

# A longitudinal study on dying in a Norwegian hospital

Liv Wergeland Sørbye

## Abstract

A research project conducted at a Norwegian hospital in 1977 ( $n=213$  deaths) was repeated in 1987 and 1997 ( $n=100$  deaths each year). The purpose was to discover if and how terminal care had changed during these 20 years. Data sources included case records, nurses' reports and interviews with close relatives approximately 12 weeks after death. The average stay in hospital decreased by one-third from 1977 to 1997. Active life-prolonging treatment, as defined by use of antibiotics, resuscitation and parenteral fluids, was greatly reduced from 1977 to 1987, but there was an increase in the use of such treatment in 1997. Interestingly, palliative treatments — either broadly defined as the giving of analgesics in general, or more narrowly as the giving of opiates only — have increased steadily over the years and are now offered to most patients. However, the findings demonstrated that the next-of-kin were less well informed about the patient's impending death in 1997 than in 1977.

(Sørbye, 1992). The main findings showed that the average length of stay of patients in hospital had decreased, palliative care had improved, the use of life-prolonging treatment had been reduced, but openness in talking about death had not improved. In 1997, a third research project was conducted to ascertain the ways in which the hospital had developed care for terminally ill patients.

## Research question

How did the hospital meet the needs of terminally ill patients in 1997 when compared to 1987 and 1977, with respect to:

- Openness about death and dying
- Use of life-prolonging treatment
- Pain management?

## Method

In 1976 a hospital, which had a suitable number of deaths per annum (approximately 230) for the aim of the research project, was chosen. In 1977 data were collected from three sources: medical case records, nurses' reports and interviews with the next-of-kin approximately 12 weeks after death. A structured questionnaire was used, and a written report was made after each interview.

In 1987 data were obtained using the same methods as in 1977. In addition, data were collected by interviewing medical staff and nurses responsible for patient care and also by observing and participating in patient care and nursing terminally ill patients. Relevant statistical data were also available from hospital records. In 1977 the study covered all deaths in the hospital during a 12-month period. In 1987 data were collected from two medical wards only.

In 1997 all the wards in the hospital were included, as in the 1977 study. All deaths were included until data had been collected on 100 patients. During the 1997 research the physicians were not interviewed and participant observations of dying patients were not conducted. The questionnaires used for the nurses and the next-of-kin

Health professionals in Norway became familiar with the hospice philosophy during the mid-1970s. This philosophy stated that health personnel should not only help to maintain life-giving physical care, but should also acknowledge mental, social and spiritual care (Saunders, 1978). Until 1977, little had been published about death and dying in Norway and there had been few contributions to the debate about death and dying, and few reviews of the literature (Rieber-Mohn, 1968; Elgjo, 1974; Skjørshammer, 1981).

In 1977, the author systematically collected and evaluated information about patients dying in a Norwegian hospital. The goal was to describe the situation and to improve terminal care for patients (Sørbye et al, 1979). In the years that followed, interest in care of the dying increased in Scandinavia. Research reports were published, official surveys were carried out and courses and seminars were arranged. Health professionals became theoretically more knowledgeable about the situation of terminal patients.

In 1987 a similar research project was carried out at the same hospital. The purpose was to discover if and how terminal care had changed during these 10 years

Liv Wergeland Sørbye is Associate Lecturer, Diakonhjemmet College, Research Department, Oslo, Norway

## A longitudinal study on dying in a Norwegian hospital

were not identical, but had several common questions regarding life-prolonging treatment, palliative care and information about death and dying.

The Resident Assessment Instrument (RAI) (Fries et al, 1991) was used in order to achieve valid clinical data surrounding the patient's last stay. This instrument provides a description of the patient's condition and needs during the last 7 days before death. The RAI is also used to record patients' advance directives (e.g. no life-prolonging treatment, no resuscitation). This instrument was not designed specifically for palliative care therefore a supplement covering special items for

the terminal phase was used during the interviews with the nurses as it had been in the 1987 study. The questionnaire used in the interview with the next-of-kin had similar questions in all three studies. Interviews with the next-of-kin produced a great deal of qualitative data, which was continuously entered on the computer for further analysis. The same researcher (the author) carried out the data collection in 1977, 1987, and 1997.

The Data Inspectorate granted permission to set up a personal register according to current regulations. Following a formal application, the governmental health service allowed the researcher access to examine information in 100 patient records, which are subject to professional secrecy.

