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## **Brief Report**

# Emergencies in Patients With Advanced Cancer Followed at Home

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## Abstract

**Context.** Patients with advanced cancer stay at home for most of their time, and acute problems may occur during home care. Caregivers may call medical services for an emergency, which can result in patients being admitted to the hospital. No data exist on emergencies in patients followed by a home care team.

**Objectives.** The aim of this multicenter prospective study was to assess the frequency, reasons for, and subsequent course of emergency calls for patients followed at home by a palliative care team.

**Methods.** A consecutive sample of patients admitted to home care programs was surveyed for a period of seven months. Epidemiological data, and characteristics of emergency calls and outcomes, as well as environmental situations were recorded.

**Results.** Six hundred eighty-nine patients were surveyed; 118 patients (17.1% of the total number of patients surveyed) made one emergency call, 23 made two calls, and four made three calls for a total number of 176 emergency calls. The mean age was 71 years (standard deviation [SD] 13), and the mean Karnofsky status the day before the emergency call was 38 (SD 14). The mean time from admission to the first emergency call was 38.4 days (SD 67), and the mean time from the first emergency call to death was 17.5 days (SD 41.5). No differences were found for age, diagnosis, gender, duration of assistance, and survival between patients making emergency calls and those who did not make a call during an emergency. Twenty-three patients were managed by phone, and 122 were visited at home for the emergency. Calls were prevalently recorded on weekdays and were primarily made by relatives. The most frequent reasons for calling were dyspnea, pain, delirium, and loss of consciousness. Calls were considered justified by home care physicians in most cases. The mean number of relatives present during the

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0885-3924/\$ - see front matter http://dx.doi.org/10.1016/j.jpainsymman.2011.07.016 emergency home visit was 2.2 (SD 1.5). The intervention was mainly pharmacological and considered satisfactory in the majority of cases.

**Conclusion.** Emergency calls are relatively frequent in patients followed at home by a palliative care team. Phone consultation or intervention at home may avoid inappropriate hospital admission. J Pain Symptom Manage 2012;44:295–300. © 2012 U.S. Cancer Pain Relief Committee. Published by Elsevier Inc. All rights reserved.

#### Key Words

Home care, palliative care, emergency medical care, palliative care emergency

## Introduction

Patients with advanced cancer stay at home for most of their time. This is the preferred place of care, although this does not always correspond to the preferred place of care at the time of death.<sup>1</sup> Other than clinical need, admission to hospital or staying at home during this period depends on many different factors, including resource availability and personal preference.<sup>2</sup>

Acute problems during the final stage of a patient's life may occur in the home setting. Caregivers may call for emergency medical services, which can result in patients being admitted to hospital. Palliative care medical emergencies as a consequence of advanced cancer account for approximately 3% of all emergency medical service calls.<sup>3</sup> In the outof-hospital or emergency room arenas, no ideal palliative care models exist. For example, in the out-of-hospital setting, less than 6% of emergency medical systems have protocols in palliative care.<sup>4</sup> The treatment of palliative care patients can be a particular challenge for emergency physicians. No educational content exists concerning palliative medicine in emergency medicine curricula (except in a few European countries), and most emergency clinicians provide primary palliative care by routinely using their best clinical judgment and experience.

Palliative home care has been found to be effective in reducing the use of hospital care during the last three months of life, <sup>5,6</sup> and emergency calls may be more likely to occur if the patient is not being attended by a home palliative care team. In a retrospective interview with bereaved relatives, the majority of emergencies calls, frequently resulting in hospital admission,

were made before patients had been enrolled to receive palliative care.<sup>7</sup> To avoid emergency situations and hospitalizations, support and responsibility should be shared with the palliative care team.<sup>3</sup> Ideally, the response to an emergency call should be managed by a team that knows the clinical situation and understands the typical home palliative care setting.

