PRACTICE OBSERVED

Practice Research

Terminal care at home: perspective from general practice

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Abstract

A survey of general practitioners in north west London was undertaken by questionnaire to elicit information about problems that they had had in looking after patients at home who were terminally ill and about their perceived needs for both training and support services. The response rate was 73% (196 of 268 doctors). Thirty two per cent of respondents frequently or always had problems in controlling pain in such patients, and 45% frequently or always had difficulties in coping with the emotional distress of patients or relatives, or both. Between 20 and 30% of respondents often had problems with inadequate support services, poor communication with support services and hospital specialists, and difficulty in admitting patients who were terminally ill.

Roughly half of the respondents thought that more training in managing pain and other symptoms that are associated with terminal illness would be of great help, and a similar response was noted for bereavement counselling. About 40% of respondents indicated that training in communicating with dying patients would be a great help in improving care and three quarters that more home nursing support was necessary.

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Introduction

Over the past 30 years the proportion of patients who die at home has fallen from 50% to 25%.[1,2] In a practice with a list of 2500 patients about six patients a year may require terminal care at home. Having so few patients to look after may result in general practitioners losing their skills in managing terminal illness, which, together with advances in the care of terminally ill patients in recent years, may lead to a lack of confidence in their ability to manage patients at home. Several reports of terminal care in the community from the perspective of general practice have been published, mainly by practitioners with an interest in this.[3-6] A study from Belfast of general practitioners and carers who looked after 118 patients with terminal illness at home documented problems that they had had.[7] There is, however, little information about the difficulties that general practitioners often experience when looking after terminally ill patients at home and about steps which might be taken to alleviate these difficulties.

We report the results of a questionnaire survey of general practitioners in north west London which was intended to elicit information about such problems and about their perceived needs for both training and support services.

Methods

A questionnaire and a prepaid envelope were mailed to 270 general practitioners who were on the list of Brent and Harrow Family Practitioner Committee and had practice addresses in the boroughs of Brent and Harrow. Two general practitioners had retired. One reminder was sent to those who did not respond initially, and 196 (73%) of 268 general practitioners replied. In addition, two other general practitioners returned the questionnaire uncompleted and indicated that they had insufficient experience of terminal care to answer the questions. One had just entered the practice, and the other was working part time. Some questions were incompletely answered, accounting for the slight variation in the denominator in the tables.

The general practitioners were asked the number of terminally ill patients just under half had difficulties in coping with emotional distress of patients or relatives, or both, frequently or always, although only a fifth had difficulties coping with their own emotional responses to death and dying frequently or always. Overall, 124 (63%) of 196 general practitioners frequently experienced one or more difficulties in patient management. Just under a third reported that support services were inadequate in most or all cases, and a slightly smaller proportion reported poor communication with services; a fifth often had poor communication with hospital specialists (table II).

Responses to questions about the need for further training were fairly consistent (table III). Roughly half the respondents felt that further training in symptom relief, communication with dying patients, and bereavement counselling would be helpful or essential to improve the care that they provided for terminally ill patients at home. Respondents were emphatic in indicating that more general nursing support and support from home nurses with special training in terminal care would be of great value. Several respondents commented that it would be useful if nurses could be present for longer periods than busy district nurses could spend. Difficulties with night nursing cover were specifically mentioned by 11 respondents. Over half expressed strong support for a domiciliary consultative medical service for patients with terminal illness. Over half (61%) felt that they could look after rather more patients and fewer (19%) felt that they could look after many more terminally ill patients at home if more resources were provided. Respondents showed no preference for a particular form of training; between 70 and 80% indicated that written material, lectures, small groups of general practitioners and nurses, and films and videotapes would be acceptable.

Overall, there were no appreciable differences in the responses by general practitioners from the two health districts (Brent and Harrow). There was no significant association between the year of graduation and either problems experienced or training requirements. There was a slight but consistent tendency for general practitioners who had looked after four or more patients with terminal illness in the past year to have fewer problems with pain control, control of other symptoms (but not incontinence), coping with emotional distress of patients or relatives, and coping with their own emotional responses to death and dying compared with those who had looked after fewer than four patients. The differences, however, were not significant. Those who had looked after fewer than four patients were slightly more likely than the others to think that more training in the four specified areas (pain management, other symptoms, communicating with dying patients, and bereavement counselling) could be helpful or essential for improving care, but the differences were not significant.

