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# **The impact of Nursing Homes staff education on end-of-life care in residents with advanced dementia: a quality improvement study**

Paola Di Giulio RN, MSc<sup>1</sup> orcid 0000-0002-1500-8692

Silvia Finetti MSc<sup>2</sup>

Fabrizio Giunco MD<sup>3</sup>

Ines Basso RN<sup>4</sup>

Debora Rosa RN, MSc<sup>5</sup>

Francesca PettenatiMSc<sup>2</sup>

Alessandro Bussotti MD<sup>6</sup>

Daniele Villani MD<sup>7</sup>

Simona Gentile MD<sup>8</sup>

Lorenzo Boncinelli MD<sup>9</sup>

Massimo Monti MD<sup>10</sup>

Sandro Spinsanti<sup>11</sup>

Massimo Piazza MD<sup>12</sup>

Lorena Charrier MD<sup>13</sup>

Franco Toscani MD<sup>2</sup>

1. Department of Public Health and Pediatrics, University of Turin, via Santena 5 bis, 10126 Turin, Italy and SUPSI, Manno, Switzerland; email: [paola.digiulio@unito.it](mailto:paola.digiulio@unito.it)

2. Lino Maestroni Foundation, Palliative Medicine Research Institute, via Palestro 1, 26100 Cremona, Italy; email: [istitutomaestroni@fastpiu.it](mailto:istitutomaestroni@fastpiu.it)

3. Department of Health and Social Services Polo Lombardia 2, Don Carlo Gnocchi Foundation ONLUS, Via Palazzolo, 21, 20149 Milano, Italy; email: [fgiunco@dongnocchi.it](mailto:fgiunco@dongnocchi.it)

4. Intensive Care Unit, SS Antonio e Biagio e Cesare Arrigo Hospital, Via Venezia, 16, 15121, Alessandria, Italy; email: [guinness05@live.it](mailto:guinness05@live.it)

5. Nursing Degree Course, University of Milan, section of Don Carlo Gnocchi Foundation, Via A.Capecelatro, 66, 20148 Milan, Italy; email: [drosa@dongnocchi.it](mailto:drosa@dongnocchi.it)
6. Agenzia Continuità Ospedale Territorio, Azienda Ospedaliero- Universitaria Careggi, Largo Brambilla 3, 50134 Firenze; email: [bussottia@gmail.com](mailto:bussottia@gmail.com)
7. Neuro-Rehabilitation and Alzheimer Disease Evaluation Unit, “Figlie di San Camillo” Hospital, Via F. Filzi , 56 , 26100 Cremona, Italy ; email: [daniele.villani50@gmail.com](mailto:daniele.villani50@gmail.com)
8. Rehabilitation and Alzheimer Disease Evaluation Unit, Ancelle della Carità Hospital, Via G. Aselli, 14, Cremona, Italy; email: [simona.gentile@ancelle.it](mailto:simona.gentile@ancelle.it)
9. Intensive Care Unit Geriatric. AOU Careggi-Largo Brambilla,3 ,50134 Firenze. Italy. email: [lboncinelli@tin.it](mailto:lboncinelli@tin.it)
10. Geriatric Institute "Pio Albergo Trivulzio", via Trivulzio, 15, 20146 Milano; email: [massimo.monti@pioalbergotrivulzio.it](mailto:massimo.monti@pioalbergotrivulzio.it)
11. Istituto Giano, Via Stazzo Quadro 7 , 00060 Riano (Rm), Italy; email: [gianorom@tin.it](mailto:gianorom@tin.it)
12. Italian Foundation of Leniterapia (FILE), Via San Niccolò, 1, 50125 Firenze, Italy; email: [file@leniterapia.it](mailto:file@leniterapia.it)
13. Department of Public Health and Pediatrics, University of Turin, Via Santena 5 bis, 10126 Turin, Italy; email: [lorena.charrier@unito.it](mailto:lorena.charrier@unito.it)

**Corresponding author: Lorena Charrier**

Department of Public Health and Pediatrics, University of Turin, Via Santena, 5 bis , 10126 Turin, Italy; email: [lorena.charrier@unito.it](mailto:lorena.charrier@unito.it)

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## **ABSTRACT**

**Context.** End-of-life care in nursing homes (NH) needs improvement. We carried out a study in 29 NHs in the Lombardy Region (Italy).

