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Palliat Med 1997; 11; 202

DOI: 10.1177/026921639701100304

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Support needs in the last year of life: patient and carer dilemmas

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Key words: caregivers; community health services; health services needs and demand; neoplasms; terminal care

The aim of this study was to identify needs for support and problems in the introduction of support to terminally ill patients and their carers. The design involved semistructured interviews with patients and carers as well as a survey of general practitioners' (GPs) views, and took place in GP practices and homes of patients in Cambridgeshire.

The subjects comprised 43 terminally ill patients, 30 carers, 80 GPs and 13 of their GP partners. The main outcome measures were quantitative data about additional help required and qualitative data on reasons for reluctance to seek help.

Needs for help with transport, personal care and housework were identified. Carers may also need reassurance from health professionals. The need for outside help may at times conflict with the need to preserve independence, dignity and familiar aspects of life. Sometimes carers may feel that there is need for more help, but that this conflicts with patients' wishes. There may also be reluctance to seek help because of a perceived lack of resources and professionals' time.

In conclusion, an increase in services is necessary but not sufficient to meet patients' needs fully. Services should be introduced in ways that help patients to preserve independence, dignity and familiar aspects of life. The perception of accessibility to health professionals may need to be improved. Carers' needs should be assessed separately from patients' needs.

Mots clés: équipes de soins; services de santé de proximité; besoins et demande de services de santé; néoplasmes; soins en fin de vie

Afin d'identifier les besoins d'assistance et les problèmes de présentation d'assistance aux patients en fin de vie et à leurs soignants, on a mené des entrevues semiestructurées avec des patients et soignants et une étude sur les opinions des médecins généralistes dans des cabinets de médecins généralistes et domiciles des patients dans le Comté de Cambridge.

Quarante-trois patients en fin de vie et 30 soignants, 80 médecins généralistes et 13 de leurs partenaires ont participé à cette étude.

On identifie les besoins d'assistance avec les transports, les soins

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personnels et les tâches ménagères. Les soignants peuvent avoir besoin d'être réassurés par les professionnels de la santé. Le besoin d'aide extérieure peut quelquefois s'opposer au besoin de préserver l'indépendance, la dignité et les aspects familiaux de la vie. Quelquefois les soignants auraient besoin davantage d'aide mais cela s'oppose aux désirs des patients. Il peut également y avoir une répugnance à chercher de l'aide à cause du manque de ressources et de temps des professionnels.

Une augmentation des services est nécessaire mais pas suffisante pour répondre entièrement aux besoins des patients. Ces services devraient être présentés de manière à ce que les patients préservent leur indépendance, leur dignité et les aspects familiaux de la vie. L'idée d'accéder à des professionnels de la santé peut être améliorée. Les besoins des soignants devraient être évalués séparément de ceux des patients.

Introduction

Of the approximately 580 000 deaths each year in England and Wales a considerable proportion occurs after a recognizable period of terminal illness, including over 140 000 deaths from malignant neoplasms.¹ Research suggests that 80–90% of patients spend most of the last year of life at home^{2,3} and that home is also the preferred place of death for the majority of patients and their family carers.^{4–7} However, the majority of patients die in hospitals and other institutions.⁸ Major reasons for admission include the need to control symptoms and insufficient availability of support in the home.^{9–12} Thus the low proportion of home deaths can partly be attributed to inadequate health and social services provision. Previous research has reported inadequacies in practical support, night support and general practitioner (GP) and district nurse support for the terminally ill.^{5,13–16}

However, availability of services is only the first step in ensuring adequate support in the home. Services also have to be introduced into the home and at the right time, so that the support helps to sustain patients and family carers throughout illness, rather than being a belated response to a crisis. While issues of communication and co-ordination are likely to be important in introduction of support, patients' and carers' own aims and perceptions also need to be considered. This is in line with thinking in British social psychology which has developed a corpus of theory and practical research based on the analysis of discourse of explanations for events in everyday life.^{17,18} By understanding how patients and carers experience dilemmas in seeking or

accepting help, and giving due consideration to these in the introduction of services, it may be more likely that adequate support is put in place at the appropriate time.

