

AperTO - Archivio Istituzionale Open Access dell'Università di Torino

Critical decisions for older people with advanced dementia: a prospective study in long-term institutions and district home care.

This is the author's manuscript

Original Citation:

Availability:

This version is available <http://hdl.handle.net/2318/1564549> since 2016-11-16T09:41:31Z

Published version:

DOI:10.1016/j.jamda.2015.02.012.

Terms of use:

Open Access

Anyone can freely access the full text of works made available as "Open Access". Works made available under a Creative Commons license can be used according to the terms and conditions of said license. Use of all other works requires consent of the right holder (author or publisher) if not exempted from copyright protection by the applicable law.

(Article begins on next page)

This is the author's final version of the contribution published as:

Toscani, F; van der Steen, JT; Finetti, S; Giunco, F; Pettenati, F; Villani, D; Monti, M; Gentile, S; Charrier, L; Di Giulio, P; End of Life Observatory-Prospective Study on DEmentia Patients Care (EoLO-PSODEC) Research Group; End of Life Observatory-Prospective Study on DEmentia Patients Care EoLO-PSODEC Research Group. Critical decisions for older people with advanced dementia: a prospective study in long-term institutions and district home care.. JOURNAL OF THE AMERICAN MEDICAL DIRECTORS ASSOCIATION. 16 (6) pp: 535.e13-535.e20.
DOI: 10.1016/j.jamda.2015.02.012.

When citing, please refer to the published version.

Link to this full text:

<http://hdl.handle.net/2318/1564549>

Title: Critical decisions for older people with advanced dementia: a prospective study in long-term institutions and district home care

Authors

Franco Toscani, MD, (1)

Jenny T. van der Steen, PhD (2)

Lorena Charrier, MD (3)

Silvia Finetti, MSc (1)

Fabrizio Giunco, MD (4)

Francesca Pettenati, MSc (1)

Daniele Villani, MD (5)

Massimo Monti, MD (6)

Simona Gentile, MD (7)

Paola Di Giulio, RN, MSc (8)

On behalf of the End of Life Observatory - Prospective Study on DEmentia Patients Care (EoLO-PSODEC) Research Group (9)

(1) Lino Maestroni Foundation - Palliative Medicine Research Institute - Cremona, Italy

(2) Department of General Practice & Elderly Care Medicine, EMGO Institute for Health and Care Research, VU University Medical Center, Amsterdam, The Netherlands

(3) Department of Public Health and Pediatrics, School of Medicine, University of Turin - Turin, Italy

(4) Health Department Polo Lombardia 2 – Don F. Gnocchi Foundation ONLUS – Milano, Italy

(5) Neuro-rehabilitation and Alzheimer's Disease Evaluation Unit, "Figlie di San Camillo" Hospital, Cremona, Italy

(6) Rehabilitation and Alzheimer's Disease Evaluation Unit, Ancelle della Carità" Hospital, Cremona, Italy

(7) Geriatric Institute "Pio Albergo Trivulzio" – Milano, Italy

(8) Department of Public Health and Microbiology, Faculty of Medicine and Surgery, University of Turin - Turin, and Mario Negri Institute, Milan, Italy

(9) EoLO-PSODEC RESEARCH GROUP:

Lombardia Region Nursing Homes: Ventura M, and Giangico F (RSA “Don Angelo Colombo”, Travagliato – Brescia); Gandolfi N (Villa Maddalena, Goito-Mantova); Saya A, and Mauro A (RSA “Don Orione”, Bergamo); Colombetti R (Fondazione “Benefattori Cremaschi”, Crema - Cremona); Pani S (Fondazione “Cremona Solidale”, Cremona); Cotticelli C (Ospedale della Carità- Casalbuttano - Cremona) ; Saba L, Spotti F (Ist. Geriatrico “P. Redaelli”, Milano); Bacchi G, and Gainotti G (Fondazione “Germani”, Cingia de’ Botti - Cremona); Belotti G, and Milesi F (Fondazione “S. Maria Ausiliatrice”, Bergamo); Rossi Borghesano S - (Residenze “Santa Chiara e Santa Giulia”, Milano); Verando E (Casa “Cambiaghi e Don A. Bellani”, Monza); Migliorati G, and Premoli M (Az. di Servizi alla Persona “Valsasino”, S. Colombano al Lambro) - Lodi); Manganelli F (Villa Arcadia, Bareggio – Milano); Caruso M (Residenza “Saccardo”, Milano); Minuti A, and Feroldi A (Residenza “Anna e Guido Fossati”, Monza); Chiesara MA (Residenza “S. Pietro”, Monza); Subashi B, Bellocchi F (Istituto Geriatrico Milanese, Milano); D’Aquino N, and Giovinazzo F (RSA “Casa Per Coniugi”, Milano); Bareggi MC, and Spertini MT (Fondazione “Menotti”, Laveno-Mombello - Varese); Zucca F, Grigis M (Casa di Riposo “S. Giuseppe”, Casnigo- Bergamo); Conte L (Casa di Riposo “O. Cerruti”, Capriate - Bergamo); Panzera T (Casa di Riposo “G.M. Venzoli”, Grosotto - Sondrio); Cattaneo C (Casa di Riposo “Ospiti della Madonna”, Pellio Intelvi - Como); Biason A (Fondazione “Mons. G. Comi”, Luino - Varese); Torchetti MR, and Pelliccioli I (Fond. “Castellini”, Melegnano – Milano); Di Maggio MG, and Villa I (Istituti Riuniti “Airoldi e Muzzi”, Lecco); Monti M, and Gandelli M (Pio Albergo Trivulzio, Milano); Vignati M (Casa di Riposo “S. Pertini”, Garbagnate – Milano); Cutaia C, and Chiarella G (Ist. geriatrico “C. Golgi”, Abbiategrasso – Milano); Bellazzi L (Fondazione “Barbieri”, Valle Lomellina - Pavia); Ribola M (Fondazione “C. F. Cella”, Broni – Pavia); Rubini E (Fondazione “Mons. A. Mazzali”, Mantova); Raineri C, and Mainini E (Fondazione “F.lli Molina”, Varese).

