General Practice Observed

The Distress of Dying

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Summary

A simple method of recording the distress of dying patients is described. Significant differences occurred between deaths at home and in hospital for three factors. Patients dying at home were (a) more likely to be fully alert shortly before death ($P < 0.05$); (b) less likely to be suffering from vomiting, incontinence, or bedsores ($P < 0.001$); and (c) less likely to have unrelieved physical distress ($P < 0.05$). No significant differences occurred in the distress of patients dying in general-practitioner compared with other hospitals, though the numbers compared were small and a larger study might prove useful.

Introduction

The purpose of this paper is to describe a simple method of assessing the distress of dying patients in a way that can be charted routinely by nurses and to report the results obtained in 50 cases.

Charts

The factors to be assessed are pain, respiratory distress at rest, impairment of consciousness, awareness of dying, depression, anxiety, malaise, relief of physical distress, vomiting, bedsores, faecal incontinence, and urinary incontinence or the presence of an indwelling catheter or both. The extent to which these occurred was assessed and recorded morning and night by the senior hospital nurse on duty. For deaths at home the charts were completed by the district nurse once or twice a day depending on the frequency with which she visited.

Pain was recorded on a vertical line chart graduated 0 to 10. The absence of pain was recorded as 0, mild pain as 1 and 2, moderate pain as 3 to 6, severe pain as 7 and 8, and very severe pain as 9 and 10. An identical chart was used for recording respiratory distress at rest. Vomiting, bedsores, faecal incontinence, and urinary incontinence or the presence of an indwelling catheter or both were recorded without any attempt being made to assess severity. The other symptoms listed were classified in a manner identical with that used by Hinton,¹ though each symptom needed to be given an appropriate numerical scale. Thus anxiety required a scale of 0 to 4 and depression a scale of 0 to 5. The absence of symptoms is indicated by 0, while the highest numeral indicates the most severe symptoms.

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Method

This was planned as a prospective study of consecutive deaths among people resident in the Llanidloes area. Previous consent for the use of the charts was obtained from general practitioners and consultants likely to be involved. The co-operation of the hospital and district nurses was obtained. The decision on when a person was dying and suitable for inclusion in the survey was made by the senior nurse on duty. She was also responsible for the clinical assessment and recording of symptoms.

As the plan was to record consecutive deaths it remained necessary to include in the survey the seven residents who died outside the Llanidloes area. The information about these people was obtained retrospectively by telephone conversation with the nurse and doctors involved. Similarly, it was considered necessary to make an assessment for the single person who died suddenly at home alone without medical or nursing care. He was an epileptic who appeared perfectly normal earlier in the day. Necropsy showed only the changes of essential hypertension. It was assumed that his death was free from physical or mental distress.

Results

Between 6 November 1969 and 25 November 1970 50 people died—33 men and 17 women. Of these, 13 died at home, 26 in a general-practitioner hospital, 4 in a chronic sick unit, and 7 in other hospitals. Their average age was 72.2 years, with a range of 41-92 years.

The duration of illness is shown in Table I and the cause of death in Table II. These tables include comparative data from the reports by Hinton¹ and Exton-Smith.²

Incontinence, Vomiting, and Bedsores.—The extent to which these symptoms occur in the dying has not been clearly indicated in previous reports. Of the Llanidloes patients 28% were troubled at some time by vomiting, 30% had bedsores, 30% had faecal incontinence, 2% had a colostomy, 20% required an

TABLE I—Duration of Terminal Illness in the Three Studies. Figures are Percentage of Deaths

	Exton-Smith ²	Hinton ¹	Llanidloes
≤ 1 Week	25.5		50.0
1-4 Weeks	36.0	3.9	34.0
4-12 Weeks	20.5	26.5	10.0
> 12 Weeks	18.0	69.6	6.0

TABLE II—Causes of Death (Figures are Percentages)

