Improving electronic information sharing for palliative care patients

Amanda Pringle, Anne Finucane, David Oxenham
Marie Curie Hospice, Edinburgh

Abstract

Coordination of services used by palliative care patients across care contexts is essential in providing patient centred care.

In Lothian, Edinburgh, a baseline audit in 2008 of patients known to all four specialist palliative care teams revealed only 49% had information available to out of hours (OOH) general practitioners (GPs).

This highlighted the poor handover and sharing of information, which are essential for providing quality care for palliative patients in accordance with their wishes, and for reducing inappropriate hospital admissions.

A number of quality improvement measures have been introduced, some nationally in Scotland, such as the roll out of Electronic Palliative Care Summaries (ePCS) – an electronic register containing up to date information including patient wishes and latest treatment decisions. In addition there have been changes to the GP Quality Outcomes Framework encouraging the use of electronic records. Locally, at Marie Curie Hospice, drivers were implemented including hosting GP education evenings promoting ePCS use, alteration of hospice discharge letter format to complement ePCS completion, in addition to offering specialist nurse support and presence at GP practice palliative care register meetings.

A re-audit in 2012 revealed that 75% of specialist palliative care patients had electronic information available to OOH services, and in 2013, 71% of patients. This represents a significant improvement in electronic information sharing across care contexts.

Building on the progress of ePCS, a new Electronic Key Information Summary is currently being rolled out across Scotland.

This quality improvement report reflects on the positive measures taken to address the important clinical need of effective electronic handover for specialist palliative care patients in Lothian. Furthermore, it highlights the ongoing requirement to continue to improve the quality and availability of electronically shared information for every patient known to palliative care services across care contexts.

Problem

Coordination of services used by palliative care patients is essential in providing patient centred care. Sharing of quality information is central to achieving this goal, especially in an out of hours (OOH) setting. Without this, latest treatment decisions, wishes and preferences are not readily available to the staff looking after these patients, often resulting in inappropriate hospital admissions.

The importance of electronic linking of up-to-date information in providing coordinated, quality care for palliative care patients has been well recognised throughout the UK with the publication of Living and Dying Well (1) and the End of Life Care Strategy (2).

This quality improvement report aims to reflect on the measures taken to address this important clinical need as well as highlight the ongoing requirement to improve the quality and availability of electronically shared information for every patient known to palliative care services across care contexts.

Background

In Scotland, before the publication of Living and Dying Well, palliative care summaries were faxed, emailed or referred via the Scottish Care Information (SCI) gateway – the secure referral system between primary and secondary care – by general practitioners (GPs) to the local OOH hub and entered into a patient's electronic record. A 'special note' was then made available to OOH GPs.

The Electronic Palliative Care Summary (ePCS) was the electronic register introduced in Scotland in 2010. It was designed to contain up-to-date information about palliative care patients, with cancer and non-cancer diagnoses. With patient consent, a central system was updated twice daily from GP records, with information such as most recent medications, health status, and latest treatment decisions (3).

Through ePCS, information is also available to other teams involved in patient care, such as NHS 24, acute receiving units, paramedics, and accident and emergency (A&E) departments. The aim is to facilitate palliative care tailored to individual patients' needs and wishes, through anticipatory care planning and excellent communication, regardless of the healthcare setting.

Elsewhere in the UK, the Department of Health has developed a similar initiative called Electronic Palliative Care Coordination Systems (ePaCCS), which localities used as a basis to develop electronic information sharing further; for example, Coordinate My Care (CMC) in London (4). A recent economic evaluation of ePaCCS suggests that there is a correlation between implementation of ePaCCS and increased numbers of patients being able to die at home, in accordance with their wishes. In addition to achieving patient centred care, this generated significant cost savings (5).

Baseline Measurement

In Lothian, a baseline audit was conducted in 2008, before the introduction of ePCS. The population included all 377 patients known to the four specialist palliative care community teams in Lothian: Marie Curie Hospice Edinburgh, St Columba's Hospice, East Lothian and West Lothian Specialist Palliative Care teams. It measured the percentage of the patient population, who had clinical information, in the form of a 'special note' available to OOH GPs.

