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

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The challenge

• Over 561,000 people die in the UK every year
• Unequal access to high quality palliative care
• 86% of all hospital admissions in the last year of life are emergency hospital admissions: only 21% of home deaths
• Poor symptom control often precipitates emergency admission, in the last days of life

(see: http://be.macmillan.org.uk/Downloads/TheRichPictureOnPeopleAtTheEndOfLife.pdf)
Anticipatory Prescribing

• ‘…ensuring 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’.

A process*:
• Prescribing
• Dispensing
• Administration (commonly by nurses)

A central aspect of end-of-life care policy (See: National End of Life Care Strategy, DH, 2008)


The nursing role in end-of-life care

- Assessing dying patients’ needs for pain and symptom control seen as central
- Enabling access to medications crucial: depends on external factors
- Some have limited knowledge/ experience = stress
- Lack of resources to support excellent community based palliative care nursing (out of hours especially)
- Heavy responsibility; little power
- Partnership working with GPs not always optimal

Risks ...... Doctor had disciplinary action over drug prescriptions

- Dr Barton's practice of "anticipatory" prescribing allowed nurses to administer the medication where necessary, the hearing was told.
- But the GMC found that in a number of cases prescriptions she had written in anticipation of patients needing strong pain relief the dose range was too wide and lowest doses too high.
- This "created a situation whereby drugs could be administered which were excessive to the patients' needs", the panel said.
- Her actions were "inappropriate, potentially hazardous and not in the best interests of the patient" according to the findings.
Marie Curie Cancer Care End of Life Care Research Programme: first round award (2010)

Understanding the role of nurses in decisions to use anticipatory prescriptions to manage symptoms and distress in the last days of life: a prospective community based case study using mixed methods
(Grant reference: C30627/A12557)

Complementary to and inspired by:
The UNBIASED study (UK - Netherlands - Belgium International SEDation study), funded in the UK by the ESRC [grant no: RES-062-23-2078]
Research questions

- What are the roles and experiences of community nurses in end of life medication decisions?
- In what ways do community nurses work with other members of the health care team to implement prescriptions written in advance of the onset of anxiety, delirium and other difficult symptoms among their patients?
- Community nurses’ decisions to use medications
- How community nurses work with doctors and pharmacists
- Views and experiences of community nurses and other staff
- The ethical / practical issues faced by nurses and other staff
- Influence on care at home (or nursing home) at the time of death
Design: mixed methods

- Ethnography
- Survey
- Systematic review
Phase one: Ethnography (Nov 2011 – May 2012)

• **Observations** - of decision making in relation to anticipatory prescriptions of medication in two regions: Midlands; Lancashire and Cumbria.
  – 4 community nursing teams
  – 4 nursing home teams

• **Interviews** - interviews were conducted with a range of health professionals at each study site

• **Key ethical issues**: ‘opt out’ process for patients and carers
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.
<table>
<thead>
<tr>
<th>Site</th>
<th>Interviews</th>
<th>Observations</th>
</tr>
</thead>
<tbody>
<tr>
<td>Midlands</td>
<td>45</td>
<td>42</td>
</tr>
<tr>
<td>• Community nursing teams</td>
<td>27</td>
<td>14</td>
</tr>
<tr>
<td>• Care home teams</td>
<td>18</td>
<td>28</td>
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<tr>
<td>Lancaster/Cumbria</td>
<td>27 (5 re-interviewed)</td>
<td>41</td>
</tr>
<tr>
<td>• Community nursing teams</td>
<td>23</td>
<td>29</td>
</tr>
<tr>
<td>• Care home teams</td>
<td>4</td>
<td>12</td>
</tr>
<tr>
<td>Total</td>
<td>72</td>
<td>83</td>
</tr>
<tr>
<td>Professions</td>
<td>Interviews conducted</td>
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<td>-----------------------------------------</td>
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<td></td>
</tr>
<tr>
<td>Nursing home nurses</td>
<td>16</td>
<td></td>
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<tr>
<td>District /community nurses</td>
<td>23</td>
<td></td>
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<tr>
<td>OOH District nurses</td>
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<td></td>
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<tr>
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<td></td>
</tr>
<tr>
<td>Community Macmillan nurses</td>
<td>8</td>
<td></td>
</tr>
<tr>
<td>Advanced nurse practitioners</td>
<td>4</td>
<td></td>
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<tr>
<td>Pharmacists</td>
<td>3</td>
<td></td>
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<tr>
<td>Doctors</td>
<td>8</td>
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</tr>
<tr>
<td><strong>Total</strong></td>
<td><strong>72</strong></td>
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Findings related to nurses’ decisions to use AMs

• **Conditions**
  – Nurses identified four main conditions that needed to be met before they would use an AM

• **Aims**
  – Nurses aimed to comfort and settle patients, using the lowest dose possible and to prevent medical call out or transfers to hospital

• **Concerns**
  – Nurses raised concerns about under and over medication, timing of use and risk of hastening death

Emotional burden an overarching theme
Conditions for use of AMs

- Symptoms assessed as both irreversible and due to entry into the dying phase;
- Patient’s inability to take oral medication;
- Patient’s contemporaneous consent gained where possible;
- Decisions to use made independently of influence from a patient’s relatives/ significant others
1. Irreversible symptoms, due to dying phase

97 year old woman, lives with daughter … daughter called 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 fieldnotes of community nurse team discussion, 01.03.2012)
2 and 3: inability to take oral medication / patient’s consent

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 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 fieldnotes of a home visit with community nurses, 10.05.2012)
4. Avoiding influence from patients’ relatives/ significant others

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, interview data 23.02.12)
Aim: to comfort and ‘settle’

- 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, interview data 01.02.2012)

- … 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, interview data 13.03.2012)
Aim: To use the lowest dose possible

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

-Nurse E: Side of caution … 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, interview data 20.04.2012)
Concerns: Not providing enough medication

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, interview data 17.02.2012)
Concerns: Getting the timing right

*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, interview data 12.12.2011).
Concerns: Perceived risk of hastening death

But there's a massive idea with morphine, 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 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. (Care home nurse, 12.12.11)

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, interview data 10.05.2012)
Emotional burden: responsibility/ lack of recognition or resources (time, cpd etc.)

- Seemingly not a moment for reflection on the circumstances and events around dying patients, …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 fieldnotes)
Implications

• Nurses require support to reduce the risk of emotional burden in AM practice
• There may be restrictions on the use of AMs in patients with uncertain prognoses, depending on interpretations of ‘end-of-life’
• The potential for some symptoms being under or untreated as a result of nurses’ concerns and/or system wide practice needs further investigation.
• Some nurses feel under pressure to reduce hospital admissions - whether there may be perverse ‘policy’ incentives to patient centred decisions is a matter for further research.
Conclusion

• This was a completely original study of a core aspect of nursing practice in mainstream community based end-of-life care

• But a number of limitations must be noted
  Complementary interview and observational data, plus respondent validation – a strength

• Triangulation from survey data (not yet published)

• This paper is now published:

Acknowledgements

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