Changes in Care Goals and Treatment Orders Around the Occurrence of Health Problems and Hospital Transfers in Dementia: A Prospective Study

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OBJECTIVES: To explore changes in care goals and treatment orders around the occurrence of pneumonia and intake problems, and whether hospitalization is in line with earlier agreed-upon do-not-hospitalize orders.

DESIGN: Data were collected as part of the Dutch End of Life in Dementia study (2007–2011), a longitudinal observational study with up to 3.5 years of follow-up.

SETTING: Long-term care facilities (N = 28) in the Netherlands.

PARTICIPANTS: Newly admitted nursing home patients (N = 372) in various stages of dementia.

MEASUREMENTS: Semiannually, physicians completed questionnaires about care goals and treatment orders, and they continuously registered episodes of pneumonia, intake problems and hospitalization. We report on changes in care goals and treatment orders during follow-up in relation to the developing of pneumonia and intake problems and on hospitalization and reasons for hospitalization.

RESULTS: The proportion of patients with palliative care goals and do-not-treat orders rose during follow-up, especially before death. Treatment orders most frequently referred to resuscitation and hospitalization (do-not order increased from 73% to 92%, and from 28% to 76%, respectively). The proportions of patients with a palliative care goal and do-not-treat orders were similar after developing pneumonia, but increased after intake problems. During follow-up, 46 patients were hospitalized one or more times. Hospitalization occurred despite a do-not-hospitalize order in 21% of decisions. The most frequently reported reason for hospitalization was a fracture, especially in patients with a do-not-hospitalize order.

CONCLUSION: Care plans, including global care goals (predominantly palliative care goals), are made soon after admission, and specific treatment orders are agreed upon in more detail when the condition of the patient worsens. Establishing care plans shortly after nursing home admission may help to prevent burdensome treatment. **J Am Geriatr Soc 65:769–776, 2017.**

Key words: dementia; advance care planning; care goals; treatment orders; hospitalization

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Dementia is a disease without a cure, and one of the key components of the quality of palliative care for patients with dementia is advance care planning.[1–3] Advance care planning is especially important for people with dementia because the gradual loss of cognitive abilities complicates decision making at the end of life.[1,4–6] In the last phase of life, the majority of people with dementia in the United States and Western Europe are admitted to and eventually die in long-term care facilities.[7] Advance care planning in long-term care in dementia concerns timely and ongoing discussions about care goals, and part of this is communication about end-of-life issues. Most of the patients in long-term care are unable to make decisions at the end of life and discussions therefore often take place with proxy decision-makers[1,4,8–11]

Informing patients and families about expected health problems that influence quality of life and survival, such as pneumonia and intake problems, can help initiate a discussion about care goals.[1,3,12–18] In addition, physicians may discuss treatment orders such as resuscitation and

hospitalization anticipating future scenarios with proxy decision-makers. A do-treat order or a do-not-treat order anticipating future scenarios can be recorded in the patient's medical file, and can be tailored to each specific scenario.[6,19,20]

Establishing care plans may be influenced by culture, organizational models, and healthcare settings.[2,21–23] An environment with physicians specialized in dementia and advance care planning who are frequently present in the long-term care facilities may promote the development of care plans.[2,23–25] In this type of setting, we found that more than half of patients with dementia had a palliative care goal shortly after admission to long-term care,[26] and 85% had documented treatment orders during nursing home stay.[20] However, no longitudinal data, and no data about care goals and treatment orders around the occurrence of expected health problems have been published so far. Therefore, the aim of our study was to explore the changes in care goals and treatment orders over time and around the occurrence of two common health problems during the course of dementia, i.e., pneumonia and intake problems. Further, we explored whether hospitalization of patients with dementia in long-term care in the Netherlands was in line with earlier agreed upon do-not-hospitalize orders.

METHODS

Data Collection

Data were collected as part of a longitudinal observational study, the Dutch End of Life in Dementia study.[27] Between 2007 and 2011, data were prospectively and retrospectively collected on 491 patients in 34 long-term care facilities. In this study we only used prospectively collected data on 372 patients with dementia at any stage admitted to 28 facilities. They were enrolled upon admission between January 2007 and July 2009. We only used the prospectively collected data because only these longitudinal data can answer our research question. Elderly care physicians were responsible for data collection by completing written questionnaires.

