Effective Delivery of Pharmaceutical Palliative Care: Challenges in the Community Pharmacy Setting.

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Abstract (250 words)

Purpose: The important role played by clinical pharmacists in the delivery of hospital based palliative care services is well documented. However, the evidence base supporting the role of the community pharmacist is limited. This study describes the challenges facing community pharmacists operating in a local palliative care network in Scotland.

Methods: Qualitative data were gathered using focus group interviews. Participants were identified from members of a Community Pharmacy Palliative Care Network attending scheduled training events. Thirty five pharmacists were recruited to one of five group interviews each lasting between 60 and 90 minutes. The interviews were recorded and transcribed verbatim. The transcripts were analysed using the Framework Approach.

Results: Three key themes emerged: medication supply; communication; education and training. Challenges to the medication supply process included: the presentation of prescriptions for medication not listed in the locally agreed stock list; the out-of- hours period; balancing legal and ethical considerations when supplying controlled drugs; and transferring medicines between locations. Communication was critical to service delivery and found to be lacking, especially when patients were transferred between care settings. Education and training of pharmacy staff, particularly locums and counter staff, and better awareness of the Network by the broader palliative care team was also identified.

Conclusions: This study has informed the development of an evidence-based action plan for the Macmillan Pharmacist Facilitators. The plan focuses on: raising awareness and integration of the Network; providing training across the palliative care team; developing prescribing tools to aid clinicians; and exploring models for information sharing.

Introduction (2879 words)

Medication, particularly analgesia is an important component of palliative care. However, timely access to medication, particularly opioids, can become problematic for patients receiving palliative care in the community setting[1,2,3]. Medication related problems appear to be common place and occur regardless of the health care system in operation[1,4,5]. For example, 49% (n=28/53) of community pharmacists surveyed in the North Dublin area[4], reported 'not having the medication in stock' as a major factor causing delay in supply of medication to patients. In Japan[5], only 77% of community pharmacists have a 'narcotics retailer license' thereby limiting the availability of pharmacies from where prescriptions for opioid pain relief could be dispensed.

In Scotland, an audit of palliative care services[6] found that access to medication, particularly unlicensed drugs was a problem for some patients. Consequently, under the Model Schemes in Pharmaceutical Care initative[7], a Community Pharmacy Palliative Care (CPPC) Network was established in each Scottish Health Board area. Pharmacies in the CPPC Network were expected to provide an enhanced pharmaceutical palliative care service. This was achieved by the Pharmacy: retaining a stock of specialised palliative care medication; arranging transportation of urgently required medicines and supporting non-Network Pharmacies, General Practitioners (GPs) and District Nurses within their local areas. A subsequent review[8], five years later, of palliative care services found that although the majority of CPPC Network Pharmacies were now carrying the additional stock of palliative care medicines, some issues remained. These included patients' being denied access to urgently required medicines, particularly Controlled Drugs out-of-hours (after 6pm and at weekends) and after discharge from hospital. In 2009, NHS Greater Glasgow & Clyde Health Board (NHS GG&C), in partnership with Macmillan Cancer Support, established a programme to improve the local provision of pharmaceutical palliative care services. Four Macmillan Pharmacist Facilitators were appointed, part time, to work in 4 localities in the West of Scotland. The localities covered a total population of approximately 430,000 and comprised 112 community pharmacies. Twenty six of these pharmacies were members of the local CPPC Network. Researchers at the University of Strathclyde were commissioned to support the development and evaluation of this new service. A key early task for the facilitators was to understand the provision of palliative care services currently provided by CPPC Network Pharmacies. This paper reports the findings of this initial investigation and outlines an evidence-based action plan to support service improvement.

Methods

Qualitative data were gathered using focus group interviews. This method was chosen because the group interview allows participants to articulate their thoughts, opinions, and attitudes, in a relatively 'naturalistic' setting[9]. The technique is also commonly used for collecting information about health service practice and delivery[10,11]. A topic guide enquiring about participants' experiences of providing palliative care services and of being in the CPPC Network was developed and used. Ethics approval was sought but deemed unnecessary, since the project was an evaluation of current service delivery. The principles of informed consent and good ethical practice were applied and observed. The focus groups were facilitated by three members of the university team who are also authors of the paper.

