

# Managing end of life medications at home—accounts of bereaved family carers: a qualitative interview study

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## ABSTRACT

**Objective** To explore how bereaved family members recall managing end of life medications when delivering care to a patient dying at home in England.

**Design** Qualitative study.

**Setting** Domestic homes in two contrasting areas in England.

**Participants** 59 bereaved family carers who have delivered care to a patient who spent a minimum of 2 weeks at home prior to their death from cancer or other non-malignant condition. Cases were excluded if the place of death was: a hospice, nursing home or National Health Service (NHS) hospital.

**Results** Participants identified a number of important concerns about managing end of life medication for the dying person at home. Although some support with medications is provided by general practitioners and nurses in the community, family carers take primary responsibility for drug administration and storage. They reported anxiety about giving correct and timely dosages, and concerns about keeping the patient comfortable without overdosing them or risking shortening their lives. In particular, they reported that certain analgesic medications, especially opioids, were considered to have a symbolic significance increasing analgesia requirements, and the use of a syringe driver was associated with deterioration and approaching death. Key barriers to managing end of life medications at home included: complex regimes; unwanted responsibility in deciding when to use 'as needed' medication; disagreements with professional staff, and anxiety about medication errors, especially if perceived to have implications for survival.

**Conclusions** Family carers require more information about end of life drugs and their effects, support and training in managing medication for a dying person.

## INTRODUCTION

In a context of limited healthcare resources, the role of family, friends and significant others (hereafter called 'family carers') in end of life care at home is increasingly important. Hospital care in the last year of life is known to account for a considerable proportion of healthcare expenditure in the UK<sup>1</sup> and the USA,<sup>2</sup> while home-based palliative care is frequently found to be less costly compared to other options.<sup>3</sup> Evidence indicates that home-based palliative care reduces the symptom burden for patients while not increasing family carers' grief during bereavement.<sup>4</sup> However, the presence of family carers able to provide care in the home is a key determinant of outcomes for patients with cancer.<sup>5</sup>

The End of Life Care Strategy<sup>6</sup> in England aims to improve the accessibility of high-quality care for everyone with advanced conditions. According to the Strategy, which describes family carers as 'co-workers' with the care team, patients should be provided with more choice over where they receive end of life care. Two-thirds of British patients would prefer to die at home, with current trends indicating a modest increase over the last decade in home deaths to 21% in 2010.<sup>7</sup> Policy initiatives have highlighted the important role of the general practitioner (GP) in managing end of life care.<sup>6</sup> For example, there has been a widespread introduction of 'anticipatory prescribing' in community-based palliative care, whereby GPs prepare prescriptions for dying patients.<sup>8</sup> This ensures that essential drugs are available within the home 'out of hours' to enable rapid symptom management and prevent unnecessary

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hospitalisation. They comprise four core drugs including strong opioids and sedatives, although the drugs actually prescribed may vary. Within the home, community nurses are often involved in decisions about the actual initiation, dosage and delivery of these medications, which some nurses report as problematic.<sup>9</sup> Survey data from bereaved carers indicate that pain management is less good than in other care settings.<sup>10</sup>

Family carers play a crucial role in supporting those dying at home. Of the 6.5 million family carers in the UK, approximately half a million do so during the end of life phase, and the majority of them are women aged 50–64 years while in older groups slightly more men provide care.<sup>11</sup> They provide physical care, emotional and social support, financial resources, advocacy and anticipatory care, and assist patients in negotiating and co-ordinating care during the final period of life.<sup>11</sup> <sup>12</sup> It is a challenging and demanding role which few people aspire to, but which may be thrust on them. Despite policy initiatives<sup>13</sup> <sup>14</sup> to address these caring demands, a large study on transitions between places of care near end of life reported that in 2013 little has changed to improve family carers' experiences.<sup>15</sup>

It is family carers, rather than GPs or community nurses, who often have to manage the safe storage and delivery of end of life medications in the home on a day-to-day basis. Evidence from a small study of 23 family carers of patients in a home hospice programme in the USA identified five conceptual factors that influenced medication management; however, major differences in healthcare systems limit its applicability in the UK.<sup>16</sup> <sup>17</sup> A survey of 98 multidisciplinary US home-hospice staff indicated that 67% rated medication management as the most important role of family carers, but only 6% routinely offered education, support and counselling to facilitate this.<sup>18</sup> Little is known about the complex realities of managing end of life medications at home in the UK from the perspective of family carers. Therefore, we elicited in-depth interview accounts from bereaved family carers of their experiences of these medications.<sup>19</sup> The study is part of a larger project exploring the experiences of family members caring for a dying older person at home.<sup>20</sup>

## METHODS

### Design

We utilised a cross-sectional qualitative research design.