The present study investigated inadequacy of provision of support in the home as viewed by GPs, patients and carers. It also investigated patients' and carers' reasons for not wanting or seeking more help.

Method

A random sample of 150 Cambridgeshire GPs was contacted by letter and asked to identify all patients on their lists with a life expectancy of one year or less, whose care had switched from curative to palliative, and who were being looked after at home. Of these, 93 GPs agreed to identify patients, including 13 GP partners who volunteered. In total, 105 patients were identified. Discussion with the respective GPs suggested that 75 patients were physically able to cope with an interview and were approached by letter: 43 patients were interviewed, 18 refused and 14 became too ill to take part. Thirty family carers who were identified by patients agreed to be interviewed. Patient and carer interviews were semistructured. GPs completed a patient-specific questionnaire for 32 of the patients interviewed.

Each interview was tape recorded, transcribed and subjected to a content analysis¹⁹ using the Ethnograph software package.²⁰ During interviews respondents were asked whether they would like more support in a number of areas. If respondents

said no, they would then often spontaneously give an explanation for their answer. These explanations were extracted for content analysis. At other points in the interview respondents often spontaneously provided explanations for their reluctance to seek additional support, both past and present. These were also extracted for analysis. Extracted segments were subsequently grouped and regrouped to form categories containing reasons representing similar themes. The log rank test was used to test differences between survival curves.²¹ Chi-square tests, Fisher exact probability tests and ϕ coefficients were used for the quantitative data analysis.²²

Results

GP sample

The mean age of the 93 GPs whose patients were identified was 43 years. They had an average list size of 1741 and mean number of partners of 4.6. In total, 66 (71%) were men, 44 (47%) were members of the Royal College of General Practitioners and 46 (49%) worked in training practices. In order to test whether participating GPs differed systematically from the population of GPs, the GP sample was compared with a random sample of 100 Cambridgeshire GPs not approached for the study. No significant differences were found between the two samples in terms of the above variables ($P > 0.05$ in all cases).

Patients and carers

The median age of the 43 interviewed patients was 65 years, and that of the 30 key carers was 55 years. Of these patients, 39 had cancer, two cirrhosis, one ischaemic heart disease (ICD) and one both ICD and chronic obstructive airways disease. Thirty-

seven reported being able to move about indoors independently, although many (24) with difficulty. Only 26 reported that they could get outside and 12 that they could use public transport independently. Analysis of date of death shows that interviewed patients were at an earlier stage of terminal illness than patients approached but not interviewed. Median time to death at referral was 215 days for interviewed patients, 88 days for patients who refused and 18 days for patients who became too ill to be interviewed. The log rank test revealed significant differences between all three groups in survival ($P < 0.05$ in all cases).

Support needs

GPs rated how well needs were met for 32 of the interviewed patients and provided ratings for 23 of their key carers. Needs were rated as well met for 30 (94%) of the patients but only for 14 (61%) of the carers ($\chi^2 = 9.04$, $df = 1$, $P = 0.003$).

Whenever one of the 43 interviewed patients stated that they had difficulty with an aspect of everyday functioning, they were asked if they would like more help with this (Table 1). In total, 18 (42%) patients wanted more help with one or more aspects of everyday functioning. Most help was wanted with transport and outdoor mobility, followed by personal care and housework. None of the patients wanted more help at night.

