

## Title

Improved patient participation through advance care planning in nursing homes – a cluster randomized clinical trial.

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# Abstract

## Objective

To investigate how implementing advance care planning with a whole-ward approach impact patient participation in nursing homes.

## Methods

This was a pair-matched cluster randomized clinical trial with eight wards in eight Norwegian nursing homes. We randomized one ward from each of the matched pairs to the intervention group. We included all patients above 70. The primary outcome was prevalence of documented patient participation in end-of-life treatment conversations.

The intervention included implementation support fostering the advance care planning with patient and next of kin.

## Results

In intervention group wards the patients participated more often in end-of-life treatment conversations ( $p < 0.001$ ). Moreover, the patient's preferences, hopes or worries ( $p = 0,006$ ) were more often documented, and concordance between treatment provided and patient preferences ( $p = 0,037$ ) and next of kin participation in advance care planning with the patient ( $p = 0,056$ ) increased.

## Conclusion

Improved patient participation – also when cognitively impaired - is achievable when regular staff perform advance care planning in nursing homes. Next of kin can have a key role.

## Practice implications

Patients with cognitive impairment should be included in advance care planning supported by next of kin. A whole-ward approach may be more sustainable than other approaches.

## Trial registration

ISRCTN registry (ID ISRCTN69571462) – retrospectively registered.

Key words: Advance care planning, nursing home/long term care, dementia, documentation, patient participation, supported decision-making, whole-system approach

# 1. Introduction

Advance care planning (ACP) is a process that supports adults at any age or stage of health in understanding and sharing their personal values, life goals, and preferences regarding future medical care (1). ACP also addresses individuals' concerns across the physical, psychological, social, and spiritual domains (2). The nursing home (NH) patients may benefit from ACP (3). However, systematic reviews found most older people residing in NHs had never talked about their preferences for end-of-life care with their family or residential staff (4), despite most older adults wanted to discuss their end-of-life care (5, 6). Furthermore, prognostic issues of dementia are avoided by health professionals (7). NH-physicians (often general practitioners) may feel uncomfortable doing ACP with patients with dementia (8), and NH managers indicated a reserve towards ACP for people with dementia (9). In addition, patients with dementia are often not included in ACP-studies in NHs (10). We included patients with dementia in this implementation study of ACP in NHs.

Patient participation in ACP may be challenging because many NH patients experience life-threatening disease and multi-morbidity (11), having pain (12) and neuropsychiatric symptoms (11, 12). ACP may therefore include choosing and preparing next of kin to make medical decisions in the event the person can no longer make his or her own decisions (1), and may enable the patients to discuss values and preferences with family (2). Although many DELPHI-study panel members viewed family inclusion in ACP as "critical", there is nevertheless tension on the inclusion of next of kin in ACP (1). Next of kin are often not included in ACP-conversations and ACP-studies (6, 10) and sometimes not mentioned in definitions of ACP (13). However, NH physicians sometimes give greater attention to next of kin and their preferences, rather than the patient, when eliciting end-of-life care wishes (14, 15).

In many ACP-programs (16-24), specially trained facilitators not employed at the ward do the ACP or use licensed ACP-programs with limited availability. Thus, the results may not be transferable or useful for many NHs and regular staff.

There is an unfulfilled potential in NHs to engage regular staff, patients – particularly those with cognitive impairment – and their next of kin in ACP. Many previous intervention studies on ACP only include patients that consent to ACP. In this implementation study we planned that all patients at the ward – i.e. the whole ward (thus a "whole ward approach") – should be invited to ACP and included in the study regardless of whether they actually participated in ACP or not. Regular staff should do the ACP and next of kin should be included if the patient consented or was not competent to participate alone. Since we planned to train regular staff and provide implementation support at a

ward level, we were more likely to influence the whole NH-ward (e.g. through “contamination”). Thus, we considered randomization cluster randomization at a ward level superior to randomization of individual patients. The implementation was supported by an ACP-guide that was freely available for all staff in the intervention units, and was planned to be revised and made publicly available, free of charge after the intervention period.

