications are given when needed.
- Research is needed to understand how decisions to use medications can be made more inclusive.

## Introduction

Poorly controlled symptoms in the last days of life can cause considerable distress for older patients, their families and clinicians [1–5]. The prescription of injectable end-of-life anticipatory medications ahead of possible need has become established as good practice internationally as a means of controlling distressing symptoms for patients dying in the community [6–9]. This practice is based primarily on the widespread belief amongst clinicians that the presence of anticipatory medications in the home reassures everyone involved, aids timely symptom relief and helps prevent crisis hospital admissions [3, 6, 7, 10–12]. Injectable medications are typically prescribed to a named patient for five common symptoms: pain, breathlessness, nausea and vomiting, agitation and noisy respiratory tract secretions [6, 13]. Table 1 details the anticipatory medications that are usually prescribed in the UK for these symptoms. Once these are issued and a prescription and administration authorisation chart completed, permission has been granted for visiting nurses, paramedics and general practitioners (GPs) to use the medications based on their clinical assessment that the person is dying and needs them for symptom management.

There is considerable variation in when anticipatory medications are prescribed in advance of death and how often they are used. They can be prescribed weeks or even months before death, including on discharge from hospital [5, 12, 13, 16, 17]. A recent UK study found that anticipatory medications were prescribed for 51% of dying patients at home or in residential care homes [13]. Prescriptions appear to be less commonplace in other countries [8, 9, 17]. Visiting clinicians often report struggling with decisions to use anticipatory medications and nurses are conscious of the need to balance the achievement of effective symptom control with the avoidance of oversedation [9, 10, 12].

There is inadequate evidence about the impact of anticipatory medications on patient comfort, safety and experiences of care [7, 11, 18]. Only one published study has investigated the views of patients about the prescription of these medications; this was perceived to be a significant event, signifying the imminence of death [18]. Three studies exploring bereaved informal caregivers' (family and friends) experiences of anticipatory medications found that they accepted prescriptions, although some participants reported receiving inadequate explanations about the drugs and their intended purpose [18–20]. Informal caregivers also expressed ambivalence regarding the helpfulness of anticipatory medications in controlling symptoms and had concerns about their safety [18–20]. Older patient and informal caregiver experiences of anticipatory medications, and their preferences for involvement in decision-making, are of critical importance and warrant more detailed investigation [13, 18, 21, 22].

Our study aim was to explore patients', informal caregivers' and their clinicians' views and experiences of the prescribing and use of anticipatory medications in the community.

## Study design

This qualitative, multi-perspective, longitudinal interview study was conducted in two English counties, with a range of urban and rural areas and levels of affluence. A social constructionist perspective underpinned the research: perceptions, actions and experiences are shaped by our engagement in social worlds [16, 23]. A patient case-based approach provided flexible study methods, enabling the patient and/or their informal caregivers to take part. Individual or dyad interviews took place after anticipatory medications had been prescribed, after medications were first administered, and 2–4 months after the first interview, regardless of medication use. A clinician involved in decisions to prescribe or use the patient's anticipatory medications were invited to participate in a separate interview. This approach enabled comparisons of perspectives over time.

The South Cambridgeshire Research Ethics Committee approved the study (reference number: 19/EE/0361). The Cambridge Positive Ageing and Cambridge Palliative and End of Life Care Patient and Public Involvement (PPI) Groups advised on the research priorities, recruitment methods, the wording of interview guides and the significance of key findings from their perspectives.

## Participant eligibility

Eligible participants were aged 18 or over, English speakers and able to provide informed consent. Patients were living at home or a residential care home and prescribed injectable anticipatory medications prior to recruitment. Informal caregivers were family or friends. Clinical teams judged if patients and informal caregivers were suitable to approach to take part to minimise the risks of causing additional burdens and stress at a sensitive time. Participants' ongoing consent was checked prior to subsequent interviews.

