

## Dying with Advanced Dementia in Long-Term Care Geriatric Institutions: A Retrospective Study

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### Abstract

**Objective:** The aim of this study is to describe the last month of life of severely demented elders in long-term care institutions, and the clinical decisions in the management of their end-of-life events.

**Design:** Retrospective exploratory study.

**Setting:** Seven Italian long-term care institutions with more than 200 beds.

**Participants:** One hundred forty-one patients with advanced (FAST stage = 7c) dementia (Alzheimer disease, vascular, other kinds of dementia, severe cognitive impairment).

**Measurement:** Diagnosis, Mini-Mental State Examination, cause of death. Data were collected from clinical and nursing records referring to the last 30 days of life: symptoms and signs, intensity and incidence, treatments (antibiotics, analgesics, anxiolytics, antidepressants, artificial nutrition/hydration, and use of restraints); the last 48 hours: cardiopulmonary resuscitation attempts and life-sustaining drugs.

**Results:** Patients were given antibiotics (71.6%), anxiolytics (37.1%), and antidepressants (7.8%). Twenty-nine patients (20.5%) were tube- or percutaneous endoscopic gastrostomy (PEG)-fed. Most patients (66.6%) were also parenterally hydrated (72 intravenously, 15 by hypodermoclysis). Some form of physical restraint was used for 58.2% (bed-rails and other immobilizers). Almost half of the patients had pressure sores. In general, attention to physical suffering was fairly good, but during the last 48 hours a number of interventions could be considered inappropriate for these patients: tube feeding (20.5%), intravenous hydration (66.6%), antibiotics (71.6%), and life-sustaining drugs (34.0%).

**Conclusions:** Some indicators imply a less than optimal quality of care (restraints, pressure sores, psychoactive drugs, and the lack of documentation of shared decision-making) and suggest that far advanced demented patients are not fully perceived as "terminal."

### Introduction

**D**EMENTIA is a long and highly debilitating illness. Its duration cannot be estimated and is still much debated, with reports of average survival ranging from 3 to 16 years.<sup>1</sup> During the illness, the patient experiences a progressive loss of autonomy and capacity, up to complete dependence and cognitive impairment. This process is gradual and its progression depends on the type of dementia, age, comorbidity, treatments, quality of care, and social networks.<sup>2</sup> In advanced stages patients frequently have to be admitted to long-term care geriatric institutions and nursing homes,

where they spend the last part of their lives<sup>3</sup> and where they are expected to receive palliative and end-of-life care. Their average age is generally more than 80 years. The prevalence of severe dementia in nursing homes may be as high as 80%.<sup>3,4</sup>

Advanced dementia is unquestionably a terminal disease, but in nursing homes and long-term care institutions this is seldom acknowledged by doctors and health professionals.<sup>4,5</sup> Patients are rarely referred to palliative care services and hospices, and are often exposed to aggressive treatments.<sup>6</sup> The literature highlights important differences not only between countries, but even between institutions and

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settings in the same country,<sup>4,7-9</sup> and suggests that major educational interventions are needed for the professionals involved in the care of patients with advanced dementia.<sup>5,10,11</sup>

In Italy the epidemiology of dementia is similar to other developed countries.<sup>12</sup> Its incidence is rising: after 2020, 213,000 new cases per year are predicted, more than 40% more than in 2000.<sup>13</sup> Although no information is available on the usual place of care and death, it is likely that given the scarcity of comprehensive home care services in Italy, the majority of demented elderly are admitted to long-care institutions, known as *Residenza Sanitaria Assistenziale* (RSA) or Health and Welfare Dwellings, set up by the Italian Ministry of Health in 1989 for people with physical, mental, and sensory disabilities, and aged persons who are not self-sufficient and/or have no family support but have no acute illness that requires hospital treatment.

RSAs are a mix of nursing home and geriatric hospital with their own staff of physicians, mostly geriatricians. These residential establishments differ widely in their numbers of inpatients, the services offered (i.e., occupational therapy, special units for patients with Alzheimer disease, day care admission), and quality of care, but very few provide palliative care consultation. Information on RSAs is scarce and mostly anecdotal, and virtually nothing is known about what treatments are provided for severely demented patients near death.