Participants were identified from amongst those attending scheduled training events for CPPC Network Pharmacies during January and February 2010. Thirty five pharmacists were recruited to one of five focus groups each lasting between 60 and 90 minutes. The interviews were recorded and transcribed verbatim. The transcripts were independently read by the three authors and subjected to a thematic analysis using the Framework Approach[12,13]. Identified

emergent and recurrent themes were coded according to the appropriate thematic reference and validated by team members through consensus.

Results

Three key themes were identified: medication supply; communication; and education and training. The themes are discussed below with participants quotes used to illustrate the findings.

1. MEDICATION SUPPLY

Discussion of the medication supply process identified four sub-themes relating to the prescribing or dispensing of medicines.

a) Unfamiliar medicines

Most participants had experience of being presented with prescriptions containing medicines which were not listed in the locally agreed palliative care stocklist. Such products were unlikely to be routinely stocked in the pharmacy. This often meant that the prescriber would need to be contacted for clarification, resulting in delays with supplying the medication.

> *"Somebody prescribed Hyoscine the other week; it was a 600 mcg ampoule whereas we always keep 400 mcg, that's what's on the list [palliative care stock list]. You then have to phone, chase up the doctors to get it changed".*

b) Prescriptions presented out-of-hours

Almost all the participants identified the out-of-hours period as being more vulnerable to problems occurring. At these times it can be more difficult to contact relevant personnel for prescription clarification and to get access to medicines which may need to be specially ordered. Additionally, at these times, the Pharmacy may be staffed by individuals not usually employed during the routine working day and thus may be unfamiliar with elements of the service.

> *"I think that is where it falls down because it's our pharmacies that are part of the scheme but we are not there as palliative pharmacists when we are needed most, which is at the weekend and 'out of hours'".*

c) Legal versus ethical dilemmas

Participants also discussed the issues they face when presented with a prescription that does not comply with the legislation. In particular for Controlled Drugs, which need to be written in accordance with the regulations. If the prescription is incomplete, it needs to be referred back to the prescriber before dispensing, potentially causing delay. The interviews illustrated the serious professional and ethical quandary faced by the pharmacists that the rest of the palliative care team and patients are likely to be unaware of:

> *"This morning I had a prescription for diamorphine and it said 'to be used as directed'. I knew the patient was very ill but I had a prescription without the full information, so it was a bit of a dilemma about how to proceed".*

> *"If it's urgent then you've got to weigh up the benefits, this patient is either going to be in pain or you just give them it, as long as you can defend yourself".*

d) Transfer of medicines between settings

The Taxi Protocol, whereby local taxis may be used to collect and deliver urgent medicines between pharmacies and patients was considered a helpful resource, but was used infrequently.

Some participants stated that the protocol was a complicated bureaucratic procedure. They preferred to deliver the medicines themselves and use the opportunity to counsel or offer support to the patient. Some also expressed reservations about handing medicines, especially Controlled Drugs to non-healthcare staff:

> *"You wouldn't use the taxi protocol cause you need to look out the palliative care folder, and the right paperwork, then you need to find the tags and the bags, then phone the taxi company, then you need to make sure it's got there, then get your bag back. It's a palaver".*

> *"Personally I just feel safer with one of my staff or I doing it than just handing it over to a taxi driver. Even though there is a protocol set up for it, I just don't feel comfortable with that, especially if it's a controlled drug".*

2. COMMUNICATION

Communication across the palliative care team was seen as an important factor impacting on service delivery. District Nurses were recognised as an invaluable source of information about the patients' clinical condition and medicine requirements. Some participants seemed to feel that the District Nurses had a better appreciation of the potential for prescription related problems to occur. They would try to minimise these where possible, for example by contacting the pharmacy in advance to pre-empt supply problems and guiding patients/carers to Network Pharmacies where appropriate. However, the discussions revealed that communication was particularly poor between care settings, especially when patients were admitted to or discharged from hospital/hospice. Some pharmacists reported being ill informed of changes that had occurred to the patient's regular prescriptions:

> *"It's a problem when they're [the patients] discharged. I have people come in saying 'I've been out of hospital for a week and I need medicine for tomorrow and all my medications have changed' and I have got no discharge letter and no idea what the medication is that's changed".*

Such problems may be amplified through the use of weekly monitored dosage systems (MDS). These can be labour intensive as they require individual doses to be dispensed into compartments separated by day and time. Almost all the participants had experience of preparing or delivering MDS to patients that had been admitted to hospital or had passed away.

