Palliative care at home: general practitioners working with palliative care teams

Kevin J Yuen, Margaret M Behrndt, Christopher Jacklyn and Geoffrey K Mitchell

ABSTRACT

- Home care is the preferred option for most people with a terminal illness.
- Providing home care relies on good community-based services, and a general practice workforce competent in palliative care practice and willing to accommodate patients' needs.
- Structured palliative care training of general practitioners is needed at undergraduate and postgraduate level, with attention to barriers to teamwork and communication.
- Good palliative care can be delivered to patients at home by GPs (supported by specialist palliative care teams) and community nurses, with access to an inpatient facility when required.
- To optimise patient care, careful planning and good communication between all members of the healthcare team is crucial.

MJA 2003; 179: S38–S40

MOST PEOPLE with an advanced, progressive incurable disease wish to spend their final days in their own home.[1] Indeed, 90% of the care of patients in their last 12 months of life occurs at home, with the support of a general practitioner and community nurse teams.[2] While 25%–40% actually achieve this aim of dying at home,[1,3,4] another 30% of patients remain at home until the final few days of life.[2]

As with other developed countries, Australia's population is ageing. The demand on palliative care resources will increase markedly in the next two decades. Coupled with this, changes in the demographics and work patterns of the general practice workforce will lead to difficulties in achieving the goal of home care for most people with a terminal illness, unless structural initiatives are put in place.

To make it possible for terminally ill patients to remain at home for most or all of their remaining life, they should have access to:

- A GP knowledgeable in and skilled in palliative care, who is prepared to make home visits and provide after-hours' cover;
- A specialist palliative care team to work with the GP; and
- Access to an inpatient facility to manage acute changes in the patient's condition, or for respite purposes.

Difficulties faced by GPs

Keeping up to date

While each Australian GP treats a median of five to seven terminally ill patients annually, this number can vary widely.[5-7] Most GPs value the role they play in palliative care, but some GPs feel uncomfortable when confronted with dying patients because of their perceived inability to keep up to date with the latest management techniques.[6] Some studies of carers' recollections of patient care indicate poorer symptom control in patients managed by GPs, as opposed to specialist units.[8,9] Other reports dispute this.[10] However, patients appreciated the care their GP gave, particularly when he or she took time to explain what was happening and continued to try to control symptoms.[9,11,12] Furthermore, it appears that GPs had a fundamentally sound knowledge of basic symptom relief.[13]

The training most GPs receive in palliative care is patchy, and dependent on local initiatives. Most recent graduates reported receiving some palliative care training at vocational training levels, but virtually none at intern level.[7,14,15] GPs' knowledge of physical symptom control has been shown to be adequate, but they are aware that they need specific psychosocial and counselling skills to work in palliative care.[6,16] However, palliative care training must compete with the myriad other areas in which GPs are required to be proficient.

Time constraints

Most GPs indicate that time is a barrier to increased involvement in the palliative care of their patients.[7] There is a perceived shortage and maldistribution of GPs, and GPs seem to be busier than ever. Time is a fundamental component of palliative care, and if time is as constrained in general practice as is claimed, GPs will not be able to provide appropriate care.

Remuneration

Until the advent of the Enhanced Primary Care Program in 1999, palliative care activities were not recognised by the

Cancer Foundation Cottage Hospice, Shenton Park, WA.
Kevin J Yuen, MB BS, FAChPM, Medical Director, and Palliative Care Consultant, Royal Perth Hospital;
Margaret M Behrndt, BSc(Hons), PhD, Consulting Medical Anthropologist/Sociologist;
Christopher Jacklyn, FAChPM, FRACGP, DipPallMed, Consultant; and General Practitioner.
Centre for General Practice, School of Population Health, University of Queensland, Herston, QLD.
Geoffrey K Mitchell, MB BS, FRACGP, Senior Lecturer in General Practice, and Director, Centre for Palliative Care Research and Education.
Reprints will not be available from the authors. Correspondence: Dr Kevin J Yuen, Cancer Foundation Cottage Hospice, 15 Bedbrook Place, Shenton Park, WA 6008. kyuen@cancerwa.asn.au

Health Insurance Commission. Patients and families were offered time-consuming care, without appropriate remuneration mechanisms in place.[7] Some doctors still consider that palliative care is an uneconomic proposition, but others value the opportunity to "walk with" patients on their final journey regardless of the economic cost.[7,17] The remuneration afforded by the Enhanced Primary Health Care items, which aim to improve multidisciplinary care planning, has the potential to facilitate communication between GPs and specialist palliative care teams. However, the complexity of this process has limited its uptake.[18,19]

Demographics

The nature of the general practice workforce is changing — there are fewer men and fewer younger practitioners. More GPs are opting for part-time work, probably reflecting a desire to balance professional lives with family and other obligations.[20]

Mitchell describes a dissonance between GPs' self-perceived inadequacies, discomfort in treating palliative care symptoms, the perceptions of carers, and their actual performance as recorded in the literature.[6] GPs can provide good palliative care, but will they remain involved, or will they, as in the case of obstetric care, increasingly defer to their specialist colleagues?[21,22] What can be done to revitalise interest in palliative care as an integral part of general practice?