**Objectives.** To compare End-of-Life care in NH residents with advanced dementia before and after an educational intervention aimed to improving palliative care.

**Methods.** The intervention consisted of a 7-hour lecture, followed by two 3-hour meetings consisting of case discussions. The intervention was held in each NH and well attended by NH staff. This multicenter, comparative, observational study included up to 20 residents with advanced dementia from each NH: the last 10 who died before the intervention (pre-intervention group, 245 residents) and the first 10 who died at least 3 months after the intervention, (post-intervention group, 237 residents). Data for these residents were collected from records for 60 days and 7 days death.

**Results.** The use of “comfort hydration” (<1000 ml/day subcutaneously) tended to increase from 16.9 to 26.8% in the post-intervention group. The number of residents receiving a palliative approach for nutrition and hydration increased, though not significantly, from 24% pre- to 31.5% post-intervention. On the other hand, the proportion of tube-fed residents and residents receiving intravenous hydration decreased from 15.5% to 10.5%, and from 52% to 42% respectively. Cardiopulmonary resuscitations decreased also from 52/245 (21%) to 18/237 (7.6%) cases ( $p=0.002$ ).

**Conclusion.** The short educational intervention modified some practices relevant to the quality of End-of-Life care of advanced dementia patients in NHs, possibly raising and reinforcing beliefs and attitudes already largely present.

**Key Words:** residential facilities, education; dementia; palliative care; nursing homes

## INTRODUCTION

Many persons with dementia die in nursing homes (NHs)(1) and their number is bound to increase, thus for most of them NHs are, for all intents and purposes, hospices. However, good end-of-life care for these persons requires professional caregivers to acknowledge their specific problems and to adopt equally specific strategies.(2)

Unfortunately there are several barriers (3-4) to the administration of palliative care in geriatric settings like NHs: lack of communication with relatives who fail to accept the approaching death of their loved ones;(5) insufficient connections with palliative care services; high staff turnover (especially nurses);(6) lack of in-house expertise;(7) and above all, inadequate or absent training of staff.(7-9) NH staff need specific competences in palliative care,(10) specially for residents with dementia. Indeed, it has been shown that, in many Italian NHs (11) several elements of palliative care are only partially provided, or not provided at all.

The vast majority of available data on the impact of educational interventions on improving palliative care in NHs has relied mostly on staff perspectives; their methodological quality was poor and there is insufficient evidence to determine whether educational interventions really promote better end-of-life outcomes.(7) Only four studies (12-15) attempted to assess changes in patients' outcomes by an audit of clinical case notes, three of which showed a statistically significant improvement in palliative care.(12,13,15) The Fondazione Italiana di Leniterapia of Florence and the Lino Maestroni Palliative Medicine Research Foundation of Cremona provided a short staff educational intervention to improve palliative care in patients with advanced dementia (AD) to a sample of NHs in the Lombardy Region. This choice was based on the belief that due to the commonalities between geriatrics and palliative care (16-17) professionals who deal with elderly patients, may have developed some experience even if often without any specific training.

The aim of this study was to compare end-of-life care procedures, drugs and outcomes related

to the palliative care of residents with AD in the Lombardy Region before and after this educational intervention.

## **METHODS**

### **Study setting**

In the Lombardy Region, accredited NHs have their own medical and nursing staffs with a law-defined ratio of  $\geq 901$  minutes/week of care per patient (18), and may be defined as “skilled NHs”. Out of a network of 34 NHs, (19) 29 (number of beds per NH ranged from 40 to 714) agreed to participate in the present quality improvement program. Their staff were informed that an audit of clinical records would be made before and after they attended an educational intervention based on a lecture and case discussion, but they were not told the specific content of the assessments.

The educational intervention is described in box 1.