We investigated whether systematic implementation of ACP in nursing homes – using a whole-ward approach – could influence the following:

- 1) Patients’ participation in conversations on end-of-life treatment.
- 2) Patients’ own expressions of future preferences, hopes and worries.
- 3) Assessment of competence to consent, the treatment given and concordance between treatment given and patient’s preferences.

This study is part of a project called ‘*End-of-life communication in nursing homes: Patient preferences and participation*’. Our research includes both qualitative and quantitative methods. For a more comprehensive elaboration of the design, intervention, implementation strategies, data collection and research ethics, we refer to the study protocol (25).

## 2. Methods

### 2.1 Design

This part of the project is a pair-matched cluster randomized clinical trial. The clinical intervention (26) was systematic ACP.

We invited NHs in the southeastern part of Norway (pragmatic reasons) to participate. We sent invitation to NHs that in a national survey (27) answered «yes» to a question on interest in participating in the project, and «never/rarely» or «sometimes» whether they already carried out ACP. NH management agreed to let wards participate in the study. In all, we invited 41 NHs to participate in the study.

Eight wards – or ‘clusters’ – from eight NHs were pair-matched based on certain characteristics. These characteristics were based on data from the national survey, KOSTRA (key figures on municipal activities in Norway) (28), and the NHs annual report and included size of the municipality. Further characteristics were size of the NH and ward (number of beds), number of hours with physician present per week, and personnel position characteristics (educational backgrounds, percentage of professionals, and ratio of part time/full time). The researchers randomly selected one ward from

each pair to a 12-month intervention period. Wards participating were long-term general care wards not designated to a specific group of patients (for instance patients with dementia or in palliative care).

We included all patients in the clusters, also those with cognitive impairment, residing 3 months or more at the ward, above 70 years and who knew Norwegian. In addition, we included patients who died up to 9 months prior to the chart review.

## 2.2 Implementation support

Each participating ward established a project team consisting of a coordinator (preferably a nurse), ward manager and NH physician. Implementation support for the intervention group included a guide for how to carry out systematic ACP (29), which we developed in cooperation with project teams from the intervention group. The implementation support also included a 2-day training seminar for the project teams, which could then train staff at the wards (a train-the trainer model (30)), supervision and follow-up of the project teams, written information to patients and next of kin, and information meeting about the project for ward staff. We developed a pocket card (a short version of the guide) for spontaneous conversations about ACP-issues in everyday situations and a template on how to document ACP (Appendix A). It was recommended that documentation of ACP was made available and easy to find in the care plan.

## 2.3 Primary and secondary outcomes

The primary outcome was prevalence of patients who participated in a conversation on end-of-life treatment (life-sustaining treatment or hospitalization).

We assessed both the primary and secondary outcomes through documentation in the patient electronic health records (EHRs). Outcomes were at the individual participant level.

Secondary outcomes were:

1. Patient's hopes or worries for the future
2. Patient's preferences for decision making processes (preferences for a proxy, or information (medical/diagnose/trajectory) to oneself or next of kin, or preferences for participation in decision-making processes)
3. Assessment of patient's competence to consent (concerning the end-of-life treatment conversations)
4. Preferences regarding future life-sustaining treatment or hospitalization:
  - a. Expressed by the patient
  - b. Next of kin's knowledge of the patient's preferences

- c. Next of kin's own opinion
5. Patients opting for life-sustaining treatment or hospitalizations
6. Provided life-sustaining treatments or hospitalizations
7. Decisions limiting life-sustaining treatments or hospitalizations
8. Assessment of patient's competence to consent to provide or not to provide life-sustaining treatments or hospitalizations
9. Concordance<sup>1</sup> between patient preferences and life-sustaining treatment or hospitalizations provided or limited.

