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Article Title: Palliative care in the community

Year of publication: 2007

Link to published version:

<http://dx.doi.org/10.1136/bmj.39174.605081.80>

Publisher statement: None

BMJ 2007;334:809-810 (21 April), doi:10.1136/bmj.39174.605081.80

Editorials

Palliative care in the community

UK programme shows promise but services also need adequate investment

Primary care has a vital role in delivering palliative care.^{1 2} In most developed countries more people die in hospital than at home,³ although substantially more people would prefer to die at home.⁴ Primary care professionals play a central role in optimising available care, but they often lack the processes and resources to do this effectively.^{1 5}

The Gold Standards Framework for community palliative care⁶ is a primary care led programme in the United Kingdom that is attracting international interest.² The framework enables general practitioners and community nurses to optimise practice by providing guidance through workshops and locally based facilitation on how to implement processes needed for good primary palliative care. It is supported by a plethora of practical tools, guidance documents, and examples of good practice.⁷ It integrates many established aspects of primary palliative care: identifying patients systematically; naming a lead general practitioner and community nurse for each patient; coordinating multidisciplinary working through regular meetings; and planning of care with patients. Good communication, with out of hours and specialist care providers is also stressed, as is the importance of support for family carers.⁶

The framework is applicable to end of life care in general, not just cancer care, and its key elements could also be applied in any culture or healthcare setting through developing locally relevant tools and processes, so enabling the delivery of more effective and equitable end of life care in the community.

The programme has evolved rapidly and has been incorporated into UK health policy. After it was piloted in 12 practices in Yorkshire in 2001, its national implementation was sponsored by the charity Macmillan Cancer Support. More recently it has been sponsored by the National Health Service End of Life Care Programme in England and the National Lottery in Scotland. As a result, the framework has now been adopted by around 3000 practices in England, which cover a third of the population, and two thirds of practices in Scotland.

Despite limited evidence of its cost effectiveness and clinical effectiveness, it was recognised as an effective programme for palliative care by the National Institute for Health and Clinical Excellence (NICE) in 2004,⁸ endorsed by the Royal College of General Practitioners in 2005, and identified in the 2006 government white paper on community services as a central aspect of future health policy in the NHS in England. The Gold Standards Framework is now firmly embedded within primary care and has raised the profile of palliative care both professionally and politically.⁷

The national evaluation of the framework has focused on 1305 practices, 73% of which completed an audit questionnaire at baseline and after 12 months in the programme. Initial results suggest that the programme led to change—most participating practices reported that they had set up registers of patients undergoing palliative care, organised regular multidisciplinary team meetings, and were more confident that they were delivering good palliative care.⁹

A qualitative study of practices that have adopted the programme found that, in general, palliative care patients were being systematically identified and that communications had improved. As a result, planning of care had improved and practitioners had more confidence in symptom control.¹⁰ However, variations in how the programme had been implemented; differences in levels of commitment among professionals within individual practices; and the increased administrative burden, particularly on the framework coordinator within the practice, were highlighted as drawbacks.¹⁰ The extent to which these problems threaten the effectiveness of the programme in future practices remains to be seen.

Despite a paucity of evidence linking structured approaches in primary palliative care with outcomes, patients and carers undoubtedly value a holistic approach with care planning, good communication, and continuity of care from primary care teams.^{11 12} While some practice based audits suggest that adopting the framework may enable more patients to die at home,⁷ it is still uncertain how widely this aim can be realised. Improved primary care practice needs to be supported by realistic funding to make community nursing care and "night sitting" services available, and to provide access to specialist palliative care support, 24 hours a day seven days a week.⁸

As populations in developed countries become increasingly elderly, care of the dying becomes ever more important as a public health issue. Primary care can fulfil a central role in delivering effective palliative care, and the Gold Standards Framework is a model that can be built upon by applying its fundamental principles within the context of the local health service.² However, it must be properly resourced, especially when competition for healthcare funding is so intense. Without this, the mismatch between preference for a home death and the prospect of this occurring will persist.

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Competing interests: DM and JD received a grant from Macmillan Cancer Support to evaluate phases 3-6 of the Gold Standards Framework and are members of the Macmillan Primary Care Research Collaborative.

Provenance and peer review: Non-commissioned; externally peer reviewed.

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