

Contemporary Themes

Terminal care: present services and future priorities

BARRY LUNT, RICHARD HILLIER

Abstract

Since 1975 hospices and other specialist services for terminal cancer have expanded rapidly. In December 1980 this survey found 72 such services in Britain providing 58 inpatient units, 32 home care teams, and eight hospital support teams. Many were outside the NHS. Inpatient units provided 1297 beds (modal size 21-25 beds) and dealt with under 7% of deaths from cancer. Home care teams provided 76.5 full-time equivalent nurses (modal size two nurses). Regional variations were considerable: from 10.9 beds/million population in Trent to 48.5 beds/million in South-west Thames; no home care nurses in Mersey and Wales, and 5.1 nurses/million in Wessex. Of 58 more services being planned, the 17 starting in 1981 will not substantially alter these regional imbalances. Respondents' opinions suggest a target of 40-50 inpatient unit beds/million population. This might be reduced if hospitals were better equipped to deal with these patients.

Suggested priorities are to redress regional inequalities, develop home care and hospital support teams rather than inpatient units, and improve teaching and training. Co-ordination of plans between the NHS and the voluntary sector is needed.

Introduction

In the next 12 months roughly 130 000 people will die of cancer in England and Wales. Most will die in hospital (59%) but 33% will die at home,¹ where the main burden of care usually falls during the last month of life.² Though many will die comfortably, others will not, for unrelieved physical symptoms and psychological and emotional distress are unhappily common.^{3, 4}

Institutions that care for the dying have existed for centuries, but recently a variety of specialist services have appeared dealing mainly with patients suffering from cancer and variously named hospices, continuing care units, palliative care units, home care teams, and support teams. These aim at achieving a better control of symptoms than is often available and to provide improved emotional, social, and spiritual support for patients and their families. Evidence of their success has, with a few exceptions,^{5, 6} been largely anecdotal.

These services rightly attract the more difficult management

problems, and because of their anecdotal success and emotional appeal they are growing fast. Health authorities face pressure to fund further developments, yet planning is made difficult by lack of information about what specialist services exist, on what scale, and with what to offer. This survey provides some of that information.

Method

A list of existing and planned services in England, Scotland, and Wales was compiled in late 1979 by writing to area medical officers, St Christopher's Hospice, and the large charities active in the care of the dying. Services were sought in the following categories:

Inpatient units—Independent hospice-type facilities or units attached to a general hospital.

Home care teams—One or more nurses providing an advisory service to patients, relatives, general practitioners, and district nurses, usually backed up by a doctor with a special interest in this work.

Hospital support teams—Doctors or nurses or both, working in a hospital, who advise their colleagues on the care of particular patients.

In January 1980 postal questionnaires (copies available) were sent to the consultant or nursing officer responsible for these services, and 58 out of 63 replied. Four of the five non-responders were less well-known charitable services and the other was an NHS unit that closed during the study. Questions were asked about administration, finance, catchment area, staffing, operational policies, and workload. Inquiries in late 1980 updated the list of existing services to December 1980 and identified as many planned services as possible.

Results

This section mainly describes the services available in December 1980 but uses the January 1980 survey to provide more detailed information on some matters.

In December 1980, 72 services or combinations of services existed, providing 58 inpatient units, 32 home care teams, and eight hospital support teams (table I). Fewer than half were within the NHS.

TABLE I—Specialist services in operation in December 1980

Administering body	Combinations of services						Total
	IPU alone	IPU + HCT	IPU + HCT + HST	HCT alone	HCT + HST	HST	
NHS	14	6	1	5	4	1	31
Sue Ryder Foundation	5	1*	—	—	—	—	6
Marie Curie Foundation	10	—	—	—	—	—	10
Independent charity	8	10	1	3	1	—	23
Private nursing home	2	—	—	—	—	—	2
Total	39	17	2	8	5	1	72

IPU = Inpatient unit; HCT = Home care team; HST = Hospital support team.
*This home care team is administratively within the NHS, though associated with a non-NHS inpatient unit.