> *"It's not unusual for us to have been delivering Dosettes© to patients week after week and someone phones up to say, "my father passed away three weeks ago, can you stop delivering" and we say, "we're very sorry but we didn't know, no-one's informed us".*

Membership of the Network was seen as supportive but could also present a challenge.

> *"The reassurance that there is support out there, if something a bit more unusual comes up, then you know where to go; you're not on your own".*

Most participants agreed with a pharmacist, who suggested that sometimes, it is difficult to provide an optimum service to individuals who present at a Network Pharmacy with minimal information:

> *"You pick up patients in the final stages of their life who aren't your regulars and you don't know anything about them. You've got no Patient Medication Record to check and*

see what doses they've been on, it really is a prescription out of the blue, you've got no back up to know that you are dispensing the right thing".

3. EDUCATION AND TRAINING

For some participants, the limited knowledge and understanding of their role by palliative care team members, was a key factor affecting their provision of services to patients and carers.

> *"I don't think a lot of GPs know who the palliative care pharmacies are, let alone what we stock"*

Participants also expressed a need for better training of their own staff, particularly counter assistants and locum pharmacists. Counter assistants were identified as the first point of contact in the dispensing process. If their ability to recognise urgent palliative care prescriptions was improved then this could avoid unnecessary delays for patients and carers:

> *"It's usually the counter staff who deal with [incoming] prescriptions so they've got to have some understanding of what's a palliative care drug and what's not; if they know what's a controlled drug they could ask further questions. Otherwise, it [the prescription] could get lost in the dispensary, you might not see it".*

The participants reported that locum pharmacists may be unaware that a pharmacy is part of the CPPC Network and what is expected of them. Whilst there was recognition of the difficulty in implementing training for locums, all agreed that this should be put in place to build on the pharmacist's core knowledge.

> *"A [resource]pack for locums ... just to give them a bit of confidence in what they're doing if they're on their own".*

Availability of routine resources for pharmacists to support clinical practice was highlighted. Standard references including the British National Formulary were mentioned but were identified as limited in providing specific palliative care information. The Palliative Care Formulary (also known as the PCF3) was found to be invaluable in identifying and cross-referencing unlicensed indications and doses of medicines[14]. During out-of-hours most participants reported that they would contact local hospices or specialist hospital pharmacists and the NHS 24 professional-to-professional service for advice or information[15]. The internet was also discussed but the practicalities of accessing and browsing web pages whilst being fully engaged in the workings of a busy community pharmacy were seen as major obstacles:

> *"The paper on the shelf is accessible - the computer's being used, someone's printing, you want to get on the internet or whatever - it can be time-consuming, restrictive. Whereas the reference on the shelf, you pick it up, it's there in black and white - you're not scrolling up and down the screen".*

Discussion

In the hospital/hospice setting, pharmacists are routinely part of the clinical team and involved in the care planning process[16,17,18]. Needham et al[19] reported on the beneficial role of community pharmacists in a small in-depth case series analysis. However, the evidence base supporting the role of the community pharmacist in palliative care service delivery is generally limited as highlighted in a recent editorial[20]. This paper adds to the literature by reporting a

model currently operating in Scotland. It provides an insight into challenges facing community pharmacists in their delivery of palliative care services.

Exploration of the medicines supply process identified issues that were out-with the pharmacist's control, most notably, incorrectly written prescriptions. This finding concurs with the study by Lucey et al[4] in which Community Pharmacists cited "incorrectly written or illegible prescriptions" as factors impinging on their delivery of service. Additionally, our study uncovered a significant ethical dilemma for pharmacists which is associated with the supply of medicines when the prescription does not meet the legal requirements. Education of both the palliative care team and patients/carers of the need for legally compliant prescriptions could help to minimise delays in medicines supply and hence avoid the distress to patients and carers.