## Recruitment

Participants were recruited through clinical care teams in six GP practices, two community nursing organisations and three community palliative care teams. A purposive sampling strategy was used to recruit patients with a variety of ages, living arrangements and a range of terminal conditions. Clinicians supplied a study invitation letter and potential participants responded directly to the research team

**Table 1.** Common symptoms and prescribed injectable anticipatory medications in the UK

Symptom	Common injectable anticipatory medications that are prescribed	Drug class	Common side effects [14,15]
Pain/ breathlessness	Morphine sulphate	Strong opioid	Nausea and vomiting; drowsiness; unsteadiness; confusion; constipation; dry mouth; itchiness or rash
	Diamorphine	Strong opioid	
	Oxycodone	Strong opioid	
Nausea and vomiting	Cyclizine	Anti-emetic	Drowsiness; headache; fatigue; dizziness; nervousness; dry mouth
	Haloperidol	Antipsychotic (used as an anti-emetic in low doses)	
	Levomepromazine	Antipsychotic (used as an anti-emetic in low doses)	
Agitation/restlessness	Midazolam	Benzodiazepine	Headache; drowsiness; over-sedation; cough; nausea and vomiting; hiccups See levomepromazine above: side effects more likely as higher doses are given for agitation or delirium See haloperidol above: side effects more likely as higher doses are given for agitation or delirium
	Levomepromazine	Antipsychotic	
	Haloperidol	Antipsychotic	
Noisy respiratory secretions	Glycopyrronium bromide	Antimuscarinic	Visual problems; dizziness; drowsiness; dry mouth; flushing; headaches; palpitations; fast heart rate See glycopyrronium bromide See glycopyrronium bromide
	Hyoscine butylbromide (Buscopan™)	Antimuscarinic	
	Hyoscine hydrobromide	Antimuscarinic	

or through their clinical team. In total, 34 patients and informal caregivers expressed interest: 16 were willing and able to take part when B.B. phoned to discuss the study and supplied the study information sheet. Also, 12 potential clinician participants nominated by patient and informal caregiver participants were approached by letter inviting them to participate: 6 replied to express interest in taking part; no nurses involved in decisions to administer anticipatory medications responded to requests to participate.

**Data collection**

Data were collected between May and December 2020 by B.B., a clinical academic and palliative care nurse with experience of conducting qualitative interviews. Semi-structured audio-recorded interviews were conducted by telephone or video, due to the Covid-19 pandemic restrictions. Three patients and informal caregiver partners asked to be interviewed together: care was taken to explore individual perspectives [24, 25]. Initial interviews with patients and informal caregivers lasted between 38 and 90 min and explored perceptions of the purpose of anticipatory medications, experiences of prescribing and what was important in their future care. Follow-up interviews lasted from 8 and 37 min. These built on earlier conversations and explored subsequent views and experiences of anticipatory medication care. Clinician interviews lasted from 22 and 48 min: these explored their perceptions of the decisions to prescribe and use the anticipatory medications and the patient’s and informal caregiver’s involvement in this care. Clinicians had

access to patient records during interviews. The interview guides were continually adapted in response to participant accounts and concurrent analysis (Supplementary file 1) [26, 27].

Data collection stopped after 11 patient cases as these provided rich and detailed insights from multiple perspectives over time [28]. Interview recordings were professionally transcribed verbatim, checked for accuracy and pseudonymised by B.B.

**Data analysis**

The data were analysed thematically using constant comparison techniques [26, 27]. Initial line-by-line coding was carried out by B.B. using NVivo 12© software, using short active codes to distil participants’ meaning and actions. K.P., a medical sociologist, independently coded five transcripts and then compared and reflected on early coding decisions with B.B.; this informed the iterative interpretive process [26, 29]. B.B. created memos on patterns, differing experiences and intriguing features in accounts and between cases: these were followed up in subsequent interviews and analysis. Concurrent data collection and analysis allowed comparisons across time points and the triangulation of views and experiences in cases [16,30]. Codes were integrated into categories and then themes to understand patterns and differences in accounts and shifting perspectives [26, 27]. The three final overarching themes, their boundaries and relevance were refined through debate between B.B., K.P. and S.B., a GP clinical academic [26, 27, 30].

