

# Domiciliary hospice care: a survey of general practitioners

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**SUMMARY.** A survey of general practitioners in two London health districts was undertaken to gauge their reaction to a domiciliary hospice team which had been available in those districts for two years. Seventy-two per cent of the 226 respondents had used the service, 23% more than four times, and 94% indicated satisfaction at having such a service available, with only 1% expressing dissatisfaction. Although the overall response to the questionnaire was positive, much constructive criticism was also received. Conducting the survey has encouraged more doctors to use the service.

## Introduction

THE North London Hospice home care service has now been functioning since 1984. It serves the north London boroughs of Barnet and Haringey with populations of approximately 300 000 and 200 000 respectively. In both boroughs over 90% of general practitioners make some use of a deputizing service. There is a 24-hour district nursing service in one borough and cover until 23.00 hours in the other. Both boroughs provide a night-sitter service for terminally ill patients, but suffer at times from financial constraints and problems with nurse recruitment.

The multidisciplinary home care service includes a part-time doctor, four full-time nurses and one-and-a-half social workers, and offers a 24-hour seven-day-a-week service. The service works in conjunction with the primary care team. Initial visits to patients are made only after obtaining consent from the general practitioner, and then the aim is to complement existing expertise, not to replace it. The majority of patients have carcinoma and are known to the team for less than four months. In 1985, 58% of patients whom the home care service helped to look after with the primary care team died at home. This is a reversal of the national statistics and a figure similar to that achieved in Birmingham.<sup>1</sup>

Prior to starting the home care service, all the general practitioners in the boroughs were sent a questionnaire via the two family practitioner committees (North London Hospice home care service, annual report 1984/85). This was to gauge interest in the proposed service and to try to obtain some indications as to the sort of service preferred. Two years later, in June 1986, it was decided to survey the general practitioners again, to ascertain their reactions to the home care service and to invite comments.

## Method

Questionnaires to 292 practitioners (162 in Barnet and 130 in Haringey) were mailed directly from the home care service with reply-paid envelopes. Non-responders were followed up three months later.

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## Results

The questionnaire was returned by 226 general practitioners, giving a 77% overall response rate (80% from Barnet and 73% from Haringey).

Twenty-eight per cent of all the respondents had not used the home care service, 49% had used it between one and three times and 23% more than four times. There were a number of reasons given for not having used the service. For example, nine general practitioners were unaware of the existence of the service, while five had either recently set up in practice, or retired from it. Nine responders said they had managed with the district nurses, or their patients had required admission. Thirty-seven stated that they had not had appropriate patients to refer or that the need had not arisen. The remainder gave no reason.

When asked, 'In general are you happy that the service is available?' 94% of general practitioners said 'yes', 1% (three doctors) 'no' and 5% answered 'don't know'. The respondents were asked whether they found it helpful that the service was available 24 hours a day. Again the positive response was high at 82%, with 2% negative and 16% not recorded or 'don't know'. Two of the five doctors who replied in the negative commented that they provided their own 24-hour service.

## Communication

Much of the work of a domiciliary specialist team involves communication with other professionals, especially with general practitioners. The question was therefore asked 'Do you feel we communicate with you too little, too much or about right?' While 63% of respondents indicated that it was about right, 13% felt there was too little communication and one respondent stated there was too much (although some of these respondents had not used the service).

To try to elicit more information about communication the general practitioners were asked whether there were other ways in which they would prefer us to communicate with them (other than what they had already experienced); 50% of the respondents thought there were not. Of the 12% who answered 'yes', most mentioned the telephone but three respondents indicated they would like more visits by the team to their surgeries, and two mentioned the possibility of some form of cooperation card, as used by midwives.

When asked 'Have you wanted to do more joint visits?' 19% of the 163 doctors who had used the service replied that they had, while 75% said they had not. Comments on this question included not knowing about the possibility of doing joint visits. Seventeen per cent said lack of time had prevented more joint visits from taking place.

The following data refer to responses of the 163 doctors who had used the service (percentages giving 'don't know' or no answer are not shown).