Community Medicine, University of Southampton, Southampton SO9 4XY
BARRY LUNT, MA, research fellow
Countess Mountbatten House, West End, Southampton SO3 3JB
RICHARD HILLIER, MD, consultant physician

INPATIENT UNITS

The inpatient units contained from two to 66 terminal care beds (mode 21-25) and provided 1297 beds in all. Most beds were designated for the terminal care of patients with cancer, except those in the Marie Curie Homes (397 beds), where patients with cancer at earlier stages of their illness were looked after. The number of inpatient unit beds/million population varied widely between regions, with Scotland and South-east England heading the "league" (table II).

TABLE II—Regional variations in the provision of inpatient units: December 1980

	Inpatient units (beds)*			Beds/million population†		
	NHS	non-NHS	Total	NHS	non-NHS	Total
South-west Thames	1 (6)	6 (138)	7 (144)	2.0	46.5	48.5
Scotland	2 (40)	4 (147)	6 (187)	7.7	28.3	36.0
North-east Thames	—	2 (116)	2 (116)	—	31.4	31.4
South-east Thames	—	3 (99)	3 (99)	—	28.0	28.0
Oxford	2 (45)	1 (14)	3 (59)	19.7	6.1	25.9
Mersey	—	2 (63)	2 (63)	—	25.6	25.6
Yorkshire	—	4 (86)	4 (86)	—	24.0	24.0
Wessex	2 (50)	2 (13)	4 (63)	18.4	4.8	23.2
West Midlands	1 (32)	3 (85)	4 (117)	6.2	16.5	22.7
North-west Thames	3 (59)	1 (12)	4 (71)	17.1	3.5	20.5
South Western	—	4 (56)	4 (56)	—	18.5	18.5
North Western	—	2 (72)	2 (72)	—	17.8	17.8
Wales	8 (16)	1 (29)	9 (45)	5.8	10.5	16.2
Northern	—	1 (45)	1 (45)	—	14.6	14.6
East Anglia	1 (25)	—	1 (25)	13.4	—	13.4
Trent	1 (25)	1 (24)	2 (49)	5.5	5.3	10.9
England, Scotland, and Wales	21 (298)	37 (999)	58 (1297)	5.5	18.4	23.9

*For most units this is number of beds designated for terminal care. For some units (mainly Marie Curie Homes) no fixed proportion of beds are designated, and because all beds are in principle available for this use all have been included.

†Based on mid-year estimates for 1979.^{7, 8}

TABLE III—Regional variations in the provision of home care teams—December 1980

	Home care teams (No of FTE nurses)			FTE nurses/ million population*		
	NHS	non-NHS	Total	NHS	non-NHS	Total
Wessex	2 (7)	2 (7)	4 (14)	2.6	2.6	5.1
South-east Thames	3 (5½)	3 (8)	6 (13½)	1.6	2.3	3.8
North-west Thames	3 (7)	—	3 (7)	2.0	—	2.0
South Western	1 (2)	2 (4)	3 (6)	0.7	1.3	2.0
North-east Thames	—	1 (7)	1 (7)	—	1.9	1.9
Oxford	1 (2)	1 (2)	2 (4)	0.9	0.9	1.8
South-west Thames	1 (½)	2 (3½)	3 (4)	0.2	1.2	1.3
Yorkshire	2 (2)	1 (2)	3 (4)	0.6	0.6	1.1
Trent	1 (2)	1 (3)	2 (5)	0.4	0.7	1.1
East Anglia	1 (2)	—	1 (2)	1.1	—	1.1
Scotland	—	1 (4)	1 (4)	—	0.8	0.8
West Midlands	—	1 (3)	1 (3)	—	0.6	0.6
North Western	1 (2)	—	1 (2)	0.5	—	0.5
Northern	1 (1)	—	1 (1)	0.3	—	0.3
Mersey	—	—	—	—	—	—
Wales	—	—	—	—	—	—
England, Scotland, and Wales	17 (33)	15 (43½)	32 (76½)	0.6	0.8	1.4

*Based on mid-year estimates for 1979.^{7, 8}
FTE = Full-time equivalent.

