

Knowledge and perceptions of a domiciliary hospice service among general practitioners and community nurses

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SUMMARY. *Within a single district health authority all the general practitioners and community registered general nurses were asked to complete a questionnaire regarding awareness and perceptions of a domiciliary hospice service. Responses were received from 127 doctors (71%) and 58 nurses (80%). Awareness of resources offered by the domiciliary hospice service was high, especially among the 102 respondents with access to the service. Eighty per cent or more of general practitioners and community nurses were satisfied with the amount of information received concerning changes in the patient's condition and who was involved in the care process. However, 33% of nurses agreed that it was difficult to know who had overall responsibility for the patient's care and 28% of nurses felt that their own contribution was under-rated. These findings were reinforced by a number of written statements submitted by the nurses. There was a desire expressed by both general practitioners and community nurses for more educational input from the domiciliary service. Overall, assistance from the service was welcomed and its special skills acknowledged. In the future planning of a comprehensive hospice service the differing needs expressed by doctors and nurses should be taken into account.*

Keywords: *domiciliary hospice care; interprofessional relations; doctors' attitude; nurses' attitude; terminal care.*

Introduction

THE evolution of hospice and community based terminal care services in the United Kingdom has been both rapid and varied over the past 20 years. The 1992 *Directory of hospice services* lists 178 hospice inpatient units, providing almost 2900 beds, 360 home care teams and 186 day care hospices.¹ The growth of such services has inevitably led to interaction with the primary health care team, traditionally the proponents of community based terminal care. The possibility of conflict can arise when issues of mutual interest, control and patient confidentiality arise.

The Exeter health authority cares for a total population of approximately 310 000 covered by 55 general practices with 180 general practitioners and 73 community registered general nurses

(Devon Family Health Services Authority and Exeter District Health Authority data, 1991). The rural population is served by 12 community hospitals, each containing general practitioner beds. There is a Marie Curie foundation hospice on the border of the health authority area in Tiverton, which has 15 beds. The domiciliary hospice service, started in 1982, is based in Exeter and serves the city of Exeter and a number of towns, mainly along the east Devon coast. Twelve MacMillan nurses, providing 24 hour cover seven days a week, and two social workers are involved, with an extensive network of volunteers coordinated by a part-time professional. Equipment is loaned and bereavement counselling is offered. Access to the domiciliary hospice service can be initiated by a number of agencies, for example, general practitioners, community nurses, carers and by self referral, but the general practitioner's permission is always sought before intervention occurs. At the time of the study there was no inpatient hospice situated in Exeter, but a hospice was scheduled to be built there.

It was considered appropriate to seek the views of the primary health care team before a new inpatient hospice service was established. A questionnaire survey was therefore undertaken in one district health authority examining the knowledge and perceptions of a domiciliary hospice service among general practitioners and community nurses.

Method

In July 1991, a questionnaire and reply paid envelope were delivered by hand to all general practice principals and full time and part time community registered general nurses in the study area. A follow-up telephone call was made to non-respondents and when necessary a further questionnaire delivered.

Using closed questions, the questionnaire addressed the following aspects: knowledge of resources offered by the domiciliary hospice service; agreement or disagreement with a number of proposals concerning the service; and opinions concerning 10 resources that a proposed new inpatient hospice should provide. The 10 resources to be included had been decided upon after discussion with the hospice services planning team and were: respite care, expert medical advice from a palliative medicine consultant (a specialist physician), educational courses for nurses, inpatient care, ability to admit patients from anywhere in the health authority, educational courses for doctors, domiciliary visits from a palliative medicine consultant, day centre care, palliative care liaison nurse and support groups for doctors and nurses involved in terminal care. The results were coded by D S and C T and entered on to a computer and correlations of interest extracted.

Results

Questionnaires were distributed to 178 general practitioners and 73 community registered general nurses. Responses were received from 127 general practitioners (71.3%) and 58 nurses (79.5%) with an overall response rate of 73.7%.