District home care service of Modena: Borsari M; Reggiani A; Balugani P; Buccella M; Cardillo A; Carillo S; Farinello A; Franchini F; Guidi MG; Luise L; Magnoni, E; Marchi K; Nava L; Sabetta A; Sani E; Sporziello M; Stermieri L.

District home care service of Reggio Emilia: Martinelli M; Pirotti M; Costi A; Boni M; Capedri S, Cavecchi S; Dailari N; Favali E; Costoli E; Fossa G; Mazzone D; Patacini P; Ruozzi G; Sironi O; Murac A; Trolla L; Begotti S; Saba A; Immovilli M; Ferrari P; Gabbi M; Saccani M.

Correspondence: Franco Toscani, MD

Dr. Toscani and Prof. Di Giulio had full access to all data in the study and take the responsibility for the integrity of the data and the accuracy of the data analysis.

Funding

This work was supported by financial contributions from the Associazione Cremonese per la Cura del Dolore-ONLUS (ACCD) that did not have any role in the design or conduction of the study, analysis of results, or preparation of the paper. The ACCD is a no-profit, officially recognized non-governmental organization.

Conflict of interest statement. The authors declare no conflict of interest

Ethics. The ethics committee of the University of Modena approved the study protocol.

Contributions

Study concept and design, data interpretation, study supervision and drafting the manuscript: Toscani F, Di Giulio P, van der Steen JT, Charrier L, Finetti S, Pettenati F, Giunco F, Villani D, Gentile S, and Monti M

Statistical analyses: Charrier L

Data management and quality control: Finetti S

Administrative, technical and material coordination and support: Pettenati F

Study organization and data acquisition: Giunco F, Villani D, Gentile S, and Monti M

Data collection: Ventura M, Giangico F, Gandolfi N; Saya A, Mauro A; Colombetti R; Pani S; Cotticelli C; Saba L, Spotti F; Bacchi G, Gainotti; Belotti G, Milesi F; Rossi Borghesano S; Verando E; Migliorati G, Premoli M; Manganelli F; Caruso M; Minuti A, Feroldi A; Chiesara MA; Subashi B, Bellocchi A; D'Aquino N, Giovinazzo F; Bareggi MC, Spertini MT; Zucca F, Grigis M; Conte L; Panzera T; Cattaneo C; Biason A; Torchetti M.R, Pelliccioli I; Di Maggio MG, Villa I; Monti M, Gandelli M; Vignati M; Cutaia C, Chiarella G; Bellazzi L; Ribola M; Rubini E; Raineri C, Mainini E; Borsari M; Reggiani A; Balugani P; Buccella M; Cardillo A; Carillo S; Farinello A; Franchini F; Guidi MG; Luise L; Magnoni, E; Marchi K; Nava L; Sabetta A; Sani E; Sporziello M; Stermieri L; Martinelli M; Pirotti M; Costi A; Boni M; Capedri S, Cavecchi S; Dailari N; Favali E; Costoli E; Fossa G; Mazzone D; Patacini P; Ruozzi G; Sironi O; Murac A; Trolla L; Begotti S; Saba A; Immovilli M; Ferrari P; Gabbi M; Saccani M.

Abstract

Objective. To describe and compare the decisions critical for survival or quality of life (CDs) made for patients with advanced dementia in nursing homes (NHs) and home care (HC) services.

Design. Prospective cohort study with a follow-up of 6 months.

Setting. Lombardy Region (NHs) and Reggio-Emilia and Modena Districts (HC), Italy.

Participants. Patients (496 total; 315 in NHs and 181 in HC) with advanced dementia (Functional Assessment Staging Tool score ≥ 7) and expected survival ≥ 2 weeks.

Measurements. At baseline, the patients' demographic data, date of admission and of dementia diagnosis, type of dementia, main co-morbidities, presence of pressure sores, ongoing treatments, and current prescriptions were abstracted from clinical records. At baseline and every 15 days thereafter, information regarding the patients' general condition and CDs (deemed critical by the doctor or team) was collected via interview with the doctor. For each CD, the physician reported the problem that led to the decision, the decision that was eventually made, the purpose of the decision, whether the decision had been discussed with and/or communicated to the family, who made the final decision, whether the decision was maintained after one week, whether it corresponded to what the doctor would have judged appropriate, and the expected survival of the patient (≤ 15 days).

Results. For 267 of the 496 patients (53.8%; 60.3% in NHs and 42.5% at home), 644 CDs were made; for 95 patients, more than one CD was made. The problems that led to a CD were mainly infections (respiratory tract and other infections; 46.6%, 300/644 CDs); nutritional/hydration problems (20.6%; 133 CDs) and the worsening of a pre-existing disease (9.3%; 60 CDs). The most frequent type of decision concerned the prescription of antibiotics (overall 41.1%, 265/644; among NH patients 44.6%, 218/488; among HC patients, 30.2%, 47/156). The decision to hospitalize the patient was more frequently reported for HC than NH patients (25.5% vs. 3.1%). The most frequent purposes of the CDs in both settings were reducing symptoms or suffering (more so in NHs; 81.1 vs. 57.0% in HC) and prolonging survival (NH 27.5%; HC 23.1%; multiple purposes were possible). For 26 decisions (3.8%), the purpose was to ease death or not to prolong life.

Conclusions. Decisions critical for the survival or quality of life of patients with advanced dementia were made for approximately half of the patients during a 6-month time frame, and such decisions were made more frequently in NHs than in HC. HC patients were more frequently hospitalized, and a sizeable minority of these patients were treated with the goal of prolonging survival. Italian patients with advanced dementia may benefit from the implementation of

palliative care principles, and HC patients may benefit from the implementation of measures to avoid hospitalizing patients near the end of life.

