

Original Article

How Do Cancer Patients Receiving Palliative Care at Home Die? A Descriptive Study

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Abstract

Context. Data regarding the circumstances of the process of death of terminally ill patients followed at home are lacking.

Objectives. The aim of this study was to describe the characteristics and assess the circumstances of the process of death of terminally ill patients followed at home.

Methods. This was a prospective survey to assess the dying process of advanced cancer patients followed at home. Within a week after death, the principal caregiver was interviewed. Information from the palliative home care team and the caregiver about expectation of death, time of death, professional and nonprofessional people present at time of death, emergency admission to hospital, and administration of drugs to resuscitate was gathered. The principal clinical issues in the last two hours also were recorded.

Results. In total, 181 of 222 caregivers provided information. Most deaths were expected. Palliative home care team physicians and nurses visited the patient on the day of death but were occasionally present at the moment of death. More than three people were generally present at time of death. More than two-thirds of patients died peacefully, without apparent suffering, and 35.7% of them received palliative sedation before dying. In the last two hours, the most frequent clinical issues were ranked as death rattle, dyspnea, and agitation. In 10 cases, emergency drugs for resuscitation were administered.

Conclusion. This study has shown how advanced cancer patients die at home and that palliative home care may be helpful in allowing a death at home, particularly when relatives are actively involved. *J Pain Symptom Manage*

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Key Words

Home palliative care, death, terminally ill patients

Introduction

The provision of palliative home care may enable an increase in the number of patients who die at home. Death at home appears to be desirable from the individual patient's viewpoint and is stated as a preference in public surveys.¹ The actual place of death results from a complex interrelationship of individual and environmental factors. A systematic review has shown that six factors were strongly associated with home death: patient's low functional status, their preferences, home care and its intensity, living with relatives, and extended family support.² Patient preference as to place of death, level of caregiver support and entitlement to private shift nursing were significantly associated with patients dying at home.³ However, the complex process of decision making about the place of death is often dynamic and contradictory,⁴ and involves the patient, the caregivers, and the professionals,⁵ as well as environmental factors including hospital or hospice facilities.²

In Italy, death at home was very frequent in early prospective studies, occurring in as many as 86% of deaths;⁶ multivariate analysis showed that a higher degree of family support was associated with home death. In a large multicenter study of palliative care units, mostly home care programs, 76% of patients died at home,⁷ which was the desired place in 90% of patients. From the historical perspective, it is notable that these studies were performed in a period when hospices in Italy were largely unavailable and palliative care services were based only on home care. About 25% of patients followed at home presented with severe symptom intensity, for which home care was practically impossible, suggesting that the best option would probably be the admission to an inpatient hospice.⁷

Regardless of the complexity of factors influencing the place of death of cancer patients, no study, to the best of our knowledge, has ever

assessed how cancer patients die at home from a clinical and environmental viewpoint. Previous articles have analyzed conceptual models of the quality of death and several domains have been identified to conceptualize the quality of death.^{8–11} However, these data were gathered from interviews of different people, including professionals, patients and relatives, but did not provide a description of what happens when a cancer patient dies at home.

In contrast to a more recent trend of more patients dying in hospital settings, palliative care might potentiate patients dying at home. Understanding how patients die also might assist in better informing family members regarding what to expect as the patient dies and in informing the medical community regarding the potential of palliative home care to meet the needs of dying patients and their families.

The Home Care—Italy (HOCAL) Group recently has been established with the intent to implement a system for obtaining information on cancer patients followed at home, given the paucity of existing data in this setting. The aim of this study was to describe the characteristics and assess the circumstances of the process of death of terminally ill patients followed at home, in relation to the type of home assistance, family, and professionals involved, and attitudes and reactions of relatives toward the imminent death, as well as the clinical manifestations of the process of death in the last hours of life.

Methods

A prospective survey was done in four palliative home care programs in different regions of Italy: Turin and Genova (Northern Italy), L'Aquila (Central Italy), and Catania (Southern Italy). Information about each home care program was gathered, including how many medical and nurse visits are usually performed during the care of a patient and family, and how many medical and nurse visits

were performed in the last two days of life of the dying patient. Palliative home care teams did not modify their activity and offered standardized assistance, without changing any protocol of intervention.

