

A qualitative study of community nurses' decision-making around the anticipatory prescribing of end-of-life medications.

Abstract

Aims: To explore community nurses' decision-making processes around the prescribing of anticipatory medications for people who are dying.

Background: Community nurses frequently initiate the prescribing of anticipatory medications to help control symptoms in those who are dying. However, little is known about their decision-making processes in relation to when they instigate anticipatory prescribing and their discussions with families and General Practitioners (GPs).

Design: A qualitative interpretive descriptive enquiry.

Methods: A purposive sample of eleven Community Palliative Nurses and District Nurses working in one geographical area participated. Data was collected between March and June 2016 via audio recorded semi-structured interviews and analysed inductively using Braun and Clarke's thematic analysis.

Results: Three themes were identified: 1) Drugs as a safety net. Anticipatory medications give nurses a sense of control in last days of life symptom management. 2) Reading the situation. The nurse judges when to introduce conversations around anticipatory medications, balancing the need for discussion with the dying person and their family's

likely response. 3) Playing the game. The nurse owns the decision to initiate anticipatory medication prescribing and carefully negotiates with the GP.

Conclusion: Nurses view pain control through prescribed medication as key to symptom management for dying people. Consequently, they own the role of ascertaining when to initiate discussions with families about anticipatory medicines. Nurses believe they advocate for dying person and their families' needs, and lead negotiations with GPs for medications to go into the home. This nurse led care alters the traditional boundaries of the GP-nurse professional relationship.

Keywords: Nursing, District Nursing, Medication, End of Life, Community, Decision-making, Death and Dying, Qualitative methods.

Summary statement

Why is this research or review needed?

- The prescribing of anticipatory medications to prevent pain and distress during the last few days of life is common practice.
- There are significant gaps in knowledge around the process of prescribing which may influence whether drugs are prescribed ahead of need or too late.
- This research will provide insight and guidance about the process of prescribing decision-making for nurses who are caring for dying people.

What are the key findings?

- Participants viewed medication as key to symptom management for dying people and having them in the home prior to need represented a safety net.
- Participants decision-making about the timing of anticipatory medication conversations considered how close to death the person appeared, whilst judging to what extent people were willing to contemplate their impending death.

- Interestingly, nurses in this study believed they led the decision to enable anticipatory medicine prescribing and led negotiations with GPs over what medications go into the home.

How should the findings be used to influence practice and research?

- Although nurses draw reassurance from having anticipatory medications available, the views of people who are dying and their families remain unknown. We suggest exploring individuals' and their families' perceptions of anticipatory medications should be a research priority.
- These findings highlight the need to better understanding the prognostic indicators that identify that someone is likely to be entering the last weeks of their life, to help inform the timely initiation of anticipatory prescribing.

Introduction

Aging populations worldwide are drawing political, public and clinical attention to the need to provide good quality end-of-life home care (Gnomes *et al.* 2012, World Health Organisation 2016). District Nurses and Community Palliative Nurses (see Box 1) have a key role in supporting terminally ill adults to die at home with dignity and respect, and in managing pain and other symptoms proactively (Sandgren *et al.* 2007, Burt *et al.* 2008, Department of Health (DH) 2008, Griggs 2010). For some individuals, supporting them to die at home involves putting in place anticipatory medications which can be given to relieve distressing symptoms in their final days of life (Faull *et al.* 2013, National Institute for Health and Care Excellence (NICE) 2015, Wilson *et al.* 2016).

INSERT BOX 1

Across the United Kingdom (UK), Australia, and in some areas of Canada and the United States of America, anticipatory prescribing has been actively encouraged to minimise the risks of people having uncontrolled symptoms or distress and to prevent unnecessary crisis admissions to hospital (Amass & Allen 2005, Wowchuk *et al.* 2009, Yap *et al.* 2014, British Medical Association (BMA) 2016). Anticipatory medications (see Box 2) are kept in the home and are primarily administered as injections by practitioners if the person becomes unable to take oral medications and develops symptoms of pain, nausea, agitation or respiratory secretions when they are dying (NICE 2015, Scottish Palliative Care Guidelines (SPCG) 2015).

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In the UK, public concerns over the now withdrawn Liverpool Care Pathway (LCP) have led to greater scrutiny of end-of-life prescribing practices. The LCP offered an explicit framework for practitioners on patient care in the last days of life (Veerbeek *et al.* 2008). Neuberger *et al.* (2013) in their critical review of the LCP's use across the UK, highlighted the dangers of over-sedation when anticipatory medications are prescribed without clear individualised rationale, or involving the person and their families in decision-making. Subsequent last days of life care guidance, replacing the LCP in the UK, has reiterated that individualised anticipatory prescribing is considered part of best practice (NICE 2015, SPCG 2015).

