

# Homecare at the End of Life

## *A Study of Fifteen Patients*

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**ABSTRACT.** The study is a part of a research project on death in a sector of a large city, involved cooperation with the Franciscan Aid "home care team". The purpose was to study death in the home setting. Fifteen deaths were registered. Participant observation in the care of 14 patients were made—a total of 83 visits to homes, 2–15 visits per patient. In one case the author had contact with the relatives, after the death had occurred. Most of the patients had cancer. Their age varied from 28 to 80 years. The observations were recorded immediately after each visit. After the death of a patient a structured interview with the closest relatives and the nurse responsible were made. Their statements were used as a basis for formulating problems for the further study and the clarification of quantitative data. Results showed that the patients who chose to leave the hospital and remain at home often had negative experiences in hospital. All the patients in this study received good palliative treatment at home. All patients were also informed about their condition. One-third of the patients were readmitted to hospital during the final days.

*Key words:* Terminal care, hospice philosophy, palliative care, home care.

### INTRODUCTION

In Norway, 75% of all deaths take place in institutions (NOU nr. 30 1984). A fundamental objective of all terminal care should be that the individual patient can him/herself choose where to die. As part of a research project on death in a sector of a large city (Sørbye 1988), death at home was studied subsequently.

In 1986 the home care service of Oslo did not have the capacity to give 24 hour care. The Deacon hospital however had their own home care team, but very few patients from 1986–87 chose to die at home. It appears that hospital staff do not encourage patients and their family to consider terminal care at home.

### RESEARCH PROBLEMS AND QUESTIONS

In the home care situation data were collected in an open dialogue. After reading the daily records in an attempt to obtain a total picture

of the patients' situation, several questions arose:

- Why did the patients choose to die at home?
- Why were they readmitted to the hospital after deciding upon palliative home care?
- How much help did the patients require from Franciscan Aid?
- Did patients accept the fact that death was unavoidable?—Did patients have existential concerns?
- Did death occur at the right time?
- Was it of important for the patients themselves to die at home?

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## METHOD

The study "Homecare at the end of life" was integrated as part of Franciscan Aid, a private humanitarian organisation, with their economical support provided by Oslo community. Its main purpose is to provide medical- and nursingcare for elderly and sick persons in their own home, on a 24 hour basis in addition to emergency telephone service. In cooperation with the Franciscan Aid's home care team participant observations in the care of terminal patients were made.

During a period of four months, 14 patients requested palliative care with support from Franciscan Aid. Five of these eventually died in the hospital. In addition, the researcher had contact with the relatives of a 15th patient who died at home.

Upon agreement from patient and family, an initial visit was made with a registered nurse from Franciscan Aid. Later the patient was visited by the observer alone (L.W.S.). On these occasions the patient often had an auxiliary nurse or an unskilled helper permanently in the house. As part of the participant observation method the researcher took part in the morning report meetings, and had continual contact with the Franciscan Aid's head nurses. After each visit the observer talks with both patient and relatives was reconstructed. A record form to note specific information was utilised. After the death of a patient, the nurse responsible for the patient was interviewed. The nurses evaluations were based on a structured question in the interview-guide, with defined variables (Sørbye 1988). The researcher subsequently contacted the patient's closest relatives about eight weeks after the death and requested permission to interview them personally. No families refused to be interviewed.

When processing the data, statements by patients, their relatives, and the responsible nurse were used as a basis for formulating problems for the study. The quantitative data gave some information; however qualitative data reflected a deeper knowledge of the dying patient's situation. In research, it is important to find and tell the truth. But how could the truth about the dying patient's experiences be tested? Testing the validity and reliability in qualitative research is difficult (Heap 1988, Kvale 1987).

Ethical and legal aspects in connection with the research were clarified before the project was started and the approval was obtained from the Committee on Research Ethics under the Norwegian Research Council for Science and the Humanities, the Data Inspectorate, the Directorate of Health and the head of each institution concerned.

