Palliative Medicine 2006; **20:** 487–492

Roles, service knowledge and priorities in the provision of palliative care: a postal survey of London GPs

Jenni Burt Department of Epidemiology and Public Health, UCL, London, **Cathy Shipman** Department of Palliative Care and Policy, King's College London School of Medicine, London, **Patrick White** Department of General Practice and Primary Care, King's College London School of Medicine, London and **Julia Addington-Hall** School of Nursing and Midwifery, University of Southampton, Southampton

Objectives: To explore general practitioners' (GPs) current involvement in and attitudes towards the provision of palliative care in primary care. **Methods**: Postal survey of 356 London-based GPs, assessing attitudes towards palliative care provision, district nursing and specialist palliative care services, and priorities for future service development. **Results**: Currently, 65% of GPs were providing palliative care to patients on their list; 72% agreed or strongly agreed palliative care was a central part of their role; and 27% wanted to hand care over to specialists. Most GPs (66%) disagreed with the statement that 'palliative care is mainly district nursing (DN) work'. Many were unaware of out-of-hours DN and specialist palliative care services. Multi-variable analysis found four GP characteristics – larger practice size, more years experience as a GP, receipt of palliative care education, and current provision of palliative care – were associated with agreement that palliative care was central to a GP's role. **Conclusion**: A minority of NHS GPs in London would rather have no involvement in palliative care in primary care. Knowledge of current services for palliative care is generally poor among GPs. These findings highlight potential gaps in services, particularly in small practices. Specialists will need to consider these factors in working with GPs to develop primary palliative care and to enable greater access to specialist palliative care. *Palliative Medicine* 2006; **20:** 487–492

Key words: general practice; palliative care; postal survey; primary care; service provision

Introduction

In the UK, the National Health Service (NHS) is promoting the improvement of palliative care in primary care (provided by GPs and district and community nurses). It aims to empower, enable, train and support these health care professionals, and encourage them, where necessary, to work in conjunction with specialist palliative care services. Programmes in support of this policy include a £6 million Government investment in education and training for district nurses (DNs) in palliative care, and an End of Life Care Strategy, which is supporting the wider uptake of three initiatives: the Gold Standards Framework (GSF), the Liverpool Care Pathway, and Preferred Place of Care plans to enhance the choice of dying at home if patients wish.[1–7] These programmes are taking place at a time of major change in the organization and delivery of primary care. In particular, the introduction of a new contract for NHS general practitioners (GPs) and the reconfiguration of out-of-hours services have altered the activities of GPs, and may affect their role in the provision of palliative care.[8,9]

Not all patients will require specialist palliative care.[10] However, for those patients who do require specialist palliative care, methods of working with specialist services can vary between GPs. Some GPs use specialist palliative care services only infrequently, whilst others use them as a resource (the most common model), or work with them as part of an extended team. A final group of GPs look to hand over care or responsibility completely to specialist services.[11] These widely varying approaches have important implications for specialist providers who offer advice and support to GPs within their local area. Knowledge of the extent and characteristics of GPs using these varying ways of working is, at best, limited. Such knowledge is important to enable greater access for patients and carers to specialist palliative care services.

We undertook a research project to examine how London's primary care professionals were providing palliative care and to explore the ways in which GPs, DNs, and palliative care specialists worked together.[12] This paper reports the results of a postal survey of GPs, investigating their attitudes towards the provision of palliative care, and their views on the roles of district

---

Address for correspondence: Jenni Burt, MRC Research Fellow, Department of Epidemiology and Public Health, UCL, 1–19 Torrington Place, London WC1E 6BT, UK.
E-mail: jenni.burt@ucl.ac.uk

10.1191/0269216306pm1159oa

and community nurses and of specialist palliative care providers.

Methods

Postal questionnaires were sent to all eligible GPs ($n = 620$) in five London Primary Care Trusts (PCTs) in 2003–2004. Participating PCTs were purposively selected to reflect the diversity of London PCTs with respect to: the provision of specialist palliative care services (single or multiple providers, and based within or outside the PCT); the provision of night DN services (available or unavailable); geographical location (inner or outer London); and deprivation levels.

The questionnaire drew upon items previously used in an evaluation of palliative care services in Cambridgeshire.[13] It covered attitudes towards providing palliative care, perceived availability of services, out-of-hours care, access to and satisfaction with DN and specialist palliative care services, priorities for service development, and educational preferences. In addition, the questionnaire asked about respondents' age, sex, number of GP principals in the practice, years as a GP, and whether they had previously worked in a hospice or specialist palliative care service. A postal strike took place during questionnaire mailing, so we sent three reminders to ensure participants received the study information. Ethical approval was obtained from the South West Multi-Centre Research Ethics Committee.