GPs and specialist teams

Palliative care began as a radically different way of caring for people with a terminal illness, and took many years to be accepted as a mainstream discipline. Over time, the outcomes that specialist palliative care teams can achieve have been clearly demonstrated. Such teams are better able to identify and deal with patient and family needs, and to provide access to other services. They can also provide improved pain control and symptom management.[23] GPs have been wary of sharing care with specialist teams, but are more willing to do so once they have experienced shared management.[24]

For some GPs, the preferred model of care is one in which the GP coordinates the patient's palliative care and works with other team members who assist in providing physical, emotional and spiritual care (unpublished data).

A major source of dissatisfaction for GPs is the problem of knowing what their role is and when they should defer to specialists.[7,25] GPs require a meaningful role, good communication and clear role delineation to be comfortable working with palliative care teams.[16] The GP's preferred role is to be the advocate for the patient in the healthcare system, but all too often it seems that this role is neither engaged nor encouraged by the specialist or palliative care community. GPs need to be willing to take this role as their own, but palliative care teams also need to be willing to offer this relationship to the GP. The different working cultures of GPs and palliative care teams need to be acknowledged and innovative solutions found that marry these competing cultures.[18] Several innovative models prove this can be done.

Models of palliative care

In Australia, there are various models of palliative care home support teams.

- In Western Australia, the Silver Chain Hospice Care Service provides, for the city of Perth, a multidisciplinary care team comprising doctors, nurses, allied health professionals, volunteers and spiritual and counselling support. The doctors in these teams are usually local GPs who have had additional training in palliative care.[26] This "embedded" doctor model contrasts with other programs that prefer to use doctors attached to palliative care teams from hospitals, or hospices who liaise with the patient's own GP.
- In Queensland, the Ipswich Palliative Care Network model incorporates a public inpatient unit, a general practice-run hospice, and domiciliary nursing services.[27] GPs are expected to provide palliative care, and there are supporting mechanisms for education (evidence-based guidelines) and peer review (weekly case conferences with a palliative care specialist) to ensure patient care standards are maintained.[27]

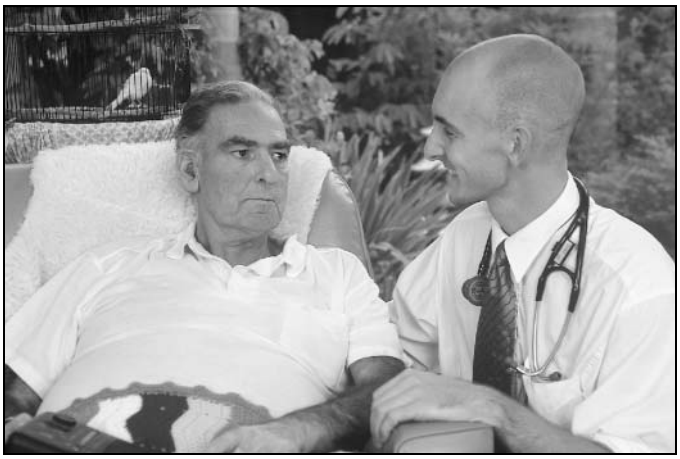
The federal government is currently funding a range of different models of palliative care delivery in rural, regional and remote settings. The government also commissioned a national study into GP education and support needs for palliative care, which has just been completed.[7] These initiatives should provide evidence-based strategies to improve palliative care training and facilitate palliative care in a range of settings, including general practice, with resulting improvement in patient care.

The role of community nurses

An invaluable member of the home-care team is the community nurse. If the nurse has palliative care expertise, teamwork between community nurses and GPs can provide high quality care for patients.[23] Nurses can give the GP and other team members a "real time" assessment of the patient and family, and can also give advice on possible therapeutic interventions or the need for inpatient admission. Community nurses are generally the "backbone" of a home-care program and, as such, need to receive sufficient skills training and team support to continue their work.

Inpatient access for palliative care patients

A crucial element of community palliative care is ready access to palliative care beds. In Ireland, one study found that 25% of GPs frequently experienced difficulty acquiring hospice inpatient beds for their patients.[28] Anecdotally, the situation in Australia is similar. The pressure on all inpatient facilities has increased steadily over the years, and, in the event that home care is not going well, it can be difficult to give GPs and home teams a solid guarantee of a palliative care bed.



Elderly patients without terminal illness

Very elderly patients who do not have a malignant illness but need palliative care present an emerging challenge that demands the attention of our policymakers and healthcare planners. These patients have an uncertain prognosis and variable care needs. Palliative care services with limited resources find it difficult to afford to care for these people in the same way they would for patients with cancer. Their non-linear illness trajectory and often complex treatment regimens lead to many practitioners taking a different approach to these patients.[29] As a result, their palliative care needs may not be adequately met.

Conclusion

The interface between GPs and specialist palliative care services must work well to ensure that quality home palliative care is available to all. Current resource constraints and pressures on general practice create challenges for practitioners, palliative care services and health administrators alike. Evidence-based models of shared care, and strategies that improve the skills and opportunities of all doctors to learn sound palliative care principles have to be initiated now, if the profession is to be as prepared as possible to meet the challenges of an ageing Australian society.