### Setting

The study was conducted in two areas: North West (NW) and South West (SW) England. These regions were selected because they both have high proportions of older people in the population.<sup>21</sup> Census data and informal discussions with professionals and

stakeholders indicated some differences between the two areas in terms of socioeconomic status, types of home ownership, ethnic and cultural diversity and health indices (such as smoking rates), which the research team believed would add diversity to the data collected.

### Sampling

We purposively sampled bereaved family carers to select those with direct experience of providing care for an older person dying at home. The inclusion criteria included: family carers of older deceased people (aged 50 years +) from any cause of anticipated death; death occurring in the home of the carer or patient; a minimum of 2 weeks care in the private home prior to death; adult carer ( $\geq 18$  years); and recruited at least 6 months but not more than 24 months following the death. The exclusion criteria included: carers who were cognitively impaired, unable or unwilling to give consent. Initially, inclusion was limited to the first 18 months of bereavement but subsequently extended to 24 months to increase the sample.

### Recruitment

Family carers were recruited through GP practices. Practice staff identified family carers who met all the study criteria, and information packs were posted to potential participants who responded directly to the research team.

### Data collection

Researchers conducted single face-to-face interviews of 15–102 min (mean=47 min) in participants' homes from December 2011 to August 2012. Participants had been bereaved for a median of 12 months (range 7–22 months). The main interview was designed to elicit chronological narratives of care provision during the end of life using open-ended questions and follow-up prompts. The interview was pilot tested with three bereaved carers and modified to include further questions about medication management. In this paper, we report on these questions only:

- ▶ To what extent were you involved in administering medications?
  - How did you feel about this?
  - Did you get any support from a pharmacist or district nurse?
  - Were any controlled drugs prescribed and, if so, did they raise any particular issues?

### Analysis

Interviews were digitally recorded and then fully transcribed. All interview transcripts were checked against audiorecordings for accuracy and anonymised. To ensure reliability, four transcripts were independently coded. On this basis, a final coding framework was applied to all transcripts using the data analysis

**Table 1** Characteristics of participants in interviews

	N=59	Per cent	Range	Median
Location in England				
North West	23	39		
South West	36	61		
Gender of carer				
Male	18	31		
Female	41	69		
Age of carer				
All	59		44–90	72
<50	1	2		
50–59	7	12		
60–69	19	32		
70–79	15	25		
80–81	16	27		
>90	1	2		
Ethnicity of carer				
White British	56	95		
White other	2	3		
Black Caribbean	1	2		
Relationship to deceased				
Spouse	43	73		
Daughter/son	15	25		
Sibling	1	2		
Gender of deceased				
Male	35	59		
Female	24	41		
Age of deceased				
All			59–98	82
50–59	3	5		
60–69	8	14		
70–79	15	25		
80–89	23	39		
>90	10	17		
Time cared for in the home			2 weeks—11 years	11 months
Cause of death				
Cancer	37	63		
COPD	1	2		
Heart disease	6	10		
Dementia	3	5		
PD	3	5		
Old age	5	8		
Renal failure	1	2		
Other	3	5		
Occupation of carer				
Modern professional	17	29		
Clerical/intermediate	15	25		
Senior managers	3	5		
Technical/craft	2	3		
Semi-routine manual	7	12		
Routine manual	3	5		
Middle/junior managers	5	9		
Traditional professional	2	3		
No paid employment	5	9		

Continued

Table 1 Continued

	N=59	Per cent	Range	Median
Occupation of deceased				
Modern professional	13	20		
Clerical/intermediate	7	12		
Senior managers	1	2		
Technical/craft	8	14		
Semi-routine manual	5	9		
Routine manual	6	10		
Middle/junior managers	8	14		
Traditional professional	5	9		
No paid employment	6	10		

COPD, chronic obstructive pulmonary disease; PD, Parkinson's disease.

software NVivo, with any discrepancies discussed. A constant comparative approach to the analysis was utilised<sup>22</sup> until saturation of themes was achieved.<sup>23</sup> These were presented at two workshops involving 33 expert advisory group members, practitioners and service users and incorporated into the final analysis. Direct quotations have been selected to highlight typical responses. To establish rigour, we adhered to COREQ guidelines.<sup>24</sup>

## RESULTS

We interviewed 59 bereaved family carers (response rate 54%) who delivered care to a patient who spent a minimum of 2 weeks at home prior to their death from cancer or other non-malignant condition (see table 1). In the SW, 52 invitations resulted in 38 responses (73% response rate), but 2 subsequently declined. In the NW, 76 invitations resulted in 31 responses (41% response rate), but 6 subsequently declined, 1 did not meet the inclusion criteria and 1 agreed to participate but then withdrew.

