

One hundred deaths in practice

A study of terminal care

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IN life only two things are certain, its beginning and its end. Whereas the former is studied and reported with detailed enthusiasm, the end is more often ignored if possible; yet we must all face death for our patients, our friends, our families and ourselves sooner or later. It is in an attempt to do this that 100 deaths occurring consecutively in a general practice between January 1969 and August 1970 are here considered in some detail. The place of death, the cause of death, the age and sex of those dying, the manner of death and the terminal state will be considered, and, as far as possible, comparisons will be drawn with other works including those of Osler (1906), Exton Smith (1961) and Hinton (1963).

Definition

The terminal state is not regarded as covering only the final death-bed scene, but the irreversible and unremitting condition at the end of a fatal illness when life holds no further prospect of being useful or enjoyable and death can be seen to be inevitable in the foreseeable future. At this stage, which the clinician must be prepared to recognize, all treatment is directed to the relief of symptoms physical or mental rather than to vain attempts to prolong life.

The place of death

The practice consists of rather more than 2,000 patients in their homes, 100 mentally subnormal patients in an institution, which is in fact their home, and 100 hospital patients in a long stay annexe for the chronic and incurable sick, these patients are at times admitted to acute general hospitals where some of them die.

Table I illustrates the place of death of each of the 100 cases considered and an

TABLE I
ORIGINS AND PLACE OF DEATH

	1 <i>Patient's home</i>	2 <i>Subnormal institu- tion</i>	3 <i>Long stay annexe</i>	4 <i>Acute hospital</i>	5 <i>Total hospital i.e. 2, 3 & 4 (per cent)</i>
Population	2000	100	100	—	—
No. of deaths from	28	14	58	—	—
Place of death (per cent)	16 16	15	58	11	84 84
Place of death of practice patients	53%				47
Place of death of U.K. patients ..	60%				40
Place of death of U.S.A. patients ..	47%				53

attempt is made to compare this with the figures of Glynn Hughes (1960) for the U.K. and similar figures for the U.S.A. It was felt that the inclusion of the two institutions, the subnormals and the chronic sick, made the practice atypical, so they were removed from the item 'Place of Death of Practice Patients' for comparative purposes.

An opinion was recently expressed that no expected death should occur outside hospital. It is hoped that this is not widely held and that those who can will increasingly be allowed to die in their own home. Certainly that appears to be the desire of most of the dying.

But one must remember the tremendous work load and responsibility undertaken by relatives who look after the dying, whose last illness lasts on average five to seven years (table IV). Although improved housing and sanitation, the district nursing service, meals on wheels and other services have done much to help, and the six weeks in hospital, six weeks at home system gives relatives a well deserved rest, much still remains to be done in this field, especially in the provision of laundry and night sitters in the terminal phase.

The age and sex of the dying

This is demonstrated in table II. The average age at death was 77 years, males 72 years, females 79 years. The oldest patients were 96, one of each sex, the youngest a woman of 41. Those dying at home and in the long stay annexe fell mostly in the 70 to 89 span, though the 10 deaths over 90 in the long stay annexe reflect the extraordinary longevity of some old folk once they have settled into this sheltered existence where their bodily needs are met and many of the risks of independent life avoided.

As would be expected, those dying in acute hospitals tended to be rather younger, but even there the mortality was at its highest between 60 to 69.

The apparent earlier incidence of death in the subnormal institution was due to the number of deaths due to an influenza epidemic (11), the other four being aged 55, 63, 69 and 84, indeed four out of the 15 subnormal patients were over 70 when they died. Two of the younger patients dying in the subnormal institution during the influenza epidemic had only just been admitted owing to the breakdown of their home conditions. Coming from the sheltered environment at home they rapidly succumbed to the infection, thus demonstrating that, under certain circumstances, admission to hospital may itself be lethal; this also applies to the very old, who do not 'transplant' well and may die

TABLE II
RELATION OF AGE TO SEX

Age	At home		In acute hospital		Long stay annexe		Subnormal institution		Total
	M	F	M	F	M	F	M	F	
40—49	0	0	0	0	0	1	1	2	4
50—59	1	0	0	1	0	2	1	2	7
60—69	3	1	1	4	2	1	3	2	17
70—79	1	4	3	0	7	10	3	0	28
80—89	0	5	0	2	4	21	0	1	33
Over 90	0	1	0	0	4	6	0	0	11
Total	5	11	4	7	17	41	8	7	100

following admission to hospital even if admission is only to give their relatives a six weeks rest.

