

Why are we not controlling cancer pain adequately in the community?

INTRODUCTION

Poorly controlled cancer pain has recently received a considerable amount of negative media attention, partly as a result of the publication of a report by Marie Curie Cancer Care that is based on interviews with patients at end of life and with their carers.¹ The report highlighted a number of unmet needs. Insufficient access to pain relief and delays in administering analgesia were expressed as particular concerns. Interviewees described carers 'having to chase prescriptions', and nurses waiting around at night for prescriptions to arrive. Concerns were raised about uncoordinated and discontinuous care, and a failure to implement appropriate anticipatory care. Out-of-hours (OOH) services were criticised for being inefficient and lacking empathy.

In a supplementary Marie Curie-commissioned survey of 1000 UK GPs,² 61% of GPs believed that their terminally ill patients got inadequate access to care at night and at weekends, and six out of 10 GPs believed that the majority of their terminally ill patients' pain was not completely relieved. The perceived reasons cited for inadequate pain relief included lack of anticipatory prescribing and poor availability of pain relief during the OOH period.

There is good evidence that cancer pain control at the end of life is suboptimal in the community. The Office for National Statistics bereavement survey (VOICES) in 2012 sampled 49207 recently bereaved informants.³ Relief of pain was reported as being provided 'completely, all of the time' most frequently in hospices (63%), and least frequently among those at home (19%).

Pain is the most frequent complication of cancer and is estimated to affect around 40% of patients at diagnosis, rising to 70% or more at the end of life.⁴ Pain is the most frequent symptom to prompt OOH primary care contact for those with an established cancer diagnosis.⁵ The recent media interest in suboptimal cancer pain management has mainly focused on failings within healthcare systems: for example, inadequacies within OOH services and lack of coordination of care. However, inadequate cancer pain management is known to be a multifactorial problem. Barriers to optimal cancer pain management involve patients, professionals, and healthcare systems. They often coexist, and are interlinked.

PATIENT-RELATED BARRIERS TO OPTIMAL CANCER PAIN CONTROL

Informed and empowered patients can contribute to the effective management of their cancer pain: if they monitor and report it, and adhere to an appropriate medication regimen. Equally, patients' prevailing knowledge, beliefs, and the resultant behaviours can contribute to suboptimal cancer pain management.⁶ Some hold fatalistic beliefs about cancer pain: for example, that pain is inevitable and should be accepted. Patients can hesitate to complain about pain and under-report pain to keep the clinician focused on other aspects of their condition during clinical assessments.⁷ Pain monitoring can be subject to recall bias and under-estimation; for example, current pain ratings taken at an appointment do not correlate well with self-reported measures in daily or hourly pain diaries.⁸ Intentional and unintentional analgesic non-adherence can also contribute to poor pain control. Patients can be reluctant to take prescribed analgesics if they believe that pain is a useful symptom that gives an indication of disease state, or if they are concerned about medication side effects, tolerance, or addiction. Late or missed doses of analgesics can also lead to suboptimal pain management.

PROFESSIONAL BARRIERS TO OPTIMAL CANCER PAIN CONTROL

Health professionals' knowledge and behaviours with respect to pain assessment and management have an important bearing on how well cancer pain can be controlled in the community. A qualitative study found that professionals working in primary care settings have particular concerns about prescribing high doses of opioids, and feel that they lack appropriate skills and knowledge about opioid prescribing.⁹ Common shortcomings in cancer pain management include failing to prescribe enough 'around the clock' long-acting analgesics; failure to prescribe appropriate adjuvant analgesics; and the prescription of insufficient

doses of breakthrough medication. It is recognised that healthcare professionals are concerned about hastening death with strong opioids. Fifty-three per cent of GPs surveyed by Doctors.net.uk² had concerns about over-prescribing medication. Some view this as part of the legacy of Harold Shipman, with evidence that prescriptions for combinations of strong opioids declined in 2005 during publicity surrounding his trial and conviction.¹⁰

Another challenge confronting healthcare professionals who manage cancer pain in the community is the increasing complexity of the cases that they encounter. Demographic changes and improvements in cancer detection and treatments mean that older patients, many with multiple comorbidities, are requiring prolonged cancer pain management in the community. Polypharmacy and analgesic side effects will pose particular therapeutic challenges in such patients. Achieving the balance between sufficient pain control and acceptable side effects is a challenge in managing cancer pain, and is probably even more difficult in this patient group. Prescribers are increasingly using combinations of opioids and opioid rotation,¹⁰ where formal guidelines are lacking and experience is necessarily taking time to accrue.

HEALTHCARE SYSTEMS

Changes imposed on the delivery of health care create another barrier to optimal cancer pain management in the community. Current models of UK OOH care are particularly relevant in this regard. Patients are now highly unlikely to be managed by a healthcare professional who knows them in the OOH period. It appears that patients with cancer living at home with pain are cognizant of this. They can perceive telephone triage as challenging, are often reluctant to 'bother' the OOH service, and have anxieties about the legitimacy of their needs.¹¹ Furthermore, OOH access to specialist palliative care services and palliative care nursing are known to be

"Barriers to optimal cancer pain management involve patients, professionals, and healthcare systems."