Consecutive patients admitted to palliative home care programs during a period of three months (January through March 2010) were surveyed and the principal caregiver was identified. Informed consent was obtained from relatives to interview and manage data. The principles outlined in the Declaration of Helsinki were followed. Demographic data were recorded, including age, gender, primary tumor, duration of assistance, people living with the patient, and socioeconomic status. Within a week after death, the principal caregiver, if he/she agreed, was interviewed regarding the following:

- Expectation of death (defined as unexpected, earlier than expected, expected in the last two days);
- Time of death (8 AM–2 PM, 2–8 PM, and 8 PM–8 AM).
- Days since the last medical visit;
- Days since the last nurse visit;
- Admission to hospital where the patient then died;
- Drugs administered on an emergency basis to resuscitate (steroids, fluids, inotropics, etc.), and the doses of these drugs;
- Who was present at time of death;
- Death in the presence of the general practitioner (GP);
- Death in the presence of the palliative home care physician;
- Death in the presence of other physicians;
- Death in the presence of the palliative home care nurse;
- Use of palliative sedation, defined as the use of sedative medication to relieve intolerable suffering in the last days of life;¹²
- Predefined issues in the last two hours were posed to the caregivers, including death rattle, dyspnea, agitation, tremor, convulsions, pain behavior, peaceful death (multiple choice, if any). Peaceful death was defined as a death free from avoidable distress and suffering for patients, families, and their caregivers,⁸ occurring without the previous signs, which were considered sources of suffering.

Statistical Analysis

Data were collected and analyzed by the SPSS Software 14.0 version (SPSS Inc., Chicago, IL). All continuous data are expressed as a mean \pm standard deviation of the mean. Statistical analysis of quantitative data, which included descriptive statistics, was performed for all the items. Frequency analysis was performed with Chi-squared and Fisher exact tests, as needed. The analysis of variables correlated to condition of death was performed by logistic and multiple regression analysis with the use of SPSS software for regression analysis.

Results

The four palliative home care programs provided a similar level of assistance, the visits ranging between two and three per week for physicians and three and seven per week for nurses, other than providing on call visits in case of need. The mean number of medical and nurse visits in the last two days of life was 1.6 (95% confidence interval [CI] 1.5–1.8) and 1.5 (95% CI 1.4–1.6), respectively.

In total, 222 patients were surveyed during the three months of the study; all consecutive patients were enrolled and 181 caregivers (81.5%) provided the information to complete the study. Of 41 caregivers who did not provide information, 19 were unavailable by phone and were lost to follow-up, three declined the invitation because of their suffering, and nine did not provide informed consent and refused to be interviewed without specifying the reason (Fig. 1). Half (11/22) of the caregivers of patients transported to hospital did not provide information (one of them also declined the invitation).

The mean duration of home care assistance was 44.4 days (95% CI 37–52). The characteristics of patients and family members are described in Table 1. The socioeconomic status was equally distributed among low, medium, and high levels. Time and modality of death, as well as people who were present at time of death, are presented in Table 2. Time of death was equally distributed between morning/afternoon and night hours. Most deaths were expected. More than three people were generally present at time of death.

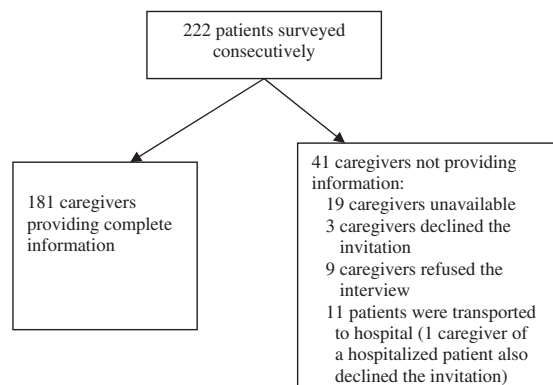


Fig. 1. Flowchart showing compliance with the survey and response rate.

In 10 cases, emergency drugs for resuscitation were administered. In 60 of 181 cases, palliative sedation was provided in the last two days of life. Admission to hospitals in the last hours was infrequent (Table 2). Of 22 patients who died in hospital/hospice, only 11 were available for analysis. Of interest, they lived alone or with only one family member (no spouse or son). Only one patient was sedated before dying with death rattle. Four patients had a peaceful death. Two, two, one, and one patients presented with dyspnea, death rattle, agitation, and convulsions, respectively, before dying.

Palliative home care physicians and nurses visited the patient on the day of death but were only occasionally present at the moment of death. Although GPs were never present at

Table 1
Characteristics of Patients Surveyed ($n = 222$) and Their Relatives

Characteristic	n (%) ^a
Patients surveyed	222
Age (years), mean (95% CI)	73.8 (72–75)
Gender (male)	144 (64.9)
Primary diagnosis	
Lung	56 (24)
Breast	44 (19.8)
Urogenital	42 (18.9)
Gastrointestinal	40 (18)
Head & neck	12 (5.4)
Others	28
Duration of home care assistance (days), mean (95% CI)	44.4 (37–52)
People living with the patients, mean (95% CI)	1.7 (1.6–1.9)
Socioeconomic status	
Low	43 (19.4)
Medium	154 (69.4)
High	25 (11.2)

^aUnless otherwise noted.