Data analysis

Pearson χ^2 tests were used to make univariate comparisons. Multiple linear regression was then used to examine attitudes to palliative care, controlling for respondent characteristics. Characteristics were grouped into three clusters – socio-demographic, experience of palliative care, and experience of district nursing services, and a regression analysis (forced entry) was undertaken for each cluster. Variables contributing significantly to each model at the $P < 0.05$ level were taken forward into a combined final regression model. Variables retained in the final model remained statistically significant at the $P < 0.05$ level.

Results

We received 356 (57%) completed questionnaires. Comparisons to both the London and the England GP workforce found female GPs were slightly over-represented (58% of our respondents versus 46% in London as a whole ($\chi^2 = 19.0$, df = 1, $P < 0.001$), and 39% in England ($\chi^2 = 53.2$, df = 1, $P < 0.001$)). Single-handed GPs were under-represented (6% of our respondents versus 18% in London ($\chi^2 = 37.6$, df = 3, $P < 0.001$), and 9% in England ($\chi^2 = 28.27$, df = 3, $P < 0.001$)). Finally, a lower than expected proportion of GPs aged 55 and over responded, compared to London GPs as a whole (21 versus 29%; $\chi^2 = 9.6$, df = 3, $P = 0.002$), although there were no significant differences by age compared to GPs in England (20%).[14]

Provision of palliative care

Most GPs (65%, 232/352) reported that they were currently providing palliative care to patients on their list: 61% to cancer patients, and 26% to non-cancer patients. Overall, most (63%) were currently caring for between one and three patients, 22% for four to six patients, and 15% (32/211) for seven or more.

The role of GPs

The majority of GPs (72%) agreed or strongly agreed that palliative care was a central part of their role, but this was less true of single-handed GPs (47%) compared to those in small (two to four GPs; 67%), medium (five to seven; 81%) or large (≥ 8; 85%) group practices ($\chi^2 = 20.5$, df = 6, $P = 0.002$).

There were no statistically significant differences in attitude between GPs of different ages or years of experience in the univariate analysis. However, in the multi-variable analysis, four GP characteristics (larger numbers of partners in the practice, more years experience as a GP, receipt of palliative care education, and current involvement in the provision of palliative care to patients on their caseload) were independently associated with agreement that palliative care was a central part of a GP's role.

Handing over to specialist palliative care

While only 27% of GPs wanted to hand palliative care over to specialists (Table 1), single-handed GPs were more likely to want to do so (53% agreed or strongly agreed; $\chi^2 = 23.4$, df = 6, $P = 0.001$). On the other hand, having worked in a hospice or specialist palliative care service was indicative of a desire not to hand over care, with 70% (21/30) of GPs with such experience disagreeing or strongly disagreeing with this statement ($\chi^2 = 6.3$, df = 2, $P = 0.043$).

Four GP characteristics (working in a smaller practice, no experience of working in a hospice or specialist palliative care setting, feeling that specialist palliative care services were less frequently available, and stating that they were not currently providing palliative care) were independently associated (multi-variable analysis) with agreement that palliative care at home should be handed over to specialists (Table 2).

Table 1 GP attitudes towards roles in the provision of palliative care (% (*n*))

	Strongly agree	Agree	No strong view	Disagree	Strongly disagree	Total
Palliative care is a central part of my role	34.7 (122)	37.5 (132)	20.7 (73)	6.3 (22)	0.9 (3)	100.0 (352)
Palliative care at home should be handed over to specialists	5.8 (20)	21.3 (74)	23.6 (82)	41.8 (145)	7.5 (26)	100.0 (347)
Palliative care is mainly district nursing work	0.9 (3)	14.5 (51)	18.5 (65)	57.4 (202)	8.8 (31)	100.0 (352)

The role of district and community nurses and palliative care specialists

Most GPs (66%, 229/348) disagreed or strongly disagreed that 'palliative care is mainly district nursing work' (Table 1). There were no significant differences in attitude by age, sex, years of experience, and having worked in a hospice. More (45%) single-handed GPs agreed or strongly agreed that palliative care was mainly DN work compared to only 18% of those in large group practices ($\chi^2 = 25.4$, df $= 6$, $P < 0.001$). No other GP characteristics were associated with their views of the roles of district and community nurses.