**Table 2.** Patient case characteristics

Case	Age range	Gender	Ethnicity	Terminal conditions—as reported by participants	Living arrangements and English county*	Number of days before death anticipatory medications prescribed	Anticipatory medications used?
1	65–74	Female	White	Cancer	Living at home with family, town in Flinton	123 days	Yes
2	85–94	Male	White	Heart failure, frailty	Living at home with family, town in Westshire	5 days	No
3	75–84	Male	White	Heart failure, frailty, kidney failure	Living alone at home, town in Flinton	Alive at last interview: drugs prescribed 184 days previously	No
4	85–94	Female	White	Heart failure, cancer	Living in care home, city in Westshire	11 days	Yes
5	85–94	Male	White	Heart failure, frailty, cancer	Living in care home, town in Flinton	Alive at last interview: drugs prescribed 113 days previously	No
6	65–74	Female	White	Cancer	Living at home with family, town in Flinton	Alive at last interview: drugs prescribed 191 days previously	Yes
7	65–74	Male	White	Heart failure, frailty, Cancer	Living at home with family, village in Flinton	97 days	Yes
8	75–84	Female	White	Cancer	Living at home with family, village in Flinton	Alive at last interview: drugs prescribed 79 days previously	Yes
9	65–74	Male	White	Cancer	Living at home with family, village in Flinton	79 days	Yes
10	75–84	Female	White	Respiratory disease	Living at home with family, village in Westshire	Alive at last interview: drugs prescribed 294 days previously	No
11	75–84	Male	White	Cancer	Living at home with family, hamlet in Flinton	29 days	Yes

\*The fictional county names of Flinton and Westshire have been used for anonymity.

## Results

### Participant characteristics

In total, 11 patient cases were completed involving interviews with six patients, nine informal caregivers, three GPs and three nurses. These focused on the care of six male and five female older patients (age range 65–94 years). Patient case characteristics are summarised in Table 2. All 11 patients were prescribed anticipatory medications for symptoms of pain, breathlessness, nausea and vomiting, agitation and noisy respiratory tract secretions. Anticipatory medications were administered in 7 of the 11 patient cases: 6 patients died during the study follow-up period. In each patient case, the patient and/or their informal caregiver took part in one or more interviews; only six patients were able or willing to take part in interviews. Clinicians took part in interviews in six patient cases; the three nurses interviewed were involved in decisions to prescribe but not to administer the medications.

In total, there were 28 interviews. The case participants and number of interviews are summarised in Table 3.

### Themes

Three interconnected themes were constructed from the data and are set out below: living in the present whilst making plans, anticipation of dying and accessing timely care. Pseudonyms are used throughout.

#### *Living in the present whilst making plans*

Clinicians considered anticipatory medications to be a tool for managing uncertainty; in contrast, patients and informal caregivers were more focused on living as well and as long as possible in the present. Patient and informal caregiver participants said they were all aware that death was approaching. However, most of their emotional and physical attention went into coping with the present, maintaining a sense of optimism and adjusting to ever-changing situations.

**Table 3.** Case participants and number of interviews per case

Case	Participation in interviews	Number of interviews—conducted individually or as a dyad
1	Patient 'Sue'	Patient × 2
2	Informal caregiver 'Sarah' (friend) GP 'Sam'	Informal caregiver × 2 GP × 1
3	Informal caregiver one 'Katie' (partner) Informal caregiver two 'Zoe' (daughter) GP 'Victor'	Informal caregiver 1 × 2 Informal caregiver 2 × 2 GP × 1
4	Informal caregiver 'Alice' (daughter) GP 'Leo'	Informal caregiver × 1 GP × 1
5	Informal caregiver 'Emily' (daughter) District nurse 'Charlie'	Informal caregiver × 2 Qualified district nurse team leader × 1
6	Patient 'Louise'	Patient × 2
7	Patient 'Liam' Informal caregiver 'Amelia' (partner)	Patient and informal caregiver together × 1 Informal caregiver × 1 (after patient's death)
8	Informal caregiver 'Mark' (grandson)	Informal caregiver × 2
9	Patient 'Joe' Informal caregiver 'Kim' (partner) Palliative care nurse 'Gail'	Patient and informal caregiver together × 1 Palliative care nurse × 1
10	'Abby' (patient)	Patient × 2
11	Patient 'Dylan' Informal caregiver 'Freya' (partner) Palliative care nurse 'Lana'	Patient and informal caregiver together × 1 Informal caregiver × 1 (after patient's death) Palliative care nurse × 1