An SPSS-compatible Swedish computer programme made for RAI was used in statistical processing and analysis of the RAI questionnaire. The questionnaires used for the nurse and the next-of-kin had several common items, and were registered in the NSD-stat (the Norwegian social science data services).

### Results

#### Sample

In 1977, 213 patients died at the hospital, 346 died in 1987 and 324 patients died in 1997 (Table 1).

#### Sex, age, diagnosis and length of stay

The mean age in 1977 was 75.7 years for men and 76 years for women. In 1987 the figures were 78.2 years for men and 81.1 years for women; and in 1997 the mean ages were 76.0 years and 78.4 years respectively. The mean age for men was stable from 1987 to 1997, but for women the mean age had decreased by 5.1 years in 1997 and returned to the mean level for 1977 (Table 2).

Immediate cause of death was stated according to the International Classification of Diseases (ICD-10) (World Health Organization, 1992)). In the 1977 study, 111(52%) patients died of cancer. The figures for 1987 were 32(32%) and 40(40%) in 1997. In 1977, 57(27%) patients died as a result of circulatory system disease. Comparable figures for 1987 and 1997 were 42(42%) and 39(39%) respectively (Table 3).

The mean number of days spent in hospital during the final period before death was reduced from 42.4 days in 1977 to 25.8 days in 1987 and to 13.8 days in 1997, particularly in those people who lived alone

**Table 1. An overview of data from 1977, 1987 and 1997. Number of deaths and sources of information**

	1977	1987	1997
Total number of deaths	213	346	324
Information from medical records	213	100	100
Personal interview with:			
Next-of-kin	210	72	56
Nurses		100	100
Physicians		100	

**Table 2. Patient characteristics according to age and sex in 1977 (n=213), 1987 and 1997 (n=100)**

Age	1977		1987		1997	
	Women	Men	Women	Men	Women	Men
Years	No.(%)	No.(%)	No.(%)	No.(%)	No.(%)	No.(%)
<69	23(24)	29(25)	5(8)	7(18)	11(21)	5(11)
70-79	42(44)	53(45)	17(28)	14(35)	18(34)	17(36)
>80	31(32)	35(30)	38(64)	19(47)	24(45)	25(54)
Total	96	117	60	40	53	47
Average	76.0	75.7	81.1	78.2	76.0	78.4

**Table 3. Cause of death classified in accordance with the International Classification of Diseases (ICD-10)**

	1977	1987	1997
Direct cause of death	No.(%)	No.=%	No.=%
II Tumours (malignant)	111(52)	32	40
VII Disease of the circulatory system	57(27)	42	39
VIII Disease of respiratory organs	14(7)	19	14
Other	31(14)	7	7
Total	213	100	100

## A longitudinal study on dying in a Norwegian hospital

(Figure 1). In 1977 the median value for the number of days spent in hospital during the final period of hospitalization was 6 days more for people who lived alone compared to those who had a spouse (30.4 and 24.5 days). In 1987 the median was 12 days and in 1997 the median had reduced to 7 days.

In 1987 and 1997 the medians were similar for people who lived alone and for those who had a spouse. The figures for 100 patients who died in 1987 and 1997 were compared with the length of stay for all deaths in the hospital in those respective years, and the data are representative. The care plans examined assessed 71% of the patients to be totally dependent on nursing staff for their care 0–7 days before death in 1977 and 1987. In 1997, 77% of the patients were totally dependent on the help of another person; this included mobilization,

i.e. moving to and from a lying position, turning and positioning while in bed.

### Information

According to medical documentation approximately 30% of the patients were assessed as having some cognitive impairment due to senile dementia, confusion or loss of consciousness. The next-of-kin estimated whether the patients were 'fully aware', 'partially aware', 'less aware' or 'not aware' that death was approaching. In 1977, 1987, and 1997, 95(47%), 33(46%) and 27(49%) respectively of the next-of-kin considered patients to be fully aware that death was imminent. Corresponding figures for the next-of-kin's evaluation were 157(78%), 50(69%) and 32(59%) respectively (Table 4). The following comments provide examples that demonstrate full awareness:

'My husband had been informed that the liver was too large, and that nothing could be done.'

'Father said "when the radiologist saw my x-rays, he remarked to me: 'I hope you have had a good life"'. Father then understood that he had only a short time left to live.'

'My neighbour had no-one besides myself to be with him. The last time I visited him at the hospital, he said: "The next ride I'll have will be to crematorium".'