The same set of slides was used for all lectures given in the intervention and all participants were provided the most relevant articles on the topics addressed. The cases were proposed by participants and offered the opportunity to reinforce the contents of the lecture. Overall it took 4 months to complete the educational intervention in each NH (lecture plus two case discussion meetings spaced 1 month apart). Education credits were offered to all participants to encourage continued participation.

### **Data collection**

To be included residents had to have a Functional Assessment Staging Tool stage (FAST)(20)  $\geq 7c$  (double incontinence; loss of all intelligible vocabulary; non-ambulatory) and have resided in the NH for at least 6 months. From each NH, trained nurses, who were not affiliated with the involved NH, analyzed up to 10 medical and nursing records of the last consecutive eligible residents who had died before the educational intervention (pre-intervention group), and 10 that had died at least 3 months after the last case discussion (post-intervention group).

Information on sex, age, FAST stage, date of NH admission, date and cause of death, major comorbidities, Do Not Resuscitate (DNR) and Do Not Hospitalize (DNH) orders were taken

from records. Specific information on nutrition/hydration (mouth, intravenous, tube), pain, number of prescriptions, tests, and interventions administered was also collected for the time periods of 60 and 7 days before death. Finally, information on hospitalizations and emergency department admissions, invasive clinical tests and interventions, palliative sedation and cardiopulmonary resuscitations was collected for the 7 days before death. The panel of experts mentioned in box 1 classified nutrition and hydration as “palliative” if given by mouth only or accompanied by comfort hydration (subcutaneous fluids administration [SFA] of <1000 ml day); by SFA only; and if no nutrition or hydration was provided. Artificial hydration at the end-of-life is often considered not appropriate or even harmful,(21) we considered a subcutaneous hydration of <1000 ml as “palliative. 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” if given by parenteral route, via nasogastric tube, or via percutaneous endoscopic gastrostomy at any point during the 7 days before death. The Ethic Committee of the Don Carlo Gnocchi Foundation approved the study, on February 20, 2013.

### **Statistical analyses**

Descriptive data are shown as absolute and relative frequencies for categorical variables and as mean and standard deviation or median and interquartile range for continuous variables. The Shapiro-Wilk normality test was performed to check the normality of continuous variables. The chi-square test or Fisher's exact test was carried out for categorical variables to assess possible differences between the pre- and post-intervention groups. For continuous variables, t-tests for independent data or Mann-Whitney tests for non-normally distributed data were used to compare the two groups. All the analyses were adjusted for clustering of patients within



NHs; p-values adjustments for multiple comparisons were then performed with Bonferroni method. For all tests, the significance level ( $\alpha$ ) was set at 0.05.

All analyses were performed with Stata 14.(22)

## RESULTS

The study started on 1 April 2013 and ended on 31 January 2015. Main characteristics of the study sample were comparable across the pre- and post-intervention groups. Overall, half of the residents had between five and eight comorbidities, and 25% more than eight (Table 1).

Almost all residents of the study sample died in their NH (pre-intervention group: 236, 96.3%; post-intervention group: 232, 97.9%). DNR and DNH orders were registered in clinical records for 1 and 2 residents respectively, in the pre-intervention group, for 1 and 4 residents in the post-intervention group.

In the post intervention group the following changes, though not statistically significant, were achieved in the 60 days before death: an increase in the number of residents hydrated and fed by mouth only and a decrease in the number of residents receiving additional fluids via IV or SFA (Table 2).

In the 7 days before death in the post-intervention group, the rate of residents receiving comfort hydration via SFA or IV increased from 16.9% to 26.8%, and even further in the 3 days before death: from 22.9% to 33.5% ( $p=0.005$ ) (data not shown). A larger number of residents received SFA (6.9% in the pre-intervention vs 22.4% in the post-intervention group,  $p=0.0006$ ) (Table 3). Moreover, though the differences were not significant, the number of tube-fed residents decreased from 38 (15.5%) in the pre-intervention to 25 (10.5%) in the post intervention group as did the number of those with a new feeding tube inserted in the 60 days before death: from 14 in the pre-intervention, to 10 in the post-intervention group. After the exclusion of 13 residents (8 from the pre-intervention and 5 from the post-intervention group) with missing information on nutrition and hydration, a trend towards a palliative approach (i.e., no feeding tubes, no administration of any IV fluid; only SFA <1000 ml) was observed with 73/232 (31.5%) receiving this approach in the post intervention vs 57/237 (24%) in the pre intervention group ( $p=0.071$ ). No major changes were observed for other interventions,