Introduction

Physicians who care for older people near the end of life frequently make difficult decisions that balance medical, ethical, psychosocial, and societal considerations. Such critical decisions (CDs) may affect the time of death (hastening or postponing it), the place of death (home, hospital or nursing homes [NHs]),¹ and/or the manner in which the person will live his/her last days.² These decisions may involve admitting a patient to a hospital or a NH or withholding or withdrawing a treatment. In the case of advanced dementia, these decisions are complicated by the patient's incapacity and often by a lack of clear preferences. In the absence of a surrogate and of advanced directives (ADs), regardless of whether the family is involved in decisions, the ultimate responsibility for prescribing treatment falls on the physician: the physician is the prescriber, and must act in accordance with her/his professional and ethical standards.³ Advanced dementia may be perceived as a terminal condition,^{4,5} but because patients can survive for years with this condition, they are often exposed to aggressive and/or inappropriate treatments.⁶

Decisions to forgo artificial nutrition and hydration are among the most difficult and controversial ones^{7,8}, but even routine clinical decisions can impact the patients' quality of life and/or survival. Examples of such decisions are whether to use restraints for patients who oppose treatments, to sedate an agitated patient, or to prescribe invasive diagnostic tests. The literature highlights important differences among countries,⁹ and it is likely that differences exist among institutions and settings within the same country.¹⁰ Few studies have described the range of CDs for this population, and most focused on specific decisions.^{11,12}

Little is known about the purposes of this kind of decisions for patients with advanced dementia. However, some papers¹³⁻¹⁷ analyzed end-of-life decisions in different countries retrospectively interviewing the physicians who had cared for the deceased person. An exploratory retrospective study¹⁸ suggested that in Italy, clinical decisions in NHs during the last months of life were mostly curative, and palliative care had only a marginal role. To date, no studies have presented all of the decisions perceived as critical by the doctors who care for patients with advanced dementia.

The primary goal of this study is to describe and compare the CDs made for patients with advanced dementia in NHs and in home care services (HC). Descriptions of such decisions may deepen our insight into the care that patients with advanced dementia receive, highlight problems faced by health care professionals in NHs and HC, and suggest areas where decision-making support is needed.

Methods

A multicenter prospective observational cohort study (the End-Of-Life Observatory: Prospective Study on DEmentia patients Care [EOLO-PSODEC] study) was conducted from June 2007 to May 2009.¹⁹ The aims were to describe the treatments, discomfort, and CDs made for patients with advanced-stage dementia.

Setting and sample

A CD is the decision to start, withdraw, or withhold a treatment that the physician and/or the health care team perceive as critical to a patient's survival and/or quality of life. The following are examples of such decisions:

- Starting a treatment: the decision to start a new treatment or to restart a treatment that was stopped previously;
- Withholding a treatment: the decision to abstain from intervening in clinical situations that might have required action according to disease-specific guidelines or as a default: e.g., deciding not to perform diagnostic tests when prostate cancer is suspected; not starting tube feeding in a dysphagic patient; or not transfusing a patient despite severe anemia;
- Withdrawing a treatment: the decision to stop a therapy/treatment once it has begun.

Because of regional regulations, the organizational model of care (NHs vs. HC) in Italy implies important differences in the services provided to patients with dementia. This study was conducted in two regions: Lombardy, where care for patients with advanced dementia is mainly provided in certified NHs, and Emilia-Romagna, where service is mainly based on HC. In 2007, in Lombardy were 631 NHs, ranging in size from 19 to 700 beds (54,000 beds total).²⁰ In these NHs, a doctor is always available: either on site in larger facilities or on call in smaller facilities. These NHs have their own staff of physicians, nurses, physiotherapists, psychologists, and health aides. Several NHs doctors are specialized in Geriatrics or Internal Medicine. The residents are older people with major disabilities and post-acute patients who need long-term rehabilitation. Some NHs have specialized dementia wards. The NHs differ widely in the numbers of inpatients and services offered (i.e., occupational therapy, day care for Alzheimer's disease patients, cognitive therapy, physiotherapy, music therapy, etc.). Very few NHs offer palliative care consultation.

In Emilia Romagna, multidisciplinary teams provide disabled older people with assistance at home. HC consists of visiting nurses, who refer for the medical aspects of care to the patient's general practitioner (GP). Only a few GPs have specialized in Geriatrics. HC may also include visits by psycho-geriatricians, palliative-care consultants, social workers, and volunteers. Patients are given HC services only if they have a specific problem that requires nursing care, such as an indwelling catheter, a feeding tube, or a pressure sore. Patients are transferred to a NH only if their family caregiver is unable to provide sufficient care at home.

All 14 NHs with >300 beds were recruited to participate in this study, and a random sample of smaller NHs of the Lombardy Region (8% of the total), stratified into 8 strata based on the number of beds, as were the 5 districts (2 urban and 3 rural) of the Reggio-Emilia and Modena Provinces of the Emilia-Romagna Region. Only one of the NHs that was contacted refused to participate. Patients with a Functional Assessment Staging Tool (FAST)²¹ score ≥ 7 were enrolled. The FAST, a test designed to assess Alzheimer's disease, measures 7 main stages of dementia. Stage 7, the most advanced stage, is divided into 6 progressive sub-stages: 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. Only patients with an expected survival ≥ 2 weeks at baseline according to their primary doctor's clinical judgment were enrolled.

Data collection

Trained nurses employed by the NHs or the districts collected the data. Where the number of eligible patients exceeded the staff's capacity to collect all data, the coordinating center selected an appropriate sample of patients using a random number table. At baseline, on a given day, the researchers abstracted information from the clinical records that included demographic data, the date of admission and of the dementia diagnosis, the type of dementia, the main co-morbidities, ongoing treatments (artificial nutrition and hydration, dialysis, rehabilitation, mechanical ventilation, oxygen, restraints), and any current prescriptions (type of medication; dosages and indications were not collected). Pressure sores were documented only if they were \geq stage II (National Pressure Ulcer Advisory Panel [NPUAP] II;²² disepithelization). Discomfort was assessed every 2 weeks until death or the end of the follow-up (6 months) using the validated Italian translation²³ of the Discomfort Scale-Dementia of Alzheimer Type (DS-DAT).²⁴ At the same time, data were collected about the patients' general condition; any changes in the treatment plan, along with the reasons for the change; DS-DAT scores; and CDs.

Physicians were interviewed to identify CDs, and patients' medical records were examined to collect data on significant health problems -for example pneumonia or severe dehydration. We asked if problems possibly involved a CD. Thus, the additional examination of clinical records was used to minimize the chance of missing a CD. When two or more decisions were reported together during the same follow-up period for the same patient, the research panel selected the main intervention: for instance, "hydration and diagnostic exams" was classified as "hydration".