Background

Community nurses in the UK play a key role in initiating the prescribing of anticipatory medications. Anquinet *et al.* (2015) in a multiple case study covering Belgium, the Netherlands and the UK, found uniquely to the UK cases, it was the community nurse who encouraged the General Practitioner (GP) to prescribe anticipatory medications in case they became needed. Wilson *et al.* (2016) surveyed 574 community nurses' experiences of anticipatory prescribing across two regions of England and found 60% of respondents identified that "in approximately 60% of incidents" they initiated decisions to prescribe medications.

There is insufficient knowledge about the nature of conversations that take place between nurses and/or GPs with individuals and their families around prescribing anticipatory medication (NICE, 2015). In two UK qualitative studies, Griggs (2010) and Griffiths *et al.* (2015) found District Nurses perceived that having open and honest conversations with families and patients about the dying process was important in proactively managing symptoms. Although both studies offer insights into District Nurses end-of-life care values and perceptions, neither study explored views or experiences around anticipatory medications conversations.

Furthermore, there is limited understanding of practitioner's decision-making around the timing of initiating such conversations. Faull *et al.* (2013), in a qualitative study exploring the challenges in anticipatory prescribing across one area in England, identified that GPs and nurses felt having enough contact with patients to build up a rapport and trusting relationship was central in enabling sensitive and timely conversations. Most participants discussed and prescribed medications "a few days" before actually being needed. Practitioners who initiated anticipatory prescribing a few weeks ahead of need did not perceive any issues providing there was good interprofessional communication.

Nurses initiating the prescribing of anticipatory medications discuss the patient's needs with the individual's GP and ask them to prescribe the drugs (Wilson *et al.* 2014). Explorative studies show that knowing and trusting other professional's judgements appears central to the successful prescribing of anticipatory medications (Faull *et al.* 2013, Anquetin *et al.* 2015). Griggs (2010) identified a lack of knowledge about end-of-life care among GPs

together with heavy reliance on nurses to specify what to prescribe. In contrast, the nurses expressed discomfort with having this responsibility placed upon them.

The research highlights several linked gaps in knowledge around the prescribing of anticipatory medications which may influence whether drugs are prescribed ahead of need or too late. More explorative research is needed to understand District Nurses and Community Palliative Nurses perspectives on initiating anticipatory prescribing. This knowledge will contribute to our understanding of nurses' end-of-life home care practice around anticipatory prescribing.

The study

Aims

The aim of this study was to explore community nurses' decision-making processes around the prescribing of anticipatory prescribing for people who are dying. The research question was "What are community nurses' perceptions of their decision-making in initiating end-of-life anticipatory medications?"

Design

This was an interpretive descriptive qualitative study (Thorne 2008). This inductive methodology is driven by the underlining philosophical argument of letting interpretations of reality around the phenomenon emerge from participant's experiences and views

(Weaver and Olson 2006). Interpretative description particularly lends itself to inductively exploring clinically orientated research questions (Thorne *et al.* 1997) and recognises the intricacies of knowledge shaped through researcher-participant interactions (Sandelowski 2000, Vaismoradi *et al.* 2013).

Sample

This study was conducted in a 350 square mile geographical locality covering rural and urban communities in one area of England. Purposive sampling was used to ensure a wide range of nurse stakeholders' perspectives (Palys, 2008). The inclusion criteria were:

Community Palliative Nurses and District Nurses who have had direct clinical involvement in prescribing anticipatory medications to individuals with terminal illnesses. The exclusion criteria were: Community Palliative Nurses and District Nurses with no experience in initiating the prescribing of anticipatory medications or no longer clinically practicing.

Community Palliative Nurses were contacted directly by email by the first author. The District Nurses worked in a different NHS Trust to the first author and their clinical lead acted as a gatekeeper, selecting potential participants and forwarding an email invitation to take part.

Data collection

Data was collected through face to face interviews, using a semi-structured interview guide, between March and June 2016. The interview guide consisted of open-ended questions and

prompts to encourage participants to openly convey their views around participant's experiences of putting in place anticipatory medications, and their perceptions of their conversations with others in doing so (Tod 2015 p.391). **The interview guide was continually adapted in response to emerging data (Braun & Clarke 2013, p85). The main focus of the study was on nurses' decision-making and novel themes around this stopped emerging after nine interviews. Nevertheless, a further two interviews were conducted to ensure we had sufficient context to explain our findings**

Interviews were conducted in a private room at the participant's work base or a hospital site and audio recorded. Interviews ranged from 27 to 57 minutes in length (mean= 39 minutes). Important features of each participant's responses and initial ideas for data analysis were documented by the first author in field notes after each interview. These informed the data analysis alongside interview transcripts (Braun & Clarke 2013 p.93).

Ethical considerations

Ethical approval was obtained from a University's Ethics Committee. Research governance approval was granted by the Trusts employing participants. **Written informed consent was obtained prior to interviewing participants'**. Discussing end-of-life care experiences, especially events perceived to have not gone well, can cause professional's emotional discomfort (Burt *et al* 2008). Participants were given time to debrief after their interview and provided with information on clinical supervision and counselling support. Participants were given the option of pausing interviews or withdrawing from the study at any time,

including after data collection, without giving a reason (Tod 2015 p.396). No participants withdrew from the study.