## 2.4 Data collection

We did chart review from patient EHR at T0 (May/June 2015) and T1 (May/June 2016). Both patients alive and those who died during the past nine months were included. We chose chart reviews because patient preferences should be documented and accessible to enable the clinicians later to respect the patient's previously expressed wishes. We considered information not accessible in an acute situation if not found after searching about 15 minutes.

TJLS collected data, except for the first NH visited where TJLS and EG did most together. Project coordinators at the wards also collected some data. The data collection form (Appendix B) was inspired by a clinical questionnaire to facilitate the process of eliciting patient preferences by Murtagh and Thorns (31), other previous research on ACP and decision-making on life-sustaining treatment.

Data included reviewing tabs with notes by physicians, the care plan and tabs with randomly selected notes by nurses and nursing aides, available case summaries, physicians' referrals and 'e-link' that provide information between NH and hospital after hospitalization.

One NH had started using EHR only a couple of weeks prior to T0. As a result, we searched mostly handwritten information at T0 at this NH.

TJLS and RP met on a number of occasions to discuss and seek consensus on coding of data. RP was blinded to which group cases discussed belonged to.

## 2.5 Sample size

We assumed the fraction of patients who 3 months (or more) after admission had participated in ACP would be 10 % in the control group and 50 % in the intervention group (32) at T1. We would need to have wards with at least seven patients in each ward, after considering type 1 and 2 error, adjusting

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<sup>1</sup> Based on patient preferences expressed at an earlier time or expressed at the time of the treatment decision.

for the effect of the clustering of patients by considering intraclass correlation (33), and assuming 10 % of eligible patients would opt out. To make it more likely to have significant results also on secondary outcomes we estimated that we had to include at least 15 patients in each ward (in total at least 120 patients in eight wards/NHs). See our protocol for further details (25).

## 2.6 Statistical analysis

We analyzed data using Generalized Estimating Equations (GEE) (34). Looking for associations between the intervention and control group wards, we compared data from the last 12 months leading up to baseline (T0) and after the intervention period (T1). The cluster sampling strategy leads to dependent observations. Overlooking dependencies can lead to a belief that data carry more information than they actually do, by treating each observation as independent (33). The GEE approach was chosen as it helps handle these dependencies, and is well suited for longitudinal and categorical data (35). Our dependent variables, the primary and secondary outcomes, had a binary distribution. We used the GEE approach to model the association between the dependent variables and the intervention and control groups from T0 to T1. We performed all data analysis using IBM SPSS Statistics version 25 (IBM Corp.).

The list of outcomes is relatively complex. To reduce the complexity, we decided to group the secondary outcomes about elicitation of the patient perspective – i.e. 1, 2 and 4a - into one variable. This decision was made after the collection of the data and after primary and secondary outcomes were established in the protocol (25). Thus for reasons of transparency, we also include analyses of each of the grouped secondary outcomes (see table 2 below). The patient expressed these needs or preferences. Furthermore, we did supplementary analyses of conversations on end-of-life treatment to explore, for example, the level of participation of patients with cognitive impairment and next of kin in ACP (see table 3 below).

## 2.7 Research ethics

NSD - Norwegian Centre for Research Data (reference number 41114), the Data Protection Official for Research, approved the study. The regional committee for medical and health research ethics (REC South East) approved (Reference number 2014/2210 REC South East) chart review without consent founded in § 18 and § 35 in the Health Research Act (36). REC South East demanded that all patients, or next of kin for patients without decision-making capacity, received written information about an opting out opportunity from chart review. REC South East granted approval for chart review from patient EHRs for patients who died up to 9 months prior to the intervention January 16 2017.

## 3 Results

The number of patients included at T1 (after the 12-month intervention period) was 151, of these 88 (58.3 %) participated also at T0. Patient characteristics were similar at T0 across the groups, except for more patients being cognitively impaired in the intervention group ( $p = 0,005$ ) (see table 1).