TABLE IV—New services planned to begin in 1981

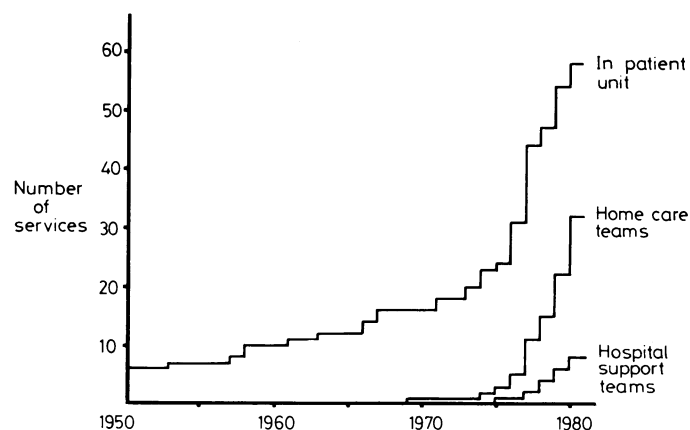
	Inpatient units (beds)		Home care teams (FTE nurses)		Hospital support teams
	NHS	non-NHS	NHS	non-NHS	
East Anglia	1 (25)	—	1 (NK)	—	—
North Western	—	—	—	1 (1½)	—
North-west Thames	—	1 (4)	—	1 (2)	—
Oxford	—	2 (25)*	—	1 (1)	—
Trent	—	—	—	—	1
Wessex	—	—	—	1 (2)	—
West Midlands	—	—	—	1 (2)	—
Yorkshire	—	2 (41)†	1 (3)	2 (4)	—
Wales	1 (25)	—	3 (7)	1 (½)	—
Scotland	—	1 (13)	—	1 (2)	—
Total	2 (50)	6 (83)	5 (10+)	9 (15)	1

*One of these is a 15-bed extension to an existing inpatient unit.
†One of these is a 33-bed extension to an existing inpatient unit.
FTE = Full-time equivalent.

TABLE V—Numbers of medical schools with specialist terminal cancer care services within their AHA(T), December 1980

Type of specialist service	NHS service	Non-NHS service	Total
Inpatient unit	7	10	17
Inpatient unit and home care team	3	10	13
Inpatient unit and home care and hospital support teams	—	1	1
Home care team	2	—	2
Home care and hospital support teams	3	—	3
Total with some specialist service	15	19*	27*
No specialist service	NA	NA	2

*Some medical schools have more than one service in their area, making these figures lower than the column sums.



Growth of services since 1950 (services in operation in December 1980 only).

South-west Thames (the best-off region) had over four times as many beds/million as Trent (the worst-off region). The NHS provided 23% of all beds, over half of them in the North-west Thames, Wessex, and Oxford regions. Seven regions had no NHS beds.

In January 1980, 22 inpatient units had defined catchment areas, from 17 000 population for a two-bed unit in rural Wales to 5 million for a unit theoretically serving the whole of Scotland. They provided from six to 171 beds/million population (median 31). Inpatient units said by respondents to satisfy their area's requirements for such services provided a median of 44 beds/million: those said not to do so, a median of 16 beds/million. Nine of the 12 inpatient units providing over 20 beds/million were said to satisfy their area's requirements for such beds; none of the six inpatient units providing under 20 beds/million were said to do so (Fisher exact $p < 0.01$, 2 tailed).

HOME CARE TEAMS

The 32 home care teams (December 1980) ranged from half a full-time equivalent (FTE) nurse to seven FTE nurses (mode two FTE nurses), providing 76.5 FTE nurses in total. Under half the home care teams, but over half the FTE nurses, were outside the NHS. Provision varied from 5.1 FTE nurses/million population in Wessex to none in the Mersey region and Wales (table III).

In January 1980, 20 home care teams had defined catchment areas, from 24 000 to two million population. The population served/FTE nurse varied from 30 000 to 500 000. There was no consensus among respondents as to a level of provision that would satisfy an area's requirements. On average each FTE nurse saw 66 new patients a year, somewhat higher for NHS than non-NHS services.

HOSPITAL SUPPORT TEAMS

The eight hospital support teams varied so widely in their characteristics that it is impossible to generalise about them. All but one were linked with home care teams. Six were within the NHS.

GROWTH OF SPECIALIST SERVICES

Specialist services have developed extremely quickly (fig). Almost all home care and hospital support teams and over half the inpatient units (40% of IPU beds) have emerged since 1975. In the past two years the number of inpatient units has increased by one-quarter, but home care and hospital support teams have more than doubled. Fifty-eight more services were found at various stages of planning. Of these, 17 had definite starting dates in 1981: six new inpatient units and two extensions, 14 home care and one hospital support teams (table IV).