GPs who agreed that palliative care was a central part of their role were significantly less likely to wish to hand over care to specialists ($\chi^2 = 61.6$, df $= 4$, $P < 0.001$), or to view palliative care as mainly district nursing work ($\chi^2 = 12.8$, df $= 2$, $P = 0.012$).

Knowledge of service availability

GPs' knowledge of the out-of-hours availability of DN and specialist palliative care services varied significantly. All five PCTs had an evening DN service, yet 11% of GPs thought that they did not have access to this, and 7% did not know if they did or did not. Three of the five PCTs had a night DN service −27% of GPs were incorrect in their knowledge of this (eg, stating that there was a service when there was none), and a further 22% did not know whether or not there was a service. Knowledge was even lower for specialist palliative care services. The percentage of GPs who did not know whether they could access specialist services during the evening, at night, or over the weekend was 33, 45 and 37%, respectively. Lack of knowledge of the availability of DN and specialist palliative care services at night rose sharply amongst those GPs who disagreed or strongly disagreed that palliative care was a central part of their role, with 72% (18/25) incorrect about district nursing availability ($\chi^2 = 8.6$, df $= 2$, $P = 0.013$) and 71% (17/24) not knowing about the accessibility of specialist palliative care ($\chi^2 = 14.1$, df $= 4$, $P = 0.007$).

Priority for future service development

Respondents' priorities with respect to future planning of services for palliative care patients are shown in Table 3.

Specialist palliative care assessment and clinical nurse specialists in the community were given the highest priority, closely followed by daytime district nursing, and in-patient palliative care beds. GP input in the form of home visits and, particularly, out-of-hours care was a lower priority, although both were still seen as important for further development.

Discussion

GPs in London varied considerably in their awareness, attitudes to and knowledge of palliative care and specialist palliative care services, although most GPs felt that palliative care was a central part of their work. GPs who worked in smaller practices, who had limited current involvement in palliative care provision, and who had less experience of or education in palliative care were

Table 2 GP attitudes towards roles in the provision of palliative care: regression analysis

	B	Standard error of B	Beta	*P*-value
Palliative care is a central part of my role: variables independently contributing towards predicting agreement*				
No. of partners in practice	0.006	0.023	0.149	0.006
No. of years as a GP	0.002	0.006	0.142	0.008
Received palliative care education	0.272	0.102	0.142	0.008
Currently providing palliative care	0.263	0.106	0.132	0.014
Palliative care at home should be handed over to specialists: variables independently contributing towards predicting agreement**				
No. of partners in practice	−0.103	0.026	−0.218	<0.001
Worked in a hospice/specialist palliative care provider	−0.388	0.196	−0.106	0.048
Specialist palliative care assessment available when needed	−0.390	0.176	−0.120	0.027
Currently providing palliative care	−0.253	0.119	−0.113	0.034

*$R^2 = 0.08$.
**$R^2 = 0.09$.

Table 3 GPs' priorities for future service development (1 = very unimportant, 5 = very important)

Service	Mean priority (SD)
Specialist palliative care assessment	4.60 (0.56)
Macmillan/specialist community nurses	4.59 (0.65)
District nursing in daytime	4.55 (0.61)
Inpatient palliative care beds (hospice or hospital)	4.54 (0.59)
Specialist telephone advice	4.50 (0.65)
Respite care	4.45 (0.59)
Social service home care support	4.31 (0.67)
District nursing at night	4.24 (0.74)
Marie Curie nurses	4.16 (0.82)
Social work assessment	4.14 (0.74)
Daytime GP home visits	4.10 (0.86)
Day hospice	4.07 (0.73)
General practice (out-of-hours)	3.76 (0.90)

more likely to see palliative care as not central to their role and more likely to want to hand over such care to specialists. However, GPs who disagreed that palliative care was central to their role were also less likely to know about the availability of local services. Amongst GPs who did view palliative care as central to their role, the relative ignorance of the availability of local specialist palliative care services, and the small numbers of patients they identified as receiving palliative care at any time, highlight the need for better structure and management of palliative care in their practices. These findings have important implications for the varying roles specialist providers might need to adopt in supporting patients effectively within primary care.