The majority of carers (69%) were women, and the majority of deceased patients (59%) were men, reflecting the fact that 73% were spouses. Three quarters of the people they cared for died from cancer. The median length of time that they had provided care at home was 11 months (range 2 weeks—11 years).

Following an extensive analysis, we selected two main themes that are presented here:

### Decision-making processes in managing end of life medication at home

#### Managing complex medications

All 59 participants were involved in managing end of life medications, especially once the patient became dependent and was in the final phase of dying. The degree to which they regarded this as burdensome was on a continuum from not at all to greatly.

'He'd been on quite a lot of tablets for some time, blood pressure, heart tablets, warfarin and other things' [A01 SW Female 78]

A number of strategies to facilitate medication management were described:

'I made a copy of all the tablets and the different times he was to have them and which ones [...] I made a chart on the computer and just printed it out each time, and that was very helpful.' [A11 SW Female 60]

#### Taking responsibility

Some participants reported the responsibility as demanding because they feared the consequences of making a mistake or because they did not fully understand the medication regimes, especially when distressed, which made decision-making difficult.

'It's a very big responsibility and I felt helpless because I felt that some things needed increasing and the nurses weren't there to do it, but at the same time I don't think it would have been right for me to have total control over it because my head was all over the place.' [B01 NW Female 77]

While most community nurses were helpful, they were not always in the home, so variation to medication, especially for 'as needed' drugs, required them to make decisions unaided. One participant perceived that the occupational background of the patient (as an industrial pharmacist) had been an advantage. This experience was echoed by carers who had qualifications as health professionals.

'He was an industrial pharmacist, so when the medication came along right at the beginning, he told me what was what and he queried the doctor. He always used to check that I was giving the tablets in the right way, but eventually of course he was unable to do that. But he had trained me well.' [B21 NW Female 80]

#### Disagreements with staff about medication

Some carers with health professional expertise challenged the prescribed medication regimes.

He had [the syringe driver] in for three days, and when he was settled, I knew he was going to die I asked them to take it out. And the doctor didn't think it was a good idea, but I said 'I don't want him dying

with this thing in his arm, and I don't want him having drugs...' [...] I felt he needed to die a relatively natural death. [B19 NW Female 70]

This was an atypical case; more often, there was a desire for family carers to decrease the burden of their own decision-making, and a concern about challenging medical care.

'I think [the nurses] need to listen to what the carer is saying; they did mostly but generally when I said she needs more sedation and they said 'well she's on such and such a dose', which apparently was quite a big dose but it still wasn't enough for her.' [B02 NW Female 57]

### Managing end of life medications at home: concerns and rewards

#### Carers' anxiety about medications

While there was recognition that these medications were necessary to provide symptom relief, some cited concerns about dosage errors, especially overdosing patients, or failing to administer the drugs when the patient becomes too ill to use the oral route.

'I was really anxious just to follow the instructions and I wrote everything down carefully that I had given her. I didn't attempt to give her an overdose, [B14 NW Male 72]

#### Perceptions about the effects of morphine

Underlying the anxieties about medication management was a specific concern about morphine or its equivalents (hereafter referred to as morphine). Some participants explained and justified the use of morphine, in the context of persuasion from nursing staff rather than any weakness or the lack of moral courage by patients.

'(Earlier) he was doing it all himself, But then when he became more sleepy then I was doing cos he was on liquid morphine then.' [A08 SW Female 66]

'[I gave him Oramorph] when he asked for it, I didn't like to give him all...just when I thought he needed it, which was probably every day. At first I thought 'Oh shall I use it or not?' [B15 NW Female 63]

While all participants agreed to the use of morphine for pain relief, some perceived morphine to reduce the awareness of the patient, which was variously described as 'a bit removed', less 'lucid', 'more and more distant' or 'very confused'. A participant attributed an increase in agitation and disinhibition to morphine usage, which poignantly robbed the dying person of dignity and left lasting distressing memories.

