Timely symptom management at end of life using 'just in case' boxes

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ABSTRACT

This article discusses the successful implementation of anticipatory prescribing using 'just in case' boxes (JICB) in primary care across the Grampian region and a subsequent follow up survey one year later. The implementation approach used local educational sessions to primary care clinicians. The survey was distributed to 65 primary care bases to gauge awareness and use of the JICB and thoughts about how the box was used. An estimate of prescription costs was undertaken using stock balance forms. The response rate was 89%. All respondents had heard about the JICB and most had used a JICB. There were 37 positive comments about the benefits to patients, 15 comments about the process and 11 negative comments, often about possible drug wastage. The cost of a prescription was estimated at £22.12. The findings have informed our ongoing educational programme and build on the strong links that exist between primary care and the specialist palliative care service.

KEY WORDS

Anticipatory prescribing • Palliative care • End-of-life care • Primary care

The aim of this article is to discuss the implementation of anticipatory prescribing at the end of life using 'just in case' boxes (JICB), in primary care settings across the NHS Grampian region in 2010–2011. Anticipatory prescribing for patients at the end of life is defined as the 'proactive prescription of injectable drugs commonly used at the end of life, which are then available in the home on an "if needed" basis' (Twycross and Wilcock, 2011).

The particular symptoms that can be anticipated in patients who are dying include restlessness, pain and respiratory tract secretions (Ellershaw et al, 2001). The aim of anticipatory prescribing is to respond promptly to these symptoms in a planned way (Scott-Aiton, 2009). This need for planning ahead is important; Taubert and Nelson (2010) highlight the difficulties faced by GPs working out of hours, when trying to access medications for palliative patients who are at the end of life. Although not mentioned in the literature, this pro-active approach to end-of-life care applies to community nursing staff as well.

The NHS Grampian Strategy Group for palliative care was allocated the task of implementing the Scottish Government's national action plan for palliative and end-of-life care (Scottish Government, 2008). Action point 6 in this plan refers to the use of anticipatory prescribing. Although this is not a new concept in end-of-life care (Amass, 2006), the regular use of anticipatory prescribing in the form of 'just in case' boxes was new to many primary care settings across NHS Grampian.

Anticipatory prescribing at the end of life forms an important element of the NHS Grampian Integrated Palliative Care Plan (Denholm et al, 2012), which builds on the work of the Gold Standards Framework (Gold Standards Framework, 2012) and our aim to avoid additional paperwork. The plan's emphasis has been on the identification of the palliative patient using the Supportive and Palliative Care Indicators Tool (SPICT) (NHS Scotland, 2012), and the assessment and review of the palliative patient using the Palliative Performance Scale (PPS) (Anderson et al, 1996). The PPS, which is simple and easy to use by different members of a care team, assesses the individual's ability in relation to their ambulation, evidence of disease with activity, self-care, intake and conscious level between 0–100%, where 0% is death. The PPS guides care activities for the palliative patient and monitors whether the patient's condition is static, increasing or decreasing. Within primary care, these tools enable clinicians to observe changes in condition, allow for advance planning and, ultimately, for end-of-life care.

Method

A pilot implementation of the JICB was undertaken with five practice areas in the Banff and Buchan locality in 2009. The findings of the pilot shaped the educational programme and paperwork for the larger implementation project.

We asked staff in these five practices to complete an evaluation form each time a JICB was used over a 3-month period, that informed us:

Table 1. Recommended anticipatory prescription

Drug	Dosage	Initial supply	Cost
Midazolam	2.5 mg subcutaneously up to 2 hourly as required for agitation/restlessness	10 mg/2 ml × 5	£3.50
Hyoscine butylbromide	20 mg subcutaneously up to 2 hourly as required for secretions	20 mg/ml × 5	£1.12
Morphine sulphate	2.5 mg subcutaneously up to 1 hourly as required for pain	25 mg/ml × 5	£3.62
	2.5 mg subcutaneously up to 2 hourly as required for breathlessness		
Levomepromazine	6.25 mg subcutaneously once daily for nausea	25 mg/ml × 5	£10.07
Water	For injections for preparation/flushing initial supply	10 ml × 10	£3.60

- How the JICB was used
- If it made a difference to the patient's care (in their opinion)
- If there were any difficulties for families in obtaining the prescribed medication
- Any suggestions about the implementation programme.

The 29 evaluation forms that were returned during the pilot phase detailed how the JICB was used and informed the implementation programme.

During the pilot phase, a JICB was issued when there was discussion and agreement between the patient, family, community nurse and GP. A prescription was issued and the prescribed medications were obtained by the family. The JICB was taken to the house by the community nurse, with the contents explained to the patient/family and the medications placed in the JICB. If the patient developed symptoms, the nurse checked the prescription sheet and administered the drug(s) as clinically indicated.