Data analysis

Interview recordings were transcribed verbatim to thoroughly capture the language used. Data was interpreted inductively using Braun and Clarke's (2013) phases of thematic analysis. Thematic analysis was adopted for its epistemological fit with interpretative description (Braun & Clarke 2006, Vaismoradi *et al.* 2013). This involved transcribing audio data; checking it against recordings for accuracy; familiarisation with the data; generating initial codes; searching for themes; reviewing themes; defining and naming themes; producing the report. Transcripts were initially coded by the first author. To ensure a rigorous level of analysis, the second author coded sections of three transcripts independently and the coding decisions were compared and reflected upon. This challenged, complemented and informed the developing analysis. An electronic database of codes and data abstracts were compiled using Microsoft Word© and these were revised during the iterative process.

Rigour

Lincoln and Guba's (1985) trustworthiness criteria were used to ensure researcher-participant's constructed realities were robust and systematic. Descriptions of the setting, data collection methods and the sample's demographic characteristics are presented to enable readers to judge the transferability of findings to their own practice (Lincoln & Guba 1985 p.316). An audit trail of decision-making processes, in moving from initial codes to final themes, were recorded in field notes. These were reviewed throughout the data analysis process. To ensure a rigorous level of iteration the first author cross-checked key decision points in the thematic analysis process with the second author, including the final candidate themes (Braun & Clarke 2006, Rapley 2011).

Findings

Eleven community nurses participated in this study: seven Community Palliative Nurses (mean years qualified= 23) and four District Nurses (mean years qualified= 18). Three of seven Community Palliative Nurses (42.9%) and one of four District Nurses (25%) held the Nurse Independent Prescriber qualification (see Box 1). **Pseudonyms have been used in quotes.**

Three overarching themes were constructed from the data: 1) Drugs as a safety net; 2) Reading the situation; and 3) Playing the game.

Theme: Drugs as a safety net

Anticipatory medications represent a safety net and give nurses a sense of control in managing an individual's last days of life symptom management. The prospect of a dying person being in distress and a practitioner being unable to act to relieve suffering was psychologically unsettling for nurse participants. They also believed that dying individuals, and their families, worried about developing uncontrolled pain or sickness and drew reassurance from knowing anticipatory medications and professional support were there if needed. Nurses felt more in control of the situation if they knew there were drugs available in the home which could be administered if the person quickly deteriorated and became distressed when they were dying:

Not only is it the families comfort, it's for us as well. I feel comfortable knowing they're there, that they're in the house ready because you do have an understanding that they are gradually deteriorating but it can change from day to day. (Alex, District Nurse)

Participants universally felt it particularly important to get medications in place to cover out-of-hour periods when practitioners who know the person are not working. Although there is access to care at these times, nurses worried that individuals might not get effective symptom management, due to out-of-hours GPs not knowing the situation and as it takes time to get medications prescribed and into the home. Conversely, participants did not want to act too prematurely in putting drugs in place. Placing medications in people's homes introduced risks around drugs going missing or being misused. The desire to get medications in place if an individual's death appears imminent is captured in the following comment:

We always try and anticipate when we've got a weekend coming up. Does this person look as though they could probably go downhill? Yes, right we need to get the drugs in before the weekend, because that is our worst nightmare, to not have anything in place. (Carly, District Nurse)

Some nurses focused on the importance of medications in supporting people in their last days of life above other support and psychosocial interventions. Other participants contextualised the role of medications as being just one aspect of holistic care. In the following excerpt, Helen was frustrated that some practitioners did not think beyond anticipatory medications when planning care with families:

I do think sometimes we feel that if we have got the just in case meds [anticipatory medications] that's it we have done everything when it's only the tip of the iceberg if you have got them in there really. (Helen, Community Palliative Nurse)

Theme: Reading the situation

Nurses judge when to introduce conversations around anticipatory medications, raising the subject in a manner with which they feel is timely and appropriate. Participants perceived that individuals and their families viewed the introduction of anticipatory medications as being a clear signal that the person was closer to death. In the following quote, Chloe recognised that introducing the concept of anticipatory medications into conversations with

individuals could cause distress although it could also serve to help people understand that they were dying:

You can see their face sort of go ... oh do I need them then, am I going to need them then? Oh now we're talking injections. You can almost hear the cogs working it can be a little bit of a warning shot. Things are changing. (Chloe, Community Palliative Nurse)

Respecting an individual's wishes and involving them and their families in deciding when to have medications in the home was central to participants' decision-making. How information was discussed, around the potential for people to have distressing symptoms in their last days of life, depended on how open individuals and their families were about dying and how comfortable the nurse felt about having these conversations. Some nurses tended to focus anticipatory medication conversations on practical information around what the drugs do and specifically how to access help when needed. Concentrating on practical aspects of care enabled nurses to maintain a more neutral conversation focus. As illustrated in the following extract, this approach to conversations with individuals played down topic areas which might cause people distress:

You would hope to have that conversation to say it may be that we don't need to do any intervention, we have got these drugs just in case ... The just in case drugs are there in case we need them, if you need an injection you can have one. (Max, District Nurse)

Participants who voiced a preference to openly explore individual's worries about dying described actively discussing with people what might happen in their last days of life and how this could be managed at home. As shown in the following extract, this helped shift the focus of conversations onto exploring individuals' concerns, the symptoms they may experience and the type of care that could be realistically provided:

I think sometimes relatives and patients just cope if they know what could happen... talking about just in case medications opens a can of worms about symptoms, about what we can do in the community and what we can't. You know what's feasible and what's not. (Helen, Community Palliative Nurse)

Participants preferred to have built up a rapport with a terminally ill person before opening conversations around end-of-life care planning including anticipatory prescribing. This gave them time to earn the person's trust, understand family dynamics and respond to cues that the person is ready to have end-of-life care discussions. There were situations where people were not ready for medications to go into the home and nurses interpreted this as individuals or their families being in denial about being closer to death. Although participants respected individual's wishes to not think about dying, this caused internal tensions for the nurses. In the following quote, Chloe's ideals of ensuring an individual's autonomy is at the heart of care decisions conflicted with her desire to put in place anticipatory care to facilitate a comfortable and dignified death:

It has to be patient focused and it has to be the right time for them. Equally sometimes you need to... it's hard, that's what makes our job so hard I think. And

not to beat yourself up you know if there's not a DNAR [Do Not Attempt Resuscitation decision] in place because they didn't want it, they didn't want it.

(Chloe, Community Palliative Nurse)

There were also times when participants had to force end-of-life conversations when they received late referrals and first met a person when they were in their last days of life. As identified in the following extract, end-of-life conversations were perceived as being more challenging if there was insufficient time to build a rapport:

Sometimes there's not enough of a build up ... because you've been referred somebody who's very poorly ... You're having to get just in case medications on that first day that you meet them and talk about DNAR and all the rest of it, and that can be quite overwhelming I think for the patient and their family. (Sue, Community Palliative Nurse)

Nurses found it challenging to accurately predict when someone is likely to die. Participants identified and acted on changes which indicated a person was in the last weeks of their life. These signs included observing when a person was starting to struggle to take oral medications or becoming increasingly fatigued. All the nurses demonstrated an intrinsic knowledge that death was approaching and that it was time to put in place anticipatory medications. As illustrated in the following excerpt, recognising dying came with experience and at times required picking up on subtle signs:

There might be little hints ... “You know the last couple of days I’ve noticed mum’s not eating as much as she normally is”. And you think to yourself okay but she’s still able to take her medication, and then you start think well maybe we should get them [anticipatory medications] in now. (Alex, District Nurse)

Theme: Playing the game

Getting anticipatory medications in place involves nurses owning the decision to initiate prescribing and carefully negotiating with GPs over what to prescribe. As the practitioners, most frequently visiting individuals at home, participants viewed themselves as acting as the eyes and ears of the GP. They would inform the GP when they felt it was time to get anticipatory medications in place. Nurses believed that most GPs looked to them to initiate these end-of-life care decisions as the nurses were perceived as having more expertise in supporting terminal care:

Actually from what I have experienced generally, the GPs a lot of them, as soon as someone has been deemed palliative, they kind of, they kind of feel a bit out, well I’m not sure they are out of their depth is the right word, they like to pass on a lot of the stuff over to the nurses. (Kelly, District Nurse)

Participants adopted a negotiation tactic to decision-making about medications with GPs. Participants perceived some GPs lacked up to date end-of-life drug knowledge and needed persuading to prescribe for all likely terminal symptoms. If GPs had different prescribing preferences to the nurse, providing these decisions were safe, the nurses would

make compromises to avoid damaging their working relationships. Nurses tailored their approach to the GPs knowledge and confidence in end-of-life prescribing. This involved making suggestions on what drugs and doses should be prescribed if the GP asked their advice or the nurse felt they needed to advocate for individuals' likely needs:

They sometimes say "we don't know what to prescribe. You know what it is and what do you think is needed?" (Max, District Nurse)

It helped when there was an established relationship of trust where the GP and nurse knew and respected each other's clinical skills. This led to effective working relationships where the nurse's views were valued but also vetted by the GP so prescribing decisions were shared. Participants, including those who could independently prescribe medications, preferred decisions to be shared as the GP was perceived to be knowledgeable and ultimately responsible for the person's care. The following quote illustrates that shared decision-making is perceived as being crucial in ensuring drug choices are safe and appropriate:

It's very rare that your suggestions are ignored. The problem is I don't like the doctors that say no to everything and I don't like doctors who say yes to everything, I like the negotiation. (Rene, Community Palliative Nurse)

Participants found that some GPs worried that medications might be used inappropriately. To ensure GPs prescribed medications when the nurse felt they were needed, participants used a variety of tactics to keep GPs up to date with the person's

deteriorating condition. These included asking the person to establish regular contact with their GP and discussing the individual's case at multidisciplinary team meetings.

