IMPROVING ACCESS TO CLINICAL INFORMATION IN AFTER HOURS COMMUNITY PALLIATIVE CARE

David Brumley, MBBS, FRACGP, FAChPM, MSc, Clinical Director, Gandarra Palliative Care Unit Ballarat Health Services, Ballarat Hospice Care Inc; Palliative Care Physician/Director, Grampians Regional Palliative Care Research Centre, Ballarat, Victoria Australia.

John Fisher, MSc, MEd, PhD, Senior Research Fellow, Centre for Palliative Care, St Vincent's Hospital and University of Melbourne; Research Manager, Grampians Regional Palliative Care Research Centre, Ballarat, Victoria, Australia.

johnfi@bhs.org.au

Heather Robinson BAppSc(Nurse), GradDipMan, DipGeront, Executive Officer, Ballarat Hospice Care Inc, Victoria, Australia.

Michael Ashby MD, MRCP, FRCR, FRACP, FAChPM, FFPMANZCA, Professor and Director, Centre for Palliative Care, St Vincent's Hospital and University of Melbourne, Victoria, Australia

Accepted for publication November 2005

Key words: improving communication, patient outcomes, essential medical data, nurse confidence

ABSTRACT

Objective:

To improve access to clinical information for nurses and doctors providing after hours community palliative care in a regional Australian setting.

Design:

This was an action research project designed to improve collation and distribution of succinct, pertinent and timely information about unstable palliative care patients to nurses and general practitioners (GPs) involved in after hours care. Each week day, each patient's purpose-designed singleinformation sheet was updated the community palliative care service computers. This sheet was designed to give key abstracted information on each patient's history, current condition, treatment and plans for future care. Patients considered to be unstable had their sheets faxed to the GPs on call.

Setting and Subjects:

This procedure was followed for all adult patients admitted to Ballarat Hospice Care Inc, Victoria, Australia between June and August 2004. The nurses and Executive Officer at Ballarat Hospice Care Inc and thirteen GPs from the Ballarat and District Division of General Practitioners were involved in the study.

Main outcome measures:

Surveys and feedback from palliative care nurses and GPs.

Results:

A one-page information sheet provided essential clinical information to nurses and doctors. The nurses' confidence markedly increased with ready access to the information sheets on a hand held Palm Pilot™. The nurses also reported improved outcomes for patients using this approach and there was favourable feedback from GPs.

Conclusions:

This project led to the development of a simple, effective and low cost means of improving communication between professionals caring for palliative care patients after hours.

Acknowledgement:

The authors sincerely thank the William Buckland Foundation for the financial support provided for this and other research projects in palliative care in the Grampians Regional Palliative Care Service, Ballarat, Victoria, Australia.

INTRODUCTION

The literature reveals that problems exist in the provision of palliative care interventions after hours, and that some of these problems may relate to lack of up-to-date clinical information. This suggests that a study designed to improve access to information about clinical issues may enhance patient, nurse and general practitioner (GP) satisfaction with the process of care.

This project aimed to develop an efficient, affordable model for provision of after hours clinical information for the after hours care of palliative care patients in the service region of Ballarat Hospice Care Inc, Victoria, Australia, which might be generalisable to other areas' services who do not have such a system.

Domiciliary Palliative Care

'Palliative care is care provided for people of all ages who have a progressive life limiting illness, with little or no prospect of cure, and for whom the primary treatment goal is quality of life' (Palliative Care Australia 2004, p.4). Patients admitted to domiciliary palliative care services spend most of their last year of life at home. Domiciliary nurses and GPs provide most of the palliative care to these patients, and high quality well co-ordinated care is essential for the best outcomes (Mitchell 2002).

The provision of nursing, medical and other supports to palliative care patients at night and after normal working hours is frequently problematical. In a review of out-of-hours palliative care in the United Kingdom (UK), Thomas (2000) reported four main areas of concern:

- communication
- reduced access to support services
- · reduced access to medical advice
- · reduced access to drugs and equipment

In developing a framework for the improvement of home care for the dying in the UK - the 'Gold Standards Framework' – Dr Keri Thomas observed that a major limitation to effective care at home is the fallibility of organisational systems (2003).