Several respondents thought that there was sometimes a discrepancy between the wishes of terminally ill patients, who frequently wanted to die at home, and the wishes of relatives, who were more likely to press for hospital admission. More support for relatives was advocated.

Only 15 (7·7%) of the respondents never used a deputising service, a further 31 (15·8%) used one only during holidays or illness, 29 (14·8%) regularly used one in the evenings, 101 (51·3%) regularly used one at night (11 pm–7 am), and 21 (10·7%) sometimes used one at night. Several respondents said that they gave relatives of terminally ill patients their home telephone numbers.

Discussion

The results of this survey suggest that general practitioners commonly experience difficulty in certain aspects of care for patients with terminal illness. Pain is a prominent symptom for such patients, and the finding that one third of respondents often had problems with pain control suggests that further training is required. It is likely that the general practitioners underestimated the amount of pain and other symptoms suffered by patients. Nevertheless, nearly half indicated that they would find training in control of pain and other symptoms helpful or essential in improving the quality of home care. The experience of the Edinburgh domiciliary terminal care team suggested that complete eradication of pain could be obtained in about 90% of men and 80% of women, with good relief in a further 7% of men and 20% of women.[2]

A desire for more support from community nurses, particularly those with training in terminal care, was frequently expressed. In general, however, problems with support services were experienced less often than problems with control of symptoms. In one of the health districts (Brent) a small team of terminal care nurses had been disbanded before the survey, but it has recently been reconstituted. This team had apparently been relatively isolated and had not been seen as part of a comprehensive community terminal care service. Hospice care is available in the North West Thames region at Michael Sobell House, Mount Vernon Hospital in Northwood, but the hospice receives only a few of its patients from the areas covered by this survey. Most terminally ill patients who require admission are therefore referred to the two district general hospitals (Central Middlesex Hospital in Brent and Northwick Park Hospital in Harrow).

The general practitioners generally seemed accessible to their patients out of surgery hours, with only a few regularly using a deputising service in the evenings and at weekends. Continuity of care might be maximised if those general practitioners who regularly used the deputising service at night (around half), but the deputising service can be instructed to contact the general practitioner personally for patients who are terminally ill. General practitioners were aware of the difficulties in communicating with dying patients and their relatives and in handling emotional distress, although only 20% had frequent difficulties with their own emotional responses to death and dying. The results suggested that those who had looked after few terminally ill patients in the past year had more difficulties and saw training as being of more potential benefit than the others, but the differences were small and not significant.

Our results suggest that more patients could be looked after in the community and that standards of care could be considerably improved with further training and support services. The exact contribution can be measured only by carefully assessing the effects of innovations in providing terminal care at home. Some schemes have apparently been used extensively by general practitioners, others have found it harder to gain acceptance in the community.[7,8]

The difficulties experienced by the doctors seem largely to reflect those experienced by patients.[9] The generally positive response of general practitioners to the questionnaire suggests that they consider terminal care an important part of their work and wish to improve their effectiveness.

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100 YEARS AGO

The condition of the sleeping-room at night calls for attention during winter, the two chief points being the regulation of heat and of ventilation. Much depends upon the size and position of the room, the number, ages, and constitutional condition of the occupants, and the actual state of the weather. The indications are, of course, to maintain a reasonably warm, uniform, and pure atmosphere. Probably not many people can sleep with comfort if the temperature of the room sink to 40° Fahr., and possibly this is rather low a limit for the majority. If the morning temperature fall to this point, some means of artificial warmth had better be adopted; and nothing is more convenient or more suitable than a small fire in an open grate, so arranged that the heat shall at no time be excessive, and that it shall die out gradually and not suddenly. Here again the state of health and sensations of the individual must be our guides. To a person in robust health, who has plentiful sources of heat within himself, and who does not know what it is to awake feeling chilly, artificial warmth of any kind at night is unnecessary, and should, therefore, be avoided. On the other hand, a thin-blooded, anæmic person, especially if prone to bronchial catarrh, should sleep in a moderately warm and equable temperature, however this may be best secured.