Treating symptom crises in the home is a key component of palliative care, but this practice has never been assessed. To the best of our knowledge, no epidemiological or clinical study exists regarding the frequency and the type of emergency calls and their outcomes in patients followed by a home palliative care team.

The Home Care Italy Group has been recently established with the intent to derive this information from cancer patients followed at home, given the paucity of existing data in this setting. The aim of this multicenter prospective study was to assess the frequency and reasons, and the subsequent course of emergency calls made by or for patients followed at home by a palliative care team.

#### Methods

A prospective study was performed by three home care programs in Italy. A consecutive sample of patients admitted to home care programs in Turin (FARO), L' Aquila (L' Aquila per la vita), and Catania (SAMO) was surveyed for a period of seven months. Informed consent and institutional approval were obtained. Any call because of an emerging problem that occurred at a time other than that associated with a regular scheduled appointment was considered. Number and time (morning 7AM-2PM, evening 2-8PM, night 8PM-7AM) of emergency calls were collected, as well as the reasons and the subsequent general management, either by a home visit or telephone advice. The choice was discretional and based on the knowledge of the case. Patient data were collected, including age, sex, diagnosis, Karnofsky status the day before the emergency call, the number of relatives present at the time of the emergency, days since enrollment in home care, survival since the intervention was made, whether the medical intervention was justified, the kind of intervention performed at home, and the outcome. Further interventions at home were recorded. The intervention was subjectively considered as satisfactory or not by the home care team. A satisfactory intervention was considered as the resolution of the clinical or environmental situation for which the emergency call was made. A specific sheet was designed to collect the data.

#### Statistical Analysis

Data were analyzed using SPSS Software 14.0 version (SPSS, Inc., Chicago, IL). All continuous data are expressed as a mean  $\pm$  standard deviation (SD) of the mean. Statistical analysis of quantitative data, included descriptive statistics, was performed for all the items. Frequency analysis was performed with the Chi-squared test and the Fisher exact test, as appropriate. All *P*-values were two-sided and *P*-values less than 0.05 were considered statistically significant.

## Results

Six hundred eighty-nine patients from the three home care programs were surveyed. In total, emergency phone calls were made for 145 patients during the seven-month period. For some patients, more than one call was made. One hundred eighteen (17.1% of the total number of patients surveyed) made one call, 23 made two calls, and four made three calls during the period of home care assistance, for a total number of 176 emergency calls. Characteristics of the patients are described in Table 1.

Primary cancer diagnoses were as follows: lung 41 patients, gastrointestinal 27, genitourinary 15, head and neck 15, liver 10, breast 10, pancreas 8, leukemia 9, and other 10. No

Table 1Demographic Characteristics of PatientsFollowed at Home Who Made Emergency Calls(n = 145)

| Characteristic                           | Mean (SD)   |
|--|-------------|
| Age, years                               | 71 (13)     |
| Gender (male), n                         | 70          |
| Karnofsky status                         | 38 (14)     |
| Admission to emergency call time, days   | 38.4(67)    |
| First emergency call time to death, days | 17.5 (41.5) |

differences were found for age, diagnosis, gender, duration of assistance, and survival between those who made emergency calls and patients who did not make phone calls during an emergency.

Calls were made at varying times throughout the day (7AM-2PM, n=92; 2-8PM, n=46; 8PM-7AM, n=7); 116, 19, and 10 calls were logged in on weekdays, holiday evenings, and holidays, respectively. Calls were made by relatives, home care nurses, or others in 111, 24, and 10 cases, respectively.

Reasons for the first emergency call are listed in Table 2. In the cases available, the causes were clinical (n = 96), pharmacological (n = 11, adverse effects of drugs), and environmental (n = 3). Calls were considered justified by home care physicians in 109 cases, and unjustified in seven cases (information is unavailable for the remaining cases).