Information Required

The extent of the information required for optimum home and after hours care of the palliative care patient appears to be boundless, yet there is a practical limit to the amount of information that can be effectively documented and shared. In a discussion of the needs in domiciliary palliative care teamwork in Perth, Smith and Yuen (1994) agreed that the following information from the treating GP was essential to the team:

- · history,
- · current clinical condition,
- · current medications,
- patient's understanding of the disease process,
- · patient's understanding of prognosis, and
- patient's expectations of care.

To this we would add that effective palliative care also requires anticipation, by experienced practitioners, of events or crisis situations that can reasonably be foreseen in a given clinical situation (King et al 2003).

It is essential to have accurate, reliable and well presented medical information, with an up-to-date drug history. Access to hospital discharge summaries and letters is also vital. Palliative care philosophy requires that care should include respect for the decisions which have been made about preference for site of care and approach to end-of-life. Thus the documentation should ideally include information regarding these issues,

appropriate contact information and the existence of any advance directive or Medical Power of Attorney. It should be standard practice to provide emergency medications for home use, and information about the availability of these when necessary.

Information Transfer

The transfer of up-to-date information about patients between doctors and nurses is a generally acknowledged problem (Burt et al 2004). Although Australian literature on the subject is limited, GPs in Victoria report problems with on-call and after hours support when they have to make decisions without medical records being readily available. Patient-held records solve some aspects of the problem, but they do not solve the immediate access to clinical or social information, for the GP or specialist, when contacted by a nurse at home after hours (Shipman et al 2000).

The method of information transfer must be adapted to individual need and involve minimum effort for the practitioner. A totally web-based solution is unlikely to be effective (King et al 2003), for even if such access is available, it will not provide immediate information to the doctor or nurse at night. Neither nurse nor doctor is likely to want to access the web for the information when woken for advice, especially in the early hours of the morning.

Grampians Health Region and Ballarat Hospice Care Inc (BHC)

The Grampians Health Region is one of five rural regions in Victoria, covering an area of 48,000 km2. Ballarat is the largest city and the tertiary referral centre for the region, which had a population of 215,536 in 2001. There were 425 referrals to the four domiciliary palliative care services in the region in 2003, with 413 admissions accepted, and approximately 140 registered clients at anv one time (personal communication: Executive Officer, BHC November 2004). Ballarat Hospice Care Inc provides after hours emergency nursing service to patients in the city of Ballarat and immediate surroundings. This service cares for about half of all the palliative care patients in the Grampians Health Region.

Concerns over communication within Ballarat Hospice Care catchment

Ballarat Hospice Care nurses commence a shift with a verbal handover of unstable patients and they have access to a clinical nursing summary and list of drugs. They do not always have ready access to a medical summary produced by the palliative care physician and/or letters from other consultants. Palliative care nurse specialists report consistent difficulty in accessing clinical information about the patients for whom they care.

International and Australian literature indicates that GPs generally find it satisfying to be involved in palliative care, but they nearly all agree that communication is a major issue (Munday et al 1999; Yuen et al 2003).

The transfer of information about individual patients and problems usually relies on informal telephone calls between doctors and nurses. Discussions with Divisions of GPs within the region indicate that they see improved transfer of information as an area of need, which is addressed in this project.

This project aimed to improve communication between existing service providers, with minimal extra effort and cost. It planned to provide a summary sheet for each patient based on a slight modification of the existing medical records used by the palliative care nurses. This project planned to coordinate the information transfer using the services of a medical receptionist to contact relevant GPs' offices, taking one to two hours per day, to keep local GPs closely connected with the care of their patients.

METHOD

Objective

To improve access to clinical information for nurses and doctors providing after hours community palliative care in a regional Australian setting.