An interesting finding, particularly for service managers, was participants' reluctance to implement the Taxi Protocol. The protocol can be used in urgent situations to collect a prescription form, or collect or deliver medication between pharmacies or to the patient's home. It had been introduced with the involvement of CPPC Network pharmacists, following reflection on incidents where there had been delays in obtaining or dispensing medicines, and hence, in symptom control, with ensuing distress to families and professionals. It did appear, to be viewed as bureaucratic. However, it was encouraging to find that some pharmacists said they would prefer to deliver the medicines themselves, to make direct contact with the patient and offer advice or support.

The unpredictable nature of disease trajectory and the diversity of the palliative care team necessitates good communication[21,22]. Our study highlights where poor communication can impact on patient care, particularly between care settings and across the palliative care team. Robust mechanisms for the transfer of clinical information between services and health professionals are therefore required. The out-of-hours period is known to be particularly problematic[23] and this was confirmed in our study. One solution being explored in Scotland is to give Community Pharmacists access to the NHS ePCS (electronic Palliative Care Summary). The ePCS contains information about the individual's medical condition, treatment, 'carers' details and their 'wishes' concerning treatment towards the end of life[24]. Another potential source of information sharing is the 'Supportive Care Register'. This is one of the documents used in the application of the Gold Standards Framework (Scotland), which is a programme based in General Practice to support planning and communication for patients receiving palliative care in the community[25]. Access to it would allow Community Pharmacists to make appropriate and safe medication-based interventions. It would be particularly helpful when a patient is specifically referred to a pharmacy because of their palliative care needs.

Improved information sharing could also be addressed through attendance of pharmacists at clinical palliative care team meetings. Attendance of pharmacists at clinical review sessions are known to improve patient outcomes in palliative care and other specialties[17,26,27]. However, the practicalities and logistics involved, particularly for single-handed pharmacists, make this challenging in the community setting. The peripatetic nature of the Macmillan Pharmacist Facilitators may provide an opportunity; either by attendance at team meetings and disseminating the information to the Community Pharmacist or by providing cover in the pharmacy to enable the community pharmacist to attend the team meetings.

Training, particularly of pharmacy support staff, to enable more effective engagement with patients, carers and health professionals was recognised as an area for action. Small changes

such as being able to identify a palliative care prescription when it is first presented would allow early identification of potential problems. Inclusion of counter staff within CPPC Network training events should provide better understanding of patients' needs resulting in a more effective and responsive service.

The qualitative nature of the study poses limitations regarding generalisability and reproducibility. Nevertheless, our intention was to provide an insight into issues faced by Community Pharmacists in their delivery of palliative care services. A comparative study with non-Network pharmacists would have given a more comprehensive description. However, we believe that this study provides a baseline upon which improvements to service provision can be developed. The overlap and commonalities between this and the few other studies investigating community pharmacy service delivery[4,5] suggest that our findings are not unique to our sample or the geographical area.

Conclusions

This study describes the challenges facing community pharmacists in their delivery of palliative care services. These findings have been used to develop an evidence based action plan for the Macmillan Pharmacist Facilitators. This programme of work is due for completion by December 2012 and includes the following:

- To raise awareness and integration of CPPC Network pharmacies within their localities and the broader Community Pharmacy family.
- To provide training to key staff groups including pharmacy support and locum pharmacists.
- To develop prescribing tools to aid GPs with medicines selection and correct prescribing of Controlled Drugs used in palliative care.
- To explore different models for information sharing between General Practice and Community Pharmacy.

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No competing financial interests exist.

References

1. Greenwald, BD & Narcessian EJ. Opioids for managing patients with chronic pain: Community pharmacists' perspectives and concerns. J Pain Symptom Manage 1999; 17:369-375

2. Kanner RM & Portenoy RK. Unavailability of narcotic analgesics for ambulatory cancer patients in NYC. J Pain Symptom Manage 1986;1: 87-89

3. Holdsworth MT, Raisch DW. Availability of narcotics and pharmacists attitudes toward narcotic prescriptions for cancer patients. Ann Pharmacother 1992; 26: 321-326

4. Lucey M, McQuillan R, MacCallion A, Corrigan M & Connaire K. Access to medications in the community by patients in a palliative setting: A systems analysis. Palliat Med 2008; 22:185-189

5. Ise Y, Morita T, Maehori N, Kutsuwa M, Shiokaw M & Kizawa Y. Role of the Community Pharmacist in Palliative Care: A Nationwide Survey in Japan. J Pall Med 2010;13: 733-737.