Competing interests

None identified.

References

1. Tiernan E, O'Connor M, O'Siorain L, Kearney M. A prospective study of preferred versus actual place of death among patients referred to a palliative care home-care service. *Ir Med J* 2002; 95: 232-235.
2. Hinton J. Can home care maintain an acceptable quality of life for patients with terminal cancer and their relatives? *Palliat Med* 1994; 8: 183-196.
3. Bruera E, Russell N, Sweeney C, et al. Place of death and its predictors for local patients registered at a comprehensive cancer center. *J Clin Oncol* 2002; 20: 2127-2133.
4. Jordhoy M, Fayers P, Saltnes T, et al. A palliative-care intervention and death at home: a cluster randomised trial. *Lancet* 2000; 356: 888-893.
5. Wakefield MA, Beilby J, Ashby MA. General practitioners and palliative care. *Palliat Med* 1993; 7: 117-126.
6. Mitchell G. How well do general practitioners deliver palliative care? A systematic review. *Palliat Med* 2002; 16: 457-464.
7. Reymond E, Mitchell G, McGrath B, Welch D. Research into the educational, training and support needs of general practitioners in palliative care. Report to the Department of Health and Ageing. Brisbane: Mt Olivet Health Services, 2003. Executive summary available at: www.mtolivet.org.au/Research/Research%20Projects/Research_projects.htm (accessed Aug 2003).
8. Addington-Hall J, McCarthy M. Dying from cancer: results of a national population-based investigation. *Palliat Med* 1995; 9: 295-305.
9. Lecouturier J, Jacoby A, Bradshaw C, et al. Lay carer's satisfaction with community palliative care: results of a postal survey. *Palliat Med* 1999; 13: 275-283.
10. Field D, Douglas C, Jagger C, Dand P. Terminal illness: views of patients and their lay carers. *Palliat Med* 1995; 9: 45-54.
11. Hanratty B. Palliative care provided by GPs: the carer's viewpoint. *Br J Gen Pract* 2000; 50: 653-654.
12. Grande GE, Todd CJ, Barclay SI. Support needs in the last year of life: patient and carer dilemmas. *Palliat Med* 1997; 11: 202-208.
13. Shipman C, Addington-Hall J, Barclay S, et al. Educational opportunities in palliative care: what do general practitioners want? *Palliat Med* 2001; 15: 191-196.
14. Barclay S, Todd C, Grande G, Lipscombe J. How common is medical training in palliative care? A postal survey of general practitioners. *Br J Gen Pract* 1997; 47: 800-804.
15. Charlton R, Ford E. Education needs in palliative care. *Fam Pract* 1995; 12: 70-74.
16. Millar DG, Carroll D, Grimshaw J, Watt B. Palliative care at home: an audit of cancer deaths in Grampian region. *Br J Gen Pract* 1998; 48: 1299-1302.
17. Field D. Special not different: general practitioners' accounts of their care of dying people. *Soc Sci Med* 1998; 46: 1111-1120.
18. Mitchell GK, De Jong IC, Del Mar CB, et al. General practitioner attitudes to case conferences: how can we increase participation and effectiveness? [editorial] *Med J Aust* 2002; 177: 95-97.
19. Harris M. Case conferences in general practice: time for a rethink? [editorial] *Med J Aust* 2002; 177: 93-94.
20. Britt H, Miller G, Knox S, et al. General practice activity in Australia 2001-02. 10th ed. Canberra: Australian Institute of Health and Welfare, 2002.
21. Fordham S, Dowdrick C, May C. Palliative medicine: is it really specialist territory? *J R Soc Med* 1998; 91: 568-572.
22. Fordham S, Dowrick C. Is care of the dying improving? The contribution of specialist and non-specialist to palliative care. *Fam Pract* 1999; 16: 573-579.
23. Hearn J, Higginson I. Do specialist palliative care teams improve outcomes for cancer patients? A systematic literature review. *Palliat Med* 1998; 12: 317-332.
24. Cartwright A. The relationship between general practitioners, hospital consultants and community nurses when caring for people in the last year of their lives. *Fam Pract* 1991; 8: 350-355.
25. Higginson I. Palliative care services in the community: what do family doctors want? *J Palliat Care* 1999; 15: 21-25.
26. Boakes J, Gardner D, Yuen K, Doyle S. General practitioner training in palliative care: an experiential approach. *J Palliat Care* 2000; 16: 11-19.
27. Mitchell G, Price J. Developing palliative care networks in regional centres. The Ipswich Palliative Care Network model. *Aust Fam Physician* 2001; 30: 59-62.
28. Walsh D, Regan J. Terminal care in the home — the general practice perspective. *Ir Med J* 2001; 94: 9-11.
29. Murray S, Boyd K, Kendall M, et al. Dying of lung cancer or cardiac failure: prospective qualitative interview study of patients and their carers in the community. *BMJ* 2002; 325: 915-916.

(Received 20 May 2003, accepted 25 Jul 2003) ❑