How did the next-of-kin become aware that the patient was dying? In 1977, 1987 and 1997, 91(45%), 34(47%) and 32(57%) of the patients' next-of-kin said that the physician had informed them, while 17(8%), 7(10%) and 2(4%) respectively reported that the nurse had informed them of the patient's prognosis (Table 5).

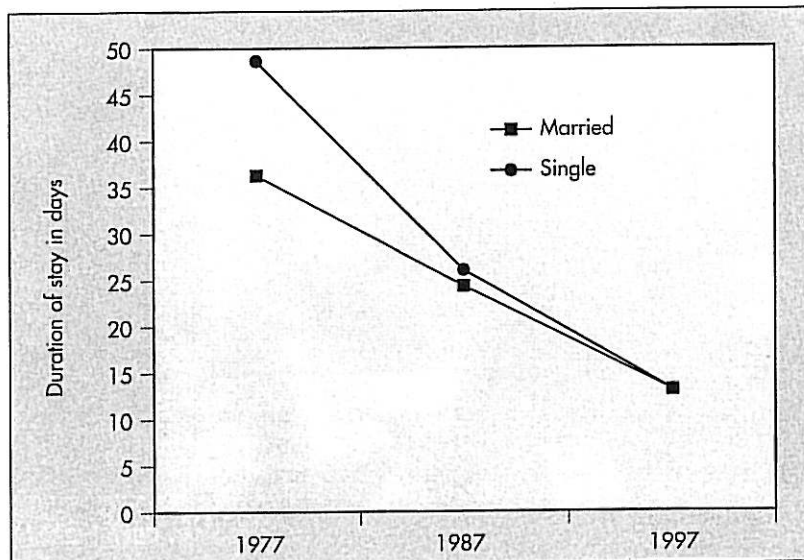


Figure 1. Duration of stay in hospital (days). A comparison of mean duration of stay in relation to marital status. In 1977,  $n=97$  married and 116 single; 1987,  $n=38$  married and 62 single; in 1997,  $n=52$  married and 48 single.

Table 4. Relatives' evaluation of the extent of awareness that death was approaching ( $n=210$  in 1977,  $n=72$  in 1987, and  $n=56$  in 1997)

	Patient			Next-of-kin		
	1977	1987	1997	1977	1987	1997
Fully aware	96(47%)	33(46%)	27(49)	157(78%)	50(69%)	32(59%)
Partially aware	33(16%)	9(13%)	10(18%)	19(9%)	13(18%)	9(17%)
Less aware	36(18%)	6(8%)	2(4%)	15(7%)	3(4%)	5(9%)
Not aware	33(16%)	5(7%)	9(16%)	10(5%)	4(6%)	3(6%)
Do not know/unclear	6(3%)	19(26%)	7(13%)	–	2(3%)	5(9%)
No response registered	6	–	1	9	–	2
Total	210	72	56	210	72	56

In 1977, 67(33%) of the next-of-kin answered: 'I understood it on my own', whereas the figures in 1987 and 1997 were lower at 17(24%) and 8(14%) respectively.

In answer to the question 'Did the patient tell you that he/she would soon die?', which was put to the nurses in 1987 and 1997, 25(25%) and 24(24%) revealed that the patient had, to different degrees, talked to them about death.

#### Active life-prolonging treatment

In 1987 the physicians were generally more cautious in giving treatment beyond palliative medicine, compared to 1977 and 1997. The number of patients treated with antibiotics decreased from 66(31%) in 1977 to 15(15%) in 1987. In 1997, however, 20(20%) patients received antibiotic treatment showing a slight increase in the number of patients receiving this therapy. In 1977, cardiopulmonary resuscitation was commenced (but failed) on 10(15%) patients.

The findings showed that 2(2%) patients received resuscitative measures in 1987

and 5(5%) in 1997. In 1977, 133(62%) patients received intravenous (IV) fluids during their last days and in 1987, 25(25%) received IV therapy. In 1997, a higher percentage of patients (36(36%)) were given a daily average of 500 ml of fluid or more during their last 7 days.

#### Relief of pain

The nurses' reports in the medical records documented an increased use of pain-relieving treatment (Table 6). In 1977, 109 (51%) dying patients received pain-relieving treatment in the terminal stages of illness. According to the nurses' reports, 19(17%) patients were still in pain. In 1987, 79(79%) patients were given analgesics, which had had little effect in 9(9%) of cases. Comparable figures in 1997 were 84(84%) and 4(4%). In 1977 morphine was usually injected subcutaneously, whereas in 1987 and 1997 continuous intravenous morphine was administered by an interval pump injection, or orally as a mixture or tablets.