District Nurses tended not to experience conflict in decision-making with GPs. They had established close working relationships with a smaller number of GPs and viewed them as being more knowledgeable about prescribing choices. Conversely, most Community Palliative Nurses experienced occasional conflicts with GPs in prescribing choices particularly when both parties tried to take the lead role in decision-making. Community Palliative Nurses valued specialist expertise over the knowledge of the GP in these situations and recognised this could cause conflict:

They don't always agree with me and sometimes you have to choose your battles, but ultimately you have got to do what's right for the patient ... I'm not afraid to be the advocate and push that forward. (Debbie, Community Palliative Nurse)

Discussion

This study offers insight into community nurses decision-making around initiating anticipatory prescribing. As Faull *et al.* (2013) and Wilson *et al.* (2015) previously identified, nurses in this study universally believed in the importance of having individually tailored anticipatory medicines available in the home. This study builds on the existing research by illuminating that nurses' decision-making in initiating prescribing is driven by a desire to give individuals and their families' reassurance, and themselves some control in managing any distressing terminal symptoms. Earlier research suggests that being unable to proactively

manage last days of life care and feeling powerless to relieve suffering causes nurses distress and is emotionally draining (Glasberg *et al.* 2007, Sandgren *et al.* 2007). Participants in the current study tended to experience heightened emotional tensions when individuals did not wish to consider planning for their last days of life but rationalised that they had done all they could by respecting individuals' wishes and autonomy.

Medications came across as the predominate intervention nurses perceived could help dying individuals. Whilst this study did not seek out to explore other ways of soothing dying persons, this was not offered by most participants. This may reflect the increasing reliance on medications to resolve or manage problems from both the public and practitioners (Busfield 2010, 2015). Conversely, Lindqvist *et al.* (2012) identified that professionals across nine countries acknowledged that non-pharmacological caregiving in last days of life was multifaceted and that the act of being there for people and their families was as important as physically giving care. However, last days of life care guidance is dominated by recommendations around the role of pharmacological interventions (NICE 2015, SPCG 2015). Griffiths *et al.* (2010) in a small observational study found community nurses avoided time consuming psychological interventions when they felt out of their comfort zone. The findings of our study suggest that further research is needed into understanding practitioners' perceptions and use of psychosocial interventions in last days of life care.

Participants' insights into their conversations around initiating anticipatory prescribing gives a voice to previously unheard complex decision-making and skilled conversations. Decision-making around conversations with individuals and their families

considered that individuals would perceive the introduction of anticipatory medications as a sign they could die soon. The nurses based their decision-making about the timing of conversations on how close to death the person appeared, whilst judging to what extent people were willing to have conversations about their impending death.

Identifying that someone is in the last weeks of their life was seen by the participants to be a major antecedent to initiating the prescribing of anticipatory medications. The signs that someone was in the last weeks of their lives are subtle and at times unpredictable (Faull *et al.* 2013). In the current study, it proved difficult for participants to quantify some of the signs they used and this knowledge tended to be learned through experience. Subtle cues that indicated someone could be in the last weeks of their lives include progressive unintended weight loss, increasing fatigue, dyspnoea, and a loss of appetite (Gold Standards Framework 2011, Griffiths *et al.* 2015). The signs that someone was approaching their last days of their life became clearer as time progressed but waiting risked missing the opportunities to get the medications in ahead of need.

Community nurses are ideally placed to spot early signs but they need the training, experience and confidence to know when to act upon them. The current study supports the need to develop robust prognostic indicators which community practitioners can use to identify the signs that someone is in the last weeks of their lives (NICE 2015).

Participants found it more rewarding and less stressful when they could build relationships of trust with families over several home visits before initiating discussions about end-of-life care. Luker *et al.* (2000) also found that building a rapport with families helps community nurses to uncover individual's understanding of their terminal diagnosis

and facilitate discussions about last days of life care. Echoing Luker *et al.* (2000) observations, if families were culturally open about death and dying, participants in the current study were more comfortable starting anticipatory medication conversations earlier. Participants showed a degree of paternalism if they sensed conversations might cause distress. Some nurses tended to explain what the medications were for in a way which played down the risks of developing distressing symptoms. This reflects Millard *et al.* (2006) ethnographical observations that the way community nurses involve individuals in decision-making, about their care in the home setting, varies considerably and is shaped by the nurse's preferences and own comfort zone. **Nurses ability to engage in interpersonal conversations about end-of-life depends upon their experience as well as personal and situational factors. Nurses own comfort zones have a direct impact on the nature of care planning for the dying.**

Participants universally prompted the GP to prescribe anticipatory medications when needed. Just as Faull *et al.* (2013) and Wilson *et al.* (2016) identified, this study found good interprofessional relationships were crucial in facilitating the prescribing of anticipatory medications. The current study adds further insight into the negotiation skills and tactics used by nurses, including leading decision-making when individual GPs were less experienced in end-of-life prescribing. Griggs (2010) concluded that nurses were frustrated and uncomfortable when GPs looked to them to recommend drugs and doses. In contrast, participants in the current study believed it was their role to make prescribing recommendations but they also drew upon the GPs skills to ensure the best decision was made. Participants who could prescribe independently still wanted the security of sharing decision-making with GPs.

