Lights and shadows on the last week of life of nursing home residents with advanced dementia: retrospective study

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Abstract

Background Barriers to palliative care still exist in geriatric settings, 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. The study aimed at evaluating the palliative appropriateness of clinical interventions and care at end of life in a cohort of 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 7 days before death, 20% were fed and hydrated by mouth, and 13.4% were tube fed. A median of five, often inappropriate, drugs was prescribed. The acknowledgement of worsening condition in clinical records was recorded for 57% of residents, a median of 4 days before death. Conclusions A full implementation of palliative care is not yet achieved possibly due to the insufficient acknowledgement of the inappropriateness of some drugs and interventions, and health professionals’ fears and prejudices regarding critical end-of-life decisions. Further studies should focus on how to improve care for NH residents.

Introduction

Dementia is an incurable condition that causes a progressive decay. This decay is characterized by co-morbidities, severe disability, 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. Persons 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.\textsuperscript{2} Thus, for most of their residents, NHs are or should be hospices in all respects.

However, barriers to palliative care still exist in geriatric settings,\textsuperscript{3} which can mean that 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.\textsuperscript{4–6} Barriers to palliative care include lack of communication with relatives who fail to accept the approaching death;\textsuperscript{1} high staff turnover (especially nurses);\textsuperscript{7} lack of competence of non-qualified personnel together with a limited number of nurses;\textsuperscript{8} and poor staff training in palliative care.\textsuperscript{9–10} Important differences among countries do exist,\textsuperscript{11} and they probably also exist among institutions within the same country.\textsuperscript{12} 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.\textsuperscript{5, 13}

\textbf{Methods}

\textit{Aim.} The aim of this multicenter study was to evaluate the palliative appropriateness of clinical interventions and care at end of life in a cohort of NH residents with advanced dementia.

\textbf{Study setting}

We used data from the Valuazione dell’Efficacia della Leniterapia nell’Alzheimer e Demenze or VELA Project,\textsuperscript{14} 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 surroundings 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 staffs with a law-defined ratio of ≥901 minutes/week of care per resident; 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, 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 ≥7c (double incontinence; loss of all intelligible vocabulary; non-ambulatory) 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. Due to the relatively limited impact of the educational intervention, 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.

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 like endotracheal suctioning, hospitalizations and admissions to the emergency department, assessment of pain and discomfort, drugs prescribed (classified according to the Anatomical Therapeutic Chemical code), 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. 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.

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. 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
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

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 NH residents, 96 (25.7%) of whom had dementia reported as the cause of death. Only one NH resident had a self-written AD; in 19 (3.9%) cases, a family member reported the NH resident’s wishes, and 60 (12.5%) 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. 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 (57.0%) NH residents, and the notification of agonic conditions 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 (4.3%) (median 15 days before death; IQR 5–41). Two (0.4%) NH residents had a DNR, seven had a DNH (1.4%), and one NH resident had both. Two hundred 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.

After the exclusion of 13 NH residents with missing information on nutrition and hydration, we observed palliative-oriented nutrition in 130 (27.7%) residents (Table 2).

Table 2

Overall, 101 NH residents (20.9%) received at least one invasive treatment or intervention in the 7 days before death (Table 3).

Table 3

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 cardio-pulmonary 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

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
dehth in hospital was almost 66%,$^{19-20}$ 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 hospitalization is of limited clinical benefit, and for
advanced dementia patients it is considered aggressive.$^{21}$ 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 showed ample space 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 useless, 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.$^{22}$ Nevertheless, relatives often
ask for substantial nutrition and hydration.$^{23}$ The limited use of subcutaneous fluids
administration could be ascribed to a lack of knowledge of this technique on the part of NH
staff.$^{24}$

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$^{25}$ and a US study,
which showed a decrease in tube feeding over 15 years (from 11.7% in 2000 to 5.7% in
2014).$^{26}$ 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 of the 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 drawn up. Lastly, some totally unjustifiable 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 takes a drastic downturn, 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.\textsuperscript{33} These findings also show the need to improve the knowledge of NH staff on these issues,\textsuperscript{14} particularly the physicians’, who are still ultimately responsible and accountable for the care, and overall, 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{6, 28}

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, the poor attitude toward implementing advance care plans, 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{34} and 60\% in the US.\textsuperscript{35}

Family involvement 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{13} The low prevalence of advance care planning suggests the tendency to avoid addressing the issue with family\textsuperscript{36} and would need investments for improvement. Advance care planning implies the involvement of family, in what have been called “expectation conversations”.\textsuperscript{37} 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{34} (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”, systematic, periodic conversations with families is 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. Critical decisions may affect the time of death, the place of death, 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 elements that are holding up a full implementation of palliative care. In particular, insufficient acknowledgement of the inappropriateness of some drugs and interventions, and health professionals’ (in particular, physicians) fears and prejudices regarding critical end-of-life 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 are intense changes in NH staff culture and popular culture 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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Tables

Table 1. Main characteristics of the 482 nursing home (NH) residents with advanced dementia (Functional Assessment Staging Tool stage ≥7c)

|                      | n   | %   | 95% CI† (%)     |
|----------------------|-----|-----|-----------------|
| **Sex 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 | 84.8| 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 | 40.4| 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.
### Table 2. Nutrition and hydration in the 7 days before death*

| Method                        | n   | %    | 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 | 21.7 | 18.0;25.5       |

†CI: confidence interval; IV: intravenous; SFA: subcutaneous fluids administration.

* Data were calculated on 469 patients (13 with missing information)

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

| Method                                           | n   | %    | 95% C     |
|--------------------------------------------------|-----|------|-----------|
| Oral/tracheal suctioning                         | 101 | 20.9 | 17.3;     |
| Blood collection                                 | 73  | 15.1 | 11.9;     |
| Peripheral vein cannulation (one or more attempts) | 53  | 11.0 | 8.2;1     |
| Insertion/repositioning of urinary catheter      | 30  | 6.2  | 4.1;      |
| Insertion/repositioning of a nasogastric tube (2 PEGs†) | 11  | 2.3  | 0.9;      |
| Insertion of a central venous catheter           | 3   | 0.6  | 0.0;      |
| Other invasive treatments*                       | 6   | 1.2  | 0.2;      |

* 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.

### 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  | 18.3 | 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     |
| Hyoscin 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