## RESULTS

### *Demographical data*

The sample was of eight women and seven men. Thirteen had cancer, one had apoplexia cerebri, and one had AIDS. The patients' age ranged from 28 to 80 years, median age 70.

Eighty-three visits to patients' homes were made. These lasted from half an hour to two hours per visit. The number of visits varied from two to 15 per patient. The time from the first visit until patient's death varied from two days to ten months.

Nine patients out of 14 lived together with their spouse, three lived alone, and two lived with a son or daughter. Two-thirds of the patients had been ill for more than a year. The Franciscan Aids office kept a record for each patient, telling what amount of help they received. During the final days spent at home, four of the patients received help from the Franciscan Aid 24 hours a day, three for 12-20 hours a day, four for six hours or less per day, and two had only "supportive talks" with a nurse and help with palliative treatment. One patient died before care could be arranged. One patient received help from the hospital's visiting team in addition to help from the Franciscan Aid.

### *Why did the patients choose to die at home?*

All of the patients and/or their relatives reported negative experiences from the hospital. They mainly had *three reasons* for wanting to die at home. The amount in the following group was three, four and five. For three of the patients there as a combination of these main reasons.

1. *The patients felt that their integrity was threatened, they were not heard.* The patients found that they were not given a voice in deci-

sions. Others took decisions that affected them. The following are two examples:

A man, aged about 75, with cancer of the palate. His daughter said: "Father felt that his integrity was threatened in the hospital. He was never given a voice in decisions. He felt his situation to be degrading. He no longer had any private life. He felt that he was totally invaded by well-meaning self-appointed experts who wanted to arrange things on his behalf. Mother died at home two years ago, cared for by us and the Franciscan Aid. Father wanted the same. He was grateful to come home to his own sitting-room."

A woman, aged about 75, with apoplexia cerebri, failure of the adrenal cortex and ulcus duodeni. Her son said: "The doctors stopped giving her essential medicines. They intended to just let her lie there and die. They did not listen to us. We wanted to be responsible for mother's treatment and so we took her home."

2. *The patients did not want any more examinations and/or treatments.* In all cases the patients and the relatives had been told that nothing more could be done to prolong life. In spite of this fact the patients were subjected to tests, examinations, and encouraged to exercise.

A woman, aged about 65, with cancer mamma. Her husband said: "The nurses wanted her to exercise all the time. She was forced to take part in activities for which she didn't have the strength. They didn't understand just how ill she was. In the end she couldn't bear it any more. She died four days after coming home. The patient said that she was thankful that she had come home, was left in peace, and felt cared for. After the first two days at home she slid into coma."

A man, aged about 30, with AIDS. His mother said: "He had done an enormous amount of work and spent a lot of money on renovating his flat. The hospital had no medicines which could stop the course of the disease. The doctors just prescribed masses of tests and investigations. He wanted to spend his last days in his flat. He died hardly a week after coming home." For the first few days he carried out minor tasks in the flat and rested on the settee in the sitting-room. He was always surrounded by family and friends. He had a nurse in the flat all the time, to give him care.

A woman, aged about 80, with cancer abdominis. Her son said: "Mother was well prepared to die. She wanted no more examinations or treatment in hospital. She preferred to come home and die in peace. I was not well myself, and it took time to make the necessary arrangements in the flat. Mother was very ill when she finally came home. She lived only a few hours." This researcher had followed the patient during her last few days in hospital. She was prepared to die. She herself knew that it was almost too late to go home, but she was determined to manage it.

3. *The patients wanted to get away from other sick people, they wanted to "live" until they died.* Younger and older patients alike said that it was depressing to be surrounded by elderly, senile and frail patients. Furthermore, all the disturbances in the ward tired seriously ill patients.