The problem that led to the each CD was selected from a predefined list based on previous research on CDs among Italian NH doctors,¹⁸ and an open-ended option was available to add information about any other decision that was perceived as critical. The doctor who made the decision was interviewed regarding the purpose of that decision; whether the decision had been discussed beforehand with, and/or communicated to, the family or to the patient's legal representative; who made the final decision; the expected survival of the patient (≤ 15 days) at the time the decision was made; whether the decision was maintained after one week; and whether it corresponded to what the doctor would have deemed appropriate. Any refusal to participate in the interview was recorded. Information about the interviewed doctors was also collected.

Statistical analyses

The data are shown as absolute and/or relative frequencies for categorical data and as the mean \pm SD or median and interquartile range (IQR) for continuous variables. The Shapiro-Wilk normality test was used to check the normality of continuous variables. The chi-square test was used for categorical variables. For continuous variables, t-tests for independent data or Mann-Whitney tests for non-normally distributed data were used to assess possible differences between the two groups. For all tests, the significance level was set at 0.05. All analyses were performed with Stata 12.

Results

A cohort of 496 patients (315 in the NHs and 181 in HC) was recruited (Table 1). Overall, one-third of the patients (34.2%) had Alzheimer-type dementia (40.0% in the NHs and 22.1% in HC). The patients receiving HC were older, more frequently male, and in more advanced stages of dementia, although they had fewer comorbid diseases. Almost all of the patients had at least one comorbid or concurrent condition (NHs 302/315, range 0-8, median 3; HC 172/181, range 0-10, median 2). At baseline, some of the NH patients received hydration (14.6%) or tube feeding (8.6%); the percentages were similar for the HC patients.

For 98 patients (20.6%; 21 patients were missing these data), the survival time at the specified follow-up period was estimated as ≤ 15 days. Only 3 NH patients had an advanced directive. In the NHs, most patients (248; 80.5%) received weekly visits from a relative; 40 (13.9%) received visitors monthly, and 20 (6.5%) received visitors less frequently. All except 6 of the NH patients (301, 95.5%) had an informal caregiver (a relative).

Follow-up

Three hundred sixty-two patients (72.9%) were followed up to 6 months: 73.2% (230) in the NHs and 73.3% (132) in HC. The reasons for not having further follow up (134; 27.1%) were death (20.2%; 100 overall, same percentages in

NHs and HC) and for 5 patients in each group, permanent (until death) admission to another institution or to the hospital without return to the NH or HC. In a few cases (24; 4.8%), the reason was not recorded.

Critical decisions and underlying problems

During the 6 months in 12.9% of the follow-ups (644/4988), CDs were made for 267 patients (95 had two or more CDs): 190 patients in NHs (60.3%) and 77 in HC (42.5%), with a range of 1-11 CDs (median 3) among the NH patients and 1-5 (median 2) among the HC patients. No CDs were made for 46% of patients (229/496). The proportion of patients without CDs was higher in HC (HC: 104, 57.5%; NHs: 125, 39.7%; $p < 0.001$). All interventions were withheld in 5.6% of the CDs (36/644). The problems that led to a CD (Table 2) were mainly infections (respiratory tract and other infections; 46.5%, 300/644 CDs) and nutritional problems (20.6%, 133 CDs), and, less frequently, the worsening of a pre-existing disease (9.3%, 60 CDs).

Typology of critical decisions

The CDs in the NHs and in HC are reported in Table 3; the most frequent was to administer antibiotics (26.6% in the NHs and 25.7% in HC); antibiotics plus hydration were provided more frequently in the NHs than in HC (18.0% vs. 4.5%). The decision to hospitalize a patient was more frequently reported in HC (25.5%) than in the NHs (3.1%). The reasons for hospitalization also differed: in HC, of the 39 hospitalizations, 6 were for acute events (falls, seizures, and other reasons), and all of the other were for the worsening of general conditions, infections and dysphagia. In contrast, in the NHs, the majority of the 15 hospitalizations were associated with acute/severe events (falls, 5 cases; anemia, 4 cases). Overall, for 61 patients (15.2% in the NHs and 7.1% in HC), the prognosis had worsened at follow-up, and these patients were expected to live ≤ 15 days. However, no NH patients with a prognosis of ≤ 15 days were admitted to the hospital; only 2 HC patients (of 42 admissions), one with a prognosis of ≤ 15 days, were admitted to the hospital. Furthermore, 3 HC patients were admitted to a NH (not shown).

In HC, the withholding of all possible interventions was also more frequent (11.5% vs. 3.7% in NHs), although in the NHs this withholding was most often applied to patients with a ≤ 15 day prognosis (10/18 vs. 4/18). The 29 CDs regarding the administration of drugs (other than antibiotics) mainly referred to steroids (16 cases) and morphine (11 cases). Other drugs were dopamine, nitrates, and laxatives (the number exceeds 29 because the decision involved administering more than one drug to the same patient in 3 cases).

Roles in the decision-making process

Physicians autonomously took over half of the decisions (57.7%, 345/598; missing information, 46); in 88 cases (14.7%), decisions were made together with the family. In only 3 cases (0.5%), the final decisions were made by the family or by the patient's legal representative; all of these decisions concerned withholding interventions. In HC, all but 4 decisions were discussed with the family (96.5%, 111/115; 41 patients were missing this information). In the NHs, only half of the CDs (50.0%; 11 cases were missing information) were discussed before they were implemented: in the other cases, they were mostly (76.0%) communicated to the family *post hoc*. In HC, all decisions to withhold all interventions were made with the family, were maintained and, with the exception of two cases, corresponded with what the physician would have preferred.

Purpose of the decisions

For 456/644 CDs (70.8%), a single purpose was reported; for 135 (21.0%), two purposes were reported; and for 11 CDs (1.7%), three or four purposes were reported (Table 4). There were significant differences in the distributions of the purposes of the decisions between the NHs and HC ($p=0.001$ selecting decisions with single purposes). In both settings, reducing symptoms or suffering (NH 81.1%; HC 57.0%) and prolonging survival (NH 27.5%; HC 23.1%) were the most frequent purposes of the CDs (additional purposes were possible). Prolonging survival was the single purpose for 63.8% (23/36) of the decisions in HC and 33.5% (45/134) in the NHs. In the other 102 cases, the purposes were prolonging life associated to reducing symptoms and suffering.