possibly due to their low prevalence, but the rate of residents who had blood samples taken decreased from 18.8% in the pre-intervention to 11.4% in the post-intervention group, while the number of residents receiving  $<3$  drugs increased from 17.8% to 26.7% (Table 4). Finally, cardiopulmonary resuscitation decreased from 52/245 (21.2%) in the pre-intervention to 18/237 (7.6%) ( $p=0.002$ ) in the post-intervention group.

Dementia was reported as the cause of death in 43/202 (21.2%) residents in the pre-intervention compared to 53/172 (30.8%) in the post-intervention group ( $p=0.226$ ). However, this information was only available for 202 (83.1%) and 172 residents (72.5%), respectively.

## DISCUSSION

This study followed a large cohort of NH residents who died before and after an educational intervention, aimed at improving palliative culture and care in NHs. The intervention was well attended by NH staff at all 29 NHs. Differently from most studies, we assessed hard outcomes, not self-reported changes in knowledge or attitudes.(7)

The NHs accreditation requirements and the structure of clinical records are the same across the Lombardy Region, and the pre-intervention and post-intervention groups were comparable.

A number of changes were achieved after the course, indicating an overall trend towards a more palliative approach: in the 60 days before death the number of residents fed by only mouth increased and the overall prevalence of those administered IV or SFA fluids decreased. In the 7 days before death the proportion of tube-fed residents decreased from 15.5% in the pre-intervention to 10.1 in the post-intervention group and IV hydration was gradually replaced with the less invasive and cumbersome SFA, which is recommended for all terminal-stage patients.(23) In fact, SFA has many advantages over IV infusions, including ease of administration and reduced costs, but the primary advantage is that it creates less discomfort for the patient, which makes this technique particularly appropriate in end-of-life treatments.(24) However, the overall use of SFA remained low, showing the need to improve the knowledge of NH staff on this technique.(25)

After the intervention, an increasing number of residents (although not significant and with much room for improvement) received a palliative approach for nutrition and hydration (24% in the pre-intervention and 31.5% in the post-intervention group;  $p=0.07$ ) the week before death. Hunger and thirst can be effectively treated with small amounts of food and fluids given by mouth, and with a good oral care,(26) but one of the obstacles to this palliative approach are physicians and health care professionals' beliefs (27) and relatives' requests to start artificial

nutrition and hydration.(28) The increase in the palliative approach that we observed may also be due to improvement in communication with relatives.(29-30)

The number of blood samples taken from residents decreased during the study period, and the number of residents on less than 3 drugs increased (the mean number of drugs, however, remained the same). The significant decrease in the rate of residents exposed to cardiopulmonary resuscitation may be attributable to a shift in perspective regarding the care of residents with advanced dementia (29-30) and/or to the increased recognition that dementia, like cancer, is a terminal illness.(31) In fact, after the educational intervention, a larger number of deaths were attributed to dementia. This is a central element, as the acknowledgement of dementia as a cause of death (32) could facilitate a palliative approach. Unfortunately, we were not able to obtain the official cause of death for all patients due to different archiving policies (most official death forms in some NHs had been sent to a central archive and were no longer available in the NHs themselves).

Differently from other countries,(33) emergency department and hospital admissions were already very low, possibly because most NHs in Lombardy can provide hospital-level interventions. We did not expect any change in DNR/DNH orders, due to the difficulties of the staff and residents to address the issue, as has also been observed in other European studies.(34)

Considering the limited nature of the educational intervention, and the lack of follow-up and reinforcement, the results obtained in this study are promising. Previous studies with a more robust design (35) and longer NH staff educational interventions (6 months) failed to show any impact on the quality of life of dementia patients. Moreover in other studies the educational intervention supported the implementation of videos for relatives (30) or of the Gold Standard Framework in Care Homes (12-14) with the implementation of organizational tools, support from facilitators, helpline and conference calls (12), the support of specialist care nurses (14),

the identification of key champions,(13) while in the present study besides the educational intervention, no other forms of support were provided, with the exception of the possibility (although it was never used) to contact experts for support.