A woman, aged about 55, with cancer mammae: "It was a shock when I realized that the doctors could not stop the disease from taking its course. I couldn't bear the thought of ending life in a hospital bed, surrounded by elderly, frail patients. I enjoyed living, and wanted to be surrounded by life until the end. I am grateful that the Franciscan Aid could help me." The patient had neurological symptoms, had motor and sensory disturbances, and sometimes had hallucinations and was confused. She was partly incontinent for urine and stools. She managed to eat without help for the first few weeks, as long as everything was made easy for her.

A woman, aged about 80, with cancer recti: "I have lived in this house all my adult life and it is natural for me to die here too. My family, can come and go. There is so much disturbance in the hospital. Some friends told us about the Franciscan Aid, otherwise it would have been too much of a burden for my husband." This patient did not have enough strength to look after herself. Except for help from the Franciscan Aid to carry out her morning toilet, she was cared for by her family.

A woman, aged about 50, with cancer mammae. Her daughter said: "Mother liked being at the Cancer Hospital and had good contact with the other patients. However when the Cancer Hospital had no more treatment to offer, she was moved to the Norwegian Lutheran Hospital. She was not happy there at

all. It was awful for her, who was so young, to see only old, frail patients around her. She wanted to come home, and the nurses contacted the Franciscan Aid." The patient depended on help for most things. She had an epidural and a bladder catheter. She had good periods when she was able both to give and receive care. In periods when she was under the influence of medication she was confused and suffered from hallucinations.

### *Why were five patients readmitted to hospital, in order to die there?*

The reasons given by relatives after patient deaths are individually.

#### *1. Acute deterioration*

A man, aged about 70, with cancer coli, stated that he and his wife knew perfectly well that he had only a short time to live. He was bedridden, but was continent for urine and had a colostomy. Except for help from the Franciscan Aid in the form of supportive talks and help to bathe him, he was cared for by his wife. He suddenly began to suffer from dysphagia, and could not drink. It was reassuring for his wife to have him readmitted to the hospital. He died one day later.

A woman, aged about 65, with cancer ovarii. The surgeon had told her after the operation that he could do no more. She went to the outpatient clinic for control examinations and was given cytostatics, but became steadily weaker. She managed her own toilet right up to the time of readmission. She was visited regularly by the Franciscan Aid. One day she suffered from acute stomach pain, and the head nurse from the Franciscan Aid arranged for her to be readmitted to hospital for examination. She died four days later.

#### *2. The relatives could not bear any more*

A woman, aged about 80, with cancer cervicis. She lived alone and became more and more frail. Towards the end of her illness she required help 24 hours a day. She was completely bedridden and incontinent for urine and stools, but had a fantastic will to live. The relatives had a long way to travel and were worn out. The patient was admitted to hospital to relieve them. She became worse and died three weeks after admission.

#### *3. It became more difficult to accept help at home*

A man, aged about 70, with cancer coli. The patient wanted to stay at home as long as he could care for himself. When he became totally dependent on help he would not accept support from the Franciscan Aid. When he discovered he was incapable of being the host in his own home, he preferred to be in hospital. He found it less humiliating to accept help there.

#### *4. Further examinations*

A woman, aged about 65, with cancer pancreatis. During the last few months of her illness she became very weak, but was able to manage her own toilet and to sit in a chair. She did not have the energy to read, watch television or listen to the radio or to music. She often said that her life provided little meaning. She was readmitted to hospital for examination. Results of the tests were apparently good, but it seemed as if she had lost the will to live. She was given fluids intravenously, and died one week after admission to hospital.

### *What type of help did the patients require from the Franciscan Aid?*

Most of the patients required palliative treatment when they were enrolled with the Franciscan Aid. Thirteen received morphine, combined anti-emetics and laxatives. One patient had an epidural catheter with a mixture of morphine and Marcain, another had a pain pump.

Twelve of the patients used the Franciscan Aid's private doctor, who visited them at home.

### *Was it possible to accept that death was unavoidable?*

Of 15 patients, two clearly stated that they accepted death. One patient was a convinced Christian and the other an atheist. The Christian radiated calmness and security, as she told of her Christian faith. The atheist appeared just as calm in his belief that death was the end of a person's existence. "We have our mission here in life", he said.