'I had my arms around him and he was talking to me normal whereas before he'd said some really horrible things, that's the morphine.' [A03 SW Female 76]

'And his speech started to go but we realised that he was so drugged we had awful trouble trying to find out whether he wanted something to drink, something to eat, to go to the loo, and I think he found it so frustrating cos he was an incredibly articulate person,' [A04 SW Female 67]

There were suggestions that the complexity of managing morphine and its side effects, such as nausea, further complicated other types of medication and disease management.

#### Symbolic significance of a syringe driver

There was a perception that a change in the route of medication administration to the subcutaneous route via a syringe driver signalled a transition to a dying status. Two participants identified that the timing of starting a syringe driver was indicative of approaching end of life, although not in all cases was effective symptom management achieved.

'On the Monday they came and put a syringe driver in, so you knew then that it wouldn't be long.' [A19 SW Female 69]

#### Rewards in managing end of life medications at home

Participants also reported that there were positive experiences in caring for a person dying at home. A critical first step in this process was feeling confident and competent to manage medication delivery either by drawing on prior healthcare training or general caregiving knowledge.

So it was okay... I think for the last few days I was giving her things like that [morphine]. [B20 NW Male 82]

One participant highlighted her feelings of satisfaction in the final hours of life, when having insisted on the withdrawal of all medication, she recalled a few precious moments when she communicated with her lucid husband, creating valued last memories.

'When all the medications ceased, he did become quite rational for about... oh... an hour. He was quite back to his old self and I sat with him and we talked (chuckles). And it was so lovely because he hadn't known me. And just in that hour he did. And then he drifted off and he wasn't really conscious anymore after that. [B13 NW Female 83]

## DISCUSSION

This qualitative study highlights family carers' accounts of the challenges of managing end of life care medications for a person dying at home. Our study adds to the existing literature, which has predominantly presented evidence from the professional perspectives of GPs,<sup>25</sup> community nurses<sup>10</sup> or hospice providers.<sup>19</sup> The current policy recommendations stress the need to facilitate more people dying at home.<sup>6</sup> The family carers sampled indicated that they had a major role in providing care and ensuring



symptom management by careful medication delivery. It is not surprising that it was perceived to be a demanding responsibility and at times for some, anxiety provoking, given that they reported little information or education to facilitate their role. Our data indicate particular concerns about how end of life drugs, especially morphine, were perceived by family carers and that a syringe driver was seen as marking a transition into the final dying phase.

#### Strengths and weaknesses of the study

The diversity of the findings was increased by purposively sampling across two areas of England. Further discussion of the analysis with key stakeholders, practitioners and service users (patients and carers) confirmed them as resonant with their clinical or practical experiences. We did not use respondent validation because of ethical concerns to minimise distress in our bereaved participants. In comparison to previous research which has focused primarily on patients with cancer,<sup>26</sup> those with other chronic conditions were included. A potential limitation of our research design was the use of cross-sectional, retrospective accounts where the experience of bereavement may have biased the self-reports provided, especially for those later in the bereavement trajectory. Future research should use serial interviews conducted throughout caregiving. Caution is also required in interpreting the findings as we collected no data from GPs, community nurses or patients. As befitting a qualitative study, our intention has been to illuminate the experiences of family carers and provide clinically useful insights, rather than to make claims of population level generalisability.

#### Strengths and weakness in relation to other studies

The participants identified several barriers to managing end of life medications at home, largely due to their inexperience compounded by an apparent lack of knowledge or access to information. This is consistent with previous research carried out in US home hospice care which highlighted the lack of specific medication management strategies offered to family carers by the multidisciplinary team.<sup>16–19</sup> This is a paradox in that health professionals, especially nurses, require extensive training and are regulated by procedures to ensure medication safety, but there was little evidence that similar attention is directed towards supporting family carers. There is evidence that external cognitive support and education promote adherence to medication in older people.<sup>27</sup> This lends support to the strategies initiated by family carers in our sample. A key finding was the degree of anxiety reported by family carers and the perception of responsibility and its burdensomeness in managing these medications. In some cases, they reported making decisions about delivering ‘as needed’ drugs or in altering dosages to achieve symptom relief, without, at times, support

from primary care professionals. Most carers’ accounts indicated that community nurses offered support either during home visits or over the telephone, but remarkably little reference was made to the involvement of GPs beyond the prescription of the drugs. Our findings accord with those from a recent ethnographic study of decision-making by community nurses about the use of anticipatory end of life medication in two areas of England, which demonstrates that initiation of the use of these types of drugs is largely at the discretion of nurses.<sup>28</sup> Furthermore, our data indicated that family carers used the initiation of a syringe driver to deliver medication as a cue to the transition to dying. They also reported considerable concerns about the use of morphine, and what has been described elsewhere as opioidphobia.<sup>29</sup> As has been observed in research on palliative sedation, there seemed to be a strong need for participants to explain that they were not seeking to hasten death.<sup>30</sup> There were advantages for those with healthcare experience in that they reported a more proactive and equal relationship with the primary care team and unsurprisingly had better access to information resources.