Figure 1 presents a flow of clusters and participants.

### 3.1 Primary outcome

Prevalence of patients who participated in a conversation on end-of-life treatment increased from T0 to T1 in the intervention group compared to the control group ( $p < 0,001$ ) (see table 2).

### 3.2 Secondary outcomes

The elicitation of the patient perspective increased in the intervention group ( $p = 0,006$ ) (see table 2).

Central to patient participation is determining the patient's competency to consent. Documentation indicated a clinically (but not statistically ( $p = 0,699$ )) significant increase (from 3 to 14 patients) in assessment of competency to consent in the intervention group. Further, we found a tendency for more documentation of preferences regarding life-sustaining treatment or hospitalization in the intervention group ( $p = 0,108$ ). Interestingly, patients were more likely to opt for life-sustaining treatment or hospitalization in the intervention group ( $p = 0,020$ ). However, caution should be noted in interpreting this result because of a potential outlier in the control group. There were no significant changes in provided life-sustaining treatments or hospitalizations ( $p = 0,248$ ) or decisions limiting life-sustaining treatments or hospitalizations ( $p = 0,906$ ). The concordance between patient preferences and treatment provided or limited increased in the intervention group ( $p = 0,037$ ).

### 3.3 Supplementary analyses of conversations on end-of-life treatment

The participation in the conversations of patients with cognitive impairment ( $p = 0,001$ ) and patients being alive at the time of chart review increased in the intervention group ( $p < 0,001$ ) (see table 3).

There was a clinically (but not statistically) ( $p = 0,056$ ) significant increase in conversations that included both the patient and their next of kin.

### 3.4 Quality and accessibility of ACP documentation in the EHR

Most chart reviews lasted half an hour or longer. Our data was for the most part easy to find.

Accessibility could nevertheless be inadequate. For example, health care personnel documented notes in only one large or general tab of the EHR, physicians in for example 'doctor's round' and nurses/nursing aides in 'nursing journal'. Tabs that were more specific and relevant to ACP was thus often underused. Examples of such tabs are "minutes", "reservation/wish" and "summary". This resulted in a large number of notes in one tab making relevant information harder to find. Relevant



information from especially nurses could be very difficult to find since there could be more than a thousand notes per year and notes were mostly untitled. The documentation found were for the most part was clear, with some exceptions. For instance, it could be unclear whether the patient or next of kin had expressed the documented preferences.

Health care personnel described the accessibility of ACP-relevant information in the EHR systems as less than optimal. Our impression was that accessibility improved after making documentation of ACP available via the care plan as part of the implementation support in the intervention group.

## 4 Discussion and conclusion

### 4.1 Discussion

#### 4.1.1 Patient participation

This implementation study indicates that implementation of ACP through a whole-ward approach can contribute to more frequent end-of-life treatment conversations with the patient, also patients with cognitive impairment, assessment of patient competency to consent, elicitation of the patient perspective, concordance between patient wishes and treatment provided or limited, and conversations including both the patient and their next of kin. It thus seems to be possible for regular staff to improve patient participation in NHs through the implementation support provided in this study.

Health care personnel got a tool, an ACP-guide (29), for doing ACP. In addition, we trained and supervised them throughout the intervention period. Improving confidence (14, 37, 38) and competence (7, 8, 39-41) in doing ACP is important to initiate ACP. The whole-ward approach to ACP, encouraged those health care personnel interested and comfortable with ACP to take part in it. By doing this, we wanted to build a culture where knowledge of ACP was widespread and hoped to stimulate curiosity and engagement about ACP at the ward. The idea was for health care personnel at the ward who knew the patient best should take part in ACP conversations. This contrasts some of the ACP-programs where external facilitators come to do the ACP conversations (16-24). Our approach is similar to a whole-system approach (42, 43). A recent systematic review suggests that successful implementation of ACP in complex settings requires a whole-system approach to bring about change that is sustainable (41).

