The last week of life of nursing home residents with advanced dementia: a retrospective study

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Abstract
Background: Barriers to palliative care still exist in long term care settings for older people, thus persons with advanced dementia may not receive adequate palliative care in the last days of their life; instead, they may be exposed to aggressive and/or inappropriate treatments. This study aimed to evaluate the clinical interventions and care at end of life in a cohort of Nursing Home (NH) residents with advanced dementia in a large Italian region (Lombardy Region). Methods: Retrospective study in a convenience sample of 29 NHs. Data were collected from the clinical records of 482 residents with advanced dementia, who had resided in the NH for at least 6 months before death, mainly focusing on the last week of life. Results: Most residents (97.1%) died in the NH. In the seven days before death, 20% were fed and hydrated by mouth, and 13.4% were tube fed. A median of five, often inappropriate, drugs were prescribed. The acknowledgement of worsening condition in clinical records was recorded for 57% of residents, a median of four days before death.
Conclusions: Full implementation of palliative care was not achieved possibly due to the insufficient acknowledgement of the appropriateness of some drugs and interventions, and health professionals’ lack of implementation of end-of-life palliative care decisions. Future studies should focus on how to improve care for NH residents.

Introduction
Dementia is an incurable condition that causes a progressive decay. This decline is characterized by co-morbidities, increased severity of physical and cognitive disabilities, acute conditions typical of frailty, the worsening of chronic co-morbidities, and dementia-related events such as recurrence of infections and eating problems, all of which require specific palliative care strategies. People with dementia can survive for years and are usually cared for in residential facilities, in particular in nursing homes (NHs), that provide many or all of the long-term care services they need until their death. Thus, for most of their residents, NHs should provide palliative care. However, barriers to palliative care still exist in long term care settings for older people, which can mean that people with advanced dementia may not receive adequate palliative care in the last days of their life; instead they may be exposed to aggressive and/or inappropriate treatments. Barriers
to palliative care include lack of communication with family members who are not ready to accept their relative dying;\(^1\) high staff turnover (especially nurses);\(^8\) limited number of nurses\(^9\) together lack of competence of qualified and nursing personnel in palliative care.\(^{10-11}\) Important differences among countries do exist,\(^12\) and they may also exist among institutions within the same country.\(^13\) Italian NHs differ widely in the number of beds they have, the services they offer, and their quality of care, but very few provide palliative care consultations.\(^6,14\)

**Methods**

**Aim.** The aim of this multicenter study was to assess the clinical interventions and care at end of life in a cohort of NH residents with advanced dementia.

**Study setting**

We used data from the Valuazione dell’Efficacia della Leniterapia nell’Alzheimer e Demenze (VELA Project),\(^{15}\) which was conducted in collaboration with the Fondazione Italiana Leniterapia of Florence and the Lino Maestroni Palliative Medicine Research Foundation of Cremona. The aim of the VELA Project was to compare end-of-life care procedures provided to NH residents with advanced dementia in the Lombardy Region, and in the surrounding areas of Florence in the Tuscany Region, before and after a short educational intervention to improve palliative care. Due to regional differences in the organization of NHs and in the services provided to NH residents with dementia, here we present only data from the Lombardy Region.

In the Lombardy Region, accredited NHs have their own medical and nursing staff with a regulatory requirement ratio of \(\geq 901\) minutes/week of care per resident;\(^{16}\) these NHs may be defined as “skilled NHs”. With few exceptions, there is at least one nurse with a bachelor’s degree available per shift. NHs in the region may also rely on consultants (geriatricians, neurologists, physiatrists, etc.) and may employ psychologists, occupational therapists, physiotherapists, or other specialists. Out of a network of 34 NHs in the Lombardy Region that participated in a previous study,\(^{14}\) 29 agreed to participate in the present study (number of beds per NH ranged from 40 to 714). To be included in the analysis, NH residents had to have a Functional Assessment Staging Tool (FAST) stage \(\geq 7c\) (double incontinence;
loss of all intelligible vocabulary; non-ambulatory)\textsuperscript{17} and have resided in the NH for at least 6 months before death.