Desian

Action research allows nurses to participate in research in the local setting, providing ample opportunity for re-evaluation and feedback (McGarvey 1993, p.372). A variety of approaches, definitions and uses of action research have emerged since it was created by Kurt Lewin (Holter and Schwartz-Barcott 1993 p.298). This project employed a *five-step* action research process outlined by McGarvey (1993, p.375) which,

- i.) identified a problem in distributing timely and appropriate information about unstable palliative care patients to nurses and general practitioners involved in after hours care, and
- ii.) considered the problem through a literature search, which led to:
- iii.) the *proposed plan of action*, which was to survey nurses and GPs to develop a single page of essential medical data relating to the history and current condition of any unstable patients.
- iv.) This plan was *put into practice* by transferring the information sheet, by fax or secure computer linkage each week day, between nurses and GPs responsible for the patients' after hours care.
- v.) The *reflective stage* of the project *considered feedback* from the nurses and GPs to assess the value of the process and make recommendations for future action.

Setting and subjects

All adult patients admitted to Ballarat Hospice Care Inc, a domiciliary palliative care service in Victoria, were invited to participate in this project, between June and August 2004, so their medical information might be shared between professionals caring for them, especially after hours. The nurses and Executive Officer at BHC, and GPs from the Ballarat and District Division of General Practitioners, were the professionals invited to participate in this study. Ethics approvals were obtained from Ballarat Health Services and BHC for this project.

Main outcome measures

The following outcome measures were planned to be used in this study:

- palliative care nurses' and general practitioners' surveys and focus group feedback;
- the number of accurate predictions of unstable palliative care patients that resulted in call-outs after hours; and
- patient satisfaction survey following after hours service (from McKinley et al 1997).

The following results and discussion section will show that the first outcome measure was very successful, but there was difficulty with the second, and reasons are given as to why the third was not used.

RESULTS AND DISCUSSION

Developing and using the After Hours Palliative Care Patient Information Sheet:

The seven palliative care staff from BHC and thirteen of the general practitioners from the Ballarat and District Division of General Practice completed a survey which led to the selection of information considered essential for handover of palliative care patients. This was recorded on a single A4 sheet, called the After Hours Palliative Care Patient Information Sheet (see Appendix A for details).

It took approximately one hour to set up each new patient's file on the BHC computer. As these files were based on MS Word, rather than a database, they were very easy to process. This procedure was very simple, efficient, effective and cheap.

King et al (2003, p.279) found that: 'the main problem reported was keeping the [hand over] forms up to date, given the rapidity with which conditions can change in palliative care.' Although at least one nurse in King et al's study said, 'It would be a nightmare to attempt to do it ... daily' (2003, p.279), the nurses in our study found it needed to be done daily to be most relevant. At the end of each week day, following their visits to the palliative care patients, the PC nurses updated their nursing notes using MS Word with desktop computers. This information was then downloaded onto the BHC central computer.

After updating their notes, the hospice nurses discussed the patients to predict which were unstable enough to possibly lead to call-outs after hours. Information sheets for these patients were faxed to the GP known to be 'on call' for each patient that evening. The current single-page information sheet, together with the Palliative Care Nurse Consultant's initial assessment notes, any letters to GPs and/or referrer, specialist appointments, hospital discharges, etc were scanned into the files for all patients and transferred to a Palm Pilot for the Hospice nurse 'on call' after hours.

LIMITATIONS

Difficulty predicting call-outs for unstable patients

Where the palliative care nurses considered a patient's condition or care situation to be unstable, and hence likely to result in an after hours call-out and/or hospital admission, the information sheet was sent to the general practitioner concerned. Over eight weeks from 7 June to 10 August 2004, 29 of the patients registered with BHC were sufficiently unstable which could have resulted in call-outs on 99 occasions. Seventeen actual call-outs resulted from these 99 predictions. In the same eight-week period, there were another 36 after hours' call-outs, which were not predicted. This difficulty with accuracy of prediction of call-outs reinforces the need to have accurate, up-to-date information readily available after hours.

Patients' satisfaction survey

The planned survey of palliative care patients' satisfaction, which referred mainly to after hours' service provided by doctors, was not undertaken as there were only four GPs who were called to attend palliative care patients after hours during this study.