Table II also illustrates the greater longevity of females especially in their homes and the long stay annexe, a preponderance that was not so marked in acute hospitals and the subnormal institution.

The length of the last illness and the terminal state

Table III again illustrates the greater tenacity with which women cling to life. Not only is their life expectancy longer but the last illness, in or out of hospital is longer (average seven years as compared to five years), as is the duration of their terminal phase (average 70 days as compared to 26 days) when often all has gone except an apparently unquenchable spark of life. This becomes more obvious as the terminal period extends, at 30 days the sexes are about equal but as the period extends to 90 and 180 days, the female percentage draws steadily ahead.

It may be that an alternative definition of the terminal state is the period spent in a geriatric long stay annexe, when there is no hope of cure or discharge. Here again the average stay of women (77 weeks) far exceeds that of men (59 weeks) emphasizing the much larger bed occupancy by women.

TABLE III
AVERAGE LENGTH OF ILLNESS, LENGTH OF TERMINAL STATE AND DURATION OF STAY IN LONG STAY ANNEXE AS RELATED TO SEX

	<i>Male</i>	<i>Female</i>
Life expectancy at birth—National*	68.7 yrs.	74.9 yrs.
Expectation at birth of living to 65 yrs.—National*	70	82
Average age of death in this series	72 yrs.	79 yrs.
Average length of last illness—years	5	7
Average duration of stay in long stay annexe—weeks	59	77
Average period terminal—days	26	70
Terminal over 30 days—per cent	22	23
Terminal over 90 days—per cent	10	17
Terminal over 180 days—per cent	3	13

*Registrar General's Quarterly Return 30.6.70

This tendency seems to be increasing and must be reflected in future planning of the geriatric services. In 1948 the long stay hospital here considered had 48 male and 53 female beds, now there are only 12 male to 85 female beds, a ratio of only one to seven. These extra female beds are all fully occupied by heavy nursing and terminal cases and the demand is likely to increase rather than decrease.

Reasons for a lesser demand for male beds in a long stay annexe may include shorter life expectancy, lesser chance of living beyond 65 years, a shorter last illness and terminal state and the fact that most men marry women younger than themselves and therefore have a spouse alive and willing to look after them at home.

The terminal state

Only patients actually under the care of the author are studied. Under the existing structure of the NHS this precludes those dying in acute hospital beds.

Table IV demonstrates the period of blessed oblivion preceding death. The most desirable consummation, instant death, came most frequently to those dying at home, who were thus spared the degradation of intensive care (Paton 1969), the anxieties of long illness and the trials of the terminal state. As compared with Exton Smith's figures from his geriatric unit, rather more were unconscious for over three hours before death, but the figures from the Middlesex Hospital quoted by Hinton (1963) (61 per cent unconscious for over six hours including 11 per cent unconscious for a week or more) are not approached, perhaps because that hospital had greater facilities for keeping the unconscious alive.

Tables V and VI illustrate the incidence of terminal symptoms and their relation to age. 'Some pain' was recorded if the patient at any time complained of any pain and it was recorded in the medical or nursing notes. 'Joint pain', often occurring with other types of pain, is the commonest and least tractable pain particularly in the older patients,

TABLE IV
PERIOD UNCONSCIOUS BEFORE DEATH—PERCENTAGES

<i>Period of coma preceding death</i>	<i>More than 7 days</i>	<i>1-7 days</i>	<i>6-24 hrs.</i>	<i>3-6 hrs.</i>	<i>Less than 3 hrs.</i>	<i>Instant death</i>
At home	0	25	19	0	19	36
Long stay annexe ..	0	24	32	12	29	3
Subnormal institution ..	0	20	20	14	20	26
Total in series	0	25	26	11	24	14
Middlesex Hospital series (Hinton 1963)	11	34	61			
Exton Smith (1961) ..	More than 3 hours		40			
This series	More than 3 hours		62			