Of 121 general practitioners who responded to the question 71 (59%) had access to the domiciliary hospice service and all of these used the service. Of the 58 community nurses 31 (53%) had access and all of these used the service.

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General practitioners and community nurses were asked if they were aware of the resources offered by the hospice service (Table 1). As expected the degree of awareness of resources offered was consistently higher among those general practitioners and community nurses having access to the service. The degree of awareness was the same or higher among nurses compared with doctors, irrespective of having access to the service.

General practitioners and community nurses were asked to indicate their agreement with a number of statements concerning the domiciliary hospice service and the results for those using the service are shown in Table 2. Many nurses felt that their contribution was under-rated when the hospice service was involved and they had difficulty knowing who had overall responsibility for the patient's care. Only 32% of general practitioners would have welcomed regular written reports, compared with 77% of nurses. Agreement with three statements concerning the domiciliary hospice service among those who did not have access to the service is shown in Table 3. While 24% of general practitioners felt that the primary health care team should be the sole provider of terminal care, 90% would have welcomed help from the hospice service.

The community nurses also volunteered a number of written statements expressing their attitudes towards the domiciliary hospice service.

'Too many people descend on the patient leaving them bewildered as to who is who.'

'The domiciliary service has a duty to cooperate with the primary health care team and not to try and go it alone.'

'The role of the simple district nurse is gradually being eroded with time ... I feel all these specialist services will take over and there will be no place for us ... we are the Cinderella of the service.'

Table 1. Percentage of doctors and nurses aware of the resources offered by the domiciliary hospice service.

Resource offered	% of GPs aware of resources:		% of community nurses aware of resources:	
	With service (n = 71)	Without service (n = 50)	With service (n = 31)	Without service (n = 27)
Advice and help with difficult symptom control	97	94	100	100
Voluntary sitters and helpers	97	84	97	89
Service of a specialized social worker	76	60	94	85
Provision of specialized equipment eg syringe drivers	100	82	100	96
Bereavement counselling and follow up	93	80	100	100
24 hour availability of nursing support	99	76	100	89
Availability of telephone advice, whether or not involved with patient	94	76	97	89
Willingness to become involved when patient is in a community hospital	69	46	87	67
Willingness to become involved when patient is in a district general hospital	68	56	94	81
Organization of educational sessions for health care teams	66	58	77	78

n = number of respondents in group.

Table 2. Percentage of general practitioners and community nurses using the domiciliary hospice service agreeing with statements about the service.

	% agreeing with statement:	
	GPs (n = 71)	Community nurses (n = 31)
We receive sufficient information from the service about any patient's progress	96	84
The service makes it clear exactly who is involved with the care of the patient	80	81
The service is quick to tell us if there has been a change in the patient's condition	96	84
The service is quick to tell us if the patient has died	97	94
The service is prompt to respond to our requests for help	94	97
When the service is involved I find it difficult to know who has overall responsibility for the patient's care	10	32
When the service is involved I feel my own contribution is under-rated	6	29
Regular written reports from the service about the patients it is involved with would be useful	32	77
Regular updates from the service on new trends and advances in terminal care would be useful	94	100
I would welcome advice from the service about the development of protocols eg for relief of nausea	90	100
I would like the chance to meet the staff of the service more often	52	71
The PHCT should be the sole provider of terminal care in the community	13	6
The staff of the service have special skills with regard to the care of the terminally ill patients	99	97
I welcome help from the service with the care of terminally ill patients	100	100

n = number of respondents in group. PHCT = primary health care team.

Table 3. Percentage of general practitioners and nurses not having access to the domiciliary hospice service agreeing with statements about the service.

	% agreeing with statement:	
	GPs (n = 50)	Community nurses (n = 27)
The PHCT should be the sole provider of terminal care in the community	24	7
The staff of the service have special skills with regard to the care of terminally ill patients	98	100
I would welcome help from the service with the care of terminally ill patients	90	96

n = number of patients in group. PHCT = primary health care team.

'Hospice nurses are great but I speak for many district nurses when I say that some bitterness is experienced by us when they get all the praise after the death of a patient and we get forgotten.'