Study respondents were GPs working mainly in inner city areas, thus limiting the generalizability of our findings. Nonetheless, participating areas were selected purposively to ensure a diversity of service provision and geographical location. The overall response rate of 57% was good for surveys of GPs.[15] However, small differences between respondents and London GPs as a whole suggest that our findings slightly under-represented the views of older GPs and those in smaller practices; a lower response in these categories is typical of many GP surveys.[16] We could not test formally for non-response bias by the degree of GPs' interest in palliative care. However, it is likely our results represent the opinions of GPs more concerned about or committed to the provision of palliative care, as demonstrated by their return of the questionnaire.[16] It is, therefore, possible that the proportion of GPs we have identified as having limited involvement or interest in palliative care is larger than that stated here.

A greater proportion of single-handed GPs, in particular, appeared to want to hand over care to specialist services, or identified DNs as taking a key palliative care role. This 'hands-off' approach to palliative care contrasts with evidence that, for other types of care, patients frequently view single-handed practitioners as providing good continuity and strong personal relationships.[17] However, single-handed GPs form a distinct minority group (9%) of NHS GPs who work in relative clinical isolation.[18,19] It is possible that lack of GP partners to share the workload may encourage some of these GPs to hand over care to specialist services entirely, where such services are easily accessible. While this may enable patient access to specialist services, it may also result in disengagement from palliative care. Whilst specialist palliative care providers and DNs, with the tacit encouragement of the GP, may become proactive and take over care in these circumstances, failure to retain GP involvement may forfeit a channel of communication which could provide informal education and support, fostering the confidence of GPs and leading to earlier referral and more holistic care of the patient.

DNs provide most of the hands-on palliative care in the home, so it is surprising that so few GPs considered palliative care to be mainly DN work.[20] This may reflect perceptions of leadership within the primary care team and the gatekeeper role of the GP in the NHS, rather than the extent of input that GPs contribute. Reports of tensions in the relationships between GPs and DNs in end-of-life care stretch back many years, and are still continuing today.[21] Poor communication and heavy workloads may lead to a misunderstanding of roles and a breakdown in co-ordination of care.[12] In London, further pressure is added by ongoing recruitment and retention problems within the DN workforce.

Lack of knowledge of local services suggests the need for continuous provision of information about local specialist services and educational opportunities in palliative care. Our results suggest that GPs who were currently providing palliative care, particularly to cancer patients, were more aware of available services by virtue of their involvement at that time. Palliative care forms only a small proportion of the work of the GPs, and it seems likely that local sources of support may not have been held firmly in mind. Innovative methods of communicating with key contacts, and the development of good relationships between specialists and generalists, may be necessary to address current gaps in knowledge. How such information and education might be provided has been subject to debate, and the role of GP Facilitators in palliative care, who provide a bridge between primary and specialist services, has been positively evaluated.[22]

Respondents rated almost all services as important for future development, and mean scores were higher than those reported for other areas of England.[23] This reported need for development may reflect perceptions of lower availability or accessibility of services (particularly specialist services) within London; again, highlighting the need for good communication about services and their uptake.

These findings point to the need for a systematic approach to palliative care within primary care which identifies patients in need, maintains links with local services, and tries to ensure the needs of patients approaching the end of life are met. In the NHS, such an approach is epitomized in the Gold Standards Framework (GSF), which aims to improve home care for the dying by optimizing the local primary care team's provision through a framework of steps, including identification, registration and monitoring. The GSF is one of the three arms of the recently published End of Life Strategy in the NHS, and has been endorsed by the Royal College of General Practitioners.[4] However, its effectiveness has not yet been fully evaluated.

It is encouraging that most responding GPs saw palliative care as a central part of their role. However, the uncertainties expressed by some GPs about their place in palliative care set an important challenge to assumptions about their future responsibilities. Traditionally, in the NHS GPs have retained a pivotal position in palliative care for three key reasons. First, they are the initial point of contact for all patients and frequently gatekeepers to further services. Second, GPs often have a key role in issues of continuity affecting patients and families, especially where there are other co-morbidities. Finally, GPs usually hold responsibility for their patients' prescribing. Recently, there have been a number of challenges to these assumptions – for example, with increased specialist involvement in prescribing. However, it remains clearly in the interest of the future development of NHS palliative care that the opportunities associated with primary care's place at the centre of the NHS are maximized.