#### Discussion

In 1977 there was a feeling of tremendous optimism regarding medical treatment and it was suggested that there was nothing modern medical technology could not manage (Ariès, 1977). In the 1980s health care in Norway was inspired by the hospice philosophy in particular that people should be permitted to die in peace without unnecessary life-prolonging treatment. In 1984 a government committee published the report *Caring for the Seriously Ill and Dying* (Norges offentlige utredninger (NOU), 1984). The committee discussed whether or not words such as 'treatment' should be included in the title, but concluded that at the end of life, the emphasis should be on adequate care with regard to symptom relief, and not treatment.

#### Sample comparison

The study method chosen in 1977 had limitations, but this is not necessarily an obstacle to evaluating the development of palliative care. In 1977 the data were obtained from the nurses' written care plans, and in 1987 and 1997 a personal interview with the nurse in charge of the individual dying patients was also included. In order to achieve a corresponding range in 1987 as in 1977, data should have been collected from surgical and medical wards, with the same number of patients as in 1977. Unfortunately, data from 1977 were not processed according to ward areas.

**Table 5. Ways in which the next-of-kin became aware that the patient would die (n = 210 in 1977, n = 72 in 1987, and n = 56 in 1997)**

	1977 No.(%)	1987 No.(%)	1997 No.(%)
Informed by physician	91(43)	34(47)	32(57)
Informed by nurse	17(8)	7(10)	2(4)
Informed by patient	-	4(6)	-
Realized on his/her own	67(32)	17(24)	8(14)
Other (did not wish to understand)	2(1)	8(11)	12(21)
Does not know/non-topic (unexpected)	24(11)	2(3)	2(4)
No response registered	9	-	-
Total	210	72	56

**Table 6. Various types of pain-relieving treatment given in the final phase of illness (n = 213 in 1997, n = 100 in 1987 and 1977)**

	1977 No.(%)	1987 No. = %	1997 No. = %
No analgesia	104(49)	21	16
Light analgesia	*	18	5
Medium/strong analgesia	28(13)	10	7
Opiates	81(38)	51	72
Total	213	100	100

\*In 1997 the research papers did not distinguish between light and medium/strong analgesia

*'On discharge from hospital cancer patients are entitled to 'open readmission', which means that patients or their families may return to hospital whenever they choose...the relatives and the patient know that they may return to the hospital at any time they like, without calling a physician.'*

For practical reasons, two medical wards were selected in 1987, and after 100 deaths, the extent of the information collected seemed sufficient. In 1987, 280(81%) of all the deaths at the hospital occurred on a medical ward, compared to 155(73%) in 1977. In 1997, deaths that occurred in all wards were registered, as in the 1977 study. Of the 12 patients who died in an intensive care ward, five patients were in surgical wards and seven were in medical wards. A total of 260(80%) patients who died had been admitted to a medical ward. Since such a large portion of the patients died on medical wards in each of the 3 years, it should be possible to compare the findings on the basis of selection.

In 1977, 210 of the next-of-kin were willing to be interviewed. At that time, it was not accepted etiquette to speak of death in public. Many expressed their need to talk about what had happened. Ordinary people had little knowledge about medical diseases and expressed a need for more information. On receiving an inquiry from the hospital, it was a matter of course to answer yes. In those days, there was possibly a deeper feeling of solidarity; the letter stated that: 'Your experiences may be useful for others'. In 1997, only 56(56%) of those approached consented to be interviewed.

One explanation for this could have been that the length of the last hospital admission had decreased dramatically and the next-of-kin may have felt that they barely knew the hospital staff. Some of the next-of-kin returned the invitation letter for an interview saying that: 'Everything was OK, we have nothing special to say', while others expressed that this was a private matter.

### Changes in the patient group

#### Sex, age, diagnosis and length of stay

In Oslo women live on average 6.3 years longer than men (78.4 and 73.1 years) (Statistics Norway (Statistisk sentralbyrå), 1998). In 1997 the average age of the women who died in this sample, was lower than the average age of men, in the total deaths in the hospital — the average age for females was 78.4 years, and 77.0 years for male patients. In 1977, 33% of those who died in Oslo were older than 80 years; the same figures for 1987 and 1997 were 44% and 53% respectively.