	Exton-Smith ²	Hinton ¹	Llanidloes
Cancer	15.0	80.0	18.0
Cardiovascular disease	21.4	13.7	36.0
Diseases of C.N.S. (mainly cerebrovascular)	37.3		24.0
Chronic Respiratory disease	8.2		8.0
Other	18.1	6.3	14.0

indwelling catheter, and another 46% had urinary incontinence. Only 26% had none of the above symptoms. Of the symptom-free patients six died within 48 hours and eight died at home. Most people dying at home were free from vomiting, incontinence, and bedsores. Of the 13 home deaths eight patients (61.5%) were continent and without bedsores. Of the 37 hospital deaths five patients (13.5%) were similarly unaffected. The increased incidence of incontinence, vomiting, and bedsores among people dying in hospitals is significant ($P < 0.001$).

Difficulties in Interpreting Charts.—In extracting from the charts figures other than those given above one has the problem of taking and analysing from diurnal linear charts information recorded in a manner similar to that normally used for temperature charts. One can take the highest, lowest, or average figures. Where the aim is to relieve distress the highest figures are most important, as these indicate the worst episodes of pain, etc. The results reported will be the highest figures recorded for each patient, so a particularly gloomy view of our findings will emerge. Where relevant lowest figures are reported in the text. In a survey of this type average figures are probably meaningless, but these are included in the tables to ensure completeness.

Awareness of Dying.—Six per cent of the patients expected to improve, 72% were non-committal, and 22% indicated an awareness that they might die; 10% expected to die soon, 10% thought they would probably die, and 2% thought they might possibly die.

Impairment of Consciousness.—Impairment of consciousness often increases as death approaches. Altogether 28% were fully alert up to the last day of life, but 40% were comatose, 20% were stuporous, and 12% were mentally confused by this time. People dying at home were more likely to be fully alert than those dying in hospital. Of the 13 people who died at home 7 (53.8%) were fully alert 24 hours before death, compared with 7 (18.9%) of the 37 dying in hospital. This difference is significant ($P < 0.05$).

Pain.—The results obtained for pain are given in Table III. With regard to the highest score 46% did not experience pain and 54% experienced pain of varying severity; 26% experienced severe or very severe pain. Of those with the lowest score 18% were always in some pain though this was usually mild.

TABLE III—Percentage of Patients who Experienced Pain

	Nil	Mild	Moderate	Severe	Very Severe	Total
Highest score recorded	46	16	12	14	12	100
Average score recorded	52	20	20	6	2	100
Lowest score recorded	82	10	6	2	0	100

TABLE IV—Percentage of Patients who Experienced Respiratory Distress at Rest

	Nil	Mild	Moderate	Severe	Very Severe	Total
Highest score recorded	20	10	44	14	12	100
Average score recorded	28	32	32	8	0	100
Lowest score recorded	60	16	16	8	0	100

Respiratory Distress.—These findings are given in Table IV. Of patients with the highest score only 20% had no respiratory distress and 80% had respiratory distress of varying severity; 26% had severe or very severe respiratory distress. Of those with the lowest score 40% always experienced some respiratory distress.

Anxiety.—Forty-four per cent of the patients were free from anxiety and 56% experienced some anxiety (Table V). At times the anxiety of 14% was so severe that they could be described as fearful.

Depression.—These findings are given in Table VI. Sixty per cent of the patients were free from depression and 40% experienced some depression. At times 12% were so severely depressed that they wanted to die.

TABLE V—Percentage of Patients who Experienced Anxiety

	Nil	Slight	Mild	Moderate	(Fearful) Severe	Total
Highest score recorded	44	14	12	16	14	100
Average score recorded	54	24	8	14	0	100
Lowest score recorded	80	14	2	4	0	100

TABLE VI—Percentage of Patients who Experienced Depression

	Nil	Slight	Mild	Moderate	(Wants to die) Severe	Total
Highest score recorded	60	14	0	14	12	100
Average score recorded	68	18	8	4	2	100
Lowest score recorded	88	8	2	0	2	100

Relief of Physical Distress.—Physical distress includes general malaise in addition to pain, dyspnoea, incontinence, vomiting, and bedsores. Altogether 54% of the patients were bedridden and 26% were completely immobile in bed when they were included in the survey. Twenty-six per cent were considered not to have suffered physical distress and 12% were completely relieved of their distress (Table VII). Altogether 34% received incomplete relief, while the physical distress of 28% was such that there were times when they were never free from their distress throughout the day. People dying at home suffered less physical distress than those in hospital. Of the 13 home deaths five patients (38.5%) experienced physical distress that was not continuously relieved compared with 26 (70.3%) of the patients who died in hospital. This difference is significant ($P < 0.05$).