Our implementation support gave attention to and encouraged participation of patients with cognitive impairment. Involving patients with cognitive impairment was an important part of our whole-ward approach. This is a novel approach in ACP (10), and recommended in a recent DELPHI

study (2). Furthermore, recommendations on how to involve persons with dementia in ACP has recently been published (43).

Our whole-ward approach also focused on involving next of kin in ACP, so they could support the patient (44). Involvement of family or significant others as early as possible in the ACP process is recommended for persons with dementia (43). Patients with cognitive impairment may still be able to contribute meaningfully in decision-making, supported by next of kin (45, 46). One concern of supported decision-making could be that the voice of the patient becomes less prominent, focusing more on the next of kin (47). Our data do not support such a concern, since our chart reviews found more elicitation of the patient's own perspectives - i.e. preferences, worries and hopes - in the intervention group.

Still, substituted decision-making, that next of kin represents the patient in ACP if the patient prefers so or is not able to participate, is a necessity for several patients in long-term care in NHs. Less than half of all patients participated in ACP in our study. Such a result is likely in part a consequence of the extent and degree of cognitive impairment in the NH population (11, 12). If possible, however, supported decision-making is preferred over substituted decision-making (48). Proxy decision-makers may experience uncertainty, especially when not guided by healthcare professionals (49). In addition, an ACP intervention was not successful in enhancing the abilities of proxies in making future decisions that were concordant with the preferences of the patient (50).

#### 4.1.2 Existential needs and future preferences

Our approach to ACP emphasized voluntary participation. An openness to what patient's wanted to discuss during ACP was encouraged during implementation support (43). ACP could entail discussions on treatment preferences, but perhaps more importantly, also existential and psychosocial needs of the patient.

We found indication of increased attention to existential needs of the patient. After the intervention, there was a clinically significant increase in the documentation of patient's hopes and worries for the future in the intervention group.

One possible criticism of ACP is that it may a way to persuade the patient that less treatment is the best plan (e.g. to reduce public costs). Previous studies have also reported reduced treatment costs as an important and desired outcome (51-53). In our implementation study, we deliberately emphasized the risk of both undertreatment and overtreatment, and the ideal of identifying the patient's preferences, rather than imposing our own ideals. After the intervention period, there was an increase in patients opting for life-sustaining treatment or hospitalizations and, at the same time,

an increased concordance between the patients' preferences and the treatment provided or limited, but no change in treatment provided. Future studies are needed to further study these possible outcomes. Future studies with bigger sample size are needed to study the possible relations between these outcomes. Furthermore, the moral question about the goals of ACP in relation to undertreatment and overtreatment, should be explicitly addressed.

#### 4.1.3 Strengths and limitations

Randomization of wards/clusters rather than individual patients enabled a whole-ward approach for our intervention and implementation support, without 'contamination' (i.e. the control group being exposed to the intervention). This strengthens internal validity. We have limited information on similarities/differences between wards and patients in this study and the general Norwegian NH context. Mean patient age and share of female patients seems comparable to another study (11). They found almost 84 % patients had dementia and almost 14 % had mild cognitive impairment (11), which is more than we found. However, we only relied upon information accessible in the EHR, and Roen and colleagues found a diagnosis of dementia in patient records for about half of the patients with dementia (11). This suggests the possibility of patients in these studies being more comparable with regard to dementia/cognitive impairment than at first sight. The whole-ward approach and opt-out procedure minimize selection bias. This contributes to better external validity.

Data consisting of review of EHR may not accurately reflect real-world practices. Researchers may overlook relevant information and health professionals may not document all relevant information. Consequently, participating NHs may be doing more ACP than reported here (54).

An upgrade of the EHR system at all intervention NHs, but not control NHs, happened during the intervention period. Health care personnel at the intervention NHs claim some documentation may have been lost following the upgrade. Consequently, we potentially underreport results from intervention NHs at T1.