"The brave new world of technology in health care offers hope for people in pain from cancer."

variable throughout the UK, and health care, social care, and third-sector services are not always joined up.

Suboptimal cancer pain management in the community is clearly a major issue confronting UK society. It is a multifactorial problem rooted in issues operating at the patient, practitioner, and health service level. Complex interventions that can tackle these issues in an effective and coordinated way are urgently needed but will be required to act on several levels. Patients should be educated about pain management, and unhelpful beliefs about analgesics should be identified and challenged. Continuous professional education about pain management, particularly opioid prescribing, is desirable. Cancer pain is rarely a static symptom. Both patients and professionals should be encouraged to communicate about cancer pain and to ensure timely reassessment when pain changes.

It seems likely that modern digital technologies could be used to address many of these requirements. Technology has already shown promise in improving informational continuity in the OOH period for patients with life-limiting illnesses. A recent study has shown that patients with cancer who have an electronic palliative care summary (ePCS) in place are less

likely to be admitted to hospital during the OOH period.¹² Information technology could support patients in monitoring, recording, and communicating about cancer pain. Digital devices that support medication adherence are becoming more sophisticated and acceptable. Regularly updated patient-reported pain scores could be integrated with contemporaneous data on analgesic use from digital medication adherence devices. Interpretation of these data by professionals and feedback to patients could support more effective pain management. The brave new world of technology in health care offers hope for people in pain from cancer. High quality research is required to identify how technology could optimise the management of cancer pain in the community.

Rosalind Adam,

Centre for Academic Primary Care, University of Aberdeen.

Peter Murchie,

Centre for Academic Primary Care, University of Aberdeen.

Provenance

Commissioned; not externally peer reviewed.

DOI: 10.3399/bjgp14X681229

ADDRESS FOR CORRESPONDENCE

Rosalind Adam

Centre for Academic Primary Care, University of Aberdeen, Polwarth Building, Foresterhill, Aberdeen AB25 2ZD, UK.

E-mail: rosalindadam@abdn.ac.uk

REFERENCES

1. Marie Curie Policy and Public Affairs. *Difficult conversations with dying patients and their families*. <http://blog.mariecurie.org.uk/wp-content/uploads/2014/03/S691-Difficult-Conversations-report.pdf> (accessed 23 Jul 2014).
2. Marie Curie Cancer Care. Marie Curie calls for 'around the clock' care for terminally ill [press release]. http://www.mariecurie.org.uk/ImageVaultFiles/id_1941/cf_100/Marie-Curie-calls-for-around-the-clock-care-for-te.PDF (accessed 23 Jul 2014).
3. Office for National Statistics. *National Bereavement Study (VOICES) 2012*. Newport: ONS, 2013. http://www.ons.gov.uk/ons/dcp171778_317495.pdf (accessed 23 Jul 2014).
4. van den Beuken-van Everdingen M, Derijke J, Kessels AG, *et al*. Prevalence of pain in patients with cancer: a systematic review of the past 40 years. *Ann Oncol* 2007; **18**(11): 1437–1449.
5. Adam R, Wassell P, Murchie P. Why do patients with cancer access out-of-hours primary care? A retrospective study. *Br J Gen Pract* 2014; DOI: 10.3399/bjgp14X677158.
6. Gunnarsdottir S, Donovan HS, Serlin RC, *et al*. Patient-related barriers to pain management: the Barriers Questionnaire II (BQ-II). *Pain* 2002; **99**(3): 385–396.
7. Cleeland CS. Barriers to the management of cancer pain. *Oncology* 1987; **1**(2 Suppl): 19–26.
8. Shi Q, Wang XS, Mendoza TR, *et al*. Assessing persistent cancer pain: a comparison of current pain ratings and pain recalled from the past week. *J Pain Symptom Manage* 2009; **37**(2): 168–174.
9. Gardiner C, Gott M, Ingleton C, *et al*. Attitudes of health care professionals to opioid prescribing in end-of-life care: a qualitative focus group study. *J Pain Symptom Manage* 2012; **44**(2): 206–214.
10. Gao W, Gulliford M, Bennett MI, *et al*. Managing cancer pain at the end of life with multiple strong opioids: a population-based retrospective cohort study in primary care. *PLoS One* 2014; **9**(1): e79266.
11. Worth A, Boyd K, Kendall M, *et al*. Out-of-hours palliative care: a qualitative study of cancer patients, carers and professionals. *Br J Gen Pract* 2006; **56**(522): 6–13.
12. Ali AA, Adam R, Taylor D, Murchie P. Use of a structured palliative care summary in patients with established cancer is associated with reduced hospital admissions by out-of-hours general practitioners in grampian. *BMJ Support Palliat Care* 2013; DOI:10.1136/bmjspcare-2012-000371.