The study was approved by the ethics committee of Don Carlo Gnocchi Foundation of Milano on February 20, 2013; it started on April 1, 2013 and concluded on January 31, 2015. In this paper we describe the last 60 days of life, with a special focus on the last 7 days of life in the entire cohort (pre and post educational intervention) of NH residents. Due to the limited impact of the educational intervention\textsuperscript{15}, the two cohorts were merged.

**Data collection**

Trained monitors collected data from clinical records, nursing records, and drug data sheets on up to 20 residents in each of the 29 participating NHs. This information included demographic characteristics, major comorbidities, and cause of death, as well as presence of the following: a comprehensive evaluation of the severity of clinical conditions, advance care planning, a legal representative (guardian), do not resuscitate (DNR) and do not hospitalize (DNH) orders, NH resident's wishes about treatment and funeral dispositions, and any other advance directive. Specific information was also collected on nutrition and hydration in the 60 and 7 days before death, as well as on dialysis, symptoms, tests and interventions administered such as endotracheal suctioning, hospitalizations and admissions to the emergency department, assessment of pain and discomfort, drugs prescribed (classified according to the Anatomical Therapeutic Chemical code),\textsuperscript{18} and palliative sedation in the 7 days before death. Nutrition and hydration were classified by a panel of experts (palliative care, geriatrics, nursing, psychology, family medicine, and bioethics) as palliative-oriented nutrition if nutrition and/or hydration were given by mouth only, if nutrition by mouth was accompanied by comfort hydration (i.e. the administration of <1000 ml of fluids/day by subcutaneous hydration), if only subcutaneous hydration was used, or if no nutrition or hydration was provided at all.\textsuperscript{15} Comfort hydration was seen as a compromise between the advisability to reduce water intake to improve comfort and reduce symptoms, and family members' expectations and beliefs about hydration.\textsuperscript{19} Nutrition and hydration were classified as non-palliative-oriented nutrition if given by
parenteral route, via nasogastric tube, or via percutaneous endoscopic gastrostomy at any point during the 7 days before death.\textsuperscript{15} The drug prescribed in the last week of life were collected from drug sheets. NH residents with missing or not updated drug sheets and those who were admitted to hospital or the emergency department in the 7 days before death were excluded from the analyses on drugs prescribed.

**Statistical analyses**

For categorical variables data are shown as absolute and relative (%) frequencies with 95% confidence intervals (CIs). Mean and standard deviation or median and interquartile range (IQR), as appropriate, were calculated for continuous variables. All analyses were performed with Stata 14, StataCorp. 2015. Stata Statistical Software: Release 14. College Station, TX: StataCorp LP

**Results**

A cohort of 482 NH residents was recruited, 26.8\% of whom had Alzheimer-type dementia. Overall, half of the residents had between five and eight comorbidities (median 6), and 25\% had more than eight comorbidities (Table 1).

Table 1. Main characteristics of the 482 nursing home (NH) residents with advanced dementia (Functional Assessment Staging Tool stage $\geq 7c$)
| Variable                        | n   | %    | 95% CI† (%)    |
|--------------------------------|-----|------|----------------|
| **Sex Female**                 |     |      |                |
| Female                         | 365 | 75.7 | 71.9;79.5      |
| **Age at NH admission, years, median (IQR†): 84.1 (79-88.7)** |     |      |                |
| Diagnosis of dementia          |     |      |                |
| Alzheimer                       | 129 | 26.8 | 22.8;30.7      |
| Not defined                     | 175 | 36.3 | 32.0;40.6      |
| Vascular                       | 138 | 28.6 | 24.6;32.7      |
| Mixed                           | 33  | 6.8  | 4.6;9.1        |
| Levis’ body                     | 7   | 1.5  | 0.4;2.5        |
| **Comorbidities**              |     |      |                |
| Genitourinary                   | 435 | 90.2 | 87.6;92.9      |
| Musculoskeletal                 | 409 | 84.9 | 81.6;88.0      |
| Gastrointestinal tract          | 135 | 28.0 | 24.0;32.0      |
| Peripheral and central nervous system | 314 | 65.1 | 60.9;69.4      |
| Hypertension                    | 238 | 49.4 | 44.9;53.8      |
| Cardiovascular                  | 237 | 49.2 | 44.7;53.6      |
| Head and neck                   | 207 | 42.9 | 38.5;47.4      |
| Vascular                        | 195 | 40.5 | 36.1;44.8      |
| Respiratory                     | 100 | 20.7 | 17.2;24.4      |
| Endocrine-metabolic             | 135 | 28.0 | 24.0;32.0      |
| Kidney                          | 55  | 11.4 | 8.6;14.2       |
| Liver                           | 30  | 6.2  | 4.1;8.4        |
| Others*                         | 18  | 3.7  | 2.0;5.4        |