#### Implications for clinicians and policymakers

In the context of the End of Life Care Strategy,<sup>6</sup> the findings from this study indicate that the family carers sampled did not believe themselves to have adequate support to safely deliver end of life medications to patients dying at home. It raises questions about the way family carers are engaged as ‘co-workers’ as described in the Strategy. Without adequate preparation, sufficient information/education and support in dealing with end of life medication, the implementation of current home-based end of life care policies seems destined to result in additional distress and burdensomeness for family carers. A correlational study from Sweden indicates that feeling of preparedness for the role of caring was significantly associated with higher levels of hope and reward and with a lower level of anxiety.<sup>31</sup> There may be opportunities to increase the role of community pharmacists to provide advice and training in the safe management, storage and disposal of medications. Our study indicates that more effective communication is required from the primary care team about end of life medications. Community nurses were most often mentioned as involved in medication delivery, and generally they were found to be supportive.<sup>10 28</sup> The responsiveness and availability of home-based nurses and physicians is known to predict caregiver satisfaction;<sup>32</sup> however, for the majority of time, family carers have to manage alone. Communication between GPs, community nurses and family carers about their roles and responsibilities regarding end of life medications may help to prevent the anxieties reported.

### Future research

Further in-depth research is needed on the roles and responsibilities of family carers regarding the use of end of life medications, especially anticipatory prescriptions. Research on the views of dying patients on medication usage and how this is negotiated with their family members is warranted. Likewise, research examining the effects of family carers' education, age and information needs is required before appropriate interventions can be designed.<sup>33</sup>

In conclusion, our study reveals how participants perceive end of life care medications as a core but largely unrecognised and undervalued function of caring for a dying patient at home. Family carers require more information about end of life drugs, their effects and support in managing these medications. When formulating suggestions for end of life care policy at home, we suggest keeping in mind the central role of family carers. Significant concerns were identified, and these need to be addressed if current UK policy to increase the number of patients dying at home is to be safely realised.

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**Competing interests** All authors have completed the Unified Competing Interests form at [http://www.icmje.org/coi\\_disclosure.pdf](http://www.icmje.org/coi_disclosure.pdf) (available on request from the corresponding author) and declare that (1) SP, MT, DS, CM, CT, SBr, XW and SBl have support from Marie Curie Cancer Care for the submitted work; (2) SP, MT, DS, CM, CT, SBr, XW and SBl have no relationships with Marie Curie Cancer Care that might have an interest in the submitted work in the previous 3 years; (3) their spouses, partners or children have no financial relationships that may be relevant to the submitted work; and (4) SP, MT, DS, CM, CT, SBr, XW and SBl have no non-financial interests that may be relevant to the submitted work.

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**Data sharing statement** Unpublished data are held by Lancaster University.