Individual assessments were performed for a maximum period up to 3.5 years (January 2007–July 2010; survival was monitored for an additional year, until summer 2011). A baseline assessment was scheduled 8 weeks after admission, followed by a maximum of five semiannual assessments. In case of death during the study period, a questionnaire about the last 6 months of life was completed within 2 weeks after death, and we refer to this questionnaire as the after-death assessment. Physicians additionally registered any incident pneumonia and intake problems on a continuous basis.

Characteristics of the patients have been published elsewhere; most patients were women (70%), at admission mean age was 84 years (SD = 7), 9% of the patients had advanced dementia (Cognitive performance Scale[28] score 5 or 6, and a Global Deterioration Scale[29] score 7), and the most common type of dementia was Alzheimer's disease (46%).[30] During follow-up, the number of patients decreased across consecutive assessments as patients died. In total, 218 patients died during follow-up; 34 died before

or shortly after the baseline assessment, and 4 patients were lost to follow-up before the baseline assessment.[30] The median length of stay until death was 8 months (25th percentile = 4, 75th percentile = 17 months).[30] The study protocol was approved by the Medical Ethics Review Committee of the VU University Medical Center in Amsterdam, and written informed consent was obtained from the families.

Measurements

The attending physicians recorded their specialty, age, number of years of experience in long-term care, and the full-time equivalents they worked in the long-term care facilities. Further, physicians recorded whether there was a general discussion with proxy decision-makers about the care goals (at baseline) and the treatment orders (at all assessments). At baseline, at every semiannual assessment, and after death, physicians recorded the main care goal. The main care goal categories were life prolongation, palliative care goal (palliative and symptomatic care goal), preserve functioning, other and no-care goals. Palliative and symptomatic goals both refer to comfort, quality of life and well-being, but differ as to whether prolongation of life is desirable.[31] In addition, physicians recorded treatment orders anticipating future scenarios. Treatment orders were assessed as a do-treat order, a do-not-treat order, or no order, and a pre-structured list of treatment orders was included in the questionnaires. First, for each treatment order separately, the physicians reported whether a discussion took place with a proxy decision-maker, and second, what decision the physician and the proxy decision maker made in advance. They did this at the baseline assessment (referring to the previous 8 weeks), at the semiannual assessments (for the previous 6–month period), and at the after-death assessment (maximum 6 months prior to assessment). Further, physicians could report the reason for not discussing treatment orders in an open-ended question. Unfortunately, at the semiannual and at the after-death assessment some physicians reported "no new order in the last six months" as "no order," when an interim discussion did not take place. So in these cases, we recoded these answers into the last available "do-treat" or "do-not-treat order." Further, physicians recorded at all assessment whether a patient was hospitalized in the previous period, including date of hospitalization and the reason for hospitalization.

Physicians registered any incident pneumonia and intake problems and the date of diagnosis on a continuous basis. Pneumonia was diagnosed by the attending physician. We defined intake problems as an eating or drinking problem as judged by the attending physician. After developing a pneumonia or an intake problem, the physician reported whether this patient had a do-not-treat order.

Statistical Analyses

We describe the physician characteristics and timing of discussions as reported by the treating physician. We calculated the proportion of patients with care goals and treatment orders. In addition, we separately reported the main care goals and the treatment orders at the

assessments before the patient developed pneumonia or intake problems (a minimum period of 6 months before), and after these health problems. Theoretically, the period between these health problems and the last assessment is at most 6 months. We only used the data of the first episode of pneumonia and the first time an intake problem occurred.

We reported any possible differences in the prevalence of palliative care goals (vs all other goals) between patients who developed pneumonia and patients who did not develop a pneumonia, and between patients who developed intake problems and who did not.

To evaluate the longitudinal changes in palliative care goals (vs all other goals), we used the generalized estimating equation (GEE) model, with an exchangeable correlation structure. The models used assessment as the independent predictor with repeated contrast levels. We separately analyzed the assessments 1 through 6, and the last assessment before death through the after-death assessment. A significant change between two consecutive assessments indicates a change at the population level (i.e., change in the total proportion of patients with a palliative goal) or at an individual level (i.e., the individual change in palliative goal). To test changes in palliative care goals around the developing of pneumonia and intake problems, we separately analyzed the last assessment before the occurrence of the health problem and the first assessment after the occurrence of the health problem.