Twenty-three patients were managed by phone, and 122 were visited at home for the emergency. The mean number of relatives present during the emergency home visit was 2.2 (SD 1.5). In the cases available, the intervention was pharmacological (n = 100), invasive procedures (n = 1), psychological (n = 5), other (n = 6), and unavailable (n = 6). The intervention was considered satisfactory in 97 cases and

 Table 2

 Reasons for the First Emergency Call

| Reason                | <u>n</u> |
|-----------------------|----------|
| Dyspnea               | 20       |
| Pain                  | 15       |
| Delirium              | 13       |
| Loss of consciousness | 10       |
| Hemorrhage            | 9        |
| Pulmonary edema       | 8        |
| Family decompensation | 4        |
| Convulsions           | 2        |
| Other                 | 37       |
| Total                 | 118      |

unsatisfactory in 12 (data were unavailable for the remaining cases).

In 23 cases, there was a second emergency call during home care (delirium n = 2, dyspnea n = 1, pain n = 5, loss of consciousness n = 5, and family decompensation n = 2 [data for other calls were not available]). The intervention was pharmacological in 14 patients, psychological in four, "other" in three, and no data were available for two patients. Twelve interventions were considered satisfactory and three were not (data were unavailable for the other cases).

Finally, for four patients, there was a third emergency call: two for delirium, one for dyspnea, and one for pain. These calls required pharmacological interventions. The intervention was considered satisfactory in three cases (one was unavailable).

## Discussion

Palliative medical emergencies resulting from the exacerbation of symptoms frequently may occur in patients with advanced cancer. Acute exacerbations of medical symptoms in palliative care patients living at home often result in emergency medical services being alerted.

This is the first prospective survey of emergencies in cancer patients followed at home. The frequency of the first call was 17.1% of 689 patients followed in three home care programs in Italy. The first emergency call occurred about 38 days after admission to the home care program.

Calls were less frequently made during the night or over the weekend. This means that emergencies may occur at any time and are not linked to hours when fewer visits at home are expected. As an alternate explanation, fewer calls may have occurred at nights and on weekends because the home care team made appropriate recommendations for potential problems in advance of these times.

In a minority of situations, an emergency call was managed by phone, providing reassurance and advice. This is more likely to be possible if potential emergencies can be anticipated in selected patients. It is good to inform the patient and the caregivers of what might be happening and what they can do in an emergency situation. It is also important to discuss end-of-life issues and what is possible in case of an emergency.<sup>7</sup>

As expected, the phone call was made in most cases by relatives, and in a minority of cases, by team nurses visiting the patient at home, possibly diagnosing a new problem requiring medical advice or a visit. The most frequent reasons for calls were uncontrolled symptoms or new situations to be managed pharmacologically or the occurrence of adverse effects of drugs. However, family distress and environmental situations may have evoked phone calls in some situations, underlining the complexity of home care, which also includes the resolution of frequent family decompensation. Changes in symptom intensity (e.g., pain or dyspnea) or new emergent situations (pulmonary edema, convulsions, loss of consciousness, hemorrhage, delirium) require an urgent intervention. In most cases, the intervention was pharmacological, although in some cases a psychological intervention for the patient and for the family was necessary. The treatment performed at home was considered satisfactory in most cases. However, this was only a subjective judgment by members of the home care team, and could be influenced by the relationship with the patient/ family, and as such, is devoid of external validity.

During the course of home care, multiple calls may be made on behalf of some patients. Of interest, family decompensation was relatively more frequent as the reason for a second call.