Table 2
Days Since the Last Visit of the PHC Team, Professionals Present at Time of Death, and Principal Issues Before Death

Parameter	n (%)
Days since the last PHC physician visit, (95% CI)	0.7 (0.6–0.9)
Days since the last PHC nurse visit, (95% CI)	0.8 (0.6–0.9)
Death in the presence of the GP	0.0
Death in the presence of PHC physician	7 (3.9)
Death in the presence of other physicians	15 (8.3)
Death in the presence of PHC nurse	4 (2.2)
Drugs administered to resuscitate	10 (5.5)
Terminal sedation	60 (33.3)
Admission to hospital at time of death	
Hospital	15 (6.7)
Hospice	7 (3.1)
Principal issues in the last two hours	
Death rattle	29 (16.0)
Dyspnea	11 (6.0)
Agitation	11 (6.0)
Tremor	2 (1.2)
Convulsions	1 (0.6)
Pain behavior	1 (0.6)
Peaceful death	126 (69.6)

PHC = palliative home care; GP = general practitioner.

time of death, other physicians, namely friends or relatives, were more frequently present.

More than two-thirds of patients died peacefully, without apparent suffering, and 45 of 126 (35.7%) of them received palliative sedation before dying. Peaceful death was not more frequent in patients who were sedated ($P = 0.432$). In the last two hours, the most frequent clinical issues were, in rank order: death rattle, dyspnea, and agitation (Table 2).

Regression analysis of variables related to peaceful death showed that this outcome was not correlated to the number of relatives or friends present at the time of death, nor to other variables like gender, socioeconomic status, and sedation. Those who died a peaceful death received more medical home visits ($P = 0.001$), had a lesser number of days/hours since the last medical visit ($P = 0.004$), and died more frequently at home than in hospital ($P < 0.0005$).

Discussion

Large studies have demonstrated the high prevalence of pain and other symptoms in the last days of life, the frequent use of life-sustaining interventions at the end of life, and the high proportion of deaths that occur

in hospital.⁸ Home has been regarded as the favorite place to die. According to caregivers' opinions, home is the preferred place of death for 93.5% of patients.¹³ The philosophy of palliative care encourages home death, providing for most of the needs of the caregivers. The expanding role of palliative care, particularly at home, may reduce the number of deaths in inappropriate places, for example, in medical or surgical units where experience with problems that arise when death is imminent is limited.¹ However, the actual place of death results from a complex interrelationship of individual and environmental factors.² In contrast to northern European countries, Italian caregivers are mostly relatives, rather than friends or neighbors. As a consequence, cultural and social attitudes, deficiencies in the health care facilities, or family structure may strongly influence the place of death in a country like Italy.^{13,14} In a recent national follow-back survey representative of the Italian population, 51% of patients died at home, meaning that many patients were admitted to acute wards unfit to provide end-of-life care.¹³

This is the first study reporting the circumstances of the process of death in patients followed at home. Data were based on reports of home care physicians and interviews with the patients' principal caregivers after their death. This approach has been validated as a reliable research method,¹⁵ although some authors consider that answers tend to overestimate positively the process of dying.¹⁶ This observation has been corroborated by the findings of this study.

This study has shown that palliative home care can provide help for those dealing with a death at home, although the extent of this should be better determined by studies that compare this setting with how similar patients die in other settings. Patients who were followed more intensively in the last hours of life were more likely to have a peaceful death and to die at home. In most cases, patients were not living alone, were assisted by more people, and at the time of death, were surrounded by a large component of their family, despite the observation that half of the deaths occurred during the night. Of interest, the few patients who were moved to a hospital before dying were living alone or with a private nonprofessional caregiver,

underlying the important role of a lack of family members.

These findings confirm previous epidemiological observations but with more striking features. Patients followed at home were more likely to die at home (45%), compared with patients followed by conventional hospital care (10%). Death at home has been reported to be associated with living together with someone.¹⁷ This finding confirms that a Mediterranean family context may be an important resource, providing a favorable environment for palliative home care and facilitating a peaceful death at home. Patients were seen in the last hours of life by palliative home care nurses and physicians, and death was almost always expected by relatives. This can explain why only in a minority of cases were patients admitted to hospital or received emergency drugs, possibly because of good communication and reassurance provided by the palliative home care team, regardless of availability of hospice or hospital beds. The high response rate provided by caregivers, higher than 80%, also suggests that a close relationship was maintained with the palliative home care team after the death of their loved one. The caregiver to be interviewed was contacted within a week of the patient's death, limiting recall bias, and the response rate was very high. The professionals who proposed the interview were the home care physicians, and this could have influenced the response in some way.