Several of the other patients said that it was difficult to accept death, irrespective of age or beliefs. A man, aged 30 stated "I know I am going to die, mother, but couldn't I have had just a few more years to live?" Woman, aged 55 said "Why must I die, why must I be sick?". Woman aged 80: "I think it would be a relief to the children if I died, but I would like to live a little longer."

### *Was the patient concerned about matters of religion and belief?*

The researcher did not take the initiative herself to talk about matters of faith and belief, but telling of her work opened the way for discussion of such matters. One patient who was an atheist said he believed that every person has a right to decide over his own life, and to end it if necessary. He himself tried to commit suicide, but was discovered before he succeeded. One patient had been in close contact with the Church as a child, but had become deeply disappointed by the Church's attitude towards homosexuals. Therefore during his last stay in hospital he sought help from the Human Ethical Association. Of those patients with Christian faith, three expressed a firm faith, and four alternated between doubt, belief and hope, often in step with fear.

### *Did death come at the right time?*

In nine of the 15 cases where death was expected the relatives stated that death had come at the right time, in four cases that it occurred too early, and in two cases that it occurred too late.

*Example of death occurring at the right time.* Wife: "We had had a rich life together. But it was dreadful at the end, he vomited so much blood. Half an hour before he died I cried to God: 'Now you must take him.' I was thankful that he was spared more suffering".

*Example that death came too early.* Wife: "It is always too early when a person you love dies."

*Example that death came too late.* Husband: "She did not deserve the final weeks. She was dependent on such large doses of morphine. She was unable to be happy at home."

### *The nurse's evaluation of the patient's discomfort in the terminal phase*

No patient was assessed as having little or much pain, but two as having moderate pain. One patient was assessed as having dyspnoea, and he was also in pain. One patient suffered from slight nausea, and one patient was assessed as having serious nausea. Three patients were assessed as slightly troubled by mucus/expectorate, while two were greatly troubled. Two patients were assessed as experiencing great/average fear and anxiety. One of them was also in pain and was troubled by mucus/expectorate. The other patient had no physical discomfort, but had not managed to accept her situation. One patient suffered from uremic cramps.

## DISCUSSION

Patients who are told that they have a serious disease often experience a crisis, with feelings of helplessness and impotence. (Cullberg 1976, Hoff 1984). Health services responsible for the treatment must help patients/families to cope, with the situation. Several patients and relatives in this study complained about poor follow-up. If the doctor himself does not have adequate time or opportunity to maintain contact including follow-up consultations with the patient, this responsibility must be delegated to another qualified person. Franciscan Aid found that only a very few of the patients had one particular doctor whom they could contact in case of emergency. Both patients and relatives said that professional and sympathetic contact was important.

The median age of the patients who chose to spend their last days at home was 70. Of those patients 87% had cancer. In 1986, 23% of all deaths in Oslo were from cancer (The Cancer Registry 1987). In this study it looks as though both the family and the various health services do a better job for this group of patients. Most cancer patients are able to manage for themselves fairly well right up to the end (Sørbye 1980). The care of a terminal cancer patient is limited in time. One-third of the patients in this study had known about their cancer for over a year. All had been told that life-prolonging treatment would not stop their disease. Therefore nothing was to be lost medically by being at home. McNulty says

that the answer to the question "Why home?", . . . "is that it is often the patient's choice, that hospital beds are needed for those who require active treatment and because of ward pressure are frequently inappropriate to the needs of the dying" (McNulty 1978).

Neither patients nor relatives said that the reason chosen to die at home was to release a bed in the hospital. However, there were many examples of hospital wards not being able to satisfy the needs of the dying. Relatives/patients considered it important to carry out tests, investigations and active life-prolonging treatment, but only as long as these activities were meaningful. Presently, it is accepted ethically to stop investigations and life-prolonging treatment in the case of dying patients (The American Medical Association 1986), however many experienced that they could obtain "peace" only by leaving the hospital. Several said that they wanted to be together with their family during their last days, and not with frail fellow patients.