The audit found that 49% of patients (n=186) had a special note in place; thus 51% of patients known to specialist palliative care teams in Lothian had no clinical information available to OOH GPs, and none of the patients had any information available to other health professionals involved in their care such as paramedics or A&E staff (table 1).

The Lothian Managed Clinical Network set a standard that at least 80% of patients known to the four specialist palliative care teams should have information available to OOH services. This baseline audit highlighted poor handover and sharing of important clinical information about specialist palliative care patients and their wishes within Lothian.

See supplementary file: ds3108.docx - "Table 1"

Design

Interventions to improve effective information sharing about palliative care patients were introduced. On a national level in Scotland, ePCS was introduced in 2008 and fully rolled out by 2010. Designed to facilitate information sharing for all palliative care patients, both general and specialist, it worked by information – inputted by GPs – being accessible to all front line staff across care contexts. It contained prompts for discussion around issues relevant to palliative and anticipatory care planning such as diagnosis, patient and family awareness of diagnosis and prognosis, preferred place of care, and resuscitation status. ePCS was designed to be a dynamic resource, completed over time and updated with changes in care plans. It aimed to be cost effective through facilitating patient choice and reducing inappropriate hospital admissions.

Other initiatives included changes to the GP Quality Outcomes Framework (QOF), Palliative Care Direct Enhanced Service to encourage ePCS completion within 4 weeks of a patient being recognised on a GP practice palliative care register (6).

Locally, at Marie Curie Hospice, we aimed to facilitate completion of ePCS through GP education evenings including promoting ePCS use, alteration of the hospice discharge letter format to complement ePCS completion, and offering specialist nurse support and presence at GP practice palliative care register meetings. Similar educational initiatives were also provided by St Columba's hospice.

Strategy

PDSA cycle 1: Our first aim was to increase the proportion of specialist palliative care patients in Lothian with an electronic summary in line with Lothian Managed Clinical Network standards. The national role out of ePCS and associated education of GPs did go some way to increasing the percentage of specialist palliative care patients with information available to OOH services. However, it became clear with the re-audit in 2012 that although there was an improvement, there were ongoing inconsistencies in the number of specialist palliative care patients with electronic OOH records; some had ePCS, and some had the older method of 'special notes'.

PDSA cycle 2: As GPs were the health professionals with access to input information to OOH records, the next stage was to increase awareness and education, and to explore the difficulties GPs were experiencing. This was incorporated into existing educational initiatives such as protected learning time events as well as annual GP education evenings at Marie Curie hospice. Each evening event was attended by 60 GPs and on both occasions were oversubscribed. In addition, St Columba's Hospice Edinburgh also ran two GP study days per annum. Areas that were highlighted included the format of hospice discharge letters. In response to this feedback Marie Curie discharge letters were changed to reflect the format of the ePCS. This helped facilitate communication between primary and secondary care in addition to ensuring areas of advance care planning, already discussed, were clearly documented.

PDSA cycle 3: To further support local GP practices, specialist palliative care nursing presence and support was offered at GP Gold Standards Framework (GSF) Palliative Care Register meetings. This was with the view to provide increased support, highlight areas of anticipatory care planning, and increase the number of palliative care patients with electronic records. This GSF meeting support was taken up by 25 (50%) of GP practices linked to Marie Curie Hospice and 20 practices linked to St Columba's hospice.

PDSA cycle 4: The GP education evenings also provided an opportunity for discussion surrounding the difficulties GPs were encountering with the interface of ePCS. This was also highlighted as an issue across Scotland by Hall et al (7). Within the GP software, Vision, ePCS was not user friendly and it was difficult to input information easily. For example, the structured inputs with drop-down options highlighted key discussions necessary to create an advanced care plan; however, it was felt that there was limited space to document important information about these discussions. This feedback has been used to inform the updated electronic record, Electronic Key Information Summary (eKIS), that is being rolled out across Scotland at present (3).