TABLE V
RELATION OF TERMINAL SYMPTOMS TO AGE

<i>Age group</i>	<i>Severe pain</i>	<i>Some pain</i>	<i>Joint pain</i>	<i>Terminal mental distress</i>	<i>Nausea dyspnoea dysphagia</i>	<i>Peaceful</i>	<i>No. of cases</i>
40-49						4 100	
50-59					1	3 75	4
60-69		3		2	4	8 66	12
70-79	3	1	4	5	6	13 50	25
80-89	2	6	9	2	4	16 50	31
90+	1		1	1		8 75	11

especially in the long stay annexe, probably associated with immobility as much as arthritis.

Mental distress, usually depression and/or anxiety, occurred in most patients during their last illness ('prior mental distress') but the term 'terminal mental distress' is reserved for those showing anxiety, depression or fear directly associated with death and becoming evident only as the end became imminent; some suffered both types.

TABLE VI
TERMINAL PAIN AND DISTRESS—PERCENTAGES

Place	Peaceful and painless	Severe pain	Some pain	Joint pain	Total pain	Other distress dyspnoea dysphagia nausea	Prior mental distress	Terminal mental distress	Total mental distress
At home	50	6	18	12	24	30	18	6	24
Long stay Annexe	48	10	10	20	20	12	22	12	36
Sub-normal Inst:	73	0	7	0	7	14	0	7	7
Osler (1906)					18			2	
Exton Smith (1961)					13	8½		6½	

As far as possible comparisons have been drawn with the findings of Osler (1906) and Exton Smith (1961) but different criteria of assessment render such comparisons of doubtful validity. Comparisons within the series based on the place of death are inconclusive. The subnormal patients appear to have had more peaceful deaths, but this may not be associated so much with their lack of intellect as with the fact that most of them died from broncho-pneumonia, 'the old man's friend', during an influenza epidemic.

The increased incidence of 'some pain' and 'other distress' among those dying at home may merely reflect the medical attendant's closer association with these patients, when perhaps he noted symptoms that the hospital nurses did not consider worth including in their reports. It is however clear that those dying at home suffered less 'terminal distress' and 'severe pain', possibly because the attendant family asked for, and got, more and earlier analgesia.

The 100 per cent incidence of 'peaceful' death in the 40 to 49 age group (table V) is directly contrary to the findings of Hinton and Saunders that the young suffer more than the old when dying. This is explained by the mental condition of all four cases, one was a severely subnormal mongol, another an advanced chronic hydrocephalic, the third had suffered severe brain damage in infancy and the fourth had been rendered virtually decerebrate by massive intracranial haemorrhage. All died of broncho-pneumonia.

The high over all incidence of peaceful and painless deaths (58 per cent) is worthy of emphasis and recalls William Hunter's last whisper, 'If I had strength enough to hold a pen, I would write how easy and pleasant a thing it is to die.'

The cause of death

The diseases causing death are shown in table VII under broad headings, but even these are often too precise in elderly patients whose liability to multiple pathology is well known. Many patients suffered from arthritis for many years succumbing eventually to pneumonia or cerebrovascular accidents. The man who committed suicide did so because he was unable to face a life of physical inactivity after three coronary thromboses. Was this not perhaps really a cardiovascular death?

The seven cases of carcinoma (table VIII) show once more that this is not necessarily a painful or distressing cause of death, four died pain free and peacefully. Exton Smith pointed out that of 33 cases less than a quarter suffered severe or moderate pain, a half had no pain, and six were not diagnosed till autopsy, while Hinton found that 'discomfort was not necessarily greatest in those suffering from cancer'.

The chronic neurological diseases present some of the longest and most intractable cases. Whereas those with disseminated sclerosis usually enjoy remarkable euphoria, this blessing is denied those with Parkinson's disease, who usually suffer pain, especially joint pain, and mental distress both before and during the terminal phase. Their distress is all too often augmented by the careless comment of an attendant deceived into thinking they cannot hear, understand and suffer, by the blank expressionless faces and inability to answer.