From a list of 10 possible resources to be offered by a proposed inpatient hospice, doctors and nurses were asked to select the five most beneficial to themselves, their team and their patients. Of the 127 general practitioners, most selected respite care, followed by expert medical advice from a palliative medicine consultant, educational courses for doctors, domiciliary visits from a palliative medicine consultant, and inpatient care. Of the 58 community registered nurses most selected respite care, followed by educational courses for nurses, domiciliary visits from a palliative medicine consultant, expert medical advice from a palliative medicine consultant, and support groups for doctors and nurses involved in terminal care.

Discussion

The growth and involvement of domiciliary hospice services in community terminal care has been accepted, and demonstrated in a number of cases, as a positive benefit to patients and their carers alike.²⁻⁴ Published surveys of the interactions between such domiciliary services and the primary health care team are few and have dealt only with the viewpoint of the general practitioner⁵⁻⁷ or the home care team support nurse.⁸ This survey has attempted to quantify the perceptions of a domiciliary hospice service among both general practitioners and community registered general nurses, and to define the perceived needs of these two groups with regard to resources for terminal care.

Awareness of the resources offered by the domiciliary hospice service was, in general, high among both general practitioners and community nurses, irrespective of whether or not they had access to the service. A large number of general practitioners appeared to be unaware that the domiciliary hospice service was willing to become involved with a patient even when the patient was in hospital. This is an important factor in ensuring continuity of care between the community and hospital and is of importance for the doctor who may be less able to visit. A sizeable minority of doctors and nurses did not appreciate the potential educational input of the domiciliary hospice service.

For general practitioners and community nurses using the domiciliary service, 80% or more agreed that communication concerning the patient's progress was sufficient and that response to requests for help was prompt. The proposal of regular written reports from the hospice service was viewed less enthusiastically by doctors than by nurses.

There was almost universal agreement concerning the special skills of the domiciliary service and welcome for the help provided. However, a number of criticisms were raised. One third of community nurses agreed that they had difficulty in knowing who had overall responsibility for the patient's care while only 13% of doctors were troubled by this. The nurses' written statements reinforced these views. In addition 28% of nurses indicated that they felt their own contribution was under-rated. This is a matter for concern and could lead to tension and breakdown of cooperation. There may be ways of improving such situations since the community nurses expressed willingness to meet with the domiciliary hospice staff more often and to receive regular updates on new trends and advances in terminal care and to receive advice on the development of protocols for symptom relief.

Almost all general practitioners and community nurses using the domiciliary hospice service disagreed with the statement that the primary health care team should be the sole provider of terminal care in the community. Of those general practitioners

without access to the service 23% agreed with the statement, although 90% and over indicated that they would welcome help from the service if available and acknowledged the special skills of the service. These general practitioners were all in rural practices and all had direct access to community general practice beds or a hospice in Somerset and the response probably reflected the reality that the primary health care team was the sole provider of terminal care in the area.

There was close agreement between general practitioners and community nurses as to which services should be offered by a new inpatient hospice, with respite care for carers, domiciliary visits and expert medical advice by a palliative medicine consultant being rated highly. Individual needs of general practitioners were apparent in their request for educational courses and likewise for community nurses in their request for specific education and support groups for doctor and nurses involved in terminal care. This is consistent with the findings of a survey of general practitioners that suggested that postgraduate education in terminal care was considered inadequate.⁹ The findings indicated a desire by both general practitioners and community nurses for educational input, and yet there was a lack of awareness of the educational services offered by the domiciliary hospice service. This would appear to be an area where needs and resources could be matched.

In conclusion, the domiciliary hospice service was found to be highly appreciated by members of the primary health care team, although a number of criticisms were expressed. Initiatives including educational input, meetings with domiciliary hospice staff and clarification of who is involved in a patient's care could improve relations. In planning new services, the needs of general practitioners and community nurses should be considered. In addition, existing resources, such as the presence of a domiciliary hospice service and community hospital beds, need to be considered in order to avoid duplication of effort and to promote better use of resources.

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