This retrospective study was therefore conducted in seven large RSAs in northern Italy, with the following aims:

1. To describe the last month of life of severely demented people ( $\geq$  Fast 7c) according to the clinical and nursing records and, in particular, the use of artificial nutrition and hydration (ANH); and
2. To describe the management of their end-of-life events.

## Methods

We conducted a retrospective exploratory study on patients who had died in the previous 12 months in seven large RSAs with more than 200 beds in the province of Cremona (Regione Lombardia, northern Italy). Four specially trained nurses not employed by the RSAs in the survey screened all the clinical and nursing records and identified eligible patients. At least two nurses concurrently analyzed all the records: problems and discrepancies were discussed on site, interviewing the doctors and nurses who had cared for the patient. All patients with a documented diagnosis of severe cognitive impairment (Alzheimer disease, vascular dementia, and other kinds of dementia), admitted more than 1 month before death and who died between March 1, 2004 and February 28, 2005 were selected. A FAST stage  $\geq$  7c was considered "severe."<sup>14</sup>

The FAST scale, a test of functioning tailored for Alzheimer disease, consists of 7 major stages with a total of 16 progressive substages from 1 to 7f. Stage 7 indicates the most advanced dementia and is divided as follows: 7a, speech limited to 1–5 words; 7b, loss of all intelligible vocabulary; 7c, no walking; 7d, unable to sit independently; 7e, unable to smile; 7f, unable to hold head up. Patients not already classified with the FAST scale were assigned the appropriate FAST stage by the investigators, on the basis of the information on clinical records.

The following data were collected from clinical records, referring to:

1. The last 30 days of life: concomitant diseases, symptoms and signs and their intensity (severe or not severe, according to information reported on clinical records) and incidence (present only one week or more), pressure ulcer, treatments (antibiotics; analgesics—WHO pain ladder,<sup>15</sup> anxiolytics, antidepressants, artificial nutrition and hydration, surgical procedures, use of restraints, and transfer to acute care).
2. The last 48 hours: cardiopulmonary resuscitation (CPR) attempts (tracheal intubation, tube/mask artificial ventilation, cardiac massage, electric cardioversion) and life-sustaining intravenous drugs (cardiokinetics, sympathomimetics, antiarrhythmics, high-dose intravenous steroids).

The existence of living wills and the documented involvement of the family in end-of-life decisions was recorded. Confidentiality was guaranteed by providing to the researcher only coded information. All the necessary authorizations were obtained and the protocol was presented and discussed before the study with the persons responsible in the RSAs. The data collection form was pilot-tested on five cases.

## Results

The clinical records were clear and fairly informative, although the cause of death was not recorded for 27 patients (19.1%).

The seven RSAs had a total of 1958 occupied beds (median, 280; range, 200–325), and five had special care units for patients with Alzheimer disease. The number of patients admitted in the year ranged from 33 to 156 (median, 98). The ratio of full-time equivalents per bed ranged from 0.41 to 0.60 for nurses' aids, and from 0.1 to 0.24 for doctors and nurses. The regional standard sets a minimum of 901 minutes of care per bed per week (including physicians, health professionals, and other personnel).

Of 476 deaths, 141 (29.6%; 95% confidence interval [CI] 25.5%–33.9%) were eligible for the survey (diagnosis of dementia and stage FAST 7c). The number in each RSA ranged from 4.6% to 8.8% (median, 7.3%). The patients' main characteristics and concomitant illnesses are presented in Table 1. As expected, the mean age is high and females outnumber men. All patients were cared for in the RSA until death.

During the month before death, 124 patients (88%) experienced severe symptoms (Table 2). Due to the problems that can arise in the advanced stages of dementia (inhalation of food, bed rest, incontinence with catheterization, and lung and urinary tract infections) fever is an expected, widespread event. Nearly half the patients suffered dyspnea, but only 26% for more than 1 week (data not shown).