In 1977, 31% of all those who died at the hospital were older than 80 years, the same figures for 1987 were 57% and 49% in 1997. It may be assumed that a smaller number of those who died in an intensive

care ward were under 80 years, but their age was higher on average. In 1987, 58% of patients were over 80 years of age.

The average age of those who died of cancer in 1997 was 72.7 years for women and 78.3 for men. In 1987 and 1997 approximately the same proportion of male and female patients died of cancer, i.e. 8% more patients died of cancer in 1997. The fact that women died at a younger age than men remains unexplained.

During this 20-year period, there have been significant changes in the number of days spent in the hospital at the last admission (*Figure 1*). In 1997 the average (mean) duration of the admission period was 13 days. Half of the patients were admitted for 7 days or less (median = 7). Corresponding figures for the whole country are mean = 11 and median = 5 (NOU, 1999).

Home-based nursing was introduced between 1977 and 1987. The Local Authority Health Care Act 1982 demanded that municipalities organize home care. There followed a large expansion in the number of nursing home places: in 1977 22% of Norwegians died in a nursing home, which corresponded to 37% in 1997 (Statistics Norway, 1999). There are several reasons why hospital admission periods have become shorter.

Outpatient treatment has improved and during the last 10 years all municipalities have developed a 24-hour nursing schedule. Health professionals including nurses and physicians are better trained and more skilled in palliative care. On discharge from hospital cancer patients are entitled to 'open readmission', which means that patients or their families may return to hospital whenever they choose. It may be easier to take a patient home, when both the relatives and the patient know that they may return to the hospital at any time without calling a physician.

This study seems to indicate that many patients are admitted to hospital only shortly before they die. Even though a larger portion of the patients were younger on admission in 1997 than in 1987, the number of patients has increased. The short stay in hospital leaves little time for staff to give psychosocial care and address spiritual needs.

The municipal health service has to a greater extent played an active role in the more recent past. Proportionally, with an increase in skills in the primary health service, the need for admission to hospital in the last phase will decrease (NOU, 1999).

*'In 1997 it was accepted practice that the physician would decide whether or not resuscitation should be considered at an early stage in during the patient's admission. As a result 78% of the patients and almost all cancer patients (93%) had DNR written on their charts.'*

### Life-prolonging treatment

There was a slight increase in the use of antibiotics from 1987 to 1997. The number of patients who received antibiotics was not greater in intensive care and surgical care than in medical wards. However, intensive care wards and the reception ward were not included in the study from 1987. The number of patients who were given treatment with IV fluids in the final stage of illness decreased from 62% to 25% between 1977 and 1987. In 1997, there was a rise in the number of patients receiving IV fluids, but only 3 of the 12 patients who died in intensive care received artificial fluid intake during the final stage of illness.

The fact that more dying patients were given IV fluids in 1997 than in 1987 may suggest that palliative care is becoming more medicalized. The extent to which artificial fluid intake actually prolongs life and/or relieves the patient's suffering is a recurring ethical question (Printz, 1989; Sutcliffe and Holmes, 1994; Musgrave et al, 1995; Husebø, 1997). Dunlop and colleagues (1995) argue that the side-effects of dehydration such as hypercalcaemia ought to be treated and fluid replacement therapy should be given to promote patient comfort.

In these three studies, attempts at resuscitation were carried out on 5% in 1977, 3% in 1987 and 5% in 1997 of each of the patient groups. No-one was resuscitated in the intensive care ward and 9 of the 12 who died there had DNR (do not resuscitate) written on the bedside chart. Two patients were resuscitated in the reception area; one was transferred to intensive care, and the other patient died in the reception ward.

In 1977 it was not usual to write DNR on the patient's chart, while in 1987 this was only done in special situations. In 1997 it was accepted practice that the physician would decide whether or not resuscitation should be considered at an early stage following admission. As a result 78% of the patients and almost all cancer patients (93%) had DNR written on their charts. This finding is supported by Sulmasy et al (1992) who found that 91% of patients with malignancy had a DNR order.

According to the medical records the DNR applied to 11 of the 12 patients who died in the intensive care unit (ICU). During recent years, there has been a change in the use of DNR orders (Wenger et al, 1997). Fewer patients who die in ICUs now undergo attempts at cardiopulmonary resuscitation (CPR), and many

more have life support actively withdrawn prior to death (Jayes et al, 1993).

