

Developing primary palliative care

Scott A Murray, Kirsty Boyd, Aziz Sheikh, Keri Thomas and Irene J Higginson

BMJ 2004;329;1056-1057 doi:10.1136/bmj.329.7474.1056

Updated information and services can be found at: http://bmj.com/cgi/content/full/329/7474/1056

These include:

References

12 online articles that cite this article can be accessed at: http://bmj.com/cgi/content/full/329/7474/1056#otherarticles

Rapid responses

12 rapid responses have been posted to this article, which you can access

for free at:

http://bmj.com/cgi/content/full/329/7474/1056#responses

You can respond to this article at:

http://bmj.com/cgi/eletter-submit/329/7474/1056

Email alerting service

Receive free email alerts when new articles cite this article - sign up in the

box at the top left of the article

Topic collections

Articles on similar topics can be found in the following collections

Other Oncology (856 articles) Chronic diseases (73 articles)

Notes

practitioners is to ensure the health of their patients, then an awareness of gambling and the issues surrounding it should be an important part of basic knowledge.

Opportunities to gamble and access to gambling will increase because of impending deregulation. What has been shown clearly from research in other countries is that, for gambling, an increase in accessibility increases not only the number of regular gamblers but also the number of problem gamblersalthough this may not be proportional.w3 This means that not everyone is susceptible to developing gambling addictions, but it also means that the more the opportunities, the more the related problems. In Australia, Canada, and New Zealand, problem gambling has increased as a result of liberalisation.

Gambling is without doubt a health issue, and an urgent need exists to increase awareness in the medical and health professions about gambling related problems and to develop effective strategies to prevent and treat problem gambling.2 w4 The rapid expansion of gambling represents a serious public health concern, and medical practitioners also need to research the impact of gambling on vulnerable, at risk, and special populations. Inevitably, a small minority of people will become casualties of gambling directly as a result of the deregulation of gambling in the United Kingdom, and therefore help should be provided for the problem gamblers.

Mark Griffiths professor of gambling studies

International Gaming Research Unit, Psychology Division, Department of Social Sciences, Nottingham Trent University, Nottingham NG1 4BU (mark.griffiths@ntu.ac.uk)

Competing interests: None declared.

- Griffiths MD. Pathological gambling: a review of the literature. J Psychiatr Mental Health Nurs 1996;3:347-53.
- Korn DA. Expansion of gambling in Canada: implications for health and social policy. *CMAJ* 2000;163:61-4.

 McKee M, Sassi F. Gambling with the nation's health. *BMJ* 1995;
- 311:521-2.
- Sproston K, Erens R, Orford J. Gambling behaviour in Britain: results from the British gambling prevalence survey. London: National Centre for Social Research, 2000.
- Griffiths MD. Adolescent gambling: risk factors and implications for prevention, intervention, and treatment. In: Romer D, ed. Reducing adolescent risk: toward an integrated approach. London: Sage, 2003:223-38.

 Lorenz VC, Yaffee RA. Pathological gambling: psychosomatic, emotional
- and marital difficulties as reported by the gambler. J Gambling Behav 1986;2:40-5.
- Muellman RL, Den Otter T, Wadman MC, Tran TP, Anderson J. Problem gambling in the partner of the emergency department patient as a risk factor for intimate partner violence. *J Emerg Med* 2002;23:307-12.

 National Research Council. *Pathological gambling: a critical review.*Washington, DC: National Academy Press, 1999.

 Rosenthal R, Lesieur H. Self-reported withdrawal symptoms and pathological gambling. *Am J Addict* 1992;1:150-4.

 Setness PA, Pathological gambling when de social issues become medi-

- 10 Setness PA. Pathological gambling: when do social issues become medical issues? *Postgrad Med* 1997;102:13-8.