In 31 cases, the purpose was to “ease death” (i.e., improve the quality of death by minimizing suffering as death approaches, in accordance with the philosophy of palliative care; the physicians surveyed were all made aware of this definition) or “not to prolong life” (in 3 cases, both purposes were stated for the same decision). In 18 of these cases, the prognosis was ≤ 15 days. “Easing death” was never the only purpose of a decision.

A minority of the CDs about whether to administer antibiotics associated with parenteral hydration (9.4%, 25/265) cited prolonging survival as their single goal (11.5%, 25/218 in the NHs and none in HC); these decisions included 13 patients with an estimated survival of ≤ 15 days. In the majority of the cases (64.1%, 170/265 CDs), “reducing symptoms/suffering” was the sole purpose of the decision (61.5%, 134/218 in NHs and 76.6%, 36/47 in HC). Less frequently (22.6%, 60/265), the two goals were combined (24.8%, 54/218 in NHs and 12.8%, 6/47 in HC). Other goals or combinations were not frequent.

The 11 NH decisions to start artificial nutrition were aimed at prolonging survival in 8 cases and at reducing symptoms and suffering in 6 cases (in 3 cases, both purposes were reported). Tube feeding was started in one NH patient who was expected to die within 15 days. “To avoid prolonging life” was the single or a concurrent purpose cited

in 7 decisions. Five hundred thirteen CDs (85.8%; information missing for 46) were maintained after one week; 577/591 CDs (97.6%) corresponded with what the doctor would have chosen for the patient (information missing for 53). We did not collect information on physicians' academic qualifications. The large majority of decisions (396/488 in NHs and 131/156 in HC) were made by doctors with >5 years of experience (NHs: 47 decisions were made by doctors with 1-5 years of experience; HC: 23 decisions were made by doctors with 1-5 years of experience).

Discussion

To our knowledge, this is the first study to prospectively describe CDs for patients with advanced dementia from the health care professionals' perspective. Other studies have reported only on specific decisions.^{1, 10-12, 25} We found that CDs were made for roughly half of the patients with advanced dementia within a 6-month time window, and such decisions occurred more frequently in NHs (60.3%) than in HC (42.5%).

When a caregiver is available and the situation (e.g., home facilities and/or availability of services) allows, relatives prefer to keep the patient at home until the end.²⁶ Patients are usually admitted to HC services only if they have specific problems that require nursing care, and to NHs if the family caregiver is not able to manage the patient at home.²⁷ This may explain the higher baseline prevalence of pressure sores in HC patients and some other differences that do not necessarily indicate poorer care in HC than in NHs. During the six-month observation period, no CDs were made for 229 patients (46.1%). This result illustrates a highly uncertain trajectory: patients with advanced dementia may also remain in stable conditions for long periods.²⁸

The problems that most frequently led to a CD were infections, especially of the respiratory system; nutritional problems; and problems related to the worsening of clinical conditions. However, the choice of treatment for controlling symptoms such as restlessness can also be perceived as a CD. Even the decision to administer opioids, a decision that most clinicians would consider to represent mere standard care, was considered a CD in 11 cases. The under-prescription of analgesics has been described previously,¹⁹ using data collected for the present study. In Italy, despite improvements that have occurred in recent years, prescribers continue to exhibit a strong bias towards the (alleged) side effects of opioids,²⁹ and training programs are needed to change this attitude. Because of these biases, in some circumstances, drugs other than opioids such as antibiotics may have been prescribed to reduce symptoms of infection instead of analgesics, with questionable effectiveness.

Because the appropriateness of some prescriptions is questionable in comparable populations¹⁹ and no widely accepted guidelines are available, a thorough risk/benefit evaluation is sometimes difficult to perform. The types of problems that led to a CD differed between NHs and HC. In the NHs, more CDs for respiratory tract infections and

fewer for other infections may reflect either a greater incidence of respiratory infections in NHs, a different perception of the “criticality” of decisions concerning respiratory infections in HC, or both.

The most frequently made CD was the decision to administer antibiotics. Antibiotics may be used to treat pneumonia or to relieve symptoms. An observational study showed a lower 10-day mortality rate in patients with advanced dementia and pneumonia who were treated with antibiotics (HR 0.51- 95%; CI 0.30 - 0.87) compared with those who were not treated;³⁰ however, there was no reduction in long-term mortality. This finding suggests that in many cases antibiotics prolong dying rather than prolonging survival. Antibiotics can also be used to improve comfort^{31,32} by reducing symptoms such as bronchial congestion and dyspnea. In one-tenth of the cases in our study, antibiotics were used only to prolong survival, primarily by treating an infection. In the large majority of the cases, the sole purpose (66%) of administering antibiotics was to reduce symptoms and suffering; in less than one-fourth of the cases, antibiotics were used to prolong survival associated to reduce symptoms and suffering.

Clinical decisions about prescribing or withholding antibiotics seem to be difficult, and prognosis may play a role in decision making.³³ The goal of prolonging life is considered inconsistent with the palliative philosophy, and it is even less appropriate in cases of advanced dementia.⁷ Nonetheless, these findings confirm the existence of a gap between the recommendations of palliative care philosophy and the positions of doctors³⁴ and nurses,³⁵ who seem, at least in Italy, culturally more inclined to prolong life and thus to favor the administration of antibiotics.

While few of the CDs in this study related to artificial nutrition (2.3%, and only in the NHs), a substantial minority of the patients had feeding tubes at baseline (almost 10%). CDs regarding artificial hydration were more common and occurred very frequently in the NHs (39.8% vs. 16.0% in HC); at baseline, as many as 15.4% of HC and 14.6% of NH patients were already artificially hydrated. Overall, 219/644 decisions regarded the start of parenteral hydration, either alone or with other interventions. Italian health care professionals seem to perceive artificial hydration as more of a basic care need than artificial nutrition.³⁶ However, it may well be possible that in many cases artificial hydration was implemented instead of tube feeding to minimize the family’s anguish, for what Hoffer calls “cosmetic reasons”.³⁷ However, the physicians stated they agreed with the decision.