In relation to making a difference to patient care, the responses included that symptom relief could be given straight away, that there was increased patient comfort without any wait for a prescription to be written and obtained, once a symptom became apparent. Such provision of prescribed medication also provided reassurance for the family. The length of time that the JICB was in a patient's house ranged from 1–21 days, with a median time of 2 days.

The comments were positive, typified by the following quotation:

'It meant that timely symptom management could be given with no wait for the GP, prescription or medications. The patient and his relatives benefited greatly, in my opinion, and [it] meant less wear and tear for the community nurses.'

Implementation phase

The implementation phase was designed to be based on an educational programme that involved meeting with small groups of clinicians in their local areas. Care at the end of life was discussed, outlining when and how anticipatory prescribing could be used. Each practice area was given a 'just in case' box as part of the programme, containing the prescription and a set of the following paperwork:

- A core contents advisory sheet (suggesting the recommended syringes, needles for drawing up and administering medication, and film dressings)
- An advice sheet for patients and families
- The guidelines for the JICB project
- The NHS Grampian subcutaneous syringe pump and recording sheet
- The local community nurse medicines recording/balance sheet
- The NHS Grampian 'symptom control in the last few days of life' guideline.

Further copies of these documents were available to clinicians across the Grampian region on the clinical guidelines intranet.

The recommended anticipatory prescription is based on recognised good palliative practice (Twycross and Wilcock, 2011) and is shown in *Table 1*. Although there are a number of options for the treatment of secretions, our preference is for the use of hyoscine butylbromide because it does not cross the blood brain barrier and therefore does not cause drowsiness or confusion (Wilders et al, 2009).

The costs were estimated using the July 2011 Scottish Drug Tariff (Scottish Government, 2011) and the Monthly Index of Medical Specialities (MIMS, 2011). It was agreed that the boxes themselves would be kept at the nursing base.

Sixty-one educational sessions were delivered at primary care bases across NHS Grampian over an 8-month period. During the educational sessions, an issue that was frequently raised was the potential of drug 'waste'. To try and monitor this issue, we designed a stock balance form and asked for these to be returned whenever a box had been used so an estimate of the costs could be made.

Approximately 1 year after the introduction of the educational programme, we designed an audit with the standard: '100% of primary care bases are aware of the "just in case" box initiative'. The audit was registered with the Clinical Effectiveness Department, NHS Grampian. Contact was made with each aligned district nursing base

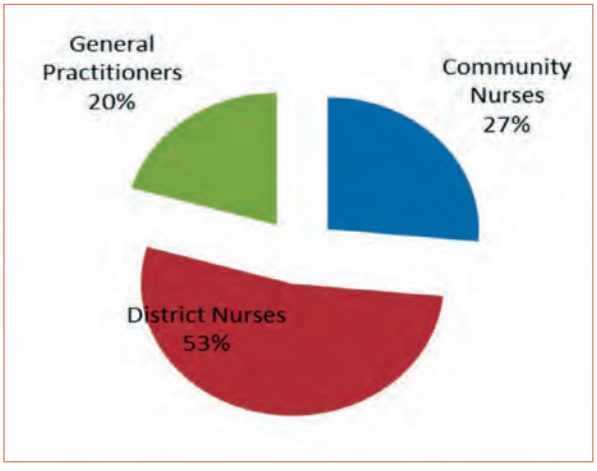

Figure 1. Designated job titles of respondents (n=83)

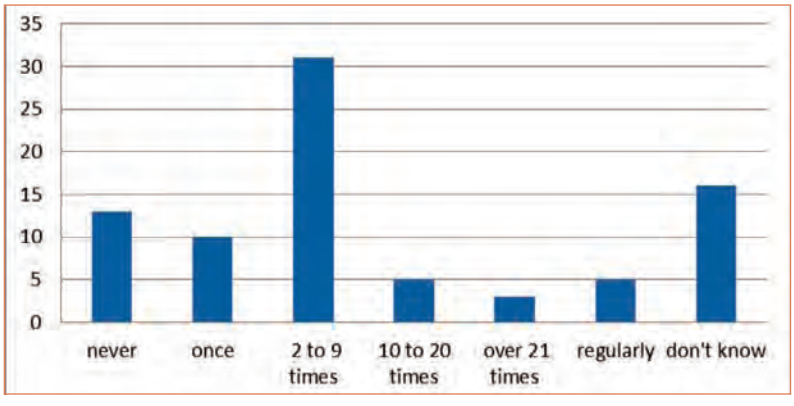

Figure 2. Number of times just in case boxes were used

across the region and they were asked if they would complete a short data capture form.