Developing primary palliative care

People with terminal conditions should be able to die at home with dignity

lthough 65% of people with cancer want to die at home, only about 30% are successful in doing so.12 A government committed to choice for patients must improve this figure.3 Developing palliative care services in primary care is essential for realising the expectations of dying people. Such services could also offer important opportunities for extending supportive humane care at an earlier stage, and to people not only with cancer but with chronic obstructive pulmonary disease, motor neurone disease, and cardiac failure, for example, who also often have palliative care needs.

Primary care professionals have the potential and ability to provide end of life care for most patients, given adequate training, resources, and, when needed, specialist advice.4 5 They share common values with palliative care specialists-holistic, patient centred care, delivered in the context of families and friends.⁶ However, until recently, apart from Macmillan general practitioners and nurse facilitators, few comprehensive workforce initiatives have been undertaken in primary care that focus on end of life care.

Many cancer patients and their carers experience existential distress long before they die.7 Recognising and alleviating such suffering is important, but it often goes unrecognised or is overlooked by services focusing on the terminal phase of illnesses. Primary care teams may know patients over long periods of time. They can readily identify patients from cancer and chronic disease registers who might benefit from an early palliative care approach. Such patients could

be identified by clinicians asking one simple question of themselves: "Would I be surprised if my patient were to die in the next 12 months?"8 By identifying such patients proactively we could deliver, simultaneously, active treatment and patient centred supportive care, through a team with whom many patients have a valued long term relationship.

Palliative care services need to be extended to patients with non-malignant conditions who have comparable concerns to and in some cases even greater unmet needs than cancer patients.9 Progress by palliative medicine specialists is hampered by issues such as uncertainty about the most effective models of care, lack of non-cancer expertise, and concerns about pressure on specialist services. General practitioners and community nurses can lead the way in providing a palliative care approach for patients with terminal organ failure illness. The first step in such an approach is for the goals of care to be discussed and agreed. Management plans are adjusted accordingly. Effective control of symptoms and maintaining quality of life are prioritised.

In the light of these important opportunities it is regrettable that the new general medical services contract has not prioritised palliative care. By day, other developments to achieve the quality indicators are taking precedence. By night and at weekends, the new unscheduled care services (which are responsible for providing care for 75% of the hours in the week) are even less well configured than previous out of hours provision to facilitate dying at home. Such services specialise in dealing with acute emergencies and, as

BMJ 2004;329:1056-7

such, often struggle to meet the medical, nursing, and social care needs of dying people and their families. These changes will greatly affect care for dying people and may increase the number of hospital admissions.

However, one important initiative is gaining momentum within primary care. The Gold Standards Framework is a resource for organising proactive palliative care in the community and is supported by funding from the Cancer Services Collaborative, Macmillan Cancer Relief, and the National Lottery. The framework provides a detailed guide to providing holistic, patient centred care and thereby facilitates effective care in the community. Other recently initiated mechanisms for developing primary palliative care include the training of general practitioners with a special interest in palliative care and the new end of life initiative in England to improve palliative care provision by generalists and to share examples of good practice.

To support such developments it is essential that primary palliative care is supported by an adequate academic base. This is admittedly a challenging arena in which to undertake research, but progress has been made in recent years in developing conceptual models and research architectures for studying end of life issues. Now we need to build on this work to ensure that the understanding and insights gleaned can be translated into effective interventions.

Every person with a progressive illness has a right to palliative care. 12 Patients desire a reassuring professional presence in the face of death. General practitioners and community nurses are trusted by patients and are in a position to provide effective, equitable, and accessible palliative care. This will happen only if they have adequate time and resources and work in a system that encourages such care. Patients

who receive holistic support in the community may be less likely to require expensive admission to hospital and often futile treatments at the end of their lives.