## 4.2 Conclusion

Better patient participation, also for patient with cognitive impairment, is achievable through a whole-ward approach where regular staff perform the ACP. Next of kin may support the patient and participate in the ACP to promote patient autonomy.

## 4.3 Practice implications

Regular staff can be trained to do ACP. In addition, patients with cognitive impairment can be included in ACP. However, support from next of kin is important. Our whole-ward approach to ACP – may foster a more sustainable implementation of ACP.

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## Conflict of interest

None declared.

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## Tables

Table 1. Characteristics of participants and wards in the control vs intervention group

Characteristic	T0 (n = 154)		P value at T0	T1 (N = 151)	
	Control = 77	Intervention = 77		Control = 75	Intervention = 76
Number of participants	Control = 77	Intervention = 77		Control = 75	Intervention = 76
Age, mean	88	86.4	0,126	88.1	86.4
Female, No. (%)	53 (68.8)	55 (71.4)	0,637	52 (69.3)	54 (71.1)
Cognitive impairment or dementia, No. (%)	53 (68.8)	59 (76.6)	0,005	62 (82.7)	67 (88.2)
Stroke, No. (%)	22 (28.6)	26 (33.8)	0,785	30 (40)	26 (34.2)
Mean no. of diagnoses	5.6	5.2	0,310	6.4	6.4
Religious affiliation unknown, No. (%)	66 (85.7)	60 (77.9)	0,658	66 (88)	60 (78.9)
Mean length of stay in months	36	30.6	0,208	34.2	30.1
Stay under a year, No (%)	15 (19.5)	22 (28.6)	0,169	18 (24)	19 (25)
Participation also at T0, No. (%)				41 (54.7)	47 (61.8)
Deceased past 9 months, No. (%)	20 (26)	19 (24.7)	0,741	12 (16)	19 (25)

Table 2. Primary and secondary outcomes. Did the EHR include documentation of the following?

Outcome	Control group	Intervention group	95 % confidence interval of the odds ratio	P value
<b>Patients who participated in a conversation on end-of-life treatment</b>				
T0, Yes (%)	12 (15,6)	10 (13)	2,34 – 15,1	<b>&lt; 0,001</b>
T1, Yes (%)	8 (10,7)	28 (36,8)		
<b>Patient's own preferences or hopes or worries</b>				
T0, Yes (%)	18 (23,4)	17 (22,1)	1,63 – 19,9	<b>0,006</b>
T1, Yes (%)	13 (17,3)	40 (52,6)		
<b>The above variable contains the following secondary outcomes:</b>				
<b>Hopes or worries for the future (expressed by the patient)</b>				
T0, Yes (%)	8 (10,4)	11 (14,3)	0,74 – 32,6	0,100
T1, Yes (%)	6 (8)	29 (38,2)		
<b>Patient's preferences for decision making processes (expressed by the patient)</b>				
T0, Yes (%)	1 (1,3)	1 (1,3)	0,78 – 325	0,072 <sup>2</sup>
T1, Yes (%)	0	14 (18,4)		
<b>Preferences regarding future life-sustaining treatment or hospitalization (expressed by the patient)</b>				
T0, Yes (%)	12 (15,6)	10 (13)	1,55 – 14,4	0,006
T1, Yes (%)	8 (10,7)	24 (31,6)		
<b>Assessment of patient's competence to consent (concerning the end-of-life treatment conversations)</b>				
T0, Yes (%)	2 (16,7)	3 (30)	0,17 – 14,1	<b>0,699</b>
T1, Yes (%)	2 (25)	14 (50)		
<b>Preferences regarding future life-sustaining treatment or hospitalization</b>				
T0, Yes (%)	26 (33,8)	28 (36,4)	0,82 – 7,56	<b>0,108</b>
T1, Yes (%)	26 (34,7)	45 (59,2)		
<b>Proportion - expressed by the patient</b>				
T0, Yes (%)	12 (46,2)	10 (35,8)	0,82 – 18,3	<b>0,088</b>
T1, Yes (%)	8 (30,8)	24 (53,3)		
<b>Proportion - Next of kin 's knowledge of the patients' preferences</b>				
T0, Yes (%)	5 (19,2)	6 (21,4)	0,16 – 1,33	<b>0,151</b>
T1, Yes (%)	6 (23,1)	7 (15,6)		
<b>Proportion - Next of kin's own opinion</b>				
T0, Yes (%)	14 (53,8)	20 (71,4)	0,04 – 3,71	<b>0,403</b>
T1, Yes (%)	17 (65,4)	28 (62,2)		
<b>Patients opting for life-sustaining treatment or hospitalizations</b>				
T0, Yes (%)	7 (26,9)	7 (25)	1,46 – 86,9	<b>0,020</b>
T1, Yes (%)	1 (3,8)	15 (33,3)		
<b>Provided life-sustaining treatments or hospitalizations</b>				
T0, Yes (%)	35 (45,4)	37 (48,1)	0,49 – 1,20	<b>0,248</b>
T1, Yes (%)	37 (49,3)	34 (44,7)		
<b>Decisions limiting life-sustaining treatments or hospitalizations</b>				
T0, Yes (%)	4 (5,2)	6 (7,8)	0,26 – 4,63	<b>0,906</b>
T1, Yes (%)	3 (4)	5 (6,6)		
<b>Assessment of patient's competence to consent to provide or not to provide life-sustaining treatments or hospitalizations</b>				
T0, Yes (%)	2 (4,8)	0	0,01 – 11,9	<b>0,546<sup>2</sup></b>
T1, Yes (%)	1 (2,8)	2 (5,1)		