The forms asked for the designation and location of the respondent as well as the following questions:

- 1. Are you aware of the 'just in case' box initiative launched by palliative care in 2010? (Yes/No/Don't know)
- 2. Do you have access to a 'just in case' box? (Yes/No/Don't know)
- 3. Do you know how often the 'just in case' box has been used by your practice? What are the diagnoses of these patients? (e.g. malignant, non-malignant, frailty/dementia)
- 4. Have there been any palliative patients at the end of life who have not been issued with a 'just in case' box? (Yes/No/Don't know). If yes, please specify reasons for this
- 5. Do you have any other comments about anticipatory prescribing and 'just in case' boxes?

The community Macmillan specialist nurses distributed the data capture sheets and a member of the audit team phoned a number of bases as well. The completed forms were returned in the internal mail system to one of the audit team (LM).

Results

Sixty-five DN bases (covering 85 GP practices) were contacted across Aberdeen city, Aberdeenshire and Moray. Completed forms were returned from 83 individuals in 58 bases, giving an 89% response rate for bases. Three city and three Aberdeenshire bases did not respond. *Figure 1* shows the designation of the respondents (n=83).

On 45 occasions, one person replied on behalf of a team, while a few forms were completed by different members of the primary care team. All the respondents indicated that they were aware of the 'just in case' box initiative, with 70 (97%) reporting that they had access to a 'just in case' box. Although the majority of respondents had used a JICB at least once, its use varied amongst the respondents as shown in *Figure 2*.

Respondents were able to identify the diagnoses of some of the patients who had been issued with a just in case box, and the majority were diagnosed with a malignancy (n=43). Five were diagnosed with a non-malignant condition and three with dementia. In relation to the people who could not specify exact numbers of patients, nine noted that their patients had a malignancy, five noted that patients had a non-malignant condition and a further six said the diagnosis was dementia/frailty. Seven reported that the diagnosis of their patients was unknown.

Thirty-four respondents noted that there had been occasions when patients approaching the end of life had not been issued with a 'just in case' box. The reasons for this were grouped into three categories: staff, patients and equipment.

Staff

The key issue here was that staff forgot that the just in case box was available. Examples of answers included 'lack of thought' or 'oversight'. However, two practices noted that they had 'declined to use it', and a further district nurse commented that the GPs were not 'proactive'.

Patient condition

The second category related to the patient's condition and there being no time to instigate a 'just in case' box. The phrase 'rapid decline' was used by some of the respondents making comment here. However, one box was not used because the patient did not want controlled drugs in the house.

Equipment

The third category related to the availability of just in case boxes and the challenge posed if only one box was available, but more than one patient needed an anticipatory prescription.

Additional comments

Sixty-three comments were made by the respondents and these have been collated into three themes: positive comments, issues requiring clarification, and negative comments.

Table 3. Estimated costs for 68 just in case boxes

Drug	Total cost for 68 boxes to nearest £	% stock remaining unused	Cost of unused stock to nearest £
Morphine	£230	60%	£138
Midazolam	£248	69%	£171
Hyoscine	£76	74%	£56
Levomepromazine	£656	75%	£493
Water for injection	£227	60%	£135
Total	£1504		£994

Positive comments

Thirty-seven comments were positive, outlining how useful the initiative had been in the planning and delivery of end-of-life care in primary care settings.

Illustrative comments include 'it clarifies the situation for all involved,' and that the use of anticipatory prescribing enables 'more planning ahead proactively.' The initiative provided guidance for practitioners and this was well received: '[it's] good to have guidelines for prescribing'; 'it is a useful resource.'

The availability of prescribed drugs was seen as a benefit for both other staff and families, especially out of hours: 'improves access to medicines when they are needed'; 'reassuring for out-of-hours colleagues to know that drugs are in house'; 'well received by families and the nursing team… medically, a good idea.'

Issues requiring clarification

Fifteen comments were made highlighting the respondents' need to understand the details of the process of implementing the 'just in case' box. The key issue was in relation to the need to have a prescription for each patient. 'There is confusion about whether drugs are individually prescribed or taken from practice stock' is an example of the comments made. There was also uncertainty about the use of the just in case boxes in nursing home settings: 'attached nursing homes unwilling to have unwanted boxes on premises.'

The final issue for clarification related to the paperwork and how the 'just in case' box works alongside a syringe pump: 'confusion about controlled drugs in JICB especially when other controlled drugs are taken into house for syringe pump and documentation.'

A number of respondents said that they 'would appreciate a training session.'

Negative comments

Eleven respondents made negative comments about the introduction of this initiative; however, four of the comments began with 'it is a good idea, but…' A few comments related to the possible waste of medicines if they were not used: 'conscious of the wastage of drugs.' Some were comments about the need to re-educate GPs about the initiative itself, while one respondent stated simply: 'We have decided not to use this scheme.' One comment also highlighted the difficulty in assessing 'the best time to discuss this with a patient and their family.'