Hospital admission occurred more frequently in HC and often resulted from an acute event, similar to the findings reported for NHs in a study by Lamberg et al.¹ The NHs in our sample were more similar to “skilled NHs” and were equipped to care for severely disabled, frail patients, with doctors on site or on call. Consequently, patients in NHs may need hospitalization only for major medical treatments, such as surgery after a fall. Other treatments are offered on site, as they are in other comparable contexts where hospital admissions are also infrequent.³⁸ The HC services considered in

this study were not equipped to deliver specialized or intensive treatments.²⁷ In an older US study, HC patients were less often admitted to the hospital and less often exposed to feeding tubes and IV medications,³⁹ but those patients were in better health (more independent and with a better cognitive performance score) compared with the patients in our study.

An almost total absence of ADs was found, confirming the findings of a previous research on NHs in Lombardy Region.¹⁸ This phenomenon is not, however, limited to Italy, as ADs are equally scarce in other European countries.⁴⁰ However, in Italy, ADs do not have legal force, and the few ADs that patients have created are simply an expression of wish rather than of will

In the NHs, CDs were more frequently aimed at reducing symptoms or suffering. Only in a minority of cases was the purpose to “ease death” or “avoid prolonging life”. In other countries, physicians may be more willing to alleviate pain or other symptoms, even if it means increasing the risk of hastening death.¹⁵ However, curative treatment with the purpose of prolonging survival was an important component of care, as evidenced by 20% of the CDs (134/644). This may be partly related to the frequent lack of legal representatives (guardians) and advanced directives.^{16,18} In these cases, the decision-making power of the NH physician is stronger than the influence of the GP on the family of a patient who is cared for at home; decisions for HC patients are more likely to be made jointly by the GP and the patient’s family. In the NHs, most CDs were only communicated with family members after they were made, despite the fact that the large majority of our NH patients received family visits every day or several times a day, and the medical staff was present for many hours of the day and during weekends. Thus, physicians would have had opportunities to share critical decisions before implementing them. In Lombardy, however, the 2012 Regional Licensing and Regulatory Directive requires treatment decisions, in case of cognitive incapacity, are made together with the court-appointed legal guardian (when available), and be communicated to the family; consequently, the type of doctor/family communication described in this paper may have changed, and the families may be more involved in the decision making or at least better informed about the decisions taken.

Several factors, such as the context (setting and culture⁴¹) and the vocational training of each professional, may affect the perception of the “criticality” of decision for older people with advanced dementia. Physicians may have different perceptions³³ that can be explored only through discussions with those directly involved in the decision-making process.

Limits

When two or more CDs were reported during the same follow-up period for the same patient, our data might have resulted in a slight underestimation of decisions (e.g., pneumonia at the beginning of the period and a food intake

problem a week later that required a different decision). The lower number of CDs for artificial nutrition and hydration in HC might be explained by the higher hospitalization rate in HC. It is possible that hydration decisions were only made in the hospital.

We asked physicians about decision making rather than relying solely on data from charts. A major challenge, however, was the involvement of the GPs of the HC patients because they often did not visit the patients with the HC nurse, and they were not always available for interviews. Nevertheless, only 21 (13.4%) interviews were missing. Unfortunately, we did not have data about later decisions that were made in the hospital.

The aim of this study was to collect data regarding decisions that were perceived as critical and not to describe all of the decisions made for patients with advanced dementia. Although it is very unlikely given the decisions that were reported, it is possible that some decisions to hospitalize a patient, withhold a therapy or start parenteral hydration were not perceived as critical.

Conclusions

Decisions that were critical to the survival or quality of life of patients with advanced dementia were made for approximately half of the patients within a 6-month time frame, and such decisions occurred more frequently in the NHs than in HC. Our study suggests that in clinical practice in Italy, advanced dementia is often not perceived or treated as a terminal illness, even by physicians whose main practice is in the NHs. Because decisions, treatments, and purposes are often focused on curing patients, Italian patients with advanced dementia may benefit from the implementation of palliative care principles. In particular, HC can implement measures to avoid hospitalization near the end of life. Such measures would also be of relevance in the care of individuals with advanced dementia in other countries with policies that aim to keep elderly patients in their homes for as long as possible.

References

1. Lamberg JL, Person CJ, Kiely DK, Mitchell SL. Decisions to hospitalize nursing home residents dying with advanced dementia. *J Am Geriatr Soc* 2005;53:1396-1401.
2. van der Heide A, Deliens L, Faisst K, et al.; EURELD consortium. End-of-life decision-making in six European countries: descriptive study. *Lancet* 2003;362:345-509.
3. Silveira MJ, Kim SYH, Langa KM. Advanced directives and outcomes so surrogate decision making before death. *New Engl J Med* 2010;362:1211-1218.
4. Mitchell SL, Teno JM, Kiely DK, et al. The clinical course of advanced dementia. *N Engl J Med* 2009;36:1529-38.
5. van der Steen JT, Onwuteaka-Philipsen BD, Knol DL, et al. Caregivers' understanding of dementia predicts patients' comfort at death: a prospective observational study. *BMC Med* 2013;11:105.
6. Davies E, Higginson IJ, Eds. *Better palliative care for older people*. WHO Regional Office for Europe. Copenhagen, 2004. Website: <http://www.euro.who.int/document/E82933.pdf>. Accessed on March 5, 2014.
7. van der Steen JT, Radbruch L, Hertogh CM, et al. White paper defining optimal palliative care in older people with dementia: a Delphi study and recommendations from the European Association for Palliative Care. *Palliat Med* 2014;28(3):197-209.
8. van der Steen JT, Hertogh CM, de Graas T, et al. Translation and cross-cultural adaptation of a family booklet on comfort care in dementia: sensitive topics revised before implementation. *J Med Ethics* 2013;39(2):104-9.
9. van der Steen JT, Kruse RL, Ooms ME, et al. Treatment of nursing home residents with dementia and lower respiratory tract infection in the United States and The Netherlands: an ocean apart. *J Am Geriatr Soc* 2004;52:691-699.
10. Teno JM, Mitchell SL, Kuo SK, et al. Decision making outcomes of feeding tube insertion: a five-state study. *J Am Geriatr Soc* 2011;59:881-886.
11. Buiting HM, van Delden JJ, Rietjens JA, et al; EURELD-Consortium. Forgoing artificial nutrition or hydration in patients nearing death in six European countries. *J Pain Symptom Manage* 2007;3:305-314.
12. Mitchell SL, Teno JM, Intrator O, et al. Decisions to forgo hospitalization in advanced dementia: a nationwide study. *J Am Geriatr Soc* 2007;55:432-438.