Whereas most patients and informal caregivers reported that they appreciated having anticipatory medications in place, some considered that too much contemplation of dying was counterproductive:

I suppose that sort of helped, knowing that I'd got things here [anticipatory medications] like when I needed it. That sort of really puts your mind at rest ... Most people sort of carry on as long as they can really. Because if not, you're just giving up, aren't you? You just think 'oh I'm going to die.'

Louise, patient, interview 1, Case 6

Prescription of anticipatory medications usually accompanied or followed clinician-led discussions of advance care planning. These discussions explored patient and family wishes regarding the avoidance of future hospital admissions, where they would prefer to have last-days-of-life care and putting in place a do not attempt cardio-pulmonary resuscitation form. These were typically reported to be one-off conversations that clinicians framed in hopeful terms of making plans to help patients remain at home and to be comfortable, encouraging the bracketing of thoughts of dying once initial plans had been made. Clinicians were especially keen to ensure that anticipatory medications were available as part of this planning so that patient and family wishes to avoid emergency admissions, particularly during the Covid-19 pandemic, could be respected:

Dylan was very fearful of going back into hospital. Also, we're in the middle of Covid ... So, everything we could possibly do to keep him at home, he wanted us to try and do.

Lana, palliative care nurse, Case 11

The choice to prescribe anticipatory medications was perceived by all interviewees to be a clinician-led decision.

Patient and informal caregiver contact with prescribers was predominantly by phone, video, or through their nurse briefly mentioning anticipatory medications and then making recommendations to a GP who prescribed the medications without making direct contact. Clinician participants recalled discussing and presenting prescribing as a recommendation for the control of possible end-of-life symptoms; however, only one patient and two informal caregiver participants remembered having detailed prescribing conversations. Anticipatory medications were also at times prescribed without discussion: two patient and five informal caregiver participants could not recall having conversations prior to receiving the bag of medicines. In other cases, participants recalled brief clinician-led conversations phrased in hopeful and vague terms that it would be helpful to have access to drugs '*just in case*' they were needed:

They talked to me about just in case medicines ... it was just, 'How about we have them in the house in case we need them' ... I don't think they were actually explained to me, but I think there was an assumption that they didn't need to be.

Emily, informal caregiver, interview 1, Case 5

Participants drew on a range of tactics to make sense of prescriptions when they recalled receiving insufficient explanations. Once prescriptions had been issued, 11 of the 15 patients and informal caregiver participants actively sought information about what the drugs were for and when they might be used. Five used research interviews to ask what individual drugs were for. Other patients and informal caregivers read the accompanying prescription and administration chart or searched for the names of the drugs on the internet to find out what they were for:

I actually Googled what they were, but it would have been nice for somebody, I think, to have just spent a short time explaining what they were.

Amelia, informal caregiver, interview 2, Case 7

Participants often held concurrent and sometimes conflicting views regarding the amount of reassurance that anticipatory medications offered. Most initially reported that everyone was comforted by having access to anticipatory medications, even if patient and informal caregiver participants reported receiving inadequate explanations about their purpose at the point of prescription. Six patients and informal caregivers shared more candid views later in interviews about the drugs and what they represented. Anticipatory medications were perceived to be a physical and significant sign that death was approaching: their presence was *'hard and fast evidence in the house'* [Victor, GP, Case 3]. These drugs were often in the home for weeks or months (see Table 2). For some, the presence of these medications was simultaneously comforting and an unwelcome reminder of impending death:

It's a bit of a comfort to know that that's there ... It's up [in] the corner and it's out of the way, and I don't look at it if I can help it.