Asking for anticipatory medications to be prescribed, especially controlled drugs, challenges the conventional GP-nurse working relationships in which the GP is historically seen to be the expert. Hudson's (2002) multiple site study of community interprofessional working found deep-rooted social and cultural differences remain where GPs are viewed as "full professionals" while nurses are perceived as a "semi-professionals" due to perceived limitations around their knowledge base and autonomy. The current study reflects that traditional role hierarchies and boundaries are becoming less distinct in practice. Although, the clinical accountability for prescribing remains with the GP unless the nurse holds an independent prescriber qualification (BMA 2016). Participants felt GPs were happy with them taking the lead in end-of-life care as the nurse was perceived to be more knowledgeable in this area. This fits with Walshe *et al.* (2010) findings that nurses often take the lead in community palliative care as this helps them exert influence and authority in their relationships with GPs without officially challenging the traditional GP- nurse hierarchy. However, in the current study participants experienced conflict when they and the GP both tried to take the lead in decision-making. This may stem from both practitioners gaining emotional satisfaction from overseeing care and working with the individual's and their families (Brown *et al* 1998, Walshe *et al* 2010). **In practice, effective decision-making occurs when nurses and GPs have built relationships of mutual respect and have established good lines of communication.**

Strengths and limitations

This study offers insights into nurses' perspectives on an area of under-researched and important end-of-life care practice. Results from this study cannot be generalised as participants were purposively sampled from one geographical locality. However, the sample size gave a meaningful picture of perceptions across the geographical area (Braun & Clarke 2013 p45) and may be transferable to similar community settings.

Accessing District Nurses through a gatekeeper created practical difficulties in ensuring a broad range of viewpoints (Oppong 2013). To abide by data protection laws, it was necessary to access potential District Nurse participants through their clinical lead who then selected whom to contact. District Nurses with less experience than the participants who were selected to be contacted may have perceived decision-making differently. Gatekeepers frequently fail to select certain individuals or groups to participate in research studies which can lead to bias towards the views of the selected participants in the findings (Rose et al. 2017).

The role of the first author as a clinical researcher and Community Palliative Nurse helped in understanding the culture within which participants worked. However, there were times where participants assumed the researcher had pre-existing insight into other aspects of their care and did not elaborate on their practice in the same way they would have with a researcher external to the clinical environment. Similarly, data was interpreted in part through a clinical lens by the first author. Checking developing themes with the second author helped refine analysis and ensured interpretations had credibility (Shenton 2004).

Conclusions

This study has shown the importance of anticipatory medicine prescribing to nurses' management of terminally ill people in the community. Nurses believe they have the skills and knowledge to conduct discussions with individuals' and their families about anticipatory medicines. Nurses in this study largely believed they led the decision to enable anticipatory medicine prescribing and led negotiations with GPs over what medications go into the home. However, the ultimate prescribing responsibility and accountability remains with the GP. To better understand what happens in practice, it would be helpful to explore GPs perspectives of anticipatory prescribing and their decision-making processes. **Modern health care is underpinned by notion of a "pill for every ill" and this can influence nurses' decision-making. However, this approach can overlook the importance of psychosocial support in the last few days of life which may be as timely and valuable.**

The findings of this study highlight that nurses perceive individuals and their families take reassurance from having anticipatory medications available. However, the views of people who are dying and their families' are unknown. It is pertinent to determine their perception of anticipatory medications, and how these fit with their care experience as a whole, including any unmet needs. In addition, decisions to instigate anticipatory medication prescribing are reliant on practitioners identifying that individuals are in their last weeks of life. The nurses in this study at times relied on tacit knowledge to identify that someone was approaching death. Research into the prognostic indicators community practitioners use, to identify that someone is likely to be entering the last weeks of their life, would inform the timely initiation of anticipatory prescribing.

References

Amass C. & Allen M. (2005) How a “just in case” approach can improve out-of-hours palliative care. *The Pharmaceutical Journal*. Available at: <http://www.pharmaceutical-journal.com/opinion/comment/how-a-just-in-case-approach-can-improve-out-of-hours-palliative-care/10019364.article> (Accessed 3 September 2016).

Anquinet L., Rietjens J., Mathers N., Seymour J., Van der Heide A. & Deliens, L. (2015) Descriptions by general practitioners and nurses of their collaboration in continuous Sedation until death at home: In-depth qualitative interviews in Three European countries. *Journal of Pain and Symptom Management* **49**(1), 98–109.

Braun V. & Clarke V. (2006) Using thematic analysis in psychology. *Qualitative Research in Psychology* **3**, 77-101.