6. Healthcare Improvement Scotland. Clinical Standards: Specialist Palliative Care. 2002. (www.healthcareimprovementscotland.org/previous_resources/standards/specialist_palliative_care.aspx). (Accessed May 2011)

7. Scottish Executive Health Department. MEL (1999). 78. Community Pharmacy: Model Schemes for Pharmaceutical Care.

8. Audit Scotland. Review of Palliative Care Services in Scotland. 2008. (www.audit-scotland.gov.uk/docs/health/2008/nr_080821_palliative_care.pdf). (Accessed May 2011)

9. Green J. The use of Focus Groups in Research into Health In: Saks M, Allsop J, Eds. Researching Health: Qualitative, Quantitative and Mixed Methods. 2007. London: Sage Publications; 113-132.

10. Smith FJ. Health Services Research Methods in Pharmacy: Qualitative Interviews. Int J Pharm Pract 1998;6:97-108

11. Britten N. Qualitative Interviews in Health Research. In: Pope C, Mays N, Eds. Qualitative Research in Health Care. 3rd ed. 2006. Oxford: Blackwell Publishing Ltd; 12-20

12. Pope C, Ziebland S, & Mays N. Qualitative Research in Health Care: Analysing qualitative data. BMJ 2000;320:114-6

13. Richie J & Spencer L. Qualitative data analysis for applied policy research. In: Bryman A, Burgess R,G (Eds). Analysing Qualitative Data. 1st ed. 1994. London: Routledge; 173-94

14. Twycross R & Wilcock A. Palliative Care Formulary (PCF3). 3rd edition. 2007. palliativedrugs.com.

15. NHS 24. Health information and self care advice for Scotland. (www.nhs24.com/content/default.asp?page=home). (Accessed May 2011).

16. Burch, PL & Hunter KA. Pharmaceutical care applied to the hospice setting: a cancer care model. Hospice J 1996;11:55-69

17. Lucas C, Glare PA & Sykes JV. Contribution of a liaison clinical pharmacist to inpatient palliative care unit. Palliat Med 1997;11:209-16

18. Gilbar P & Stefaniuk K. The role of the pharmacists in Palliative Care: Results of a survey conducted in Australia and Canada. J Palliative Care 2002;18:287-292.

19. Needham DS, Wong IC & Campion PD. Evaluation of the effectiveness of UK community pharmacists interventions in community palliative care. Palliat Med 2003;16:219-225

20. O'Connor M, Pugh J, Jiwa M, Hughes J & Fisher C. The Palliative Care Interdisciplinary Team: Where is the Community Pharmacist? J Palliat Med 2011;14:7-11

21. Eastaugh AN. Approaches to palliative care by primary healthcare teams: J Palliat Care 1996;12: 47-50

22. Barclay S. Rogers M & Todd C. Communication between GPs and co-operatives is poor for terminally ill patients. BMJ 1997;315:1235-36

23. Gray N, Allanson H & Reeves N. Access to medicines out of hours- the views of service users and carers. Pharm J 2008; 281: 447a

24. Scottish Government. The electronic Palliative Care Summary (2009). (www.scimp.scot.nhs.uk/documents/ePCSPatientInformationLeaflet.pdf). Accessed May 2011

25. NHS Scotland. Gold Standards Framework (Scotland). http://www.gsfs.scot.nhs.uk/index.html. Accessed June 2011

26. Finley PR, Crimson ML & Rush AJ. Evaluating the Impact of Pharmacists in Mental Health. Pharmacotherapy 2003;23:1634-644

27. Schumock GT, Butler MG, Meek PDC, Arondekar B & Bauman JL. Evidence of economic benefit of clinical pharmacy services: 1996-2000. Pharmacotherapy 2003; 23: 113-32