Out-of-hours palliative care in the UK: perspectives from general practice and specialist services

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SUMMARY

Palliative care within the community requires well coordinated multidisciplinary teamworking, involving both primary and secondary care practitioners. 'Out-of-hours' periods are a potentially problematic time for delivery of high quality care. We report on two national surveys—one of medical directors of out-of-hours general practitioner cooperatives, the other of medical directors of specialist palliative care units. The aim was to describe general practitioners' and specialists' perspectives on the availability and scope of community nursing and specialist palliative care services.

The results point to wide variation in service provision within the community. The two groups differed strikingly in their perceptions, the general practitioners being much less positive than the specialists about the availability of specialist advice and admission to specialist units out of hours.

Equitable out-of-hours palliative care services of high quality are unlikely to be achieved without dialogue between primary and secondary care based providers, local needs assessment and adequate resourcing.

INTRODUCTION

Most patients with cancer spend 90% of their last year of life at home[1] and also express a wish to die there[2]. In that last year, complex medical, social and psychological problems can arise, and many patients require well coordinated community palliative care from multidisciplinary teams[3], some of it outside normal working hours[4,5].

The ability to look after a patient at home will often depend on the availability of adequate professional nursing care[6], but out-of-hours nursing provision is reported to be highly variable[7]. In addition, although specialist palliative care should ideally be accessible to all, whenever needed[8,9], little is known of its availability[10].

Many general practitioners (GPs) see palliative care as central to their role[11], some of them developing this special interest to become GP palliative care facilitators[12]. Whilst most GPs would accept that specialists provide complementary services, there exists the potential for a clash of perspective between primary and specialist palliative care[13–15]. Primary care professionals are likely to point, in particular, to the inaccessibility of specialist services at certain times of the day or week[16]. Over 70% of GPs in the UK are members of 'out-of-hours' cooperatives, and the medical directors of these cooperatives (themselves practising GPs) should be valuable informants on out-of-hours community care. Here we report a survey of GPs' and specialists' perspectives on the scope and availability of community nursing and specialist palliative care services.

METHOD

Two postal questionnaire surveys were performed. The first was of medical directors of the 174 out-of-hours cooperatives that are members of the National Association of GP Co-operatives. They were asked about their experience of out-of-hours services provided by community nurses and the availability and quality of specialist palliative care.

The second was a survey of medical directors of all 224 specialist palliative care units (SPCU), identified from the *UK Hospice Directory* 1999. SPCU directors were questioned about their present practices with regard to accepting admissions out of hours and the advice services offered to primary care professionals out of hours. In addition they were asked what difficulties might arise if they were encouraged to provide 24-hour open access to their beds. 'Open access' was likened to the ability of GPs to refer to specialists for emergency admission to acute hospital beds to admit patients.

RESULTS

GP cooperative survey

Replies were received from 133/174 directors (76%). Table 1 gives details of the cooperatives.

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Table 1 **Characteristics of cooperatives, *N*=133**

	Median	*Range*
Patients covered by cooperative	120 000	22 500–1 000 000
GPs per cooperative	64	9–430
Urban cooperatives (>80% urban patients)	68 (51%)	
Mixed urban/rural (20–79% urban/rural patients)	54 (40%)	
Rural cooperatives (>80% rural patients)	6 (5%)	
Unspecified	5 (4%)	

Access to community nursing

Only 65 (49%) indicated that there was 24-hour access to community nursing locally, and 8 (6%) had no out-of-hours access at all. 99 (75%) indicated some access to night sitting services but only 27 (20%) said that this service could be accessed with ease.

Access to specialist palliative care services

Whilst the great majority of respondents (125, 94%) reported the availability of specialist palliative care services 'in hours', only 50 (37%) believed that they could obtain specialist advice and 41 (31%) access to specialist beds out of hours. Satisfaction with specialist advice was rated as high or moderate by 44/50 (88%) of those with access to it. At times advice was available only from a junior staff member, which was considered unsatisfactory.

Whilst 94 (71%) wanted access to specialist palliative care beds out of hours, comments on their own experience suggested that out-of-hours admission to palliative care beds would seldom be needed. There was also a view that since beds are normally full during working hours it would be pointless trying to admit a patient out of hours. Hence, those needing inpatient care were normally admitted as emergencies to general hospital beds.

Specialist palliative care unit survey

Of the 224 units surveyed, 182 (81%) replied. Of these, 11 were non-bedded units and 16 were GP units with no specialist input. These units were excluded from the analysis. 2 functioned as a single unit and completed only one questionnaire. Therefore a total of 154 responses were analysed: 112 units were independent (with a median 30% NHS funding), 41 NHS and 1 unspecified. The median number of beds was 15 (range 6–80).

Out-of-hours activity

14 (9%) specialist units did not accept any admissions out of hours and 61 (40%) would take only patients who were known to them. When asked their views of open access, out of hours, for GPs to admit appropriate patients, 112 (73%) said that this would need either major changes or would be impossible to provide. Apart from lack of resources, objections included inappropriate admission (including patients who should have been admitted to acute medical wards), beds being blocked by social admissions, the disruption caused to the running of the hospice, and loss of control over admissions. Just one unit already offered such open access, and reported that it worked well and did not lead to inappropriate admissions.

Asked about out-of-hours advice, 137 (89%) said that they provided such a service for GPs. 67 had written to GPs to tell them about this service, the rest relying on newsletters or informal contact. Some respondents were worried that too much publicity regarding out-of-hours advice might cause the service to be overwhelmed by requests for help. Full results are available on our website [www.warwick.ac.uk/primarycare/].

DISCUSSION

This study has confirmed that nationally there is patchy access to community nursing and palliative care services out of hours. There is evidence that, even where services do exist, they are poorly publicized and communication between primary care and specialist services leaves much to be desired.

The reported lack of availability of community nursing in certain areas is in keeping with results of another recent study[7] and has implications for other groups of patients, such as those with chronic illnesses. This needs to be addressed by primary care and community trusts[17].

GP cooperative directors perceive that out-of-hours access to specialist palliative care beds and advice is limited. At times this necessitates emergency admission to a general hospital bed which is seen as inappropriate. Most of these GP directors responded positively to the idea of open access to specialist beds out of hours, though not feeling it would be needed often. Conversely, most of the SPCU medical directors were unenthusiastic, believing that inappropriate admissions would result.

Perhaps one reason why so few GP directors (37%) realized that a local specialist advice service was available, when 89% of SPCU medical directors claimed to offer such a service, was that the need seldom arose. Another was that some SPCU directors did not want to publicize their advice services for fear of overuse. The comments we received from GP medical directors suggested little reason for this fear; moreover, an audit in Leicester indicated that a well

publicized out-of-hours advice service received under a hundred calls in its first year of operation (Lloyd-Williams M, Rashid A, personal communication). Overall, the concern expressed by SPCU medical directors seems to be misplaced.

Since high quality care for the terminally ill depends on well coordinated multidisciplinary teamworking, the deficiencies in comprehensive provision and the poor communication between primary and specialist care identified by this study are likely to impede the delivery of such care. Adequate community nursing should also be provided. Fears and misunderstandings should be addressed by local needs assessment[18], dialogue between primary and specialist palliative care, and jointly developed guidelines for admission of patients to specialist palliative care beds.

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