See supplementary file: ds3168.docx - "Table 2 and Figure 1"

Post-Measurement

A re-audit of electronic information summaries was performed in January 2012, a year following full role out of ePCS. This was conducted in a way comparable to the baseline audit in 2008. OOH patient records for all 346 patients known to the four specialist palliative care teams in Lothian on 31 January 2012 were accessed and the presence of an electronic palliative care record in the form of ePCS or 'special note' was recorded.

This audit found that three quarters of patients known to the Specialist Palliative Care services in Lothian had information available to OOH services. An ePCS was being used in 185 (53%) cases but was being 'backed up' by the older method of communicating via 'special notes' in around a quarter of cases. This revealed a significant improvement in information available to OOH teams since the introduction of electronic summaries. The quality of the ePCS records was crudely measured by assessing the completion of fields; the majority of records were 31-40% complete (table 2, figure 1).

A re-audit on 8 May 2013 revealed 71% of specialist palliative care patients in Lothian had electronic information available to OOH clinicians (table 1). This may reflect the afore mentioned technical difficulties with ePCS and possible lack of confidence among users before the new updated eKIS system roll out.

The proportion of patients with cancer and non-cancer diagnoses, known to the specialist palliative care teams in Lothian, was also recorded as part of the latter audits. The number of patients with non-cancer diagnoses increased from 9% in 2012 to 11% in 2013 (table 3).

See supplementary file: ds3169.docx - "Table 3"

Lessons and Limitations

The use of ePCS was audited in patients known to specialist palliative care teams in Lothian. Findings from this study may not be representative of the use of electronic summaries in other regions across Scotland.

In Scotland, building on the success of integrated information sharing through electronic summaries such as ePCS, eKIS is now being introduced. eKIS has incorporated ePCS and also extends the benefits to other patients with long term conditions. It is to include an improved user-friendly interface, with more space for clinical information, and will ultimately allow inputs from multiple sources to ensure care plans are up to date.

Many patients who are identified for palliative care would benefit from having electronically shared information in place; however, our data only assesses this in patients referred for specialist palliative care.

The quality and usefulness of the data contained in electronic summaries was not fully assessed as part of the audit. Quality of electronic records has been highlighted as a very important issue that is difficult to assess and quantify, but which is central to patient centered, up to date care. Further work is required to establish accepted measurement of quality outcomes. Systems such as Coordinate my Care have measured success in terms of achieving preferred place of death and reduced hospital admission rates (4).

Conclusion

The introduction of electronic summaries – and educational interventions increasing awareness about them – have possibly contributed to an increase in the number of patients, known to specialist palliative care services in Lothian, with electronic summaries from 50% in 2008 to 71% in 2013. This represents a significant improvement in the availability of patient information to OOH clinicians across care contexts. Work, however, remains to assess fully the quality of these individual records, their impact on patient care, and the potential economic savings in Scotland.

References

1. Scottish Government. Living and Dying Well: A national action plan for end of life care in Scotland. Edinburgh; 2008.
2. Department of Health. End of Life Care Strategy - Promoting high quality care of all adults at the end of life; 2008.
3. Scottish Clinical Information Management in Practice. Care Summaries. NHS Scotland; 2013. www.scimp.scot.nhs.uk/better-information/care-summaries
4. Smith C, Hough L, Cheung C, et al. Coordinate My Care: a clinical service that coordinates care, giving patients choice and improving quality of life. BMJ Support Palliat Care 2012;2:301-7
5. NHS Improving Quality. Economic Evaluation of the Electronic Palliative Care Coordination System (EPaCCS) Early Implementation Sites; 2013.
6. NHS Employers. Quality and Outcomes Framework guidance for GMS contract 2013/14. Palliative Care; 2013. www.nhsemployers.org/Aboutus/Publications/Documents/qof-2013-14.pdf
7. Hall S, Murchie P, Campbell C, et al. Introducing an electronic Palliative Care Summary (ePCS) in Scotland: patient, carer and professional perspectives. Fam Pract 2012;29:576-85.

Declaration of interests

Acknowledgements

team at NHS Lothian Unscheduled Care Services for their contributions.