13. Rietjens JA, van der Heide A, Onwuteaka-Philipsen BD, et al. A comparison of attitudes towards end-of-life decisions: survey among the Dutch general public and physicians. *Soc Sci Med* 2005;61:1723-1732.
14. Cohen J, Bilsen J, Fischer S, et al. End of life decision making in Belgium, Denmark, Sweden and Switzerland: does place of death make a difference? *J Epidemiol Community Health* 2007;61:1062-1068.
15. Löfmark R, Nilstun T, Cartwright C, et al. for the EURELD Consortium. Physicians' experiences with end of life decision-making: survey in 6 European Countries and Australia. *BMC Med* 2008;6:4.
16. Evans N, Pasman HR, Vega Alonso T, et al. End-of-Life decisions: a cross-national study of preference discussion and surrogate decision-maker appointments. *PLoS ONE* 2013;8(3): e57965.
17. Simionato L, Di Giulio P, Dimonte V, et al. Decisions affecting quality of life or survival for severely demented persons. A survey on doctors and nurses of nursing homes and districts. *J Hospice Palliat Nurs* 2010;12:378-384.
18. Di Giulio P, Toscani F, Villani D, et al. Dying with advanced dementia in long-term care geriatric institutions: a retrospective study. *J Palliat Med* 2008;11:1023-1028.
19. Toscani F, Di Giulio P, Villani D, et al. End of Life Observatory-Pro prospective Study on Dementia Patients Care Research Group. Treatments and prescriptions in advanced dementia patients residing in long-term care institutions and at home. *J Palliat Med* 2013;16:31-37.
20. Directory of the Regione Lombardia RSAs. Website:

<http://www.dati.lombardia.it/Famiglia/Elenco-RSA-Accreditate/vef4-8fnp>. Accessed on June 11, 2014.
21. Sclan SG, Reisberg B. Functional assessment staging (FAST) in Alzheimer's disease: reliability, validity, and ordinality. *Int Psychogeriatr* 1992;4:55-69.
22. National Pressure Ulcer Advisory Panel (NPUAP) Staging System. <http://www.npuap.org/resources/educational-and-clinical-resources/npuap-pressure-ulcer-stagecategories/> Accessed on April 12, 2014.
23. Dello Russo C, Di Giulio P, Brunelli C, et al. Validation of the Italian version of the Discomfort Scale - Dementia of Alzheimer Type. *J Adv Nurs* 2008;64:298-304.
24. Hurley AC, Volicer BJ, Hanrhan A, et al. Assessment of discomfort in advanced Alzheimer patients. *Res Nurs Health* 1992;15:369-377.

25. van der Steen JT, Ooms ME, van der Wal G, Ribbe MW. Pneumonia: the demented patient's best friend? Discomfort after starting or withholding antibiotic treatment. *J Am Geriatr Soc* 2002;50:1681-1688.
26. Livingston G, Leavey G, Manela M, et al. Making decisions for people with dementia who lack capacity: qualitative study of family carers in UK. *BMJ* 2010;341:c4184.
27. Directory of the Regione Emilia-Romagna RSAs. Website-
http://guidaservizi.saluter.it/NV_Online/nv_prestdetails.aspx?Prest_Code=80 Accessed on July 18, 2014.
28. Gill TM, Gahbauer EA, Han L, Allore HG. Trajectories of disability in the last year of life. *N Engl J Med* 2010;362:1173-80.
29. Toscani F, Di Giulio P, Brunelli C, et al.; End-of-Life Observatory Group. How people die in hospital general wards: a descriptive study. *J Pain Symptom Manage* 2005;30:33-40.
30. van der Steen JT, Lane P, Kowall NW, et al. Antibiotics and Mortality in Patients with Lower Respiratory Infection and Advanced Dementia. *J Am Dir Ass* 2012;13:156-161.
31. van Der Steen JT, Pasman HR, Ribbe MW, et al. Discomfort in dementia patients dying from pneumonia and its relief by antibiotics. *Scand J Infect Dis* 2009;41:143-151.
32. van der Steen JT. Prolonged life and increased symptoms vs. prolonged dying and increased comfort after antibiotic treatment in patients with dementia and pneumonia. *Arch Intern Med* 2011;171:93-94.
33. van der Steen JT, Helton MR, Ribbe MW. Prognosis is important in decision making in Dutch nursing home patients with dementia and pneumonia. *Int J Geriatr Psychiatry*. 2009;24(9):933-6.
34. Lacey D. Tube feeding, antibiotics, and hospitalization of nursing home residents with end stage dementia: perceptions of key medical decision makers. *Am J Alzheimer Dis Other Dem* 2005;20:211.
35. Basso I, Dimonte V. Un'indagine sulle decisioni degli infermieri sull'assistenza al paziente con demenza avanzata. *Assist Inferm Ric* 2013;32:73-83.
36. Valentini E, Giantin V, Voci A, et al. Artificial nutrition and hydration in terminally ill patients with advanced dementia: opinions and correlates among Italian physicians and nurses. *J Palliat Med* 2014; 17(10):1143-1149.
37. Hoffer LJ. Tube feeding in advanced dementia: the metabolic perspective. *BMJ* 2006;333:1214-1215.

38. Reyniers T, Houttekier D, Cohen J, et al. What justifies a hospital admission at the end of life? A focus group study on perspectives of family physicians and nurses. *Palliat Med* 2014;28(7):941-948. [Epub ahead of print]
39. Mitchell SL, Morris JN, Park PS, Fries BE. Terminal care for persons with advanced dementia in the nursing home and home care settings. *J Palliat Med* 2004;7:808-816.
40. Evans N, Pasman HR, Vega Alonso T, Van den Block L, et al. End-of-Life Decisions: A Cross-National Study of Treatment Preference Discussions and Surrogate Decision-Maker Appointments. *PLoS ONE*, 2013 8(3): e57965. doi:10.1371/journal.pone.00579659.
41. Lynn J, Arkes HR, Stevens M et al. Rethinking fundamental assumptions: SUPPORT's implications for future reform. *J Am Geriatr Soc* 2000;48:S214-221.