Katie, informal caregiver 1, interview 1, Case 3

### *Anticipation of dying*

Patient and informal caregiver participants reported that they had rarely discussed explicitly the process and experience of dying with clinicians, beyond being told anticipatory medications could be given by visiting nurses to keep the person comfortable. These often matched with clinician participants' accounts of conversations about dying within patient cases. Clinicians varied regarding the amount of discussion they were willing to enter into with patients and informal caregivers about the process of dying. One patient told his GP that he recognised he was dying and feared it was going to be distressing. Sam, his GP, took this as permission to provide explicit details about possible symptoms and the role of individual anticipatory medications in the management of pain and distress. In contrast, Sue, another patient, wanted detailed information about the dying process, and the symptoms she might have, but struggled to find a clinician willing to discuss this. Her oncologist had previously indicated that death would be quick, and Sue hoped they could have a further candid conversation together:

I just don't know, you know, what's going to happen. I'd rather everyone tell me the truth ... She [the oncologist] did say death would be pretty quick, it's not going to be a long lingering thing anymore. But it's just [getting] any ideas of what else is going to happen to me, I'd like to know if she can tell me.

Sue, patient, interview 1, Case 1

Patients and informal caregivers considered that dying was likely to be distressing without medication. Whether the act of being prescribed anticipatory medications had served to put this idea into participants' minds was unclear. Patients

and informal caregivers shared their ideal image of death, which was of the person dying comfortably in their sleep or having well-controlled symptoms; most added the caveat that they realised this was unlikely. Having drugs available was considered a practical answer to help deal with unknowns:

I would like him just to close his eyes and go to sleep and not to be in any pain of any sort, but I don't know what life's got in store for him. So, if they [anticipatory medications] have to be used I would be quite happy to go ahead with it.

Katie, informal caregiver 1, interview 1, Case 3

Informal caregivers were concerned about the physical distress for the patient if they experienced pain, and the potential impact of witnessing their deterioration and suffering. A corresponding concern for patient participants was lessening the negative impacts of the process of dying on those close to them. Anticipatory medications were perceived as useful interventions to aid with symptoms, but they were not considered central in the relief of the pressures on families when they were dying. Patients voiced that their preferences for where they received care were always provisional and open to revision to help their families cope and to be able to retain positive memories of their lives at home:

I would actually prefer to go to the hospice, however, if my family wanted me to stay here, I would do that too ... I don't want my little house to have memories of me dying in it, and I don't want my family to have memories of me dying in my little house. But if that's what they want then I'm personally flexible in doing whatever is easiest for them.

Abby, patient, interview 1, Case 10

Unclear conversations about the role of anticipatory medications, or conflicting views on their effects, left some questioning whether drugs would speed up the dying process. One informal caregiver became wary that injectable drugs could be used easily by families and clinicians to sedate patients and hasten death. Liam, a patient, had received an injection to calm him whilst Amelia, his partner, had been out shopping: he was then very sleepy until the next day. Amelia had subsequently become extremely cautious about Liam being over-sedated. Amelia decided they would only call the nurses to give injectable drugs as a last resort and was very concerned about their side effects and the potential for drugs to be misused:

When I had the episode, as I said, a couple of months ago, I thought how easy it is for someone just to come and, in my terms, bump somebody off. So, yeah, no, they stayed in the cupboard, for purely an emergency only ... He went the way that I wanted him to go, and he wanted to go, which was natural ... With drugs he would have just, just let him lay there and vegetate. And I couldn't mentally cope with that.

Amelia, informal caregiver, interview 2, Case 7

### *Accessing timely care*

Getting anticipatory medications administered posed a significant challenge for six families, despite previous clinician

**Table 4.** Cases where requests were made to administer drugs

Case	Person who requested drugs were first administered	Professional group that first administered the drugs	Anticipatory medications used?
1	Family	District nurses*	Yes
2	Friend	Not given by the district nurses* despite repeated requests	No
4	Family	District nurses*	Yes
6	Patient	District nurses*	Yes
7	Family	District nurses*	Yes
8	Patient and family	District nurses*	Yes
9	Family	Paramedics as district nurses* unable to visit	Yes
11	Family	District nurses*	Yes

\*District nurse is used to describe either community staff nurses or qualified district nurse team leaders: patients, families and GPs identified both positions as 'district nurses.'