There is, however, a wide variation in end-of-life care (Prendergast et al, 1998), and at the hospital in this study, the DNR decision was rarely included in the patient's medical record. It was documented in 10 of the 100 patient records that the patients had expressed a wish not to be resuscitated — i.e. documented advance directives (ADs). Many studies show that most patients wish to be involved in decisions regarding CPR, and many wish to have some kind of AD (Kerridge et al, 1998). Studies show that a specific procedure for obtaining ADs is seldom used (Aarons and Beeching, 1991; Simpson, 1994; Voltz et al, 1998).

### Pain relief

Anxiety about death is often expressed in terms of fear of pain (Rui et al, 1982). In the 1977 study, nurses and physicians both showed more restraint in the use of opiates. It was frequently expressed in the nurses' reports that the patient was not to be made dependent on morphine. Such considerations were not expressed in the studies from 1987 and 1997.

In 1977 there was apparently little knowledge on how different drugs could be combined in order to achieve the desired effect. In the period up to 1987 there was a process of increasing awareness. The hospice philosophy focused on the relief of pain (Saunders, 1978; Breivik, 1979). In Norway conferences were held on death and dying, and pain management courses were developed. In 1984 the public report *Caring for the Seriously Ill and Dying* (NOU, 1984) was issued and advisory groups were established throughout Norway.

In 1984, an advisory group on death and dying was set up at the study hospital and focused on training its own employees. Even though the number of patients who died of cancer had decreased during the period between 1977 and 1987, the number receiving pain relief had increased. Pain-relieving treatment in the final phase of illness was given to 51% in 1977, 79% in 1987 and 84% in 1997 (Table 6).

The data obtained do not provide any details on the dosages of opiates administered, or the frequency of administration. The interviews with the nurses and the next-of-kin, confirm that patients dying in 1997 were very often given adequate pain relief in the final stages of illness, but in

*'According to Norwegian law medical staff have a duty to inform patients and their relatives about their prognoses, however, the doctor may decide if the patient is 'strong enough' to cope with a bad message.'*

certain instances pain relief could have been increased earlier. Both the next-of-kin, the nurses and the written reports suggest that pain medication could have been increased some days before death to relieve the patients' pain more effectively.

### **An open approach to death and dying**

In order to give holistic treatment and care, there must be contact, a sense of trust, and an openness about death and dying between patients, families and health professionals. The patient's right to be informed is stated in the Physician's Rights and Duties Act 1980; Ethical Guidelines for the Nursing Profession (Norwegian Nurses' Association, 1983); and *ICN Code for Nurses* (International Council of Nursing, 1973); and the dying person's bill of rights (Whitman and Lukes, 1975).

Patients are entitled to have access to their medical records. However, few patients exercise this right (Iversen and Iversen, 1988). Several studies show that 80–90% of the patients wish to be informed about their conditions, and this figure has remained stable over the last 40–50 years (Kelly and Friesen, 1950; Gilbertsen and Wagensteen, 1961; Cartwright, 1964; Rui et al, 1982; Meredith et al, 1996). In 1997 the next-of-kin reported that 49% of the patients were fully aware that death was approaching. This figure has remained relatively stable, i.e. 47% in 1977 and 46% in 1987.

In all three studies, approximately 70% of patients were assessed as being cognitively intact. However, during this 20-year period a decreasing number of relatives felt that they were fully aware — 78%, 69% and 59% in 1977, 1987 and 1997 respectively.

In all three studies, it was the doctor who informed the relatives in approximately half of the instances. In 1987, 10 relatives had received information from a nurse. In 1997, this number had decreased to four. Physicians, on the other hand, informed 10 more people in 1997 than in 1987. Thirty-five per cent of people realized by themselves that they were dying or had been informed by others; this figure remained constant throughout the entire study period.

While 33% of the next-of-kin in 1977 understood that the patient would die without being informed by medical staff, only 14% answered this way in 1997. A greater number of the relatives had answered that others had informed them of the patient's

prognosis. This was explained by the following quotations: 'I didn't wish to understand'; 'No-one said anything directly, I would have accepted that it was over'.

Health personnel agreed that the patient should be informed about his/her situation, but that it is far easier to communicate with the next-of-kin than speak to the individual patient. In 1987 and in 1997, health professionals were asked if the dying patient had spoken to them about the fact that they would shortly die. In both studies, 25% answered affirmatively. In 1977, 50% answered that the next-of-kin had not spoken to the patient about death. The corresponding numbers were 35% in 1987 and 39% in 1997. It appears as though a change may have taken place on the part of relatives between 1977 and 1987, but that there has not been an increase in openness by medical staff.