Of the 30 interviewed carers, 12 (40%) stated that more help should be provided with one or more aspects of everyday functioning. Comparison of the 30 cases for whom both patient and carer data were obtained suggested a greater tendency among patients to endorse help with outdoor mobility while carers endorsed more help with housework. However, differences were small and nonsignificant, and there was overall remarkable similarity

Table 1 Number and percentage of patients wanting more help with an area of functioning out of patients experiencing at least some difficulty with that area ($n = 43$)

	Patients with difficulties wanting more help <i>n</i> (%)	Total no. of patients with difficulties <i>n</i> (%)
Getting in/out of bed	0 (0)	26
Getting outside	8 (23)	35
Transport	11 (32)	34
Personal care	7 (21)	33
Night care	0 (0)	5
Shopping and errands	2 (5)	38
Housework	9 (21)	42

between patient and carer views, given that GPs were significantly less likely to rate carers' needs as being well met compared with those of patients ($P = 0.003$).

Only two (5%) patients said they wanted their GP to visit more often and three (7%) that they wanted their GP to spend more time during consultations. Of the 24 patients who currently had contact with a district nurse, none wanted the nurse to visit more often and only one (4%) wanted the nurse to spend more time. Carers were, however, significantly more likely than patients to want the GP and the district nurse to see the patient more often. Six of 30 carers versus two of 43 patients wanted more frequent contact with the GP. Five of 18 carers but none of 24 patients receiving district nurse help wanted more frequent contact with the district nurse (for both Fisher exact probability $P < 0.05$).

There was a correlation between GPs' rating of patient needs and patients' wish for practical help (ϕ coefficient = 0.357, $P = 0.04$), i.e. patients who

had their needs well met according to the GP did not tend to state that they wanted more help, while the patients whose needs were rated as not well met stated that they wanted more help. No relationship was found between GPs' ratings and carers' responses, neither in terms of need for more practical help, nor for more contacts with GPs and district nurses.

Explanations for not wanting more help

In their questionnaire responses GPs reported that six (19%) of 32 patients had been offered services that had been refused. Content analysis of patients' and carers' explanations for not wanting or seeking more help suggest that a number of considerations may delay or prevent help seeking.

Patients' explanations for not wanting or seeking more help could be grouped into three main categories and one miscellaneous category.

Statements in the first category simply expressed that the present situation was satisfactory. Thirty-six

Box 1 Patient quotations expressing the wish to preserve independence and dignity

No, I prefer to be independent. If it's going to come, it's going to come. I'll do it in my own time.

I said 'The hardest thing I do is washing parts'. 'Well, we'll send someone to bathe you'. Not while I'm able to do it myself!

And I said 'Who would [give me a bath]?' and she said 'Me'. I said 'Oh, no I couldn't, you're too young' ... And I thought she was too young to see me undressed if you understand my meaning.

Box 3 Patient quotations expressing a perception that resources are limited and other people have greater needs

[The GP] said 'We don't see you. You don't bother us', like, he said. Didn't think that was necessary. They're so busy, you know, thousands of people, hundreds anyway, that they have to go to see every day.

[The home help] has got people worse off than we are, love. There's two or three ladies all by themselves, we have got one another. We ain't much good to one another, but we're here.

Although I'm bad enough, but I mean there's a lot of people worse off than me. And I sometimes say to [the GP] when she comes, you know, 'I'm sorry to have got you out', you know. I feel I'm being a nuisance.

Box 2 Patient quotations expressing the wish to preserve familiar aspects of life

Well I feel confident with [my husband] because I know he knows my way and I know his way. So we're more comfortable that way. With a stranger coming in, well, I know they are not strangers long when they keep coming in, but with a district nurse or anyone coming in it's not the same.

But [my wife] don't want these to come, they come from half past eight in the morning. Next door, she don't like it, and I shouldn't want to get up that early either.

No, I've had [my private help] and she's chosen by my daughter and I've got accustomed to her and shouldn't want anybody else.

Box 4 Carer quotations expressing conflict between carer and patient views

[The patient] is a contrary old man and stubborn old man he's got to be at death's door before he gets up to you anyway, he just likes to do it himself.