TABLE VII
CAUSE OF DEATH

Place	Cardio Vasc.	Resp'y	CVA	Ca.	Diseases				Suicide	Total
					CNS	Liver	Kidney	Blood		
Home ..	10	3	1	1					1	16
Acute hosp.	3	3	1	1		1	1	1		11
Long stay annexe ..	15	22	8	5	7			1		58
Subnormal institution	4	11								15
Total ..	32	39	10	7	7	1	1	2	1	100

In addition to the 10 patients shown as dying from cerebrovascular accidents no less than 23 in the series had suffered strokes although death was later due to other causes. It has been truly said that 'even those surviving six months after a stroke have a greatly reduced expectation of life and death, when it comes, may bring welcome relief to tragically stricken invalids and sorely tried relatives' (Adams 1965).

Agate (1969) has pointed out the preponderance of cardiovascular and neurological diseases in geriatric wards and this is confirmed in table VII, especially as no less than 15 of the 22 dying from respiratory disease in the long-stay annexe had been suffering from strokes or other neurological lesions before developing a fatal pneumonia.

Treatment

It is not proposed to deal with details of treatment beyond a few personal impressions.

Especially with elderly patients the fewer and the simpler the medicaments prescribed the less likely are they to upset the patient and the more likely are they to be taken both

TABLE VIII
TERMINAL CARCINOMA CASES

<i>Diagnosis</i>	<i>Age</i>	<i>Place of death</i>	<i>Nature of death</i>
Carcinoma body of uterus	85	Long stay annexe	Peaceful and painless
Carcinoma of breast	87	Long stay annexe	Peaceful and painless
Carcinoma of prostate	96	Long stay annexe	"Some pain"
Carcinoma of ovary	91	Long stay annexe	Peaceful and painless
Carcinoma of breast	69	Home	Severe pain—dyspnoea, terminal mental distress
Secondaries in brain (primary ca. bronchus) asymptomatic and undiagnosed	75	Acute hospital	Transient headache 2-3 hours, pareses, loss of consciousness and death within 24 hrs., diagnosed at autopsy.
Carcinoma of stomach	79	Long stay annexe	Peaceful and painless

in hospital and at home (Sprunt 1970). Liquids are more likely to be swallowed, tablets to be pouched or spat out in the bed. Injections are not always easily administered at home and suppositories are then useful substitutes, especially aminophylline for dyspnoea, and Proladone for pain.

Chloral, Welldorm or Trichloryl are useful, harmless and economical hypnotics. Promazine and chlorpromazine are invaluable as tranquilizers, barbiturates cause confusion and are seldom indicated.

In *Matters of life and death* Cicely Saunders has drawn attention to alcohol as one of the best sedatives for terminal patients and as an excellent adjunct for the relief of pain. Certainly Brompton's famous cocktail of morphia, cocaine, gin and honey remains outstanding for relief of pain and production of euphoria. In severe pain morphia by injection should never be withheld in the terminal state; nausea is an overfeared side effect, of the 100 cases considered 44 received one or more injections of morphia, only one complained of nausea. Digitalis is a more common cause of nausea in the elderly.

Probably the commonest cause of discomfort, incontinence, nausea and distress in the terminal state is faecal impaction. A rectal is often the most rewarding of investigations, a Dulcolax suppository the most effective of treatments.

Finally the dying patients greatest need is water. Our first and last needs are air and water, our first and last reflexes to breathe and suck. A dry tongue condemns the attendants more than any words and, just as the nurse should not await a cry of pain before administering an analgesic, so she should not wait for the patient to ask for a drink.

Psychotherapy

This has recently been discussed in the *British Medical Journal*, *Quarterly Journal of Medicine and World Medicine* (1970), and it has been suggested that specially trained psychotherapists and social workers be deployed in the terminal phase. It might be difficult to avoid too close an association between their services and the probable sequence; few wish to be measured by the undertaker while still alive!