Further, we calculated the hazard ratio of hospitalization in the first year after admission, and the proportions of patients who were admitted to a hospital during follow-up. To explore whether hospitalization was in line with treatment orders discussed earlier, we compared these with the most recent treatment orders before hospitalization. Analyses were performed with SPSS 20.0.0 (IBM, 2011).

RESULTS

Physician Characteristics

Of all physicians, 81% were elderly care physicians, 15% elderly care physicians in training, and 4% had other specialties; thus, 96% of the physicians received training in palliative care.[32] Physicians' mean age was 41.2 years (SD = 9.2), and they had an average of 10.5 (SD = 8.1) years of experience in long-term care. The mean full-time equivalent that physicians worked in the long-term care facilities was 0.8 (SD = 0.2).

Discussions About Care Goals and Treatment Orders Anticipating Future Scenarios

Physicians discussed care goals with proxy decision-makers of 80% (262/327) of the patients within the first 8 weeks after admission. The proportion of patients with a palliative care goal increased significantly from 57% on admission to 65% in the 6 months afterward, and increased significantly from the last semiannual assessment before death to 90% at the day of death (Table 1). Although 19% of the patients did not have a care goal on admission, most of these patients (94%) did have a care goal in the 6 months afterward (Table 1).

Physicians had discussions about treatment orders with proxy decision-makers for 80% of the patients at baseline, for 27–51% across the semiannual assessments, and for 79% in the last 6 months of life. The most frequently reported reasons for not discussing treatment orders semiannually were (in total, 377 reasons were reported by physicians): there was no need to reassess the treatment orders (n = 136), treatment orders were already clear (n = 75), there were no changes (n = 55), and the condition of the patients was stable (n = 32).

The most frequently discussed treatment orders anticipating future scenarios were resuscitation and hospitalization. The proportion of patients with a do-not-resuscitate order rose from 73% shortly after admission to 84–91% across the semiannual assessments, and rose further to 92% in the last 6 months of life (Figure 1). The proportion of patients with a do-not-hospitalize order increased from 28% to 42–59% and further to 76% in the last 6 months of life (Figure 1).

Changes in Decisions Around Developing Pneumonia and Intake Problems

At baseline, care goals for patients who subsequently developed pneumonia or an intake problem were very similar to care goals for patients who did not develop these problems (Table 1). The proportion with a palliative care goal was 72% at the semiannual assessment prior to episodes of pneumonia and intake problems (Table 1). We found an upward trend of prevalence of palliative care goals related to the development of pneumonia. Related to intake problems, we found a significant upward trend in the proportion of patients with a palliative care goal, and the proportion at the day of death was significantly larger than patients who did not develop an intake problem (95% vs 84%) (Table 1).

At baseline, there was also no difference in distribution of treatment-orders between patients who developed pneumonia or intake problems, and those who did not. We found an upward trend of prevalence of do-no-treat orders related to the development of pneumonia similar to the whole sample, and for intake problems we found a stronger increase of the proportion patients with do-not-treat orders over time (Table 2 and Figure 1). For example, of the patients who developed pneumonia, the proportion with a do-not-hospitalize order was 25% at baseline, which rose to 35% before the occurrence of pneumonia and to 46% after developing pneumonia; of the patients who developed an intake problem, the proportion with a do-not-hospitalize order was 33% at baseline, which rose to 49% before occurrence of intake problems and to 62% after developing intake problems.