The most frequently reported symptom in clinical records was drowsiness (27 patients). Drowsiness, rattles, hypotension, and dyspnea were often recorded together during the last days of life and are to be interpreted as premortem signs. The number of patients with seizures was unexpectedly low.

Pain was never measured with a specific scale. When present, it was only recorded, mostly by the nurses, in clinical

TABLE 1. MAIN CHARACTERISTICS OF THE ONE HUNDRED FORTY-ONE PATIENTS

	No.	%
Gender M	33	23%
F	108	76%
Age (mean)	86 (SD 7.7, range 59 to 103)	
Length of stay (years)	4 (SD 4.2, range < 1 to 23)	
FAST stage		
7c	71	50
7d	43	30
≥7e	27	19
Cause of death		
Cardiopulmonary failure	51	36
Cardiopulmonary arrest	22	15
Other organ failure	20	14
Infection	7	5
Cancer	4	2
Others	10	7
Not specified	27	19
Concomitant illnesses		
Cardiovascular illnesses <sup>a</sup>	38	26
Musculoskeletal illnesses/osteoporosis	36	25
Infection (lung and UTI)	32	22
Respiratory failure	27	19
Other organs failure <sup>b</sup>	24	17
Diabetes	22	15
Cerebrovascular illnesses	20	14
Heart failure	19	13
Cancer	13	9
Senile cachexia	11	7
Epilepsy	5	3
Others	26	18

<sup>a</sup>Atrial fibrillation, hypertension, ischemic vasculopathy.

<sup>b</sup>Liver, kidney, thyroid.

records, and was usually described as mild or severe. Pain was recorded in 1 of 4 patients, and in 23 cases it was described as severe, and occurring more than once per week. The majority of patients with pain were prescribed analgesics (28/37; 75.6%; analgesics were administered to 8 patients for

whom pain was not reported). Overall, 19 were treated with strong opioids: 11 regularly (step 3 of the WHO pain ladder); 7 as needed; and 1 not known. One patient was treated with weak opioids regularly (step 2 of the WHO pain ladder); the others received as-needed analgesics (nonopioids

TABLE 2. SYMPTOMS REPORTED THE MONTH BEFORE DEATH

Symptoms and signs	Severe symptoms			
	no.	%	no.	%
Fever	91	64	58	41
Dyspnea	56	39	20	14
Bed sores	67	47	36	25
Pain	37	26	23	16
Emesis	37	26	14	9
Edema	34	24	15	10
Restlessness	29	20	14	9
Drowsiness	27	19	13	9
Premortem signs and symptoms <sup>a</sup>	24	17	10	7
Bleeding	21	14	2	1
Seizures	3	2	1	0
Choking	1	0.7	1	0.7
Others	62	44	22	15

<sup>a</sup>Hypotension, drowsiness, rattles, dyspnea.

TABLE 3. USE OF RESTRAINTS

	No.	% <sup>a</sup>	% <sup>b</sup>
Any restraint	82	58	
Bed rails	73	51	89
Abdominal restraints	13	9	69
Upper limb restraints	4	2	25
Lower limb restraints	2	1	—
Other restraints	8	5	50
	2 immobilizing belt		
	4 arm-chair table		
	2 splints		

<sup>a</sup>% of 141 patients.

<sup>b</sup>% of the patients always restrained with the specific restraint.

and/or weak opioids). The use of strong opioids varied greatly among the RSAs: from 0% to 37% of the patients who received analgesics.

In the last 30 days of life 101 patients (71.6%) were given antibiotics (85% had fever or urinary tract infection); 53 (37.1%) were prescribed anxiolytics (27 on a regular basis, the others on an as-needed basis), and 11 antidepressants (7.8%); 20 (37.7%) patients who were administered anxiolytics suffered restlessness.

Overall, 29 patients (21%) were artificially fed: 25 through a nasogastric tube and 4 from a percutaneous endoscopic gastrostomy (PEG), often associated with parenteral hydration. Artificial nutrition varied within RSAs from no patient to 8 artificially fed. Most patients (94/141; 66.6%) were also hydrated (72 intravenously, 15 by hypodermoclysis; 7 not known).