assurances that the drugs would be given by nurses if needed. A lack of detail on what dying might involve and when drugs would be used made it hard to know when to telephone the nurses to request an injection. Once contacted, the nurses would ultimately decide whether a visit and administration of anticipatory medications were needed. Medications were eventually given in seven of the eight patient cases in which their administration had been requested by patients or families (see Table 4). When nurses were unable to visit, one informal caregiver resorted to calling out a paramedic to start giving the medications:

I'd spoke to Joe's wife and she had initially called the district nurses and they hadn't been able to come out, they had given some advice about continuing to take oral medication and it was at night-time. I think Joe then had more uncontrolled pain ... and the paramedics were called. They actually were the first people that administered the medication.

Gail, palliative care nurse, Case 9

Patients who were able to clearly express their preferences did not experience difficulties with nurses starting injections: their requests for drugs were met swiftly. In contrast, five informal caregivers said they had to convince nurses to start injectable medications after patients appeared to be in pain or distress: these patients were unable to express their preferences regarding drugs at the time. The nurses only visited for short periods and often did not arrive until the patient appeared calmer or was resting. Alice, an informal caregiver, was with her mother when she became particularly distressed. She recalled having to advocate strongly for drugs to be given when a nurse, who did not know her mother, visited the care home and assessed that they were not needed.

Anticipatory medications were perceived to be of no value if nurses would not administer them. One informal caregiver reported that, despite repeated attempts, they were never able to convince the nurses to give medication for the patient's significant pain and distress in the days before his death. Sarah, a friend, could not be present to advocate for their use when the nurses visited as they came at unpredictable times. Sarah had asked the GP to intervene and to tell the nurses to give the drugs, but the GP (a participant in the research) considered that the nurses had more end-of-life care

expertise, and it was their decision to make. Sarah was very frustrated that injectable medications had not been given:

It upset me ... They [the district nursing team] should be communicating with us, asking us, and work as a team, but it just didn't feel like that ... They [anticipatory medications] were useless because nobody would give him anything.

Sarah, informal caregiver, interview 2, Case 2

Informal caregivers reported that it was easier to persuade nurses to administer further doses once anticipatory medications had been started; the first dose set a precedent. Getting drugs administered during the night was largely uncomplicated, with nurses usually visiting within an hour of being telephoned. Informal caregivers also found it far easier once an unambiguous symptom control plan had been agreed and they understood visiting nurses' criteria for administering medication:

Ruth was quite distressed about the pain ... I phoned the district nurse, and they were there within half an hour ... They told me that they were giving her a part dose of a morphine, and if it wasn't enough in an hour's time or so just to ring back and they could give her the other half. That's basically all we needed to know really.

Mark, informal caregiver, interview 1, Case 8

Most patients and informal caregivers reported that symptoms were partially or fully relieved with periodic injections of anticipatory medications, or after the commencement of continuous doses of medications via a syringe pump. Access to timely anticipatory medications, once started, continuity of care and consistent district nursing or specialist palliative care support was commonly reported to make important differences in care experiences. There was also some doubt amongst informal caregiver participants regarding whether medications fully relieved symptoms or instead caused over-sedation and impeded communication:

From 1 o'clock on the day he died he didn't seem as if he was in a lot of pain. But on the other hand, you couldn't understand what he was trying to say ... You couldn't be sure whether it was all a lot better or just that he was too drugged up to express it.

Freya, informal caregiver, interview 2, Case 11

Visiting nurses interpreted the validity of prescriptions in different ways, and informal caregiver and clinician participants perceived that this impacted on timely symptom control. Differences in skills, levels of experience and the judgements of visiting nurses posed problems for families, and they requested the help of specialist palliative care teams to improve continuity of care issues, when they were involved. Informal caregivers struggled to understand why individual nurses interpreted prescriptions differently, especially if they would not give prescribed medication:

On the morning before he died, he was in a huge amount of pain and very, very uncomfortable and distressed, and the nurse came in . . . She looked at the thing [the medication chart] and she said, 'oh well, this is no good, I can't do this. I'll give him his normal one and I'm going to have to go off to the surgery with this and I'll be back' . . . And she took this bloomin' piece of paper that we had all this fuss and bother for days for it to be right.