Hospitalization

Overall, the hazard rate for hospitalization in the first year was 0.12 (95% CI 0.08–0.17). During follow-up, 46 patients were hospitalized (eight patients two times, one patient three times and one patient five times). One of these patients was admitted to an intensive care unit in the last 14 days of life. Of the 60 hospitalization decisions, 15 were referred to hospital in the first 8 weeks of admission,

Table 1. Most Important Care Goals and Changes in Palliative Care Goals over Time

Care Goal	Assessment	N	Life Prolongation (%)	Palliative (%)	Preserve Functioning (%)	Other (%)	No Care Goals (%)	Change in Palliative Care Goal (P-Value)
All patients	1	(326)[a]	1	57	21	3	19	
	2	(221)	5	65	23	4	2	0.003
	3	(172)	5	65	27	2	2	0.936
	4	(122)	5	69	23	2	1	0.253
	5	(76)	4	70	25	0	1	0.813
	6	(34)	6	65	24	3	3	0.809
	At the day of death	(211)	1	90	4	1	4	0.000
Neither problem	1	(158)[a]	0	53[f]	22	3	22	
	2	(115)	4	65	23	5	2	0.004
	3	(92)	5	61	30	1	2	0.660
	4	(67)	7	66	25	1	0	0.392
	5	(42)	2	69	26	0	2	0.680
	6	(18)	6	56	28	6	6	0.482
	At the day of death	(74)	1	84 [g]	8	1	5	0.005
Pneumonia	1	(86)[b]	3	63[f]	14	3	16	
	before	(78)	4	72	13	4	8	
	after	(73)[c]	3	73	18	3	4	0.880 [h]
	At the day of death	(57)	4	86 [g]	5	0	5	
Intake problems	1	(102)[d]	0	60[f]	18	5	18	
	before	(100)	2	72	15	4	7	
	after	(94)[e]	1	93	5	0	1	0.000 [h]
	At the day of death	(81)	1	95 [g]	2	0	1	

Changes in palliative care goals (vs all other care goals) over time was measured with GEE with repeated contrasts between two consecutive assessments. The p-value provides an indication for change over time over two consecutive assessments at a population level and at an individual level.

Van Soest et al.[26] reported only care goals at assessment 1 and at the day of death.

[a]Thirty-four patients died before or shortly after the baseline assessment. We used a shortened baseline assessment, to complete only the data of patient characteristics that we deemed not particularly vulnerable to recall bias. Four patients were lost to follow-up before the baseline assessment.

[b]Fifteen patients developed pneumonia before the baseline assessment; these cases were therefore removed from the selection for analyses. In 44 patients, the baseline assessment was also the assessment before developing pneumonia.

[c]Fifty patients died within 6 months after developing pneumonia, so the assessment was also the after-death assessment and refers to the care goal at the time of death.

[d]Seventeen patients developed an intake problem before the baseline assessment and were therefore removed from the selection for analyses. In 48 patients, the baseline assessment was also the assessment before developing an intake problem.

[e]Seventy-nine patients died within 6 months after developing intake problems, so the assessment was also the after-death assessment and refers to the care goal at the time of death.

[f]No significant differences at baseline in proportions of patients with palliative care goals (versus all other goals) between the subgroups.

[g]No significant differences at the day of death in proportions of patients with palliative care goals (versus all other goals) between patient who developed a pneumonia and patients who did not develop a pneumonia ($X2 = 1.026$, $P = .331$).

We found a significant larger proportion palliative care goal (vs all other goals) at the day of death in patients who developed an intake problem than patients who did not develop an intake problem ($X2 = 4.902$, $P = .027$).

[h]The P-value provides an indication for changes in palliative care goals (vs all other care goals) over two consecutive assessments: the last assessment before the occurrence of the health problem and the first assessment after the occurrence of the health problem).

16 in the last 6 months of life, and 29 hospitalizations occurred in between. Of the patients who were hospitalized during follow-up, 6% had life prolongation as care goal, 49% had a palliative care goal, 39% had preserve functioning as care goal, 2% had another care goal, and 12% had no care goal. Further, 57% (27/47; missing n = 13) had a do-hospitalize order, 21% (10/47) had a do-not-hospitalize order, and 21% (10/47) had no order (Table S1). The most frequently reported reasons for hospitalization were bone fractures (43%; 25/58 (23 hip fractures, 1 jaw fracture, 1 rib/humerus fracture); missing n = 2), cardiovascular problems (12%; 7/58), and urogenital problems (10%; 6/58; Table S1). A fracture was the reason for hospitalization for 6 of the 10 patients with a do-not-hospitalize order.