Admissions to hospital were rare (only 2 patients, for surgical problems).

Some form of physical restraint was used for most patients (82, 58.2%): 73 had bed-rails (65 on a permanent basis,) and 26 had other immobilizers (ankle/wrist immobilizers, immobilizer belt, safety vest, immobilizer belt with braces, etc.; Table 3). Of the 82 restrained patients, 38 (46%) were also sedated.

Shortly before death, some form of emergency intervention and/or diagnostics were implemented in 60 cases (42.5%; Table 4), including four CPRs.

The degree of medical "interventionism" varied among RSAs: except for oxygen therapy, some emergency intervention was attempted for 0%–53.9% of patients who ultimately died.

The involvement of the family in decisions related to patients' care was only rarely noted in the clinical record (16, 11.3%); this might include discussion about admission to the hospital or the decision to reinsert a nasogastric tube. No advanced directives were recorded because living wills are not yet legal in Italy.

## Discussion

This study describes the last month of life of severely demented patients living in RSAs. The sample is representative of the RSAs of the area surveyed; because of different regional rules, the organization and services provided to patients may vary from region to region.

Concomitant illnesses are similar to those reported by other studies.<sup>16,17</sup> Symptoms such as fatigue and drowsiness,

normally common in this type of population, were specified only in a limited number of clinical records, presumably because they are considered usual clinical features of the illness, therefore "normal" and expected. This may explain the differences from the study by Brandt et al.,<sup>16</sup> in which the most frequent problems were generalized weaknesses, respiratory problems or dyspnea, and somnolence and fever, and were related to food or fluids inhalation

The prevalence of seizures was lower than the 10%–22% reported by Mendez and Lim.<sup>18</sup> A possible explanation is that the observation time was only the last month, not the whole duration of the disease, or that this symptom might have been underreported or gone unrecognized.

Almost half of the patients had pressure sores in the month before death, a high rate compared to figures reported for nursing homes residents in Holland,<sup>16</sup> for patients who died in Italian hospitals (27% had sores and 8.4% severe sores),<sup>19</sup> and for terminal demented patients (35%).<sup>20</sup>

In general adequate attention was paid to physical suffering, as evidenced by the fairly widespread use of analgesics, especially opioids, in patients likely to be suffering pain, although there was wide variability among RSAs.

Bed-rails were used for more than half the patients on a permanent basis. The use of other forms of restraints (abdominal or limb restraints) was much less frequent (< 8%). Limb restraints were used for patients receiving intravenous therapy or with a nasogastric tube. Twenty-seven percent of patients were both restrained and given anxiolytics which in some cases could serve as chemical restraints even at low doses. Physical and chemical restraints could be indicators of ineffective management of pain or other distressing symptoms, which demented persons mostly express by restlessness.<sup>21, 22</sup>

We cannot say how many times relatives were actually involved in end-of-life decision making, but in any case, only rarely was the involvement recorded: documentation of these nonclinical aspects of care, with such profound ethical and legal implications, should be encouraged. Relatives have their own opinions on end-of-life decisions, and discussions should be encouraged and documented in clinical records.

A philosophy of care of severe demented persons more oriented to "aggressive" than palliative treatment is confirmed not only by the use of life-sustaining intravenous drugs, CPR, and some diagnostics but also by other findings. In particular, the number of tube-fed patients, even if lower than in other studies,<sup>11,23–25</sup> was still high, because tube feeding is considered ineffective in these patients and is often associated with negative outcomes.<sup>3,9,12,26</sup>

TABLE 4. EMERGENCY INTERVENTIONS WITHIN FORTY-EIGHT HOURS BEFORE DEATH

Intervention	No.	%
O <sub>2</sub> therapy	42	29
Life-sustaining drugs	34	24
Bronchial suctioning	11	7
ECG	25	17
Blood analysis	5	3
Cardiopulmonary resuscitation	2	2
Other	3	2

ECG, electrocardiogram.