As regards ventilation, it is hardly any longer necessary to insist upon the necessity for pure air, both by night and by day. In summer it is a good practice, for those in health, to sleep with open windows (draughts being guarded against), but this wholesome practice should not be persisted in during the winter season, if experience show that it is not readily tolerated. A fall of temperature of 10° during the night is not uncommon in our climate, and would be dangerous to many persons if sleeping with open windows. The bronchitic especially must be watchful in this regard, while on the other hand nervous persons and exhausted brain-workers, if free from all tendency to pulmonary weakness, may justifiably risk a little cold for the sake of pure air.

An impression prevails in many quarters that there is something actually noxious about night-air, *per se*, an idea for which there is no adequate foundation. It is no doubt true that, in low-lying marshy districts, exhalations frequently arise after sun-down, and are likely to be unwholesome; but this objection does not apply to houses in good situations, and further, the really dangerous time is rather the hours immediately after sunset than those usually devoted to sleep.

These remarks on dress, sleep, exposure, etc., while universally applicable more or less, apply with peculiar force in the case of children. They lose heat more readily than adults, and are more seriously affected by chill. They, therefore, need thorough protection against changes of temperature, and the common practice of exposing their legs and arms cannot be too strongly condemned. There can be no doubt that the careless and needless exposure of children is one of the most fruitful causes of infant mortality, causing not merely pulmonary diseases and rheumatism, with its long train of sad sequelæ, but intestinal and renal affections, and, in fact, a preponderating proportion of the maladies to which infant flesh is heir. (*British Medical Journal* 1886;i: 215.)

Salt cod-fish has been introduced among the articles of diet of the French soldier. The Minister of War, after having consulted the Sanitary Council of the army on the subject, has ordered salted fish to form part of the ordinary military rations. It must be of good quality, and captains commanding regimental companies and squadrons or batteries of artillery, with a view to avoid any possible accidents, are ordered to watch that no fish is used which presents traces of alteration, as is frequently indicated by a rose-tint of the muscular tissue, or which is deteriorated in any other respect. One of the chief purposes aimed at in the introduction of salted fish as a part of the rations of the French troops is announced to be the help the consumption of it will afford to the crews of the fishing vessels, from which the most valuable recruits of the Military Marine, or Government Naval Service, are obtained. Salt cod may be acceptable to the troops as a variation in diet, but can hardly be regarded as an economical description of food, so far as its nutritive qualities are concerned. (*British Medical Journal* 1886;ii: 935.)

who had been cared for at home in the past year, the proportion who, in their opinion, wished to die at home, and the proportion who actually died at home. For group practices where a patient may have been looked after by more than one partner respondents were asked to include only patients for whom they had taken major responsibility. The options in answering the latter two questions were: none, around 25%, around 50%, around 75%, all. Further questions included 10 possible problems in the care of terminally ill patients at home. The question was worded: "In your experience which of the following cause problems in looking after terminally ill patients at home?" Respondents were asked to indicate how helpful extra training and more support might be.

Respondents were also asked: "If somewhat more resources could be provided would this enable you to look after any more terminally ill patients at home?" The possible responses were: no, somewhat more patients, considerably more patients. Finally, they were asked how information should be provided: written material, lectures, small groups of general practitioners, or films and video tapes.

The year of graduation and the use made of deputising services were also recorded on the questionnaire. The use of a deputising service was considered relevant because of the implications for the continuity of care for the patients who were terminally ill and their families.

Results

Over 90% of respondents had looked after at least one patient who was terminally ill in the past year: 16 (8%) had not looked after any, 95 (48%) had looked after one to three, 56 (29%) had looked after four to six, 16 (8%) had looked after seven to nine, and 13 (7%) had looked after 10. Sixty six per cent (129 of 194 respondents) believed that half or more terminally ill patients wished to die at home, but only 41% (80/194) stated that half or more actually died at home (table I).

TABLE I—*Answers from respondents on deaths at home (number (%) of respondents)**

	Proportion of terminally ill patients				
	None	Around 25%	Around 50%	Around 75%	All
Patients wishing to die at home	10 (5)	55 (28)	57 (29)	63 (32)	9 (5)
Patients who actually died at home	21 (11)	93 (48)	46 (24)	34 (17)	

* For partnerships only the doctor who took responsibility for the patient is included.