The Franciscan Aid uses nurses for only 25% of the time spent caring for the patient (Paus 1987). This functions well as long as nothing unexpected happens. Both relatives, patients and helpers said that it was reassuring to know that they could call one of the head nurses at any time of day or night. None of the five who chose readmission to hospital had had help for more than six hours a day. "For 90% of that time the patients are enrolled with the Franciscan Aid, relatives manage to provide the care themselves . . . About one-third of the terminally ill patients visited by the Franciscan Aid are readmitted to hospital" (Paus 1987). In this material, one of the five who were readmitted to hospital had acute stomach pain and needed further investigation. In the other four cases, according to the researcher's assessment, there was no reason why they should not have died at home. In other cases the Franciscan Aid experienced that the patient was readmitted to hospital because the relatives were afraid of death, "entering their territory". Or the patients did not want to trouble the relatives by dying at home.

The Franciscan Aid staff was good at giving palliative treatment for the observed group. Only in one case did a nurse tell she felt medically inadequate. The patient had uremic cramps, and lay in bed for two days before

receiving effective palliative treatment. Here help should have come sooner.

Several associated the name Franciscan Aid with religion, and it was then natural for the patients to talk about faith and beliefs. It is difficult to assess to what extent religious belief gives a feeling of security before approaching death. Experience from a study of 280 dying persons (Sørbye 1980) showed that many of the dying were frightened and anxious. Religious persons are just as frightened of pain and suffering as persons who are not religious. It is hard to say goodbye to loved ones, irrespective of what one believes in. These experiences are supported by the work of Kübler-Ross (1969) and Feifel (1965).

Irrespective of age patients stated it was difficult to accept death. Particularly patients younger than 70 years said that death came too early, and they had many troubling thoughts. All parties were informed about what was to happen. This was in distinct contrast to death in a nursing home or hospital (Sørbye 1980, 1988).

Openness and closeness were shown to be the most important qualities when a person died at home. The family had an opportunity to give the dying person all the care they could. The dying maintained their identity. Four of the patients died in their own bed, placed in the sitting-room. This took care of their need for personal contact. All the patients had one of the family with them when they died, also those who were readmitted to hospital.

## CRITICAL COMMENTS

In the patient's home, the author found it difficult to separate her role of researcher from the role of nurse, especially since there was often no registered nurse present.

There are clear rules attached to a structured interview. The results must be presented in a form that allows control, verification and criticism (Hellevik 1980). In a research report, a structured interview form may be enclosed as an appendix, and the results presented in tables and figures. A structured interview form cannot have more alternative answers than the researcher has decided beforehand. From a phenomenological—hermeneutical angle, the more detailed the questions, the

more positive the approach, since it gives the researcher a wider and more detailed picture of the topic in question (cf. Kvale 1983). A qualitative interview produces a record of the informant's feelings, thoughts and experiences. In this case the researcher's own background of experience, sensitivity and empathy are decisive for what data are collected. There is a continual interaction between researcher and informant. Another researcher would probably have obtained different results. Does this make the results less true, less scientific? Qualitative researchers maintain that if their work has communicated new insight—new knowledge, then this is science, irrespective of whether the research is reproducible or not (Wadel 1971). It is important that validation be incorporated into the research process (Glaser & Strauss 1967, Kvale 1983). In order to increase validity different methods to collect my data were used (Heap 1988). When presenting the data the author has emphasised professional experience and commonsense, and the results have been considered in relation to the relevant literature.

## CONCLUSION

In this material most of the patients who chose to die at home had cancer. The decision to die at home was often taken after negative experiences in the hospital. Families carried out the greater part of the homecare, but it was essential that they could call on qualified help at any time. The patients received good palliative treatment, and said that they were met with openness and closeness. The patients and the relatives were grateful that the patient could be at home. The relatives did not consider it an admission of failure that one-third of the patients were readmitted just before they died.

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