## Satisfaction with the service

To gauge the amount of discontent with the service, general practitioners were asked whether there had been instances when they had disagreed with the approach of the home care service. Nine per cent of users said they had disagreed at times, while 91% said they had not. The main reason for disagreeing can be

summed up by the comment: 'You tend to offer too much symptomatic advice'.

When asked what had been particularly helpful about the service respondents mentioned 'availability', for example:

'24-hour service — if I am not available you are likely to know better than my partners'.

Thirty-five doctors felt that support and advice for patients and families was most helpful. General practitioners also found the service of help to themselves, for example in the area of pain control or general support:

'Joint visiting and advice on details of medication (as I need this information only rarely, I know I am not up to date on details of terminal medication)'; 'Sharing the pain of witnessing the patient and family suffering ... and helping to "pace" the necessary action and discussion'; 'The opportunity to phone your office easily and talk to the nurse or doctor involved'.

Four doctors specifically mentioned that they found the availability of the subcutaneous syringe driver useful for patients who are unable to take oral medication. Four indicated that the service helped patients to stay at home:

'Specialist advice readily given then enables me in most cases to keep my patients at home'.

#### *Relatives and bereavement*

The questionnaire asked whether the doctor thought the service was helpful for relatives, and if so, in what ways. Some doctors who had not used the service answered this question; there was a positive response from 167 respondents. Once again many of the comments mentioned 'support' and expertise'. One doctor replied:

'Gives them [the relatives] confidence to care for the dying patient at home'.

However, the respondent who replied negatively was concerned that the service can confuse relatives because the general practitioner and district nurse also attended the patient.

An aspect of the work which has not been so highly developed is bereavement follow-up, and this was reflected by one respondent who said there had not been any feedback from families about this. However, 44% thought the bereavement follow-up was about right, and 3% that there was too much but no one thought there was too little; the majority had no opinion.

#### *Discussion of the diagnosis*

Comment was invited about the way in which the diagnosis was discussed with the patient. Of the 163 doctors who had used the service, 6% thought the approach 'excellent', 47% that it was 'good', 9% 'satisfactory', 4% 'not good' and one respondent replied 'very poor'. A favourable comment was:

'From my experience and my partners' patients the service seems to combine pragmatism and sensitivity very well'.

One of those who was less enthusiastic about our approach commented:

'I am not always totally convinced that overt discussion of diagnosis with patients is helpful'.

We would accept that.

#### *Supply of drugs*

On some occasions the service provides medication such as anti-fungals or aperients and notifies the general practitioners afterwards. This did not cause problems for 89% of doctors, but had caused difficulties for 2%. The comments varied between 'No difficulties in the cases I've shared' and 'I would rather know first'.

A further four questions were asked about medication, one of which was 'Have we been helpful or not when making suggestions about analgesia?' Again comments were invited, and 79% replied positively, 10% felt the suggestions had been mainly helpful, while 4% of users thought not. We then asked 'Have we been helpful or not when making suggestions about other medication?' The results were similar to those for the previous question, with 71% of users replying 'yes', 15% 'mainly helpful', 4% 'no'.

A more general inquiry was 'Would you prefer the home care service to be involved with medication less or the same?' In replying, 69% of users indicated they would prefer the same or more involvement, and 6% wanted less. Comments ranged from 'About right — I like to feel in control, but always happy to discuss and accept advice' to 'I do not wish the patient to feel I am of secondary importance'.

Only 15% of doctors gave further comments or suggestions relating to the home care service's involvement in medication. Many of these comments were about communication: 'The more we work together the better', and another requested 'Stronger involvement in analgesics and anxiolytics particularly'.

#### *Overall comments*

When inviting overall comments, the general practitioners were encouraged to be as frank as they wished. Forty-two per cent of all the respondents expressed praise and encouragement, but there was also some criticism from others. A sample of the replies are given below:

'Instead of being supportive, you are getting the whole family anxious about the provision of minor items of care with great urgency'.