<b>Concordance between patient preferences and provided, or decisions to limit, life-sustaining treatment or hospitalizations</b>				
<b>T0, Yes (%)</b>	4 (11,1)	1 (2,4)	1.14 – 77.6	<b>0,037</b>
<b>T1, Yes (%)</b>	4 (10,3)	7 (20)		

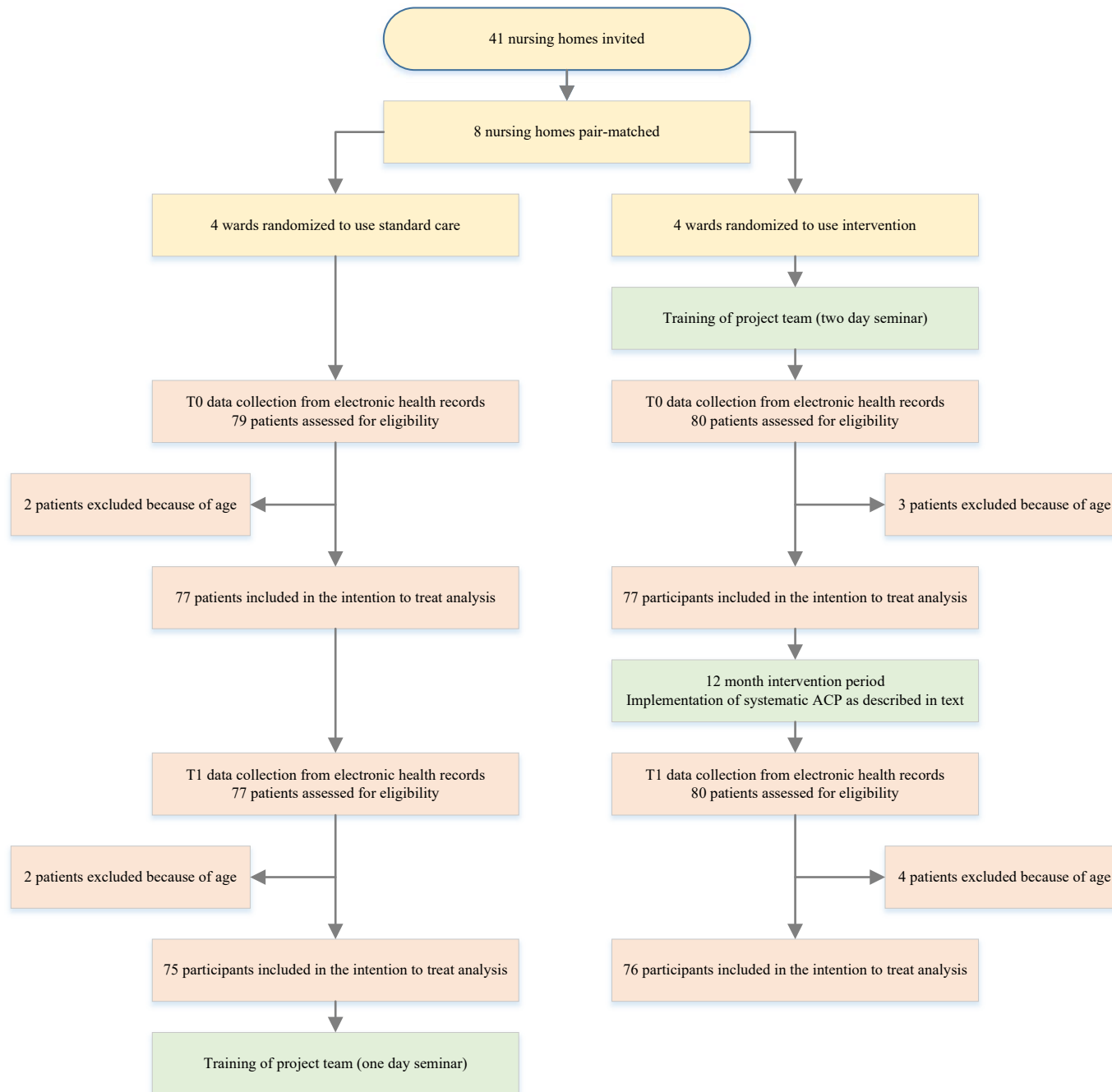
Table 3. Supplementary analyses of conversations on end-of-life treatment. Did the EHR include documentation of the following?

<b>Outcome</b>	<b>Control group</b>	<b>Intervention group</b>	<b>95 % confidence interval of the odds ratio</b>	<b>P value</b>
<b>Participation of patients with cognitive impairment or dementia</b>				
<b>T0, Yes (%)</b>	9 (17)	6 (10,2)	2,43 – 13,8	<b>&lt; 0,001</b>
<b>T1, Yes (%)</b>	7 (11,3)	20 (30)		