### **Reflections**

Nurses are the coordinators of the multidisciplinary team; they are responsible for 24-hour care and inform the different professions about the patients' special needs. Part of the nurse's role should involve acting as the patient's advocate and ombudsman if nurses are to assist patients and their supporters to achieve their wishes in the final stages of illness.


According to Norwegian law, medical staff have a duty to inform patients and their relatives about their prognoses, however, medical staff may decide if the patient is 'strong enough' to cope with a bad message. Experiences with the next-of-kin indicate that communication regarding death and dying could be improved.

When life-prolonging treatments are withdrawn or are not going to be commenced this must be documented in the medical records. The use of the DNR order has to be based on ethical considerations. The doctor responsible should be required to be up to date in palliative medicine and nurses should give qualified reports on the effects of different symptoms.

Relatives have been with the patient through different phases of the illness and together they have passed through periods of hope and hopelessness. In most cases the next-of-kin is the person who is able to give the dying patient most comfort. It can be hard to accept that the patient's death is unavoidable and it is important that members of the multidisciplinary team are available to give advice and palliation at any time.

## Conclusions

The findings from this comparative study show that openness with regard to communicating with the patient about his/her forthcoming death has not changed significantly during this 20-year period. The use of life-prolonging treatment such as antibiotics and parenteral fluid intake decreased from 1977 to 1987, and increased in 1997. The use of DNR orders on the chart changed from being very rarely used in 1977 to being used in 78% of medical records in 1997.

During this 20-year period, the patients have received improved pain relief (Table 6). The duration of hospital stay was greatly reduced over the study period. The patient's last admission to hospital is probably not always the right time to inform patients and relatives that death is impending. Conversations about death should take place in a local environment in the presence of family members, friends and primary health professions. 

*Thanks to the Norwegian Cancer Society for its financial support during this research; to the nurses and relatives who agreed to be interviewed about the patients' last days of life; to Gunnar Ljunggren for assisting with the computer programme for the Research Assessment Instrument; and also to Peter F Hjort for his advice on writing this research.*

- Ariès P (1975) *Essais sur l'Histoire de la Mort en Occident du Moyen Age a nos Jours*. Editions du Seuil, Paris
- Aarons EJ, Beeching NJ (1991) Survey of 'do not resuscitate' orders in a district general hospital. *Br Med J* 303(6816): 1504-6
- Breivik H (1979) Strong opiate analgesics in cancer pain. *Tidsskr Nor Lægeforen* 99: 946-8
- Cartwright A (1964) *Human Relation and Hospital Care*. Routhledge & Kegan Paul, London
- Dunlop RJ, Ellershaw JE, Baines MJ, Sykes N, Saunders CM (1995) On withholding nutrition and hydration in the terminally ill: has palliative medicine gone too far? A reply. *J Med Ethics* 21: 141-3
- Elgjo R (1974) Do we need a Norwegian St. Christopher's hospital? (In Norwegian) *Sykepleien* 61: 1030-2
- Fries B, Ljunggren G, Winblad B (1991) International comparison of long-term care: the need for resident-level classification. *J Am Geriatric Soc* 39: 10-6
- Gilbertsen VA, Wagensteen OH (1961) Should the doctor tell the patient that the disease is cancer? Surgeons' recommendation. In: *Symposium of the American Cancer Society: The Physician and the Total Care of the Cancer Patient*. American Cancer Society, New York: 80-5
- Husebø S (1997) Fluid for dying patients? (In Norwegian) *Omsorg Nord Tidsskr Palliative Med* 3: 26-30
- International Council of Nursing (1973) *ICN Code for Nurses*. ICN's board of directors in Mexico City, Mexico
- Iversen I, Iversen T (1988) Hvem benytter pasientjournalen? (Who uses patients' records?) *Sykepleien* 14: 8-10.
- Jayes RL, Zimmerman JE, Wagner DP, Draper EA, Knaus WA (1993) Do-not-resuscitate orders in