*Others: other cancers (15); anemia (2); pressure sores (1)

†CI: confidence interval; IQR: interquartile range.

Almost all residents (468, 97.1%) died in the NHs (median age at death: 89 years, IQR 83.6-93.1), 69 (14.7%) of them had a family member present during the last hours of life (this information was available for 358 residents). Cause of death was available for 374 (77.6%) NH residents, 96 (25.7%) of whom had dementia reported as the cause of death. Only one NH resident had a self-written advanced directive (AD); in 19 (3.9%) cases, a family member reported the NH resident’s wishes, and 60 (12.4%) residents had guardian. In six (1.2%) cases, the family reported the resident’s preference
for cremation.

In the 60 days before death, 378 (78.4%) NH residents were fed only by mouth; 43 (8.9%) were fed by mouth and intravenous or subcutaneous integration; and 43 (8.9%) were tube fed; data where missing for the remaining 18 residents. During the 60 days before death, a new feeding tube was placed in 26 NH residents (of the 63 with a feeding tube in the 7 days before death, 37 had already had it at 60 days).

**7 days before death**

A substantial worsening of clinical conditions (sometimes defined as “terminal conditions”) was recorded in the clinical records a median of 4 days (IQR 2-11) before death for 275 (57.1%) NH residents, and the notification of impending death was recorded a median of 1 day before death (IQR 0-3) for 150 (31.1%). Advance care planning was drawn up for only 21 NH residents (4.4%) (median 15 days before death; IQR 5-41). Two (0.4%) NH residents had a DNR, seven had a DNH (1.5%), and one NH resident had both.

Two hundred and nine residents’ clinical records included a registration of discussions with families on the worsening of residents’ conditions, which took place a median of 3 (IQR 1-7) days before death. Eighty-six of these records also reported a discussion with the family of decisions to be made, which took place a median of 6 (IQR 2-20) days before death.

Table 2 shows data about nutrition and hydration, after the exclusion of 13 NH residents with missing information; we observed palliative-oriented nutrition in 130 (27.7%) residents.

| Table 2. Nutrition and hydration in the 7 days before death |
|-------------------------------------------------------------|
| **n** (n=469)* | **%** | **95% CI† (%)** |
|----------------|-------|-----------------|
| IV† hydration (alone or supplement) | 227 | 48.4 | 43.9;52.9 |
| Nutrition/hydration by mouth only | 94 | 20.0 | 16.4;23.7 |
| SFA† only (or SFA+ mouth) | 70 | 14.9 | 11.7;18.1 |
| Tube feeding | 63 | 13.4 | 10.3;16.5 |
| Parenteral Nutrition | 15 | 3.2 | 1.6;4.8 |
| Comfort hydration (IV and SFA) | 99/455 | 21.8 | 18.0;25.5 |

†CI: confidence interval; IV: intravenous; SFA: subcutaneous fluids administration.
* 13 residents with missing information on nutrition and hydration

Overall, 101 NH residents (21%) received at least one invasive treatment or intervention in the 7 days before death (Table 3).