The use of systemic antibiotics (more than 70% of patients) was also much more widespread than in other studies on severely demented end-of-life patients,<sup>17</sup> thus suggesting inappropriate administration/prescription<sup>27,28</sup> more than for symptom control. Also the use of anxiolytics and antidepressants is hard to justify in these severe patients.

Even if in some cases intravenous hydration was used for intravenous drugs, hypodermoclysis, generally considered a less bothersome way to provide water,<sup>29</sup> was adopted only in approximately 15% of artificially hydrated patients.

Oxygen therapy by facial or nasal mask was remarkably widely used. Oxygen has been considered a “palliative” treatment,<sup>17</sup> but might well be futile or even “aggressive” when applied without documented hypoxia, since it can easily cause oxygen overload and unwanted effects, even worsening the dyspnea.<sup>30</sup>

It is not easy to determine the inappropriateness of some interventions, because they depend on many factors: health care system, health care providers, relatives’ wishes, lack of advanced directives, and cultural attitudes. As the study was carried out in the last month of life and there is no consensus on the definition of terminality in far-advanced dementia, it is likely that some vital decisions (tube feeding, antibiotics, etc.) were taken long before this time. Moreover, the reasons for certain decisions are only rarely reported in clinical records.

A determination of appropriateness of care would require information on the time and reasons for prescriptions, treatments such as artificial feeding or drugs, and on the expected prognosis of the patient. Nevertheless, some findings, as the unacceptably high prevalence of bedsores, calls for prompt corrective measures.

The wide variety of attitudes toward tube feeding and strong opioids among RSAs and the lack of instruments for evaluating pain and/or distress show the different treatment philosophies and a shared lack of systematic assessment of patients’ needs.

The data tend to confirm the “aggressive” treatment of demented patients, that severe dementia patients are not considered terminal, and reports from other countries.<sup>4,6,17,31</sup> The fact that dementia itself is never mentioned as cause of death implies that, unlike cancer or cardiac failure,<sup>32,33</sup> it is not considered an illness that causes death. This may partly explain why palliative care philosophy is not regularly adopted in the majority of patients, and an “active” treatment prevails. In general, “cardiac arrest” was reported as cause of death, confounding the last event of life with the process that actually started and led to death. This stresses the need, particularly for demented patients, for a careful medical culture sensitive to the problems of dying people, thus able to discriminate between the various the events concerning death.

The hindrances to any moves toward a palliative care culture cannot be blamed solely on physicians: decisions about withholding life-sustaining treatments, nutrition, and hydration are difficult in a setting in which cognitive impairment is combined with the total absence of any kind of advanced directives.

### Study Limits

The findings of the study are limited to severely demented patients; the aims and philosophy of care for less severe pa-

tients may be different. The retrospective nature of the study does not allow us to fully understand clinical decision-making. A further prospective study aimed at describing decisions (to start, not start, or withdraw a treatment) perceived as relevant for the survival and quality of life of demented patients, and the reasons behind them, is now in progress, to describe complex choices and to help disentangle the weight and role of clinical, cultural, and environmental influences.

### Conclusions

Even if there are some signs of improvement in the direction of more palliation in the care of demented people, much remains to be done in RSAs, which are in the frontline in the care of elderly people. In spite of the limitations of a retrospective design, indicators of less than optimal quality of care are still visible such as restraints, pressure sores, use of psychoactive drugs, and the lack of documentation of shared decision-making. These findings suggest that end-of-life demented patients are not perceived as “terminal,” and do not always receive appropriate palliative care. This will further imply that, if “nonpalliative” treatment prevails and severe cases are treated as hospitalized patients, RSAs will be more and more similar to hospitals and this will require redesigning the organization and standards of personnel, thus unaffordably—and uselessly—increasing the costs of care, without necessarily improving either survival or quality of life.

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The study protocol was formulated independently by the investigators. As the study did not interfere with living persons, and is entirely funded by a nonprofit foundation, its approval by ethics committees is not mandatory in Italy. However, it was submitted to, and approved by, an independent ethics committee, the *Comitato per l’Etica di Fine Vita* (Floriani Foundation of Milan), which can be considered *super partes*.

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