The problem is at the moment, you know, we have to say to him you really need this, you really need that. 'No I don't'. That's one of the main problems.

She can't get in the bath, so I've always washed her down in the bath, sort of, but I mean, at the moment it's very difficult ... the district nurse would come, I know, but I don't think she would like that. So, at the moment we're managing.

patients made 99 statements suggesting that the situation was satisfactory in relation to one or more aspects of help. Either there was no need for help, the patient was managing or the current informal or formal support was sufficient. However, for 21 patients (30 statements) the expressed satisfaction was dependent on informal carer support.

The second set of statements also suggested that the situation was satisfactory, but in this case actual preference for not receiving additional help was expressed. These statements mainly related to help with everyday functioning and appeared to fall into two subcategories. Twenty patients made 31 statements expressing reluctance to receive more help, owing to a desire to maintain their independence and dignity (Box 1). Ten patients also made 16 statements expressing reluctance to receive more help, owing to a desire to preserve familiar aspects of life and protect against intrusion (Box 2).

Statements in the third category revealed that the situation was not perceived to be satisfactory, and in an ideal world the patient may have wanted more help; however, there was a reluctance to ask. Twenty-three patients made 71 statements suggesting reluctance to seek help because they felt that their problem was not legitimate given limited resources and the number of people requiring help. Thus they appeared to pace their demands according to perceived limitations of the available services (Box 3). Such statements for a large part related to contacts with GPs and district nurses, who were perceived as busy and stretched to the limit.

In the miscellaneous category a number of themes was identified, including patients not wanting help because of lack of interest or not feeling well. Some statements suggested that the patient had reduced his or her expectations in relation to everyday functioning. Other explanations were dislike of the solution offered, reluctance to seek help because of worries about the effect of treatment, and resistance to counselling or psychological support because it may increase anxiety or worry.

Seventeen carers (64 statements) stated that more help was not wanted because they felt that the patient did not want it. There was evidence of a difference between the patient's and carer's views of help needed in 14 of these cases (Box 4). Otherwise, carers' explanations for not wanting or seeking more help could be grouped into similar categories as those for patient statements.

Statements from 22 carers (52 statements) expressed that the present situation was satisfactory in relation to one or more aspects of help. However, for 20 carers this depended on informal support. Fourteen carers (32 statements) suggested that the situation was fine and expressed an actual preference for not receiving more help. These statements contained the themes of preservation of independence and dignity, and protection of familiar aspects of life which were expressed in patient statements. Four also expressed a sense of duty. Ten carers (22 statements) also expressed a reluctance to bother health professionals as resources were perceived to be limited.

Discussion

Patients were most likely to want more help with outdoor mobility, housework and personal care. The emphasis on outdoor mobility is probably due to the patient sample being in a relatively early phase of terminal illness (median seven months from death). For this group it was important to retain their mobility, which was starting to slip away. This contrasts with other research emphasizing the need for more help at night,¹³⁻¹⁵ which is more relevant to the later stages of terminal illness. Help with outdoor mobility and with night care therefore address needs at different stages. Both are important if adequate support is to be provided throughout the total course of illness.

The content analysis revealed that the simple proportion of patients and carers expressing want of more help does not give a complete picture of need. Patients' desire for help with everyday functioning was balanced against a need to maintain independence, dignity and familiarity. In other words, patients face a dilemma. Desire for help may conflict with their desire to stay in control of their lives at a time when they are moving toward greater dependency. Such dilemmas are part and parcel of much of everyday life but are seldom revealed by simple questionnaire methods.¹⁷ GPs' reports that help offered is sometimes refused perhaps confirm that patients are not always ready to accept help at a time when health professionals judge it to be appropriate clinically.