However, against these advantages should be set the observation reported in this paper that some GPs are keen to pass on the responsibility for working with patients who have palliative care needs, and see themselves as not having a palliative care role. While this is a minority view, it is not clear if this is a rising or falling trend, or if it is the result of national changes in the responsibilities of GPs. The role of the GP in the NHS has changed from one of predominantly clinical hands-on care, to a mixed clinical and leadership role. In palliative care, the role of key contact with patients approaching the end of life may now be undertaken more by DNs and community clinical nurse specialists than by GPs. If this is the case, there is a pressing need to ensure that this is recognized within the structure and organization of palliative care in primary care. Whatever future role GPs play in palliative care, it is likely that their gatekeeper role to other services will be maintained. To ensure patients receive early and easy referral to specialist palliative care support when necessary, such services – particularly those based in the community – will need to be visible, flexible and accessible, and innovative in maintaining good channels of communication.

Acknowledgements

The authors thank the King's Fund for funding this study, and all the GPs who took the time to participate in this survey. We are also grateful to Dr Dan Altmann, Dr Stephen Barclay and Professor Irene Higginson for their advice, to Steve Dewar for his support, and to Floss Chittenden for administrative support.

References

1 Department of Health. A plan for investment. A plan for reform. *The NHS cancer plan*. Department of Health, 2000.
2 NICE. Improving supportive and palliative care for adults with cancer. The manual. *Guidance on Cancer Services*. National Institute for Clinical Excellence, 2004.
3 Department of Health. *Building on the best: choice, responsiveness and equity in the NHS*. CM 6079, 1-71. The Stationery Office, 2003.
4 Thomas K. The Gold Standards Framework in community palliative care. *Eur J Palliat Care* 2003; **10**: 113–15.
5 Ellershaw JE, Murphy D, Shea T, Foster A, Overill S. Development of a multiprofessional care pathway for the dying patient. *Eur J Palliat Care* 1997; **4**: 203–208.
6 Ellershaw JE, Wilkinson S. *Care of the dying: a pathway to excellence*. Oxford University Press, 2003.
7 Storey L, Pemberton C, Howard A, O'Donnell L. Place of death: Hobson's choice or patient choice? *Cancer Nurs Pract* 2003; **2**: 33–38.
8 Department of Health. Investing in general practice. *The new general medical services contract*. Department of Health, 2003.
9 Department of Health. Raising standards for patients. New partnerships in out-of-hours care. *An independent review of GP out-of-hours services in England*. Department of Health, 2000.
10 Franks PJ, Salisbury C, Bosanquet N, *et al*. The level of need for palliative care: a systematic review of the literature. *Palliat Med* 2000; **14**: 93–104.
11 Shipman C, Addington-Hall JM, Barclay S, Briggs J, Daniels L, Millar D. How and why do GPs use specialist palliative care services? *Palliat Med* 2002; **16**: 241–46.
12 Burt J, Shipman C, Addington-Hall JM, White P. *Palliative care: perspectives on caring for dying people in London*. King's Fund, 2005.
13 Barclay S, Shipman C. *Supporting primary palliative care strategy development in Cambridgeshire*. Personal Communication 2005.
14 Department of Health. *General and personal medical services statistics. England and Wales, 30 September 2003*. Retrieved from http://www.publications.doh.gov.uk/public/nhsworkforce.htm
15 Sibbald B, Addington-Hall JM, Brenneman D, Freeling P. Telephone versus postal surveys of general

practitioners: methodological considerations. *Br J Gen Pract* 1994; **44**: 297–300.

16 McAvoy BR, Kaner EFS. General practice postal surveys: a questionnaire too far? *BMJ* 1996; **313**: 732–33.

17 Curtis SE. The patient's view of general-practice in an urban area. *Fam Pract* 1987; **4**: 200–206.

18 Green JM. The views of singlehanded general-practitioners – a qualitative study. *BMJ* 1993; **307**: 607–10.

19 Majeed A. The future of singlehanded general practices. *BMJ* 2005; **330**: 1460–61.

20 Goodman C, Knight D, Machen L, Hunt B. Emphasizing terminal care as district nursing work: a helpful strategy in a purchasing environment? *J Adv Nurs* 1998; **28**: 491–98.

21 Seale C. Community nurses and the care of the dying. *Soc Sci Med* 1992; **34**: 375–82.

22 Shipman C, Addington-Hall JM, Thompson M, *et al*. Building bridges in palliative care: evaluating a GP facilitator programme. *Palliat Med* 2003; **17**: 621–27.

23 Barclay S, Todd C, McCabe J, Hunt T. Primary care group commissioning of services: the differing priorities of general practitioners and district nurses for palliative care services. *Br J Gen Pract* 1999; **49**: 181–86.