- intensive care units. Current practices and recent changes. *J Am Med Assoc* 270(18): 2213-7
- Kelly WD, Friesen SR (1950) Do cancer patients want to be told? *Surgery* 75: 98-101
- Kerridge IH, Pearson SA, Rolfe IE, Lowe M (1998) Decision making in CPR: attitudes of hospital patients and healthcare professionals. *Med J Aust* 169(3): 128-31
- Meredith C, Symonds P, Webster L et al (1996) Information needs of cancer patients in West Scotland: cross-sectional survey of patients' views. *Br Med J* 313(7059): 724-6
- Musgrave CF, Bartal N, Opstad J (1995) The sensation of thirst in dying patients receiving hydration. *J Pall Care* 11(4): 17-21
- Norges offentlige utredninger (NOU)(1984) *Pleie og Omsorg for Alvorlig Syke og Doende*. 84:30 (Norwegian official assessments. Caring for the seriously ill and dying). Offentlig dokumentasjon og informasjon i Norge (ODIN), Oslo
- NOU (1999) *Livshjelp: Behandling, pleie og omsorg for alvorlig syke og doende* 99:2 (Norwegian official assessments. Help to live: treatment and care for the seriously ill and dying), ODIN, Oslo
- Norwegian Nurses' Association (1983) *Yrkesetiske retningslinjer for sykepleiere* (The Norwegian Code for Nurses). Norsk Sykepleierforbund, Oslo
- Printz LA (1989) Withholding hydration in the terminally ill: is it valid? *Geriatric Med* 11(43): 84-8
- Prendergast TJ, Claessens MT, Luce JM (1998) A national survey of end-of-life care for critically ill patients. *Am J Respir Crit Care Med* 158(4): 1163-7
- Rieber-Mohn H (ed) (1968) *Den siste fiende. Fem betraktninger om døden* (The last enemy. Five reflections about death). Dreyer: Oslo
- Rui H, Bjornland K, Skipenes G, Haugen K, Purvis K (1982) Holdninger til døden og dødspleie i Norge (Attitudes towards death and terminal care in Norway). *Tidsskr Nor Lægeforen* 102: 1625-9
- Saunders C (ed) (1978) *The Management of Terminal Disease*. Edward Arnold, London
- Simpson SH (1994) A study into the uses and effects of do-not-resuscitate orders in the intensive care units of two teaching hospitals. *Intensive Crit Care Nurs* 10(1): 12-22
- Skjorshammer M (1970) *Døden i sykehuset*. (Death in hospital). Unpublished doctoral thesis, Institute of Psychology, University of Oslo
- Statistics Norway (Statistisk sentralbyrå) (1998) *Statistical Yearbook of Norway 1998*. Statistics Norway, Oslo/Kongsvinger
- Statistics Norway (Statistisk sentralbyrå) (1999) *Statistical Yearbook of Norway 1999*. Statistics Norway, Oslo/Kongsvinger
- Sulmasy DP, Geller G, Faden R, Levine DM (1992) The quality of mercy. Caring for patients with 'do not resuscitate' orders. *J Am Med Assoc* 267(5): 682-6
- Sutcliffe J, Holmes S (1994) Dehydration: burden or benefit to the dying patient? *J Adv Nurs* 19: 71-6
- Sørbye LW, Aarseth S, Husom O, Johansen J, Hjort PF, Skartseterhagen SA (1979) Nøkkelspørsmål i dødspleien: når er tiden inne? (The key question in terminal care: when is the right time?) *Tidsskr Nor Lægeforen* 99: 1300-6
- Sørbye LW (1992) Har omsorgen for døende pasienter endret seg? (Has the care of dying patients in hospitals changed?) *Tidsskr Nor Lægeforen* 112: 1264-7
- Voltz R, Ayakabashi S, Reese C, Ohi G, Sass HM (1998) End-of-life decisions and advance directives in palliative care: a cross-cultural survey of patients and healthcare professionals. *J Pain Symptom Manage* 16(3): 153-62
- Wenger NS, Pearson ML, Desmond KA, Kahn KL (1997) Changes over time in the use of do not resuscitate orders and the outcomes of patients receiving them. *Med Care* 35(4): 311-9
- Whitman HW, Lukes SJ (1975) Behaviour modification for terminally ill patients: the dying person's bill of rights. *Am J Nurs* 75: 98-101
- World Health Organization (1992) *International Statistical Classification of Diseases and Related Health Problems (ICD-10)*. 10th revision. World Health Organization, Geneva

## KEY WORDS

- Life-prolonging treatment
- Palliative treatments
- Information
- Pain relief
- Death and dying
- Relatives' views