Limited GP involvement

Only two of the four GPs, who were called to attend palliative care patients during the two months of this study, had been sent a copy of their patients' information sheet. This provided insufficient data to draw conclusions. However, incidental feedback from several other GPs, who had received the one-page information sheets, indicated that the information would have been useful had they been contacted about their patients after hours.

Benefits for nurses

Although only four GPs were involved in after hours' call-outs for palliative care patients during this study, the palliative care nurses certainly gained benefit from it. Below are summaries of comments from a feedback questionnaire and a round-table discussion with the six palliative care nurses and the EO who participated in this project at BHC.

After some initial concerns, the nurses found the information sheets and computers easy to use and very beneficial to their practice. A simple MS Word-based

program was used, which only demanded elementary word processing skills, rather than a more complex database. Updating the information sheets daily made the nurses more thorough in their reporting, especially the section on Expectations of Care, where very specific comments were noted.

Nurses' confidence markedly increased, because they had immediate access to each patient's:

i. full medical history,
ii. treatments,
iii. current status,
iv. up-to-date medications list,
v. progress notes,

vi. risks and problems,
vii. symptom control,
viii. contact information,
ix. doctors' letters, and
v. expectations of care.

Nurses also saved time because they did not have to go to the office to collect patients' notes before either phoning back or visiting the patients after hours. With the nurses on call having all relevant information on hand, it meant they could respond to the pager rapidly and give accurate information for all patients, even those they had not previously seen. This reduced nurses' concerns or worry about not knowing patients and the patients did not have to repeat their medical history to each new nurse who visited them.

Nurses felt more confident with assessments, which led to patients' outcomes being improved due to nurses' increased knowledge. For example, reduced chances of error when administering drugs, in keeping with results from Bates and Gawande (2003), who found that improved communication and readily accessible knowledge prevented errors and adverse events. Although nurses still needed to contact GPs for drug orders, there was a feeling that there was 'less need to call for help [as nurses were] better equipped [and could] pick up problems more accurately.'

Nurses could give more thorough information to GPs and Accident and Emergency staff when necessary, to help provide more sound medical treatment for their patients. The nurses reflected this also helped them present as being more professional in their practice with other medical colleagues. Nurses could confidently tell the doctors to 'call back if more information is needed,' knowing they would be able to provide current information as it was readily available (on a Palm Pilot in this study).

Problems and future development

With a considerable amount of new information coming in each day to be updated on computers, it was difficult to restrict it to one page (see Appendix A), which was done in order to facilitate faxing to GPs. In future:

- i. without the need to fax a single sheet to GPs, the notes can be extended to more than one page;
- ii. the bottom of the information sheet will be used for medications and long history;

iii. the 'symptoms: severity 1-10' will not be used unless there is a drastic change, so this list will be used as a check list for 'current problems', with the addition of 'fatigue' (see Appendix A).

The minor duplication of nursing notes, which occurred in this study, will be reduced when each nurse has a desktop computer and Palm Pilot, which BHC has decided to implement, due to the success of this project. When they each have a Palm Pilot, the nurses will be able to enter notes directly during home visits. This will facilitate the processing of information to update each person's records on a daily basis, when the nurses return to Hospice.

This study provided a single sheet of salient information on a Word-based program. This would work on a laptop or a personal computer accessible by mobile phone, as well as on the Palm Pilot. The message, not the medium, is the key finding in this project.

CONCLUSION

The palliative care nurses in this study reported improved outcomes for patients due to the nurses' more confident approach, based on better knowledge about the patients' history, current condition and treatments, and plans for future care.

Informal feedback from GPs who received the faxes on their patients found the information to be valuable, even though it was not needed for after hours call-outs by many GPs in this study.

Although there was some initial uncertainty among the palliative care nurses about filling in the information sheet and implementing a computer-based recording system for palliative care patients, once they quickly became used to the simple MS Word-based program storing the data from the comprehensive information sheet, they found it to be remarkably convenient, very effective, efficient and empowering.