SCOPE FOR MEDICAL EDUCATION

Of the 29 undergraduate medical schools in Britain, 27 had some sort of specialist service in their AHA(T), but only 15 AHA(T)s had such services within the NHS (table V). By the end of 1981 all except two medical schools will be in areas with an inpatient unit (11 in the NHS) and 19 medical schools will be in areas with inpatient units combined with home care teams (four in the NHS).

Discussion

This survey almost certainly included all existing services, because information was obtained and checked from several well-informed sources. Coverage of planned services is inevitably less sure, and these figures are only an indication of future provision.

Since 1978 the growth of these services has been rapid. Although this may mean success at a time of financial stringency, it also gives cause for concern. Firstly, this expansion has been paid for largely by voluntary funds which will continue only in the short term. After three years most of the new home care teams will be funded by the NHS,⁹ though the implications of this have received little consideration other than at a local level. Secondly, this growth is taking place in the absence of any overall policy on terminal care, and it is reasonable to question whether further specialist services are really the best or the only solution to the problems of the terminally ill.

Despite the developments of the past five years there remain considerable regional inequalities in the provision of inpatient unit beds and home care nurses, although the optimum scale of services is uncertain. So how many inpatient unit beds are required?

Previous suggestions have ranged from 20 to 117 beds/million population.¹⁰⁻¹² This survey suggests that fewer than 20 beds/million is inadequate and 40-50 beds/million may be needed. But these figures are based on the *opinions* of consultants and nursing officers in existing inpatient units as to the adequacy of their own services. An estimate of the number of patients who might be referred is also relevant. Parkes³ found that 20% of patients with terminal cancer in hospital suffered severe, mostly unrelieved pain—about 300 patients/year/million population. As inpatient unit beds have an average work load of 9.4 patients/year¹³ 32 beds/million would be needed to deal only with these patients in severe pain. At St Christopher's Hospice 66% of patients admitted have pain problems.¹⁴ If this is generally true of inpatient units it indicates that about 45-50 beds/million would be required, a figure in agreement with that from the present survey. Hospital support teams might reduce this requirement by improving the control of symptoms in existing hospitals.

The country as a whole falls short of this optimum figure, with an average of 24 beds/million. Only the South-west Thames region had the 40-50 beds/million suggested by this survey. Wales and five English regions had fewer than 20 beds per million—the level below which provision was definitely seen as inadequate. By the end of 1981 this will still be true in the Trent, Northern, North-west, and South-west regions. The pattern of inequality is typical, the South-east being better off. Given known variations in duration of stay, bed occupancy,

and readmission rates¹³ the 1297 existing beds in inpatient units may be expected to deal with about 10 500 new patients a year, about 7% of all deaths from cancer. Not all these patients will die in the units: some are discharged home. So how many home care nurses are required to deal with these patients and with those who are never admitted to an inpatient unit?

Parkes's study is again relevant.³ Among patients at home terminally ill with cancer, 28% suffered severe, mostly unrelieved pain, representing 240 patients/year/million population. If the home care teams deal only with these patients in severe pain this suggests that four nurses/million will be required if each sees an average of 66 new patients a year, the figure found in the present study (though this varied widely). Since home care nurses are known to deal with a wider range of problems than pain alone, this estimate must be a minimum.

Currently only two regions (South-east Thames and Wessex) approach or exceed four home care nurses/million population. This year's new developments are unlikely to alter this state of affairs. Regional inequalities are even more pronounced than for inpatient units. By the end of 1981 Scotland and half the English health regions will still have under two home care nurses/million population, the south-west and north fairing worst.

The results of this survey point to some priorities for future service developments.

(1) The regional imbalance in provision of services should be redressed, particularly for home care teams where inequalities are greatest. This should be done now while services are growing and there is room for manoeuvre. Improvements could be achieved if the NHS encouraged the voluntary sector to favour the regions at present worst provided.

(2) The development of home care teams should take priority over further inpatient units. This makes sense at a time of financial restraint. Moreover, the regional imbalance measured by the criteria discussed above is greater for home care teams than for inpatient units. The National Society for Cancer Relief has shown an admirable lead here by providing initial funding for many of the existing home care teams.