Data from the literature about emergencies in patients followed by a home care team are practically nonexistent. Many articles deal with the activities of emergency teams at home or in emergency departments, rather than patients calling the members of their own home palliative care team. Indeed, visits to the emergency department can be expected to increase in the next decade as the population ages.<sup>8</sup> Palliative medical emergencies and end-of-life decisions resulting from the exacerbation of cancer account for approximately 3% of all out-of-hospital emergency room visits in Germany.<sup>9</sup> In the treatment of emergencies in palliative care, there are potentially serious conflicts that may result from different therapeutic concepts the of

palliative medical care and emergency medical services.<sup>10</sup> Most emergency physicians feel uncertain treating palliative care patients. Advanced training in palliative care medicine and end-of-life care should be integrated into emergency medical training.<sup>3,4,8,11</sup> It has been reported that patients seem to favor continuity of care and admission to an oncology ward directly.<sup>12</sup> As an alternative, a team of hospice nurse specialists, acting at the request of a well-recognized emergency system, can provide a concrete and useful response to problems of unwanted hospitalization in acute emergencies for home-based terminally ill patients.<sup>13</sup>

This study has some limitations, inherent to home care studies. A very simple data set was chosen to facilitate data collection (some of which were missed) to provide preliminary information. The findings of this survey should be implemented in subsequent large studies. Also, no specific protocol was used, leaving the decision to visit the patient at home on an emergency basis up to the physician, who knew the environment and the clinical problems to be faced at home. Specific symptoms and known family situations previously assessed as major problems should be considered as risk factors for an emergency phone call in future studies, although many situations remain unpredictable. Moreover, the lack of a control group of conventional care may limit the findings of this study. However, it was not considered feasible to assign patients with advanced cancer to imprecise conventional care in the last weeks of life, as it would not be as effective as palliative care.<sup>14</sup> Finally, the intervention was considered satisfactory by home care team as a subjective judgment of the resolution of the cause of the emergency call. This judgment may be influenced by the relationship of team members with relatives and patients and/or grateful behavior. Thus, the potential efficacy of the intervention should be considered with caution.

In order for a terminal cancer patient to find the remainder of his life fulfilling, the role of home care is important. Home palliative care may prevent admissions to the hospital or emergency rooms, which are often unfit for this kind of patient, as the personnel there has no palliative care experience and is unaware of the patient's history and trajectory

of disease.<sup>15</sup> This could potentially produce inappropriate admissions to the intensive care unit, where patients may be resuscitated despite orders to the contrary, and when palliative care may offer the best option. In a prospective study analyzing the profile of cancer patients admitted to an emergency department, the main reasons were the unavailability of beds in specialized cancer units and limited home care because of poor hospitalcommunity coordination and lack of social and psychological assistance. Chronically ill patients nearing the end-of-life report improved satisfaction with palliative care and demonstrate less acute care use, resulting in lower costs of care. In addition, patients enrolled in palliative care programs were more likely to die at home than comparison group patients.16 Moreover, emergency teams do not always adapt their treatment to the will or supposed will of the patient. The reasons for this usually concern legal uncertainties and unknown advance directives.<sup>3,8,10</sup> In Italy, it is unusual to provide advance directives. Of interest, there is a risk that any advance directive may not be taken into consideration according to a new law, which is being discussed and examined in the Italian Parliament.

## Conclusion

Emergency calls for patients admitted to home care are relatively frequent and occur independently of the hours when fewer visits at home are expected. Phone calls are made in most cases by relatives. The most frequent reasons for an emergency call were uncontrolled symptoms and, in a minority of cases, family distress. Patients followed at home by a palliative care team may avoid unwanted hospitalization, possibly resulting in cost savings. However, the efficacy of interventions at home should be better evaluated with specific tools, as the present data may be influenced by the environmental situation, a subjective interpretation, or a simplistic evaluation on a yes or no basis.

Further research needs to be carried out in this area to determine how best care may be achieved, taking into account local resources and the changes in practice that have resulted from continuing treatment much longer into the course of the disease. The organization of health care services has to take into account patient preferences to balance efficiency and patient satisfaction. Training in palliative care may need to be extended to groups other than the oncologists.<sup>12</sup> Whereas in some European countries, palliative care training is mandatory for medical students and in other disciplines, this is not the case in Italy at the moment. Overall, more clinical investigations concerning end-of-life care and unresponsive palliative care patients in emergency medical situations are necessary.

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