Over 90% of respondents had problems at least occasionally with control of pain, incontinence, other symptoms, and the emotional distress of patients or relatives, or both (table II). More importantly, a third indicated that they experienced problems with pain control frequently or always, more had problems controlling other symptoms either frequently or always, and

TABLE II—*Problems general practitioners experienced in looking after terminally ill patients and problems with services (number (%) of respondents to questionnaire)*

	Never	Occasionally	Frequently	In all cases
Experienced by general practitioner				
Controlling pain	13 (7)	119 (61)	58 (30)	4 (2)
Controlling incontinence	12 (6)	129 (67)	50 (26)	2 (1)
Controlling other symptoms (dyspnoea, insomnia, anorexia, confusion, etc)	6 (3)	108 (55)	79 (40)	3 (1)
Coping with emotional distress of patients and relatives	12 (6)	96 (49)	73 (37)	14 (7)
Coping with your own emotional responses to death and dying	69 (36)	85 (44)	33 (17)	7 (4)
Problems with services				
Inadequate support services (nursing, home help, etc)	45 (23)	91 (47)	53 (27)	6 (3)
Poor communication with support services	56 (29)	88 (45)	46 (24)	4 (2)
Poor communication with hospital specialists	53 (27)	100 (51)	37 (19)	4 (2)
Difficulty in admitting patients to hospital or hospice (to give family a break or for control of symptoms)	49 (25)	99 (51)	40 (21)	6 (3)
Lack of availability of appropriate analgesics from local pharmacists (particularly controlled drugs)	119 (61)	71 (36)	5 (3)	1 (0·5)

TABLE III—*How helpful would the following be in helping you to provide improved care to terminally ill patients at home? (Number (%) of respondents)*

	No help	Some help	Very helpful	Essential
	Training			
In pain management	21 (11)	79 (41)	69 (36)	24 (12)
In control of other symptoms (incontinence, dyspnoea, insomnia, etc)	18 (9)	80 (42)	79 (41)	14 (7)
In communicating with dying patients	24 (12)	87 (45)	62 (32)	19 (10)
In bereavement counselling	20 (10)	77 (40)	76 (40)	20 (10)
	Services			
More general nursing support	6 (3)	39 (20)	109 (57)	38 (20)
Support from home nurses with special training in terminal care	8 (4)	28 (15)	110 (58)	45 (24)
Specialist domiciliary consultative medical service for terminally ill patients	22 (11)	62 (32)	94 (49)	13 (7)

Audit Report

Reimmunisation of teenagers in a central London practice

The Department of Health and Social Security's guidelines, *Immunisation Against Infectious Diseases*, recommends giving reinforcing doses of tetanus and polio vaccine to teenagers.[1] In our local health authority these are offered to school leavers, but it was difficult to discover which schools offered reimmunisation, and when, because teenagers registered with our practice attended schools in three districts.

At the end of 1983 and 1984 all registered teenagers aged between 14½ and 15½ were identified from the computerised age-sex register and offered reimmunisation. Half were written to directly, and a letter was sent to the parents of the others. In 1984 non-responders were written to again and also asked whether they had been revaccinated elsewhere. Of 278 teenagers, 32% responded to the first request, but a total of 59% of the girls and 46% of the boys responded to both letters. This was moderately satisfactory since roughly 10% of our patients move away each year. Girls were more compliant than boys ($\chi^2 = 3{\cdot}99$; 1 df; $p < 0{\cdot}05$). We were informed of only 13 teenagers who had been revaccinated before our study began.

Both general practitioners and district health authorities provide preventive services, often duplicating each other's work and doing poorly the tasks that each considers to be the other's responsibility. Better preventive services could be delivered in general practice if primary care teams accepted that surveillance of vulnerable groups and preventing ill health are as important as treating the sick. This also seems to be the view of the Royal College of General Practitioners.[2] Vulnerable groups can be identified quickly with a computer. More patients might carry a card recording preventive procedures which may be used as a "shared care card" by general practitioners, clinical medical officers, and school doctors, as in the hospital and community maternity services. I thank our practice nurses Liz Metcalfe and Rosie Price for help and Merlin Amable for typing the paper. MICHAEL MODELL, general practitioner, James Wigg Practice, Kentish Town Health Centre, London NW5. (*Accepted 8 April 1986*)

1 Joint Committee on Vaccination and Immunisation. *Immunisation against infectious disease*. London: Department of Health and Social Security, 1984.
2 Working Party. Royal College of General Practitioners. *Healthier children—thinking prevention*. London: RCGP, 1982.