Only a small percentage of patients said that they wanted more frequent contacts with the GP and

none more frequent contact with the district nurse. However, patients' reasons for not seeking more help from health professionals suggested they perceived that their time and resources were limited. Hence patients may pace their demands accordingly, and the lack of criticism may reflect patients' low expectations rather than their actual desire for contact. At times, patients' statements could be viewed as rationalizations for not receiving the desired support. Past research suggests that patients may prefer to employ such rationalizations rather than lose faith in the health professions on which they depend.²³ An example is the ambivalence in one patient's reply when asked if she would like the GP to see her more often:

I don't know really. I miss — . I don't think it's necessary for me to see him unless I really need it, ... if they're so busy, and other people are more sick ... I think I should only see him when I really need him enough to call him out, because they're so busy.

Comparing oneself with someone 'worse off' is also a recognized strategy for coping when under threat.²⁴ Such downward comparison strategies have been reported in patients with serious medical problems.^{25,26}

Although carers were no more likely than patients to state that more practical help should be provided, their explanations suggested that this was often because they believed the patient would not accept it. Carers may therefore often not express a need for help because this conflicts with a desire to respect the patient's wishes. Thus the carer's role contains its own dilemmas in relation to acceptance of support.

GPs rated carers as significantly less likely to have their needs well met than patients. The lack of correlation between GP ratings and carers' expression of need for help may be attributable to carers' experience of such dilemmas rather than a misjudgement by the GP. The potential difficulty of the carer's situation is further illustrated in the finding that patients' and carers' satisfaction with the present situation often depended on the carer's ability to provide help.

One area in which carers did express a desire for more support was in relation to contacts with the GP and district nurse, perhaps reflecting support needs specific to the role of the carer. Carers' rea-

sons for wanting more visits were often in terms of needing someone to 'keep an eye on things':

I would like, not for any medical reason, purely as a backup system that there is someone there, that if something happened that I haven't personally seen, they would see ...

Carers thus need the reassurance of the frequent presence of a health professional when faced with the responsibility of looking after a dying person, which is after all a new experience for most relatives. Carers may still be less likely to express desire for contacts than they otherwise would because of a reluctance to bother doctors and nurses.

These results suggest that we cannot address the problems of home support solely by considering expressed need for help. Analysis of patient and carer statements suggests that the issue is more complex. On the one hand, patients and carers may have aims and concerns that conflict with the immediate requirements for practical help. On the other, they may pace their demands for contact with health professionals according to what they feel they should be entitled to, not according to what they need.

This has implications for the manner in which support should be introduced. Practical help may be resisted if its introduction does not allow for patients' need for maintenance of independence, dignity and familiar aspects of life. Paradoxically, early referral, allowing early familiarization with a key worker who prepares, co-ordinates and introduces all other support, may lead to a greater sense of control, allow gradual adaptation and reduce the number of strangers entering the home. Benefits of early referral can be exemplified by a patient explaining what is good about her district nurse:

She tries to build up a rapport ... I think, mainly, yes, she tries to build up a one-to-one relationship so that if I do have any problems in the future then ... it's going to be easy to have her around a lot more ...

However, if patients are reluctant to seek help because of a perceived lack of resources rather than a difficulty in acknowledging the future of their illness, more emphasis may need to be placed on improving the perception of accessibility. This also suggests a need for regular monitoring of the patient's condition, as patients may otherwise be

unlikely to place demands on GPs and nurses until there is a crisis.

Finally, the results highlight the need to support the carers, and that carers should be assessed independently of patients as their perception of need may be different. However, the best way of helping carers may in many cases be to help patients to come to terms with their increased need for outside help.

Acknowledgements

We thank GPs, patients and carers for their participation. We also thank Melanie Johnson for help in initiating the project and our steering group members, Sandra Betterton, Liz Challis, Jan Date, Janet Doyle, Catherine Johaheer and Glenys Pennock, for their advice and support. The study was a Cambridgeshire Family Health Services Authority project funded by the Department of Health and East Anglian Regional Health Authority. It was approved by the Cambridge, Huntingdon and Peterborough Local Research Ethics Committees.

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