Braun V. & Clarke V. (2013) *Successful qualitative research: A practical guide for beginners*. Sage Publications, London.

British Medical Association (2016) *Focus on anticipatory prescribing for end-of-life care*. British Medical Association, London. Available at: <http://bma.org.uk/support-at-work/gp-practices/service-provision/prescribing/focus-on-anticipatory-prescribing-for-end-of-life-care> (Accessed 3 September 2016).

Brown J., Sangster M. & Swift J. (1998) Factors influencing palliative care: qualitative study of family physicians' practices. *Canadian Family Physician* **44**, 1028-1034.

Burt J., Shipman C., Addington-Hall J. & White P. (2008) Nursing the dying within a generalist caseload: a focus group study of district nurses. *International Journal of Nursing Studies* **45**(10), 1470-1478.

Busfield J. (2010) 'A pill for every ill': Explaining the expansion in medicine use. *Social Science & Medicine* **70**, 934-941. Doi:10.1016/j.socscimed.2009.10.068

Busfield J. (2015) Assessing the overuse of medicines. *Social Science & Medicine* **131**, 199-206.

Department of Health (2008) *End of life care strategy: Promoting high quality care for adults at the end of their life*. Department of Health, London. Available at: https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/136431/End_of_life_strategy.pdf (Accessed 3 September 2016).

Faull C., Windridge K., Ockleford E. & Hudson M. (2013) Anticipatory prescribing in terminal care at home: What challenges do community health professionals encounter? *BMJ Supportive & Palliative Care* **3**(1), 91-97.

Glasberg A., Eriksson S. & Norberg A. (2007) Burnout and 'stress of conscience' among

healthcare personnel. *Journal of Advanced Nursing* **57**(4), 392-403.

Gnomes B., Higginson I., Calanzani N., Cohen J., Deliens L., Daveson B., Bechinger-English D., Bausewein C., Ferreira P., Toscani F., Menaca A., Gysels M., Ceulemans L., Simon S., Pasman H., Albers G., Hall S., Murtagh F., Haugen D., Downing J., Koffman J., Pettenati F., Finetti S., Antunes B. & Harding R. (2012) Preferences for place of death if faced with advanced cancer: a population survey in England, Flanders, Germany, Italy, the Netherlands, Portugal and Spain. *Annals of Oncology* **23**, 2006-2015. doi:10.1093/annonc/mdr602

Gold Standards Framework (2011) *Prognostic indicator guidance (PIG)*. 4th edn. The Gold Standards Framework Centre in End of Life Care. Available at:

<http://www.goldstandardsframework.org.uk/cd-content/uploads/files/General%20Files/Prognostic%20Indicator%20Guidance%20October%202011.pdf> (Accessed 1 September 2016).

Griffiths J., Ewing G. & Rogers M. (2010) "Moving Swiftly On." Psychological support provided by District Nurses to patients with palliative care needs. *Cancer Nursing* **33**(5), 390-397.

Griffiths J., Ewing G., Wilson C., Connolly M. & Grande G. (2015) Breaking bad news about transitions to dying: a qualitative exploration of the role of the district nurse. *Palliative Medicine* **29**(2), 138-146.

Griggs C. (2010) Community nurses' perceptions of a good death: A qualitative exploratory study. *International Journal of Palliative Nursing* **16**(3), 140–149.

Hudson B. (2002) Interprofessionalism in health and social care: the Achilles' heel of partnership? *Journal of Interprofessional Care* **16**(1), 7-17.

Lincoln Y. & Guba E. (1985) *Naturalistic inquiry*. United States: Sage Publications.

Lindqvist O., Tishelman C., Hagelin C., Clark J., Daud M., Dickman A., Benedetti F., Galushko M., Lunder U., Lundquist G., Miccinesi G., Sauter S., Furst C. & Rasmussen B. (2012)

Complexity in Non-pharmacological caregiving activities at the end of life: an international qualitative study. *PLoS Medicine*. Available at:

<http://journals.plos.org/plosmedicine/article?id=10.1371/journal.pmed.1001173> (Accessed 4 January 2017). Doi: <http://dx.doi.org/10.1371/journal.pmed.1001173>

Luker K., Austin L., Caress A. & Hallett. (2000) The importance of 'knowing the patient': community nurses' constructions of quality in providing palliative care. *Journal of Advanced Nursing* **31**(4), 775-782.

Millard L., Hallett C. & Luker K. (2006) Nurse-patient interaction and decision-making in care: patient involvement in community nursing. *Journal of Advanced Nursing* **55**(2), 142-150.

National Institute for Health and Care Excellence (2015) *Care of dying adults in the last days of life*. National Institute for Health and Care Excellence, London. Available at: <http://www.nice.org.uk/guidance/ng31/evidence/full-guideline-2240610301> (Accessed 3 September 2016).

Neuberger J., Guthrie C., Aaronovitch D., Hameed K., Bonser T., Harries., Charlesworth-Smith D., Jackson E., Cox D. & Waller S., (2013) *More care less pathway: review of the Liverpool Care Pathway*. London. Available at: https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/212450/Liverpool_Care_Pathway.pdf (Accessed 3 September 2016).