Of interest, at the time of death, other physicians, namely relatives or friends, were more frequently present in comparison with palliative home care physicians or GPs. These data could be interpreted as a need for intimacy, efficacy of reassurance during the last visits of the palliative home care team, awareness of the imminent death, the limited role of GPs in terminal care, or unavailability.

Finally, the goal of palliative care at the end of life, that is, a peaceful death, was achieved in about 70% of patients. This term was used to define a process without apparent suffering for patients and family members. Quality of dying and death also has been defined as a personal evaluation of the dying experience as a whole, including a subjective evaluation of the patients' expectations and values.¹⁸ However, this would have implied that patients had to be involved

early in the study, and this was not considered feasible because in the Mediterranean culture, patients dislike talking about their death when they are severely ill, and an intervention would have compromised this kind of study. Timing for the interview was chosen to obtain the best information before the memory of the patient's dying would fade.

The findings of this study could be reasonably attributed to a good level of terminal care in the last days of life. About one-third of patients received palliative sedation before dying, but the percentage of peaceful death was not strictly related to this intervention. These figures appear more relevant in comparison with previous experiences. About 12%–25% of patients have been reported to be sedated before dying,^{7,19} although defined criteria and information about the intensity of palliative home care activity were lacking. The relatively higher percentage of sedation at home may reflect the quality and the strength of the palliative home care teams selected for this study compared with conventional care.

The most frequent signs in the last two hours of life were death rattle, dyspnea, and agitation. In this study, we tried to select specific objective circumstances, very easy to measure, rather than rating subjective symptoms, a task that would have limited the interpretation of measures by relatives of the dying patients.

Conceptual models of the quality of death have been recently proposed. Several domains, including physical, psychological, social, spiritual, and existential experiences, the nature of health care, life closure and death preparation, and circumstances of death, have been identified to conceptualize the quality of death.^{8–10} Several factors were considered important at the end of life by patients, families, physicians, and other care providers and were different among these categories of persons.¹¹ However, the aim of this study was first to provide information in a descriptive form about how patients die and what happens in these circumstances at home when patients are followed by a palliative home care team, rather than collecting opinions regarding the quality of death, which depends on too many factors, or confirm constructs obtained by questionnaires. For these reasons, we have chosen realistic and reasonable items, easy to be interpreted by

a caregiver, given that it was expected that the palliative home care team would not have been present in most cases. These terms were clearly realized, as confirmed by the high response rate. Thus, these simple data can be helpful in preparing future studies, based on real circumstances rather than conceptual issues. Also, the definition of successful death could be questioned. However, this term was easily recognized by relatives and corresponded to definitions previously provided.⁸ We were unable to find similar information regarding how patients die and the circumstances of dying at home in the literature. The only data available were those gathered from some very old studies performed in a hospice setting, just assessing signs and symptoms rather than the circumstances of dying. In an early study performed in a hospice home care program examining the last two days of life, 91.5% of patients were reported to die peacefully.²⁰ In a hospice setting, dying patients were prospectively investigated to assess the changes of physical signs and medical interventions in terminally ill patients whose death was presumed to be imminent. Death rattle preceded the occurrence of respiration with mandibular movement and peripheral cyanosis, which appeared in the last five to seven hours. Authors also evaluated the level of consciousness, observing that the ratio of awake, drowsy, and comatose patients was 8, 42, and 50, respectively, in the final six hours.²¹

Two nonrandomized studies have compared the quality of the care received at the end of life. As expected, relatives of patients who died at home monitored by specialized groups gave a better assessment of the circumstances of death irrespective of their sociodemographic characteristics, the symptom control, or the therapeutic measures used. In one study, the good-death score in the home-death group was significantly higher than that in the hospital-death group.²² In another study, there was no indication that dying in an institution or at home involves major differences and quality of dying.²³ Both studies, however, did not analyze the real circumstances of death, which was the main aim of this observational study.

Study limitations include the descriptive nature of the study and a lack of comparison group, for example, hospital or hospice setting

or patients dying at home without palliative home care, to truly determine whether palliative home care is optimal.

Of relevance for future studies, assessment of caregivers, for example, the impact of having their loved one dying at home on caregiver well-being (e.g., bereavement and financial distress), could add further information. Also, the instruments and some dichotomous outcomes were chosen to help caregivers provide simple answers to simple questions, without adding further burden for the caregiver.²⁴ The aim of this study was to assess the last hours of life of patients who died at home from a clinical and environmental perspective. As how people die remains in the memories of those who live on,²⁵ the experience of death should be regarded as fundamental for managing end-of-life care. Although complex studies of end of life are difficult to perform because of objective limitations from an ethical point of view, a good level of palliative home care and an appropriate familiar environment may allow the achievement of an optimal outcome.

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