Our educational intervention used discussion based on real cases in order to tailor the contents to the interest of, and questions from, participants. This critical case analysis was specific to each NH and was attended by their multidisciplinary teams (including nurse's aides) thus facilitating a free and lively discussion among different professionals. Even if data on advanced care planning were not collected in the same manner as in other studies,(12-14) several elements support the presence of a change towards a less aggressive end-of-life care approach among dementia patients.

Nevertheless, some limitations should be considered. A critical issue could be the short gap of time to measure the outcomes of the intervention and the lack of measurement of staff's reactions to the educational intervention; however, our outcomes reflect complex decisions (nutrition and hydration strategies; withholding cardiopulmonary resuscitation) that likely reflect a change in perspective. Another limitation is the lack of a comparison group. However, only 8 months elapsed from the end of data collection in the pre-intervention and the start of data collection in the post-intervention group, and to our knowledge no major events could have justified the changes observed. The data were collected from clinical records and assessors were not blind: the provision of strict definitions of events may have limited potential assessment bias.

Other limitations are the self-selection of our participating NHs, which could have been more motivated to change; and the choice of the medical interventions selected to be monitored, which were limited by the retrospective study design. A sample size definition was not possible due the lack of data on end-of-life care of dementia patients in Italian NHs.

Finally, the lack of follow-up prevented us from measuring the extent to which the obtained improvements were maintained over time.

## **CONCLUSIONS**

A short educational intervention proved effective in starting a change in practices relevant to the quality of palliative care among patients with advanced dementia in Italian NHs. It is highly possible that this intervention raised and reinforced beliefs and attitudes already present, and provided up-to-date arguments for clinical views that had already been deemed correct, but had not been implemented. Despite the results of the educational intervention, there is still much that can be improved to increase the quality of care of terminal dementia patients.

## **DISCLOSURES**

### **Authorship**

Concept or design of the work, FT, PDG

Acquisition, analysis or interpretation of data; SF, LC, IB, FP, DR

Draft of the article, FT, PDG, LC

Critical revision of the article, FT, PDG, LC, IB, FG, AB, DV, SG, LB, MM, SS, MP

Approval of version to be published All

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**Conflict of interest.** All the authors declare that there is no conflict of interest

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

**Data management and sharing.** Dataset will be available on request [istitutomaestroni@fastpiu.it](mailto:istitutomaestroni@fastpiu.it)

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**Table 1. Main characteristics of residents with advanced dementia who died before (pre-intervention group) and at least 3 months after (post-intervention group) an educational intervention on palliative care.**

	Pre-intervention group		Post-intervention group		p-value
	(n=245)		(n=237)		
	n	%	N	%	
Sex (Female)	179	73.4	186	78.5	0.215
FAST ≥7c	245	100	236		
Mean age at admission (SD)	82.5	(8.6)	83.9	(7.7)	
Median (IQR)	83.5 (78.4-88.4)		84.8 (79.7-88.7)		0.106
Mean age at death (SD)	87.7	(8.3)	89.1	(6.8)	
Median (IQR)	88.8 (83.0-92.6)		89.1 (84.4-93.9)		0.108
Comorbidities					
Genitourinary	224	91.4	211	89.0	0.498
Musculoskeletal	209	85.3	200	84.4	0.958
Low gastrointestinal tract	181	73.9	181	76.4	0.477
Peripheral and central nervous system	159	64.9	155	65.4	0.765
Hypertension	114	46.5	124	52.3	0.135
Cardiovascular	117	47.8	120	50.6	0.470
Head and neck	104	42.4	103	43.5	0.759
Vascular	103	42.0	92	38.8	0.412
Gastrointestinal tract	73	29.8	62	26.2	0.322
Respiratory	51	20.8	49	20.7	0.990

Endocrine-metabolic	61	24.9	74	31.2	0.053
Kidney	27	11.0	28	11.8	0.789
Liver	10	4.1	20	8.4	0.110

Data are frequencies (absolute and percentages) if not otherwise stated.