(3) Hospital support teams should be encouraged. They have the potential to make a great impact on the care of terminally ill patients in hospital, without the capital costs incurred by inpatient units. There is now a good opportunity to see if the need for specialist units can be reduced in this way.

But more specialist services may not provide the best answer. Improved teaching and training of staff might be more effective in improving standards of care generally.¹⁵ The proximity of most medical schools to inpatient units and home care teams provides considerable scope for this.

Because of the regional inequalities, the considerable activity in the voluntary sector, the uncertain financial implication for the NHS, and the need to train doctors and nurses, we suggest that plans for further terminal care services should be carefully co-ordinated in each health region to ensure the best use of voluntary, NHS, and university resources.

We are grateful to Avril Knight, information officer at St Christopher's Hospice, who collected most of the information on planned services, and to the Wessex Regional Cancer Organisation for advice and assistance.

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A detailed report of the January 1980 survey¹³ and reprints are available from BL, Community Medicine, South Academic Block, Southampton General Hospital, Southampton SO9 4XY.

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Letter from . . . Chicago

Gang of ninety-five

GEORGE DUNEA

Earlier this year we watched the spectacle of five learned computers disagreeing by as much as one forty-thousands of a second on how to send off the spaceship Columbia into the stratosphere. But now that these "initialisation" difficulties have been overcome, the computers might have wept that there is no more space left to conquer, were it not for the prospect of diversifying into the health care business. In this they have the wholehearted support of Dr Lawrence Weed, who, having irreversibly confused past generations of young doctors and gullible professors with his problem-orientated medical records system, has now shifted focus to a computerised future.¹ Clearly expressing his priorities, Dr Weed finds himself wondering what might be "the best combination of systems, tools, and people for solving any health care problem in the context of the individual patient's life." Not that he might want to solve any of these problems *outside* the context of anyone's life, unless perhaps by extending his system to purgatory or to limbo, where virtuous pagans such as Homer and Moses or Socrates might be re-educated to present their data base in a more organised manner while awaiting admission to heavenly paradise.

Yet we are relieved to find that systems and computers come first in the Weed cosmogony and people last, thus solving the dilemma of "how to fit the physician into the overall scheme."¹ No longer will "any single provider need to maintain the illusion of being a total physician." Nor will students have to "sweep superficially through an enormous amount of material and memorisation." To the distress of none but professional curriculum revisers, "training for the many tasks of medicine need not be extensive."¹ Housewives or robots or retrained unemployed workers will learn to look into ears and eyes and pancreatic ducts, but always within the context of a single individual. Armed with "up-to-date maps for all travellers through the health-care landscape," these tourists will carry

corrective feedback loops around their necks and refer only puzzling cases to the five computers. Strict auditing systems should monitor computer morality, remembering the excesses of that lusty old computer whose programmatic tapes indiscriminately impregnated sheeps, goats, and unsuspecting virgins.² For the age of chivalry is dead, and computers are no more to be trusted than planners or politicians.

Bulls to be gored

Yet President Reagan, recovering from the attempt on his life, remains popular. Indeed, there is something remarkable about this 70-year-old man setting about to restore the standing of the presidency and the credibility of his country, and actually carrying out the promises he made during his campaign. Even more remarkable, in a system where the executive requires much skill to get the legislature's co-operation, is Mr Reagan's apparent ability to put his programmes into effect. Not that supply-side economics will necessarily restrain inflation, increase productivity, or reduce unemployment. But many think that the old remedies have failed and that new approaches are worth trying.

In May Mr Reagan achieved quite a triumph in having Congress approve a \$36-billion spending cut for fiscal year 1982, thus reversing a decade-long pattern of ever-increasing government spending. Nobody really expected trouble in the Senate, but the 253 to 176 vote in the House, obtained with the help of conservative Democrats, was a considerable achievement. The details have now been sent back to the congressional subcommittees, which must decide where to make the mandated cuts, while the full House meanwhile must address the President's proposals for reducing taxes. Most of the cuts approved by the May vote will affect social programmes such as food stamps, school lunches, aid to handicapped children, environmental programmes, transport, welfare, and various benefits and subsidies. Major changes will also take place in the financing of health care, where some \$4 billion will be cut.

And so, weather permitting and with the blessing of the Congressional subcommittees, to paraphrase the traditional posters announcing the ritual slaughter of six strong Andalusian