Table 1: Population baseline characteristics

	Nursing home patients (n=315)	Home care patients (n=181)	p-value
Demographics			
Male gender (%)	15.2	30.9	<0.0001
Age, mean (SD)	84.5 (8.4)	87.0 (7.3)	0.0007
Dementia			
Years since dementia diagnosis, median (IQR)	6.0 (4-9)*	6.0 (4-9) †	0.81 §
Years since dementia diagnosis, mean (SD)	7.0 (4.6)*	6.76 (3.6) †	0.61
FAST stage (%)			
FAST 7A,B	22.2	8.8	<0.0001
FAST 7C-F	77.8	91.2	
Discomfort			
DS-DAT median scores (IQR)	9.0 (4-15)	6.0 (3-11)	0.0004§
Type of dementia (%)			
Alzheimer’s disease	40.0	22.1	<0.0001
Vascular dementia	29.5	29.3	0.94
Mixed dementia	22.5	32.6	0.014
Fronto-temporal dementia	0.6	0.6	0.91
Lewy bodies dementia	0.3	1.7	0.11
Main health problems (%)			
Musculoskeletal	64.4	26.0	<0.0001
Ankylosis/contractures	59.4	39.2	<0.0001
Heart disease	48.9	50.8	0.67
Vascular disease, including stroke	36.5	30.4	0.16
Urologic disease	27.3	23.8	0.38
Metabolic disease	24.4	21.5	0.46
Pressure sores	17.1	33.3	<0.0001

Respiratory disease	15.9	12.7	0.33
Psychiatric disease	14.6	8.3	0.04
Cancer	9.2	5.5	0.14
Skin problems	8.9	11.1	0.43
Infections	1.6	1.1	0.66
Treatments (%)			
IV hydration (any) or S.C.	14.6	15.4	0.79
Tube feeding	8.6	9.9	0.61

* n=306;

† n=159;

§=Mann-Whitney

Table 2. Problems that led to a CD in nursing homes and home care

Problems and number of decisions	Nursing home (CDs n=488)		Home care (CDs n=156)		p-value
	N	%	N	%	
Infections: respiratory tract	143	29.3	26	16.6	0.002
Pneumonia (including aspiration pneumonia)	111	22.7	18	11.5	
Other respiratory tract infection	32	6.6	8	5.2	
Infections: other	89	18.2	42	26.9	0.02
Other non-respiratory, non-urinary severe infection	61	12.5	35	22.4	
Urinary tract infection	28	6.4	7	4.6	
Nutritional problems	96	19.6	37	23.7	0.27
Severe dysphagia	56	11.5	31	19.8	
Dehydration	22	4.5	4	2.5	
Food refusal	18	3.6	2	1.3	
Worsening of general conditions	84	17.2	37	23.7	0.07
Worsening of a pre-existing disease	37	7.6	23	14.8	
General worsening/coma	18	3.6	2	1.3	
Restlessness	16	3.2	5	3.2	
Drowsiness	10	2.0	1	0.6	
Events that would require hospital admission	3	0.6	6	3.8	
Other conditions	76	15.5	14	8.9	0.04
Anemia (≤ 7 Hb)	15	3.1	2	1.3	
Falls/trauma	15	3.1	2	1.3	
Vomiting/diarrhea	8	1.6	0	0	
Cancer	7	1.4	0	0	
Seizures	6	1.2	1	0.6	
Syncope/hypotension	5	1.0	2	1.3	
Other*	20	4.1	7	4.6	

* Other: ≤ 5 decisions total: pain (5), stiffness (4), pressure sores (3), hypoglycemia (2). Other conditions that were reported only once: deep venous thrombosis, delirium, electrolyte imbalance, wasting, coagulation deficiency, drowsiness, hemorrhage, bleeding from PEG, relieving the family's burden.

Table 3. CDs in nursing homes and in home care

	Nursing home (CDs=488)		Home care (CDs n=156)		p-value
	n	%	n	%	
Antibiotics	130	26.6	40	25.7	0.81
Artificial hydration (I.V. or S.C.)	106	21.7	18	11.5	0.005
Antibiotics+hydration	88	18.0	7	4.5	<0.0001
Diagnostic exams	30	6.2	8	5.1	0.64
Symptom control (analgesics, sedatives for restlessness)	30	6.2	7	4.4	0.44
Drug administration (mostly steroids)	22	4.6	7	4.5	0.99
Admission to hospital	15	3.1	39	25.5	<0.0001
No intervention	18	3.7	18	11.5	0.0002
Discontinuation of drugs	12	2.5	3	1.9	0.74
Enteral nutrition	11	2.3	0	0	0.11
Discontinuation of palliative sedation	8	1.6	2	1.3	0.81
Deep or terminal sedation	7	1.41	1	0.7	0.49
Discontinuation of other treatments*	5	0.8	1	0.7	0.74
Discontinuation of artificial nutrition or hydration	4	0.8	0	0	0.63
Blood transfusion	3	0.6	0	0	0.81
Hydration and drugs	2	0.6	0	0	0.98
Other (≤ 5 decisions)†	9	1.8	4	2.6	0.57

* NH: drugs+sedation, sedation, hydration, nasogastric tube, antibiotics+hydration.

HC: hydration+lab exams.

†Fluid thickeners (5), use of restraints (2), physiotherapy (1), administration of food supplements (1), hydration + opioids (1), surgical cleaning of the wound (1), bladder catheter (1), oral feeding (1).

Table 4. Purposes of the CDs

Purpose	NH (CDs=488)			HC (CDs=156)		
	Total		1 purpose	>1 purpose	Total	
	n	%	n	n	n	%
Reduce symptoms/suffering	396	81.1	268	128	89	57.0
Prolong survival	134	27.5	45	89	36	23.1
Avoid/stop futile treatments	39	8.0	15	24	16	10.3
Avoid prolonging survival	25	5.1	7	18	1	0.6
Ease death*	8	1.6	0	8	0	0
Other	18	3.7	10	8	2	1.2

The purpose was missing for 11 CDs in NHs and 29 in HC.

No doctor's interview took place for 21 CDs: in 8 cases because of organizational problems and in 13 cases because the doctor was unavailable.

* i.e. improving the Quality of Death by minimizing suffering as death approaches, following the Palliative Care philosophy