Stock balance sheet analysis

We estimated the drug costs of 68 'just in case' boxes using the stock balance forms returned throughout the first year of implementation. We are aware that more boxes were issued, but stock balance forms may not have been completed. Furthermore, four boxes had oxycodone as an alternative to morphine prescribed.

Table 3 shows the total cost of medicines, percentage unused stock, and the cost of unused stock. The prescription cost equates to £22.12 per patient.

Discussion

Anticipatory prescribing has been reported as good palliative care practice (Department of Health (DH), 2004; Dickman, 2010; Russell and Tandon, 2011). Indeed, it has been noted that 'anticipatory prescribing is better than reactive prescribing in terms of pain relief' (Timmins, 2011) because it might prevent the need for visits out of hours to prescribe breakthrough medication (Fergus et al, 2009). Anticipatory prescribing forms an element of the Gold Standards Framework (GSF) and was seen as an improvement to end-of-life care when the GSF was adopted (Walshe et al, 2008).

This programme is suitable for nurse independent prescribers as the recommended drugs are included in the formulary for Nurse Independent Prescribers (NHS Scotland, 2006), and the recommended amounts comply with the supply regulations in Practice Standard 16 (Controlled drugs) of the Nursing and Midwifery Council Standards of Proficiency for Nurse and Midwife prescribers (NMC, 2007). However, as with all prescribing, it should only be carried out if it is within the practitioner's area of competence and practice. For any prescriber who is in need of a reminder, clear dosage recommendations are included in the JICB, along with the phone number of the specialist palliative care service who can offer advice.

This audit aimed to follow up the introduction of the 'just in case' box approach to anticipatory prescribing for palliative patients dying in primary care settings. All of the respondents were aware of 'just in case' boxes, therefore, the audit standard has been met, although we are aware that this audit does not reflect every primary care practitioner across the region. One of the challenges was maintaining links with district nursing teams over the implementation period as there was some service re-alignment in Aberdeen city. A potential limitation of the audit was the variance in how practitioners were asked to complete the form. Despite these limitations, the audit has shed light on the use, need for ongoing education, and both positive and negative issues in relation to the scheme.

Overall, the feedback indicates that this has been a positive experience for most respondents who have used the 'just in case' box as part of end-of-life care planning and delivery. Although the use has been dominated by patients

with malignancy, it has also been considered for patients dying of other conditions and the contents can be modified according to need. It has provided some continuity of care for patients, especially out of hours, and reassurance that prescribed medication is available for use if needed. It appears to confirm the findings of earlier studies about the reassurance provided when anticipatory prescribing has been considered (Fergus et al, 2009; Taubert and Nelson, 2010; Timmins, 2011).

The issues respondents raised in the points for clarification highlight the importance of continuing to monitor and offer ongoing education following the introduction of an initiative. The comments will allow us to feed back to all practice areas across the region, and an educational session on 'just in case' boxes will be offered as part of our ongoing seminar programme.

It is also useful to receive negative comments about a programme. A more challenging issue is the reluctance by GPs to prescribe for patients in advance, or for patients that are unknown to them (especially out of hours), as highlighted by Griggs (2010).

The estimation of the associated drug costs has allowed us to provide feedback on the actual costs of the 'just in case' prescriptions. Contents of the JICB were reviewed in light of the stock balance forms. The most expensive item is levomepromazine and, although it was not frequently used, it was considered to be clinically important for it to be included in the box. Overall, although a significant amount of medicines were unused, 77% of boxes issued had at least one drug used. While it may seem wasteful to have drugs prescribed that are ultimately returned to the pharmacy unused, the availability of these drugs may provide more rapid symptom control and prevent an admission to hospital, allowing a patient to die in their own home. In order to address the concerns, one of the recommendations in this implementation programme has been to recommend that the initial prescription is for five ampoules of each drug, rather than 10.

Conclusion

Anticipatory prescribing has been recommended in the national palliative and end-of-life action plan. This article has described the implementation of this approach by way of 'just in case' boxes within primary care across a geographical region in Scotland. A one-year follow up has highlighted the positive and negative responses from health professionals, and raised issues that need clarification in relation to the use of anticipatory prescribing.

Overall, this has been a positive development that enables a prompt, planned response to the symptoms associated with dying. Over many years the specialist palliative care service has built strong links with primary care colleagues and on reflection, this has contributed to the success of the implementation and involvement with the follow-up audit. The project has reinforced the need for education to be a continuous process rather than a single 'event' approach, as feedback and auditing ensures we are in a position to monitor and address issues that arise. **BJCN**

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LEARNING POINTS

- Anticipatory prescribing is a key feature of end-of-life care in primary care settings
- An educational approach to implementation is successful when delivered in local settings
- The cost of an anticipatory prescription was £22.12

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