DISCUSSION

To the best of our knowledge, this is the first longitudinal study that describes the changes in care goals and treatment orders around the occurrence of health problems in patients with dementia during nursing home stay. We found that care plans, including global care goals, were made shortly after admission. The proportion of people with palliative care goals was unchanged after pneumonia, and increased substantially after intake problems and in the period shortly before death (last 6 months of life). Treatment orders most frequently referred to resuscitation and hospitalization. Although hospitalization was rare, one fifth of those with a do-not-hospitalize order were hospitalized. The most frequently reported reason for
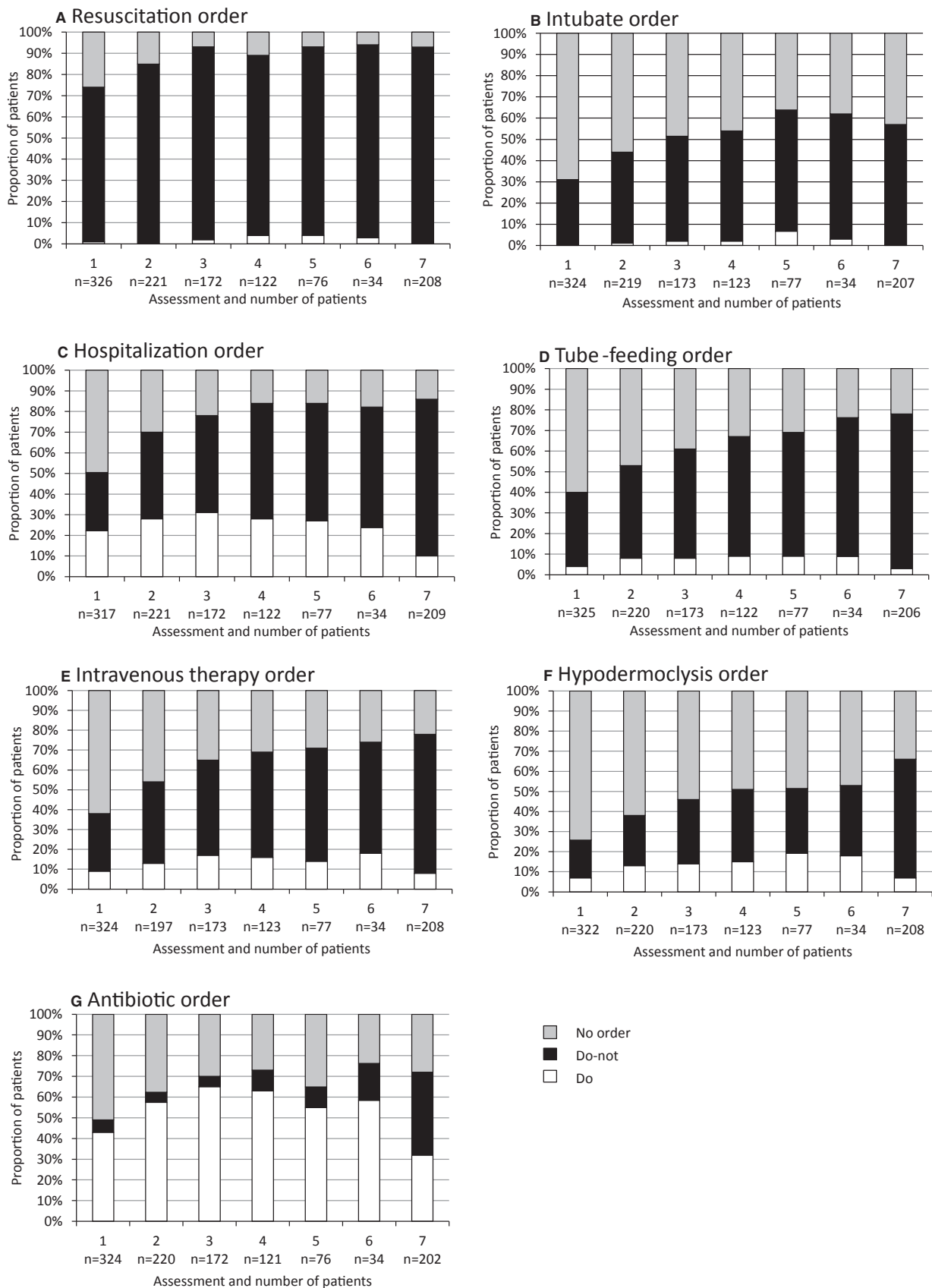
Figure 1. Trajectories of treatment orders over time of all patients. The numbers 1 through 7 on the *x*-axis refer to the assessments. 1 = baseline assessment, 2–6 = semiannual assessments, 7 = after-death assessment.