### REFERENCES

- Hatziaandreu E, Archontakis F, Daly A, *et al.* *National Audit Office. The potential cost savings of greater use of home- and hospice-based end of life care in England.* Cambridge: RAND Corporation, 2008.
- Riley GF, Lubitz JD. Long-term trends in Medicare payments in the last year of life. *Health Serv Res* 2010;45:565–76.
- Smith S, Brick A, O'Hara S, *et al.* Evidence on the cost and cost-effectiveness of palliative care: a literature review. *Palliat Med* 2014;28:130–50.
- Gomes B, Calanzani N, Curiale V, *et al.* Effectiveness and cost-effectiveness of home palliative care services for adults with advanced illness and their caregivers (review). *Cochrane Library* 2013;6:1–128.
- Gomes B, Higginson IJ. Factors influencing death at home in terminally ill patients with cancer: systematic review. *BMJ* 2006;332:515–21.
- Department of Health. *End of life care strategy: promoting high quality care for all adults at the end of life.* London: Department of Health, 2008.
- Gomes B, Higginson IJ. Where people die (1974–2030): past trends, future projections and implications for care. *Palliat Med* 2008;22:33–41.
- 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;3:91–7.
- Wilson E, Seymour J. Understanding the role of nurses in the management of symptoms and distress in the last days of life. In: Sterckx S, Kasper R, Mortier F. eds. *Continuous Sedation at the End of Life.* Cambridge: Cambridge University Press, 2013:100–16.
- <http://www.ons.gov.uk/ons/rel/subnational-health1/national-survey-of-bereaved-people-voices-/2013/index.html> (accessed 28 Jul 2014)
- Payne S. EAPC Task Force on Family Carers White Paper on improving support for family carers in palliative care: part 1. *Eur J Palliat Care* 2010;17:238–45.
- Payne S. EAPC Task Force on Family Carers White Paper on improving support for family carers in palliative care: part 2. *Eur J Palliat Care* 2010;17:286–90.
- Department of Health. *Carers at the heart of 21st-century families and communities: a caring system on your side. A life of your own.* London: Department of Health, 2008.
- Department of Health. *Recognised, valued and supported: next steps for the carers strategy.* London: Department of Health, 2010.
- Hanratty B, Lowson E, Holmes L, *et al.* *Transitions at the end of life for older adults: patient, carer and professional perspectives.* Final Report to NIHR SDO, 2013.
- Lau DT, Kasper JD, Hauser JM, *et al.* Family caregiver skills in medication management for hospice patients: a qualitative study to define a construct. *J Gerontol: Soc Sci* 2009;64:799–807.
- Lau DT, Berman R, Halpern L, *et al.* Exploring factors that influence informal caregiving in medication management for home hospice patients. *J Palliat Med* 2010;13:1085–90.
- Joyce BT, Lau DT. Hospice experiences and approaches to support and assess family caregivers in managing medications for home hospice patients: a providers survey. *Palliat Med* 2013;27:329–38.
- Grande G. Palliative care in hospice and hospital: time to put the spotlight on neglected areas of research. *Palliat Med* 2009;23:187–9.
- Payne S, Brearley S, Milligan C, *et al.* The perspectives of bereaved family carers on dying at home: the study protocol of 'unpacking the home: family carers' reflections on dying at home'. *BMC Palliative Care* 2012;11:23. <http://www.biomedcentral.com/1472-684X/11/23>

- 21 [https://www.gov.uk/government/uploads/system/uploads/attachment\\_data/file/6871/1871208.pdf](https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/6871/1871208.pdf) (accessed 9 Oct 2013).
- 22 Strauss A, Corbin JL. *Basics of qualitative research: techniques and procedures for developing grounded theory*. 2nd edn. Thousand Oaks, CA: Sage, 1998.
- 23 Seale C. *The quality of qualitative research*. London: Sage, 1999.
- 24 Tong A, Sainsbury P, Craig J. Consolidated criteria for reporting qualitative research (COREQ): a 32-item checklist for interviews and focus groups. *Int J Qual Health Care* 2007;19:349–57.
- 25 Barclay S, Maher J. Having the difficult conversations about the end of life. *BMJ* 2010;341:c4862.
- 26 Thomas C, Morris S, Clark D. Place of death in the Morecambe Bay area: patterns and preferences for place of final care and death among terminally ill cancer patients. *SocSci Med* 2003;58:2431–44.
- 27 Higgins N, Regan C. A systematic review of the effectiveness of interventions to help older people adhere to medication regimes. *Age Ageing* 2004;33:224–9.
- 28 Wilson E, Morbey H, Brown J, *et al*. Administering anticipatory medications in end-of-life care: A qualitative study of nursing practice in the community and in nursing homes. *Palliat Med* 2014. doi:10.1177/0269216314543042
- 29 World Health Organization. *Ensuring balance in national policies on controlled substances. Guidance for availability and accessibility of controlled medicines*. Geneva: World Health Organization, 2011.
- 30 Seymour J, Rietjens J, Bruinsma S, *et al*. Using continuous sedation until death for cancer patients: a qualitative interview study of physicians' and nurses' practice in three European countries. *Palliat Med* 2014. doi:10.1177/02692116314543319
- 31 Henriksson A, Arestedt K. Exploring factors and caregiver outcomes associated with feelings of preparedness for caregiving in family caregivers in palliative care: a correlational, cross-sectional study. *Palliat Med* 2013;27:639–46.
- 32 Guerriere DN, Zagorski B, Coyte PC. Family caregiver satisfaction with home-based nursing and physician care over the palliative care trajectory: results from a longitudinal survey questionnaire. *Palliat Med* 2013;27:632–8.
- 33 Grande GE, Farquhar MC, Barclay SI, *et al*. The influence of patient and carer age in access to palliative care services. *Age Ageing* 2006;35:267–73.





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