Table 3. Invasive treatments/interventions in the 7 days before death

| Treatment                                                                 | n   | %    | 95% CI          |
|--------------------------------------------------------------------------|-----|------|-----------------|
| Oral/tracheal suctioning                                                 | 101 | 21.0 | 17.3;24.6       |
| Blood collection                                                         | 73  | 15.1 | 11.9;18.3       |
| Peripheral vein cannulation (one or more attempts)                       | 53  | 11.0 | 8.2;13.8        |
| Insertion/repositioning of urinary catheter                              | 30  | 6.2  | 4.1;8.4         |
| Insertion/repositioning of a nasogastric tube (2 PEGs†)                  | 11  | 2.3  | 0.9;3.6         |
| Insertion of a central venous catheter                                   | 3   | 0.6  | 0.0;1.3         |
| Other invasive treatments*                                               | 6   | 1.2  | 0.2;2.2         |

* Other treatments (residents could be exposed to more than one treatment): Enema (2); Glycaemia measurement (2); Hemogasanalysis (1); Flu vaccine (1)
†CI: confidence interval; PEG: percutaneous endoscopic gastrostomy.

In the 7 days before death, nine residents were sent to the emergency department and then discharged, while 14 were admitted to hospital (2.9%). Pain and/or discomfort were assessed for 192 (39.8%) residents. In 13 (2.7%) cases, palliative pharmacological sedation was provided; 70 residents (14.5%) underwent resuscitation attempts, 62 of which were performed by NH staff: five as cardiopulmonary resuscitation, and 66 with life-saving drugs.

Data on drugs prescribed were available for 316 (65.6%) NH residents, with a median of five (IQR 3-7) drugs; 22.2% NH residents had two or less (Table 4).

Table 4. Prescriptions in the 7 days before death classified according to the Anatomical Therapeutic Chemical (ATC) code.17
| Category                                          | ATC code     | n  | %    | 95% CI† (%) |
|--------------------------------------------------|--------------|----|------|-------------|
| Anticoagulants - Antiplatelets                    | B01A         | 166| 52.5 | 47.0;58.0   |
| Drugs for acid related disorders                 | A02          | 153| 48.4 | 42.9;53.9   |
| Cardiovascular System                             | C            |    |      |             |
| Cardiac therapy                                  | C01A, C01D  | 130| 41.1 | 35.7;46.6   |
| Beta blocking agents                             | C07          | 31 | 9.8  | 6.5;13.1    |
| Anti-arrhythmic class I-III                      | C01B         | 8  | 2.5  | 0.8;4.2     |
| Antibiotics (antibacterial/antimycotics)          | J01;J02     | 107| 33.9 | 28.6;39.1   |
| Diuretics                                        | C03          | 110| 34.8 | 29.5;40.1   |
| Opioids                                          | N02A         | 108| 34.2 | 28.9;39.4   |
| Laxatives                                        | A06          | 96 | 30.4 | 25.3;35.4   |
| Vitamins and mineral supplements                 | A11; A12    | 88 | 27.8 | 22.9;32.8   |
| Antipsychotics                                   | N05A         | 79 | 25.0 | 20.2;29.8   |
| Benzodiazepine derivates                         | N05CD        | 70 | 22.2 | 17.6;26.7   |
| Steroids                                         | H02AB        | 58 | 18.4 | 14.1;22.6   |
| Drugs for the respiratory system                 | R            | 37 | 11.7 | 8.2;15.2    |
| Antiepileptics                                   | N03          | 30 | 9.5  | 6.3;12.7    |
| Insulin and other glucose lowering               | A10          | 27 | 8.5  | 5.5;11.6    |
| Acetaminophen                                    | N02B         | 24 | 7.6  | 4.7;10.5    |
| Antidepressants                                  | N06          | 24 | 7.6  | 4.7;10.5    |
| Anti-parkinson                                   | N04          | 23 | 7.3  | 4.4;10.1    |
| Antiemetics                                      | A04          | 19 | 6.0  | 3.4;8.6     |
| Hyoscine Butylbromide                            | N07          | 14 | 4.4  | 2.2;6.7     |
| Thyroid drugs                                    | H03          | 17 | 5.4  | 2.9;7.9     |
| Others*                                          |              | 29 | 9.2  | 6.0;12.4    |