Oppong S. (2013) The Problem of sampling in qualitative research. *Asian Journal of Management Science and Education*. Available at: [http://www.ajmse.leena-luna.co.jp/AJMSEPDFs/Vol.2\(2\)/AJMSE2013\(2.2-21\).pdf](http://www.ajmse.leena-luna.co.jp/AJMSEPDFs/Vol.2(2)/AJMSE2013(2.2-21).pdf) (Accessed 8 September 2016).

Palys T. (2008) Purposive sampling. In *The Sage Encyclopedia of Qualitative Research Methods* (Given L. ed). Vol.2. Sage: Los Angeles, pp. 697-698.

Rapley T. (2011) Some pragmatics of data analysis. In *Qualitative research: Issues of theory, method and practice* (Silverman D. ed.) 3rd edn. Sage Publications, London.

Rose J., Akister J. & **Redsell S. (2017 – publication pending)** Do Families With Mental Ill Health Have a ‘Voice’? Gatekeeping in health and social care research? *Accepted by Parental*

Sandelowski M. (2000) Whatever happened to qualitative description? *Research in Nursing & Health* **23**, 334-340.

Sandgren A., Thulesius H., Petersson K. & Fridlund B. (2007) "Doing good care" – a study of palliative home nursing care. *International Journal of Qualitative Studies on Health and Well-being* **2**, 227-235.

Scottish Palliative Care Guidance (2015) *Care in the last days of life*. NHS Scotland. Available at: <http://www.palliativecareguidelines.scot.nhs.uk/guidelines/end-of-life-care/care-in-the-last-days-of-life.aspx> (Accessed 13 October 2016).

Shenton A. (2004) Strategies for ensuring trustworthiness in qualitative research projects. *Education for Information* **22**(2), 63-75.

Thorne S. (2008) *Interpretive description*. Walnut Creek, CA: Left Coast Press.

Thorne S., Kirkham S. & MacDonald-Emes J. (1997) Interpretive description: a noncategorical qualitative alternative for developing nursing knowledge. *Research in Nursing & Health*, **20**(2), 169-177.

Tod A. (2015) Interviewing. In *The research process in nursing* (Gerrish k. & Lathlean J. eds.). 7th edn. Wiley-Blackwell, United Kingdom, pp. 387-400.

Twycross R., Wilcock A. & Howard P. (2014) *Palliative Care Formulary*. 5th edn.

Palliativedrugs.com Ltd, Nottingham.

Vaismoradi M., Turunen H. & Bondas T (2013) Content analysis and thematic analysis:

Implications for conducting a qualitative descriptive study. *Nursing and Health Sciences*

15(3), 398-405.

Veerbeek L., Zuylen L., Swart S., van der Mass P., Swart S., Vogel-Voogt E., van der Rijt C. &

van der Heide A. (2008) The effect of the Liverpool Care Pathway for the dying" a multi-

centre study. *Palliative Medicine* 22, 145-151. doi: 10.1177/0269216307087164

Walshe C., Caress A., Chew-Graham C. & Todd C. (2010) Nurses' feelings of 'ownership' of palliative care patient: findings from a qualitative case study. *Progress in Palliative Care*

18(6), 346-351.

Weaver K. & Olson J. (2006) Understanding paradigms used for nursing research. *Journal of Advanced Nursing* **53**(4), 459-469.

Wilson E., Morbey H., Brown J., Seale C. & Seymour J. (2015). Administering anticipatory medications in end-of-life care: a qualitative study of nursing practice in the community and in nursing homes. *Palliative Medicine* **29**(1), 60-10.

Wilson E., Seymour J., Morbey H., Payne S., Brown J. & Seale C. (2014). Anticipatory prescribing in end-of-life care. *Nursing Times* **110**(44),24-25.

Wilson E., Seymour J. & Seale C. (2016) Anticipatory prescribing for end of life care: a survey of community nurses in England. *Primary Health Care* **26**(9), 22-27. doi: 10.7748/phc.2016.e1151

World Health Organisation (2016) *Palliative care for non-communicable diseases: a global snapshot in 2015*. World Health Organisation. Available at: http://apps.who.int/iris/bitstream/10665/206513/1/WHO_NMH_NVI_16.4_eng.pdf?ua=1 (Accessed 20 October 2016).

Wowchuk S., Wilson E., Embleton L., Garcia M., Harlos M. & Harvey M. (2009) The palliative medication kit: and effective way of extending care in the home for patients nearing death. *Journal of Palliative Medicine* **12**(9), 797-803.

Yap R., Akhileswaran R., Heng C., Tan A. & Hui D. (2014) Comfort care kit: Use of nonoral and nonparenteral rescue medications at home for terminally ill patients with swallowing difficulty. *Journal of Palliative Medicine* **17**(5), 575-578. doi:10.1089/jpm.2013.0364.