Undoubtedly terminal patients appreciate the unhurried opportunity to talk (Agate 1969). This has been pointed out by Professor Hinton and would seem to play a major part in Dr Cicely Saunders' care. Nowadays doctors are reputed to be too busy to spend long visiting, one wonders what business is more important than the comfort of their dying patients. Nor can such conversations be conducted by two or more doctors on a ward round standing at the bottom of the bed. The patient is surely entitled to the opportunity to talk freely to a sympathetic doctor or nurse if he feels the need; the doctor and nurse must be prepared to be honest, tactful, sympathetic and informed. Is this not perhaps the acme of a good bedside manner?

Those wishing a simple and sensible guide to the conduct of these often difficult and distressing relationships can do worse than refer to Professor Cramond's article (1970).

Most terminal patients, possibly 80 per cent, probably know what is about to happen (Cappon 1959 and Saunders 1959) but many cannot and some do not want to face the facts. There seems little merit in making them do so with brutal bluntness. Indeed it is incredible how those who have been told the cruellest truth can refuse to face it and continue to expect a cure. It is wise to beware of those who demand to be told the truth, too often what they are demanding is not the truth but reassurance.

In obstetrics there are three parties, the mother, babe and obstetrician, at death again there are three parties, the doctor will be wise as well as kind to remember the needs of the anxious and grieving relatives as well as those of the dying patient.

Euthanasia

As already stressed treatment of the terminal patient is directed to the relief of symptoms rather than the prolongation of life, indeed such relief sometimes shortens life marginally. But the idea of deliberately setting out to kill a patient with or without the latter's 'consent' must surely be repugnant to the majority of our profession.

On the other hand to officiously keep alive a patient who would otherwise undoubtedly die can only be justified if he can be offered a quality of life that is not mere existence, and when the patient will only lead an unconscious vegetable existence it would seem quite pointless. Artificially to restart an old person's heart has been aptly described by Lord Platt as meddling. While the possibility of the Post Office issuing forms of application for the destruction of elderly and unwanted relatives as envisaged by Lord Brock in a discussion on this matter sounds macabre, as does the prospect of euthanasia hotels forecast in 'Tomorrow's World'.

On the other hand euthanasia by neglect has been practised for many centuries in many societies and whether old ladies are left to be eaten by wolves on snowy mountains in ancient Greece or hidden away in old, dilapidated, under staffed institutions by an affluent, disinterested population, the effect is much the same. Surely if our society is to claim to be civilized it must be prepared to provide comfortable and dignified accommodation adequately staffed and serviced for those coming to the end of their lives, even at the cost of some of the luxuries and excesses of affluence.

Summary

A hundred consecutive deaths in the author's practice are considered. Of those from his own general practice 53 per cent died at home; 58 died in a long-stay annexe, 11 in acute hospital wards and 15 in an institution for the subnormal. Sixty-one per cent died between 70 and 89 years of age. The greater longevity of women, the greater length of their last illness, terminal state and stay in the long-stay annexe are shown, bearing out the greater toughness and durability of the so-called weaker sex. The terminal state is considered in some detail, a plea is made for simpler and fewer drugs in these

cases and for personal, honest, kind and sympathetic attention to the dying and their relatives.

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EXPERIMENTAL COMMUNITY CARE PROJECT

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When the professor of clinical epidemiology and dean of the new medical school at Southampton, Professor E. D. Acheson, gave his inaugural lecture in May 1970, he said that a medical school could no longer be considered to consist of a faculty of medicine in a university, and a teaching hospital and its satellites. A substantial part of the resources of the school should be devoted to introducing the undergraduate to medicine outside the hospital. The modern medical school, in his view, had a duty to criticize, and to experiment in the system of medicine in which it operated, and also to try to strengthen the links between those whose work lay mainly within the hospital and those whose work lay mainly in the community outside.

The Foundation has made a grant of £77,700 over seven years to enable Professor Acheson to test and demonstrate new methods of providing primary and continuing medical care (including general practice) in units to be established in Southampton and the surrounding countryside. In particular he and Dr J. A. Forbes, the director of the community care project, will be assessing results in a group practice where each of the practitioners takes responsibility for patients in a different age group, children, old people, women of childbearing age, and so on, and will compare those results with what happens in an otherwise similar group practice where the general practitioners give the traditional, comprehensive kind of care.

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