100 YEARS AGO

As a proof of the old adage, that "the wish is father to the thought," we are pleasurably startled now and again with the announcement, in the newspapers, that a cure has been discovered for that fell disease, the Saxon bane, consumption. This announcement comes round with about the same regularity as that of the famous sea-serpent, whose remains, if the animal could only be caught, would meet with a cordial welcome in our museums of comparative anatomy. These alleged remedies generally reflect, to some limited extent, the then current views as to the pathology of this terrible affection, and they thus secure for themselves a share of the popularity which almost invariably surrounds the last new hypothesis, until by-and-by they die a natural death, sometimes after having diverted a certain quantity of pecuniary benefit into the pockets of the ingenious authors of the respective "cures." We are all familiar with the gushing accounts in the daily papers, especially those which affect sensation concerning some new hypothesis, which, from a very germ or embryo, is developed into a full-grown adult discovery. To it is attributed all the power for good, and all the authority, which attaches to remedies whose usefulness has been attested by clouds of medical men and patients. Koch discovers a crooked organism in the intestines of cholera patients, and forthwith cholera is no more; he lights upon another in connection with tuberculosis, and behold the problem is solved—in the newspapers. The difficulties, the doubts, the uncertainties, all are forgotten in the would-be accomplishment of a "consummation devoutly to be wished." During the past week, however, we have been treated to a more novel phase of this tendency, and one possibly more open to criticism than the majority of such effusions which interest and may even amuse, while they can scarcely do any harm. Within a few days of the appearance in a lay contemporary of a sensational article on the reported good results obtained in one or two cases of phthisis by the inhalation of the spores of the "bacterium termo," by an Italian physician, a letter is published in the same journal from a medical gentleman, named Lambert, residing in Liverpool, in which he claims to have effected—or rather partly effected—the cure of a very advanced case of phthisis. So eager is this eager benefactor to give the world the benefit of his experience, that, unwilling to lose valuable time in checking the results by even one other observation, or even in completing the cure of the case he has in hand, he rushes into print with an enthusiastic and glowing account of the wonders he has achieved. That his conduct is irregular and open to misconstruction, he candidly admits; but he conceives his indebtedness to the writer of the article on the subject to be so great, that he is unable to restrain himself from proclaiming it *urbi et orbe*, and substantiates his assertions by appending his name and address. His excuse for thus deviating from the more usual course is that "tears may be dried, sorrows soothed, hopes revived, and lives saved," by means of this new bacterium, which he finds of such "thrilling interest and great promise." We shall await the results with some anxiety, not so much, indeed, the results of this gentleman's further experience, for the subject is being investigated by men whose zeal and ability are probably at least equal to his own, less his *ad captandum* style, but to know exactly what opinion to form as to the radical wisdom of the author of this wonderful semi-cure, who prefers confiding the results of his reflections, confessedly immature and inconclusive, to the general public, rather than, by judicious and systematic inquiry, aiding in the dissemination and verification of what should be, according to his views, a great advance in the treatment of phthisis. (*British Medical Journal* 1886;i: 456.)

Our Paris correspondent forwards particulars of a remarkable trial for murder held recently at Rodez, in the south of France, where a self-accuser was proved to be innocent, and the true criminal detected by medical evidence. Last August, a woman, named Mélanie Vieu, went to register the death of a child, which she had wrapped up in her apron. The registrar counted the child, as is customary, and observed finger-marks on its throat. The mother then declared that she had strangled her infant. She was sent to prison; but Dr. Desmoni, who had been directed to examine the body of the child, stated that it had certainly been strangled, but not by its mother. Her hand was more delicately formed than that of the murderer, which had left its impression on the child's neck. The fingers of the guilty party must have been short and thick, the index-finger being unusually short, and apparently devoid of a nail, defects which the witness indicated as valuable clues for the discovery of the murderer. Mélanie Vieu finally admitted that the murderer was a man called Bonuet, and that she was his servant. The accused was arrested, and his index-finger was found to be one centimètre shorter than the average length of that member, and its nail had been destroyed by accident or disease. Bonuet was sentenced to six years' imprisonment. (*British Medical Journal* 1886;i: 81.)