TABLE VII—Percentage of Patients who Experienced Physical Distress

	Nil	Relieved	Unrelieved and Inconstant	Unrelieved and Constant	Total
Highest score recorded	26	12	34	28	100
Average score recorded	28	32	32	8	100
Lowest score recorded	46	30	18	6	100

Dying at home Compared with Hospital.—Twenty-six per cent of the patients died at home, which is probably less than the national average. The presence of a general-practitioner hospital probably accounts for the low proportion of domiciliary deaths, as it provides a greater choice for patients, relatives, and doctor about where death will occur. The duration of terminal illness for deaths at home and in hospital was similar. Thus of those dying at home 7 (53.8%) died within a week and 4 (30.8%) within a month, while 2 (15.4%) survived a longer period. The duration of all deaths is shown in Table I. There was no significant difference in the ages of those dying at home compared with hospital. Ten patients over 70 years old died at home and 21 in hospital. Patients dying at home were (a) more likely to be fully alert 24 hours before death ($P < 0.05$); (b) less likely to be suffering from vomiting, incontinence, or bedsores ($P < 0.001$); and (c) less likely to have unrelieved physical distress ($P < 0.05$). It is possible that the presence of an alert mind and the absence of symptoms requiring constant nursing care determined the site of death of these patients.

Dying in a General-practitioner Hospital compared with Other Hospitals.—Twenty-six people died in a general-practitioner hospital and 11 in other hospitals. These figures are small and no significant difference occurred in any of the factors examined. It is possible that a larger survey would be useful, as at a significance approaching the 5% level patients dying in a general-practitioner hospital were less likely to experience severe pain or moderate to severe anxiety.

Discussion

Objective reports on the distress of dying patients have been made by Hinton¹ and Eston-Smith.² This survey differs from

those of Hinton and Exton-Smith in method, type of patient studied, and environment.

In Llanidloes the method used was entirely dependent on observations made by State-registered nurses. The 220 patients in Exton-Smith's survey all died in a geriatric unit. His information was obtained "from personal observation and close enquiry from the nursing staff." Hinton's study was confined to a teaching hospital. He interviewed 102 dying patients and later questioned the sister or staff nurse about the state of the patient in the last few hours of life. The oldest patients were in Exton-Smith's group, with an average age of 80 years. The average age of the Llanidloes patients was 72.2 years. A direct comparison cannot be made with the patients in Hinton's study, who were probably much younger, with 46.1% under the age of 60 and only 19.6% over 70 years old.

The duration of illness for the three surveys is shown in Table I. An important reason for the observed differences is that completely different methods were used for assessing the duration of terminal illness. Hinton determined it from the onset of first symptom to the time of first interview, and Exton-Smith on the duration of stay in hospital. In Llanidloes the critical point was a decision by a nurse that the patient was dying.

The cause of death differed considerably in the three surveys (Table II). In particular 80% of Hinton's patients died from cancer. He reported that discomfort was not greatest in patients dying from cancer but "patients dying from heart failure or renal failure or both, had most physical distress." Exton-Smith thought the pain experienced by those with rheumatoid arthritis to be particularly great.

The extent to which vomiting, incontinence, and bedsores occurred is not apparent from the other two reports. Exton-Smith stated that 7.7% of patients had distressing symptoms other than pain. The symptoms he included in this group were protracted vomiting, dysphagia, and dyspnoea. Hinton found nausea or vomiting in (19) 18.6% of the patients when first interviewed. In Llanidloes 28% vomited while only 26% were completely continent and free from vomiting or bedsores.