*Others: Allopurinol (M04 11), Drugs for benign prostatic hypertrophy (Tamlusosin, Finasteride)
(G04AC, 10), Antidiarrhoics (A07, 5), Ursodesoxycholic acid (A05AA02 4), Drugs for treatment of hyperkaliemia and hyperphosphatemia (V03AE, 3), Hormone antagonists (L02, 2), Baclofen (M03BX, 2); only 1: Epoietine (B03); Rociverine (A03AA)

†CI: confidence interval

Discussion

This study presents data on a large cohort of NH residents with advanced dementia who died in a NH located in a large region of northern Italy. Differently from other studies, in which one-third of NH residents were hospitalized in the last month of life and the rate of death in hospital was almost 66%, the vast majority of our residents died in NH: only 4.7% of them were admitted to hospital or sent to the emergency department. This low figure may be considered positive, as for people with advanced dementia, hospitalization can be aggressive and of limited clinical benefit. The availability of a full-time physician, and the fact that all NHs that participated in the present analysis are skilled NHs, may account for this result.

In general, although the care received by NH residents with advanced dementia in the last 7 days of life demonstrated scope for improvement, it also showed a preference for non-aggressive treatment. Sixty days before death, the vast majority of NH residents (78.4%) were fed only by mouth, but, as expected, that number decreased to nearly one in five (20%) the 7 days before death. Overall, in the last 7 days of life one-third of NH residents received palliative-oriented nutrition. It is broadly acknowledged that tube feeding in people with advanced dementia is ineffective and even harmful, and that possible symptoms of dehydration can be effectively treated with small amounts of fluids (by mouth or by subcutaneous fluids administration) with good oral care. Nevertheless, relatives often ask for substantial nutrition and hydration. The limited use of subcutaneous fluids administration could be ascribed to a lack of knowledge of this technique on the part of NH staff.

The figures we report related to feeding tubes, namely the number of patients who died with a feeding tube in place, are higher than those reported in a Dutch and a US study, which showed a decrease in tube feeding over 15 years (from 11.7% in 2000 to 5.7% in 2014). Nevertheless, our
results reflect a substantial positive trend when compared with the findings of a previous study (tube feeding 21.0% vs tube feeding and parenteral nutrition 16.6%; intravenous hydration 66% vs 48.4%) carried out in 2005 in a smaller sample of NHs in the same region. The same trend toward a less aggressive approach is shown by the decreased use intravenous fluid administration (from 67% to nearly 40%). Further positive findings concern the use of drugs, with the increased use of opioids (from 4.9% at baseline to 34.2% in the last week of life) and acetaminophen (from 4.5% to 7.6%); the low rate of blood samples taken (less than 2 patients out of 10); and the low rate of other invasive treatments/interventions.

Some aspects still require closer scrutiny and improvement, in particular clinical factors. Inappropriate prescriptions, such as anticoagulants/antiplatelets and anti-arrhythmics classes I-III, continue to be used. Diuretics, beta-blocking agents, antipsychotics, and antibiotics, even if considered “sometimes appropriate”, seem to be overly prescribed in the last 7 days of life; (hyoscine, steroids, and antacids may have been prescribed as symptomatics). There was also an overuse of procedures like intravenous catheter placement and an underuse of subcutaneous fluids administration.

The acknowledgement of the worsening of resident’s conditions was reported in the clinical records of 57% of NH residents a few days before death (median 4), but only 21 of these residents had a care plan in place. Lastly, some questionable, considering the advanced dementia stage of residents, resuscitation attempts were carried out (14.5%, mostly with drugs). The trajectories of decline in persons with dementia are uncertain, therefore it is not easy to assess when a resident is approaching death. If acknowledgement of the proximity of death takes place only when a resident’s health conditions rapidly declines, the opportunities to provide palliative care and hospice referral decrease. The difficulty of defining terminality, and of reliably estimating survival in people with advanced dementia requires structured investments to produce effective tools to identify and evaluate these factors. These findings also show the need to improve the knowledge of NH staff, included physicians, on these issues. This need is reflected in the urgency placed on national
regulatory bodies and international scientific boards to produce up-to-date, widely accepted
guidelines on the pharmacological approach to take with patients with dementia who are at the end
of their life.\textsuperscript{7, 29}