Scott A Murray clinical reader

Kirsty Boyd honorary senior lecturer

Aziz Sheikh professor of primary care research and development

Primary Palliative Care Research Group, Division of Community Health Sciences: General Practice Section, University of Edinburgh EH8 9DX (Scott.Murray@ed.ac.uk)

Keri Thomas national clinical lead palliative care

Cancer Services Collaborative, Birmingham, B24 0DE

Irene J Higginson professor

Department of Palliative Care and Policy, King's College, London SE5 9RJ

Competing interests: None declared.

- Higginson I, Sen-Gupta GJA. Place of care in advanced cancer. J Palliat Med 2004;3:287-300.
- World Health Organization. Palliative care: the solid facts. Copenhagen: WHO, 2004.
- 3 Department of Health. Building on the best: choice, responsiveness and equity in the NHS. London: DoH, 2003.
- 4 Harding R, Higginson I. What is the best way to help caregivers in cancer and palliative care? A systematic literature review of interventions and their effectiveness. *Palliat Med* 2003;17:63-74.
- 5 Charlton R. Primary palliative care. Oxford: Radcliffe Medical Press, 2002.
- Buckley G. General practice and palliative care. Eur J Gen Pract 1995;1:51-2.
 Murray SA, Kendall M, Boyd K, Worth A, Benton TF. Exploring the spiritual
- 7 Murray SA, Kendall M, Boyd K, Worth A, Benton TF Exploring the spiritual needs of people dying of lung cancer or heart failure: a prospective qualitative interview study of patients and their carers. *Palliat Med* 2004;18:39-45.
- Lynn J. Serving patients who may die soon and their families: the role of hospice and other services. *JAMA* 2001;285:7:925-32.
 Murray SA, Boyd K, Kendall M, Worth A, Benton TF. Dying of lung can-
- 9 Murray SA, Boyd K, Kendall M, Worth A, Benton TF. Dying of lung cancer or cardiac failure; prospective qualitative interview study of patients and their carers in the community. BMJ 2002;325:929-32.
- 10 Thomas K. Caring for the dying at home. Companions on a journey. Oxford: Radcliffe Medical Press, 2003.
- 11 National Institute for Clinical Excellence. Improving supportive and palliative care for adults with cancer. London: NICE, 2004.
- 12 World Health Organization. Better palliative care for older people. Copenhagen: WHO, 2004.

Emergency care networks

Are needed to coordinate the options available to patients in an emergency

gral part of the NHS since 1948. First medical and surgical emergencies were referred directly to the acute care firms and were seen initially by house officers. Patients with trauma, both minor and major, were seen by casualty officers in the casualty department. Over the next 25 years, "casualty" gradually evolved into accident and emergency medicine, which became an independent specialty in the 1970s. Since then the number of people attending emergency departments has inexorably risen, with a similar increase in the number of people "waiting for attention." The philosophy was "first come, first served," but with the most seriously ill patients taking precedence.

The situation changed dramatically in 2000 with the publication of the *NHS Plan*.¹ This contained two targets for emergency departments—that by 31 March 2003, 90% of attendees in emergency departments should be seen and discharged or admitted within four hours, and that this figure should rise to 100% (now amended to 98%) by the end of 2004. These targets were supported by a key document, *Reforming Emergency Care*, in 2001.² As

a result major changes and improvements have occurred, to the benefit of patients with urgent needs. Waiting in emergency departments has decreased considerably, with more than 95% of patients dealt with in less than four hours, long trolley waits down to a handful, and improved satisfaction of patients.³ But is that enough?

The success of emergency departments has led to new problems. A further increase in the number of people attending has resulted, presumably because patients find it easier to go to emergency departments than to make an appointment with their general practitioner and partly because arrangements for out of hours work in the community have changed. But could there be more appropriate and more convenient care for patients elsewhere? Pressure within the hospitals for more seriously ill patients has been increasing. Diagnosing the need for admission quickly is one thing, but finding a bed and a specialist team to deal expeditiously with the patient quite another.

The main focus so far has been on the emergency department, whereas emergency care is a problem for the whole system. If one starts with a person with an

BMJ 2004;329:1057-8