SD: standard deviation; IQR: interquartile range.

**Table 2. Patient management in the 60 days before death among residents with advanced dementia who died before (pre-intervention group) and at least 3 months after (post-intervention group) the educational intervention on palliative care.**

	Pre-intervention group (n=245)		Post-intervention group (n=237)		p-value
	n	%	n	%	
Nutrition/hydration by mouth only	182	74.3	195	82.3	0.085
Nutrition/hydration by mouth plus fluids (IV or SFA)	29	11.8	14	5.9	0.27
Tube feeding	25	10.2	18	7.6	1.000
Parenteral nutrition	-		1	0.4	--
Assessment of pain/discomfort	34	13.9	21	8.9	0.845
Median number of drugs (IQR)*	6	(3-8)	5	(3-8)	1.000

\* Data on drugs administered was available for 181 residents in the pre-intervention group and 174 residents in the post-intervention group.

SFA: subcutaneous fluids administration; IV: intravenous; IQR: interquartile range.

**Table 3. Nutrition, hydration and treatments in the 7 day before death among residents with advanced dementia who died before (pre-intervention group) and at least 3 months after (post-intervention group) the educational intervention on palliative care.**

	Pre-intervention group (n=245)		Post- intervention group (n=237)		p-value
<b>Nutrition and hydration</b>	n	%	n	%	
Nutrition/hydration by mouth only	47	19.2	47	19.8	1.000
IV hydration	128	52.2	99	41.8	0.318
SFA	17	6.9	53	22.4	0.0006
Tube feeding	38	15.5	25	10.5	0.318
Parenteral Nutrition	7	2.9	8	3.4	1.000
Comfort hydration (IV and SFA)	39/231	16.9	60/224	26.8	0.102
<b>Treatments</b>					
Blood collection	46	18.8	27	11.4	0.729
Tracheal suctioning	54	22.0	47	19.8	1.000
Other invasive treatments	46	18.8	45	19.0	1.000
Emergency department visits	9	3.7	2	0.8	0.522
Hospital admissions	8	3.3	6	2.5	1.000
Discomfort and/or pain assessment	88	35.9	104	43.9	1.000
Palliative sedation	5	2.0	8	3.4	1.000



Median number of drugs (IQR)	5	(3-8)	5	(2-8)	0.486
Patients with <3 drugs*	33	17.8	43	26.7	0.36

IV: intravenous; SFA: subcutaneous fluids administration. \* Data on drugs administered was available for 182 (74%) residents in the pre-intervention group and 185 (78%) residents in the post-intervention group.

### **Box 1. Description of the educational intervention offered at each participating NH**

Main characteristics:

- It was open to all staff (doctors, nurses, nurse's aides, and other personnel)
- It consisted of a 7-hour lecture followed by two 3-hour meetings conducted one and two months later.
- Contents: the content of the lecture was determined by a panel of experts in palliative care, geriatrics, nursing, psychology, family medicine, and bioethics, and it offered training in palliative care philosophy and advanced dementia; the appropriateness of end-of-life interventions and prescriptions; pain and discomfort; dyspnea and symptoms management; artificial nutrition and hydration; and end-of-life care. Ethical and relational aspects were also considered, including communication and advanced care planning.
- Case discussions: proposed by participants and based on the clinical records of advanced dementia residents who had died in that NH, were critically analyzed and discussed.
- Attendance. the meetings were well attended. Over 750 participants (346 nurses –including 46 head nurses-, 140 nurses aids, 128 doctors, 70 physiotherapists, 36 occupational therapists, 24 psychologists, 7 social workers, and 1 bioethicist consultant) attended the meetings, representing 70% of NH staff at the participating NHs.