'Unlike many general practitioners in London, we offer a 24-hour, seven-day-a-week service and are well used to managing our own terminally ill patients. Over the past 15 years we have rarely been stuck for the next answer, or needed help which we could not obtain within our own resources. We could benefit from help at times, but it is all a matter of how it is handled. We are not keen on our gentle doctor-patient trust being thrust asunder by a death squad. We play a much more delicate role, present, approachable and hopefully competent'.

'I think the service has improved during the last two years (or maybe I've got used to working with you)'.

'Wish we'd had such a service 20 years ago'.

'Without your help and support many of the patients would have been admitted to hospital, instead of spending their last few days in their own homes with their families'.

'On the whole very good — though makes the doctor feel a little inadequate occasionally — perhaps rightly so sometimes'.

'I like the cooperative approach, particularly your ability to have a combined meeting with a general practitioner'.

'Maybe I'm too biased, but I think your service is fantastic'.

#### **Discussion**

The original aim of the survey was to gauge the reaction of general practitioners to the home care service in order to try to

improve the service provided. Some hospices have surveyed their local general practitioners, for their own information, but not published their findings. However, Haines and colleagues<sup>2</sup> reported that 89% of respondents to their questionnaire expressed support for a domiciliary consultative medical service for patients with a terminal illness. While there is never occasion for complacency, the overall response to the North London Hospice home care service from general practitioners is favourable.

One important facet of the work of a hospice home care service is in establishing a useful and complementary working relationship with the general practitioner, without producing discord. According to this survey, only 9% of those who had used the service (7% overall) felt we had done this badly. Joint visits with general practitioners are offered and carried out on occasions. Seventy-five per cent of respondents who had used the service appeared satisfied with this, while 19% wanted to do more joint visits with us. These figures perhaps reflect some ambivalence, in which the home care service may share. Some joint visits may turn out to be more of a public relations exercise, but visible cooperation between general practitioner and home care service can be of great value to the family. Most of the general practitioners approved of the level of communication. The suggestion of a cooperation card is interesting, and this may well be worth introducing especially in more difficult cases. However, the home care service always writes in the district nurses' notes as well as their own. A few general practitioners already communicate via district nurses' notes, and perhaps more could be positively encouraged to use this as a routine means of supplementing telephone and personal contact.

Of particular interest was the response to questions concerning medication. Most team members carry small amounts of medication, such as laxatives or anti-emetics. It relieves the strain on patient and family if treatment can be started immediately, without the anxiety of having to rush to the general practitioner for a prescription. However, whenever possible the general practitioner is telephoned for permission prior to commencing treatment. The majority seem to have found little difficulty with this approach, but clearly this is an area requiring caution and should not be a decision taken lightly. Only 2% of the doctors were frankly critical of our actions here, but clearly we are not perfect, and are still learning.

Finally, conducting the survey seems to have encouraged more doctors to use the service, first by reminding them of our existence, and second by the gradual establishment of more mutual tolerance and cooperation.

### References

1. Rees WD. Changes in prescribing for terminal care patients in general practice, hospital and hospice over a five-year period. *J R Coll Gen Pract* 1987; **37**: 504-506.
2. Haines A, Booroff A. Terminal care at home: perspective from general practice. *Br Med J* 1986; **292**: 1051-1053.

### Acknowledgements

Thanks are due to Professor Eric Wilkes and Dr John Horder for their helpful comments and advice on the presentation of this survey.

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The Royal College of General Practitioners

## Terminal Care: the Role of the Primary Health Care Team

The Royal College of General Practitioners, in collaboration with Napp Laboratories Ltd, is holding a study day on terminal care, at Durham University on Friday 23 September 1988.

The study day aims to explore the psychological aspects of terminal illness, advice and support for the patient and carer, bereavement, as well as the role of the hospice and other associated voluntary organizations.

It is hoped that delegates will include general practitioners, geriatricians, district medical officers, community and practice nurses, health authority, community health council and family practitioner committee personnel as well as representatives from the voluntary organizations involved.

The cost of the study day is £20.00 per delegate. For further details, please contact Janet Hawkins, Conference Administrator, Royal College of General Practitioners, 14 Princes Gate, Hyde Park, London SW7 1PU (01-581 3232).

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