Freya, informal caregiver, interview 2, Case 11

What's the words Freya said? The team here at [Hospice at Home Service] was 'an oasis of calm in a pantomime of chaos' . . . My God, that's such a powerful statement! But that's really sad, that actually we were the only team they perceived that actually knew what we were doing.

Lana, palliative care nurse, Case 11

Informal caregivers carried out hidden work to ensure that anticipatory medication supplies were replenished, and that professionally valid prescription and administration authorisation charts were available. Even when informal caregivers had been told that nursing teams had assumed responsibility for these activities, there were frequently last-minute stock issues and a reliance on families to anticipate and solve problems. This additional responsibility for joining up medication care was time-consuming and frustrating:

We found ourselves doing a lot of backing and forthing to the pharmacies and the doctors to get the stuff we needed, and that was quite frustrating.

Mark, informal caregiver, interview 2, Case 8

## Discussion

Our study offers new and detailed insights into the views and experiences of patients, informal caregivers and their clinicians regarding the prescribing and use of anticipatory medications over time. The most striking finding was the variable and often vague nature of recalled conversations with clinicians about the process of dying and the role of anticipatory medication in planned care. The arrival of medication with limited or no prior discussions may reflect the reduction in the numbers of GP home visits during the Covid-19 pandemic, with consultations and prescriptions been done remotely [22,31,32]. However, remote prescribing based on district nurses and palliative care team recommendations regularly occurred before the pandemic [3, 13, 33].

When patients and informal caregivers in our study were focusing their limited energy on living in the present, and

when vague planning conversations matched participant preferences regarding the amount of information they wanted, this helped them to bracket thoughts of care in the last days of life. Maintenance of positivity, continuity of daily life and trying not to dwell on death form a frequently observed cluster of coping mechanisms that older people use to deal with terminal diagnoses and protracted dying [1, 34–38]. However, participants in our study who wanted practical, detailed discussions about the dying process ahead of time, including its uncertainties, had to work hard to find clinicians willing to have these conversations. Previous studies exploring patients' and informal caregivers' experiences of end-of-life medication care also found that people infrequently received sufficient information about drugs and the physical changes associated with dying, leaving families with unresolved concerns about the possibility of pain and suffering [4,18,19,21,39]. Other studies have found community nurses and GPs report tailoring conversations about anticipatory medications depending on their own information sharing preferences and their perception of patients' and family members' willingness to talk about dying [3,12,18]. The majority of patients and informal caregivers in our study would have liked more information than they recalled being given about dying and anticipatory medication; they resorted to accessing alternative sources of information to make sense of the purpose and possible effects of anticipatory medication.

The presence of anticipatory medications in the home was simultaneously reassuring, a source of unease and, for some, a portent of approaching death. These findings mirror studies exploring clinician and families' experiences of prescribing conversations [3,12,18] and patient reservations concerning anticipatory medications that were occasionally recorded in clinical records [13]. Informal caregivers expressed concern that the administration of injectable medications could impede patients' abilities to communicate or could cause over-sedation and potentially hasten death. These findings matched those of studies that investigated family caregivers' and community nurses' concerns about the possible adverse effects of administered injections [10,21,40,41].

The promise of accessibility to timely, nurse-administered anticipatory medications proved not to be the case, at least initially when informal caregivers requested that the drugs be given. Nurses appeared to value their own assessments of symptoms, or those reported by patients, more than the informal caregivers' views of patients' discomfort. Our findings correspond with those of Wilson et al. (2015) [10], who observed that nurses would administer anticipatory medications if they judged that symptoms were irreversible and due to dying, whereas they took care to make these decisions without the influence of relatives; this was to avoid being 'unduly swayed' by families [10]. This approach restrains the voice and influence of informal caregivers, who provide the bulk of care and often know the patient best. Vermorgen et al. (2021) similarly found that informal caregivers were rarely treated as experts by experience or considered to be equal members of the end-of-life care team [42].