Table 2. Treatment Orders Around the Developing of Pneumonia and Intake Problems

Do-Not-Treat Order	Baseline %	Decided Before Health Problem %	Decided After Health Problem %	Shortly Before Death[b] %
Neither problem (n)	(158)			
Resuscitation	69			94
Intubate	28			55
Hospitalization	28			72
Tube-feeding	35			76
Intravenous therapy	28			72
Hypodermoclysis	19			51
Antibiotics	7			33
Pneumonia (n)	(86)[a]	(86)	(86)	(58)
Resuscitation	80	87	89	91
Intubate	33	40	51	58
Hospitalization	25	35	46	67
Tube-feeding	39	50	59	66
Intravenous therapy	25	36	48	57
Hypodermoclysis	19	23	30	55
Antibiotics	4	2	10	36
Intake problem (n)	(103)[b]	(105)	(105)	(81)
Resuscitation	73	87	91	96
Intubate	33	48	54	62
Hospitalization	33	49	62	85
Tube-feeding	41	53	65	80
Intravenous therapy	34	47	55	61
Hypodermoclysis	20	33	46	69[c]
Antibiotics	5	8	18	40

[a]Fifteen patients developed pneumonia before the baseline assessment; these cases were therefore removed from the selection for analyses. In 44 patients, the baseline assessment was also the assessment before developing pneumonia.

[b]Seventeen patients developed an intake problem before the baseline assessment and were therefore removed from the selection for analyses. In 48 patients, the baseline assessment was also the assessment before developing an intake problem.

hospitalization was a fracture, especially in the group of patients with a do-not-hospitalize order.

We found that care plans were often established shortly after admission. Care plans were generally not reassessed as long as the condition of the patient was stable. Resuscitations and hospitalization were the most acute decisions and the most frequently discussed treatment orders in our study. We found an upward trend in the prevalence of nontreatment orders and a strong increase before death. We found a similar upward trend in the prevalence of nontreatment orders for patients who developed pneumonia or an intake problem. Moreover, our study, like other studies, suggests that intake problems are a relevant trigger for discussions and an important signal of a worsening condition.[17,21,33,34] Although infection of the respiratory system may lead to critical decisions about treatment,[23] pneumonia may have been perceived as an intercurrent and reversible disease, unlike intake problems in patients with dementia.

Hospitalization was rare in our study; only 1 in 10 patients was hospitalized in the first year after admission. A do-not-hospitalize order did not always prevent hospitalization, as demonstrated by the 10 patients we found with a do-not-hospitalize order who were subsequently admitted to the hospital. However, these patients mainly had (hip) fractures, which generally require surgery to improve the quality of life.[35,36]

Our findings may reflect Dutch medical practice in long-term care. In the Netherlands, quality of life is an important aspect in end-of-life decisions and often outweighs life prolongation. Forgoing medical interventions is accepted practice.[37] This may result in the fact that the majority of patients having a palliative care goal and this may lead to do-not-treat orders. Comparing our findings with other studies, we found some differences that may reflect different policies, organizational models and health care settings.[2,38,39] First, we found a higher prevalence of do-not-hospitalize orders than Houttekier et al. in a retrospective Belgian study (76% in the last 6 months of life in the Netherlands vs 57% in the last month of life in Belgium).[40] We also found a higher prevalence of do-not-hospitalize orders than Lamberg et al. in a study from the United States (42–59% at least 6 months before death versus 34% at 6 months before death).[25] Patients in the United States with do-not-hospitalize orders were less likely to be hospitalized than patients without a do-not-hospitalize order.[41] Second, we found a notably smaller proportion of patients who were hospitalized than Houttekier et al. in the Belgian study (8% were hospitalized in the Netherlands in the last 6 months of life versus 20% in Belgium)[40] and smaller proportions than in studies from the United States (12% were hospitalized in the Netherlands during nursing home stay vs 16–25% in the United States during nursing home stay).[25,42,43] Finally, reasons for hospital admission in our study were mostly (hip) fractures, and in a few cases cardiovascular problems, urogenital problems, and gastrointestinal bleedings, while in the United States infection and pneumonia were found to be the most common reasons for hospitalization.[41]