Having ready access to each patient's:

i. full medical history,
ii. treatments,
iii. current status,
iv. up-to-date medications list,
v. progress notes,
vi. risks and problems,
vii. symptom control,
viii. contact information,
ix. doctors' letters, and
v. expectations of care,

markedly increased the palliative care nurses' confidence in working with the patients, their peers and other medical personnel. These benefits to practice were delivered at a low cost. The system developed in this study is simple, readily accessible and available free of charge from the authors. It should be emphasised that the abstracted information sheet used in this study does not remove the need to record fuller clinical data from initial patient assessment and progress monitoring, nor does it generate data. Many systems now integrate clinical information and data gathering functions in the one information technology database system. This increases staff work load and cost considerably, and may or may not meet the out-of-hours needs of a service, which was the aim here.

REFERENCES

Bates, D.W. and Gawande, A.A. 2003. Patient safety: improving safety with Information Technology. *The New England Journal of Medicine*, 348(25): 2526-2534.

Burt, J., Barclay, S., Marshall, N., Shipman, C., Stimson, A. and Young, J. 2004. Continuity within primary palliative care: an audit of general practice out-of-hours co-operatives. *Journal of Public Health*, 26(3):275-276.

King, N., Thomas, K. and Bell, D. 2003. An out-of-hours protocol for community palliative care: practitioners' perspectives. *International Journal of Palliative Nursing*, 9(7):277-282.

McGarvey, H. 1993. Participation in the research process: action research in nursing. *Professional Nurse*, 8(6): 372-376.

McKinley, R.K., Manku-Scott, T., Hastings, A.M., French, D.P. and Baker, R. 1997. Reliability and validity of a new measure of patient satisfaction with out of hours primary medical care in the United Kingdom: development of a patient questionnaire. *British Medical Journal*, 314(7075):193-198.

Mitchell, G.K. 2002. How well do general practitioners deliver palliative care? A systematic review. *Palliative Medicine*, 16(6):457-464.

Munday, D., Douglas, A. and Carroll, D. 1999. GP out-of-hours cooperatives and the delivery of palliative care. *British Journal of General Practice*, 49(443):489.

Palliative Care Australia 2004. Standards for Providing Quality Palliative Care for All Australians (4th edn). Deakin West, ACT: PCA. www.pallcare.org.au/Portals/9/docs/Standards%20Palliative%20care.pdf.

Shipman, C., Addington-Hall, J., Barclay, S., Briggs, J., Cox, I., Daniels, L. and Millar D. 2000. Providing palliative care in primary care: how satisfied are GPs and district nurses with current out-of-hours arrangements? *British Journal of General Practice*, 50(455):477-478.

Smith, M. and Yuen, K. 1994. Palliative care in the home: the GP/home hospice team. *Australian Family Physician*, 23(7):1260-1265.

Thomas, K. 2000. Out-of-hours palliative care: bridging the gap. *European Journal of Palliative Care*, 7(1):22-25.

Thomas, K. 2003. The Gold Standards Framework in Community Palliative Care. European Journal of Palliative Care, 10(3):113-115.

Yuen, K.J., Behrndt, M.M. and Mitchell, G.K. 2003. Palliative care at home: general practitioners working with palliative care teams. *Medical Journal of Australia*, 179(6):Suppl. pp.38-40.

Appendix A: After hours palliative care patient information sheet **BALLARAT HOSPICE CARE INC AFTER HOURS INFO SHEET** Name: Address: Phone: UR No.: DOB: **Carer Name:** Relationship: Phone: **GP Name:** Fax: Phone: NOK: Phone: Specialist: **Brief History: Primary Diagnosis: Secondary Diagnosis: Current Clinical Condition:** Stable Unstable Deteriorating Terminal **Current treatment:** Symptoms: Severity 1 -10 Pain 1 Anxiety Pain 2 Depression Nausea / Vomiting Appetite Drowsiness Constipation Dyspnoea Restlessness/Agitation Mobility [fatigue] **Current medications:** Allergies: Drug Name Dosage / Route Recent changes / Problems **Expectations of Care:**

Last updated:

Patient Carer Preferred place of dying

Preferred place of care

Treatment options