Hinton pointed out that an awareness of dying increases as death draws closer; 75% of his patients indicated such an awareness during the final weeks. The Llanidloes figure of 22% is much lower, probably because the nurses did not seek this information but recorded only information volunteered by patients. It is similar to the 25% reported by Exton-Smith, so from these two studies it seems likely that about a quarter of dying patients indicate an awareness of approaching death to their attendant nurses. Altogether 3.2% of Exton-Smith's patients and 10% of those in Llanidloes expected to die soon, while the figures given by Hinton range from 6% at the first interview to 20% during the last week of life.

Impairment of consciousness increases as death approaches; 34% of Hinton's patients were unconscious for at least 24 hours before death. Of Exton-Smith's patients 58.6% were mentally alert and 41.8% confused during the terminal illness, with 40% unconscious for at least three hours before death. In Llanidloes 28% were fully alert 24 hours before death, with 12% mentally confused, 20% stuporous, and 40% comatose. There seems agreement between the three surveys that about 40% of dying patients are comatose some hours before death.

In Exton-Smith's study 13.6% of the patients suffered moderate to severe pain. Hinton found that 65.7% had pain, though the severity was not classified, and 18% of those with pain failed

to receive adequate relief. In Llanidloes 46% did not have pain and 54% had pain; 18% were always in some pain, while 26% experienced severe or very severe pain. Hinton stated that dyspnoea is more difficult to relieve than pain, nausea, or vomiting and that out of 17 patients suffering from respiratory distress 14 (82%) failed to obtain relief. In Llanidloes only 20% had no respiratory distress at rest, and at times 26% had severe or very severe distress, though some dyspnoeic patients were also comatose.

A few patients (3.2%) in Exton-Smith's study showed severe anxiety and were afraid to be left alone. Hinton found that 64.7% showed at least slight anxiety and 12.7% experienced moderate anxiety, but none were classified as fearful. In Llanidloes 56% showed at least slight anxiety, while at times 14% were fearful. Hinton included as severely anxious or fearful only patients who had been fearful, agitated, or panic-stricken for most of the week. In Llanidloes any transient state of fearfulness that the nurses noted was included.

Depression was found in 2.7% of Exton-Smith's patients, while Hinton found that 66.7% experienced some depression and that 16.7% showed moderate or severe depression. In Llanidloes 40% experienced at least slight depression, while 26% were moderately or severely depressed. Altogether 12% of the Llanidloes patients wanted to die, which is higher than the 5% reported by Exton-Smith. Hinton pointed out that 65% of depressed and 52% of anxious patients remain unrelieved.

Exton-Smith gave no figures about the relief of symptoms and no indication of the drugs used. Hinton reported that one-third to one-quarter of the patients received no drugs at all, while 45.1% received opiates, barbiturates, or phenothiazines. Out of 71 patients interviewed by Hinton during the last week of life 16% experienced almost continuous physical distress and 27% had physical distress some of the time. In Llanidloes 12% received no drugs, though this includes two patients admitted to hospital in coma and a sudden death at home; 34% received opiates, 26% phenothiazines, and 20% other sedatives. Only 26% were thought to have had no physical distress.

Conclusion

In contrast to many subjective reports very few objective assessments have been made on the distress of dying. The charts used provided a useful pictorial image, the significance of which was easily assessed. Few doctors spend much time with dying patients so the observations recorded by nurses provide a much more comprehensive assessment than most doctors will make alone. The use of these charts made me realize the large extent to which the terminally ill under my care were receiving inadequate relief from their sufferings. This finding was particularly important as I had previously considered my management at least adequate. The use of pain charts by those responsible for the care of the terminally ill can be a salutary experience.

I am most grateful to the nurses who completed the charts and to the doctors who consented to these being used on their patients.

References

- ¹ Hinton, J. M., *Quarterly Journal of Medicine*, 1963, 32, 1.
- ² Exton-Smith, A. N., *Lancet*, 1961, 2, 305.