Strengths and Limitations

Our study was unique in that we investigated the changes in care goals and treatment orders from nursing home admission until death, and the longitudinal design allowed for studying changes related to pneumonia, intake problems, and hospitalization. Some limitations should be acknowledged. First, we reported our results mainly from the perspective of physicians. Although physicians have an important role in initiating advance care planning, other disciplines can also play a role in observing needs and initiating advance care planning.[1] Second, any pneumonia and intake problems were recorded continuously, but we assessed changes in care goals and treatment orders semiannually. Third, physicians reported for each treatment order separately whether a discussion took place and which decision was made in advance. In case an interim discussion did not take place and the physician reported "no order" instead of "no new order in the last 6 months," we recoded these answers into the last available "do-treat" or "do-not-treat order." Recoding this data may underestimate the proportion of "no order," and may overestimate the proportion of "do-treat/do-not-treat orders." However, in practice it is very likely that an order only changed from a "do order"/"no-order" into a "do-not- treat order," and

moreover it is very likely that an order only changed when this is discussed with family. For example, for resuscitation orders, we checked the recoded answers with the reported reason for not discussing treatment orders. In 91%, physicians explained that no discussion was needed because the condition of patient was stable and/or the treatment orders were already clear.

Recommendations

Dementia is a disease without a cure, and while many people diagnosed with dementia will die with or from this disease, intercurrent diseases and burdensome symptoms frequently develop during the disease trajectory.[1] Therefore, a strong focus on palliative care needs is recommended. This call for an active focus on advance care planning. Our findings suggest that establishing care plans shortly after nursing home admission helps to prevent burdensome and unnecessary treatment such as hospitalization. Although not all scenarios can be discussed beforehand,[2,3,9,31,44] discussion of the most common health problems and the most acute decisions is recommended when establishing a care plan.[1,17,21,40] Communication with proxy decision-makers about the circumstances and conditions surrounding future scenarios such as pneumonia, intake problems, and hospital transfer is important to reduce burdensome, unnecessary treatment and to help patients and families prepare for the future.[40,45]

In the Netherlands this is supported by an organization model with ample availability of physicians specially trained in elderly care medicine, who see their patients and relatives frequently. Elderly care physicians are employed by the nursing homes and follow a 3-year training, which includes training in advance care planning and palliative care.[32] Elderly care physicians have a strong and often decisive influence on decision making[32,46,47] and facilitate discussions on advance care planning and establishment of care plans.[9] Characteristics of this type of organization model may have a positive influence on advance care planning in dementia care. Further, there is a strong policy tendency from the government to postpone nursing home admission as long as possible. As a consequence, there will be more and more patients living at home and treated in primary care with more severe stages of dementia. Therefore, it is very important to establish care goals in an earlier phase of dementia to provide adequate care in primary care also.

There is an emerging need to understand how professionals deal with decision-making in dementia and how establishing care goals and anticipation to the most common and acute health problems may influence care outcomes and quality of care. Therefore, future cross-national and qualitative research, in particular participant observation research, may explore the rationale of care actions that do not correspond with the care plan that was established in advance. Future studies should examine what level of detail is most effective for care planning at different times, for example proximate to transitions, such as hospitalization, acute problems and gradual decline.

CONCLUSION

Care plans, including global care goals (predominantly palliative care goals), for patients with dementia in Dutch long-term care facilities, are drawn up soon after admission and are reassessed and discussed in more detail when the condition of the patient worsens. Care plans that anticipate expected health problems in the trajectory of dementia and that anticipate the most acute decisions may help prevent burdensome, unnecessary treatment such as transfers to the hospital.

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SUPPORTING INFORMATION

Additional Supporting Information may be found in the online version of this article:

Table S1 Hospitalization during follow-up

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