Critical decisions also require closer scrutiny and improvement. One of the most disappointing
findings was the extremely low presence of ADs, whether they were self-written or communicated by
relatives, and the scarcity of guardians and/or surrogates. In Italy, the legal representative must be
appointed by a magistrate, generally at the request of the health care provider, such as general
practitioners and/or the NH doctor, which is not always a fast procedure. This may explain the scarcity
of DNR and/or DNH orders in our study (overall 8 NH residents) and even the use of palliative
pharmacological sedation. DNR and DNH orders are far more common in other European countries:
2.4\% in our study, but 21.0\% in Holland,\textsuperscript{35} and 60\% in the US.\textsuperscript{35}

Family involvement in decisions were documented in only 86 clinical records and a recent study
reported that most decisions are first taken by the physicians and only later communicated to
relatives.\textsuperscript{14} The low prevalence of advance care planning suggests the tendency to avoid addressing
the issue with family\textsuperscript{37} and would need efforts for improvement. Advance care planning implies the
involvement of family, in what have been called “expectation conversations”.\textsuperscript{38} Only 3.4\% of NH
residents were involved in conversations on desired end-of-life care in the van der Voot et al. study\textsuperscript{35}
(although more than 60\% were cognitively competent at admission), and even if NH staff say they are
available to speak with NH residents’ relatives about death and dying when they are “terminal”,\textsuperscript{37}
systematic, periodic conversations with families are a crucial instrument to reducing the NH staff’s
uncertainty in clinical decision-making and to improve the family’s perceptions of quality of care in
NHs.\textsuperscript{38-39}

Critical decisions may affect the time of death, the place of death,\textsuperscript{32} and the way a person will live
her/his last days. If a patient is incapacitated and there is no surrogate and/or ADs, the ultimate
responsibility for treatment decisions falls on the physician, whose decisions may be affected by
several factors, such as the context (setting and culture), personal and societal values and constraints, and medical training that is overly focused on curing. A framework that shares this planning with the family may reduce the temptation to lean on defensive medicine, which may be partially responsible for resuscitation attempts, placement of feeding tubes, the drawing of blood samples, the avoidance of writing DNR/DNH orders, etc. This implies that, in spite of the spread and seeming acceptance of the principles and methods of palliative care, at least in NHs, prejudices and fears persist.

**Strengths and weaknesses**

Our results are limited by the retrospective nature of the study and by data retrieval from clinical records; some aspects such as relatives’ involvement in decisions may have been under-reported. Although this is a multicentric study, each NH contributed the same number of cases, thus limiting the possible over-representation of residents from larger NHs. Data were collected by expert, trained researchers, which may have limited interpretation problems.

**Conclusions And Implications**

Notwithstanding some clear improvements in the quality of palliative care, which reflects a substantially positive trend toward a less aggressive approach provided to NH residents with advanced dementia in their last days of life, there are still some barriers to a full implementation of palliative care. In particular, insufficient acknowledgement of the inappropriateness of some drugs and interventions, and reluctance to implement end-of-life palliative care decisions. In order to provide full palliative care to NH residents with advanced dementia, up-to-date, widely accepted guidelines on a pharmacological approach for persons with advanced dementia are urgently needed, as well as changes in NH staff and general population cultural approach to death and dying in order to outline clinically correct care strategies that can be agreed upon by NH residents and their families.

**Declarations**

**Research ethics and patient consent.** The study was approved by the Ethic committee of Don Carlo Gnocchi Foundation of Milano on February 20, 2013.

**Consent for publication.** Not applicable.
Availability of data and material. The datasets used and/or analysed during the current study are available from the corresponding author on reasonable request.

Competing interests. The authors declare that they have no competing interests.

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