Participants reported that administered medications generally helped with comfort and pain control. This corresponds with research into clinicians' and informal caregivers' views of the importance of having anticipatory medications available [3,10,12,18,41]. However, the confidence and assertiveness of informal caregivers to navigate healthcare systems were major factors in accessing timely anticipatory medication care. Payne et al. (2015) found that family members appreciated nurses relieving them of complex symptom control responsibilities when injectable medications were started [21]. In contrast, our study showed that informal caregivers assumed a role of heightened vigilance in their dealings with healthcare services and felt they needed to continually advocate on the patient's behalf. Negotiation with nurses regarding when such care would and should be given was made more difficult for informal caregivers because they had to learn professional rationales and varying criteria for the administration of anticipatory medications. Informal caregivers experienced more success in getting medications administered once they understood the criteria visiting nurses used.

Clinicians rely heavily on families to ensure that anticipatory medications and professionally valid prescription and administration charts are available. May et al. (2014) propose that 'the burden of treatment' must be considered from the perspectives of the patient and their support networks to ensure that the work of care is appropriate and sustainable [43]. As older patients near death, they and their increasingly fragile support networks can become overwhelmed by the burdens of information-gathering, monitoring symptoms and the effectiveness of anticipatory medications, collecting prescriptions and coordinating fragmented professional care. This collective work is widely unrecognised and under-acknowledged; clinicians and community healthcare services routinely expect and rely on informal caregivers to have the capacity, will and skills to undertake increasingly complex, quasi-professional medication management activities alongside their other caring roles [18,44,45]. Yet, our findings suggest informal caregivers acquired knowledge and experience is under-recognised by clinical teams.

### Strengths and limitations

The patient case approach was limited by not always being able to recruit the patient or hold follow-up interviews, reflecting the challenges of researching dying care [18,24]. Older patients with fluctuating cognitive impairments were unable to consent to participate in two patient cases. Consequently, the analysis focused on understanding similar and divergent accounts and comparison between cases rather than primarily within-case analysis [26, 30]. B.B.'s professional background and social science training influenced the interpretation of data [46]. To aid reflexivity and rigour, key decision points of the interpretive analysis were discussed and refined with K.P. and S.B. [26, 27, 29]. Decisions in attributing significance to findings were also shaped through discussions with both PPI Groups.

The findings offer insights into clinical practices that are likely to be transferable across the UK and countries with similar community healthcare structures. Patients had a variety of conditions, ages and lived in diverse geographical settings with varying degrees of support. However, participants were required to speak English and were typically from a white background, limiting the transferability of the findings to diverse communities. The voices of nurses involved in decisions to administer anticipatory medications were missing: this is important to address in future research.

### Conclusions and recommendations

Anticipatory medications are simultaneously reassuring and a source of unease to older patients and their informal caregivers. These concerns are exacerbated where people have limited opportunities to discuss dying care and the role of the drugs in symptom control. The subject of anticipatory prescribing should be used as an opportunity to hold open and honest conversations about families' concerns and the realities of dying, provided patients and informal caregivers indicate that this is their preference. These conversations need revisiting as preferences change and the realities of dying at home unfold; particularly for older patients dying with non-cancer conditions and multimorbidity, for whom illness trajectories are commonly less predictable and the dying phase protracted.

Anticipatory medications are generally perceived as a useful and practical intervention that helps to control symptoms when everyone agrees on when to use them. However, the widespread perception that once these medications are available, patients will receive timely and appropriate care does not reflect experiences of care. Future research is needed to understand how complex, nuanced decisions to use medication can be made more inclusive and to incorporate patient and informal caregiver experiences of illness and care. Nurses' decisions to administer medication should take into consideration informal caregivers' insights into patient discomfort and distress, especially when individuals are no longer able to communicate their needs.

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**Data Availability Statement:** The anonymised quantitative data used in this study may be requested by researchers through contacting the lead author (BB). Given the sensitive subject nature of the anonymised qualitative data, they may be made available to researchers with evidence of a study protocol and Research Ethics Committee approval, and on completion of a data use and sharing agreement..

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