<b>Participation of patients alive at the time of chart review</b>				
<b>T0, Yes (%)</b>	7 (12,3)	7 (12,1)	2,21 – 22,5	<b>0,001</b>
<b>T1, Yes (%)</b>	6 (9,5)	24 (42,1)		
<b>Included the patient only</b>				
<b>T0, Yes (%)</b>	11 (14,3)	9 (11,7)	0,14 – 1,36	<b>0,150</b>
<b>T1, Yes (%)</b>	8 (10,7)	14 (18,4)		
<b>Included next of kin, but not the patient</b>				
<b>T0, Yes (%)</b>	14 (18,2)	18 (23,4)	0,26 – 5,66	<b>0,807</b>
<b>T1, Yes (%)</b>	18 (24)	20 (26,3)		
<b>Included both patient and next of kin</b>				
<b>T0, Yes (%)</b>	1 (1,3)	1 (1,3)	0,00 – 1,08	<b>0,056<sup>2</sup></b>
<b>T1, Yes (%)</b>	0	16 (21,1)		
<b>Included either the patient and/or next of kin</b>				
<b>T0, Yes (%)</b>	26 (33,8)	28 (36,4)	0,13 – 1,10	<b>0,075</b>
<b>T1, Yes (%)</b>	26 (34,7)	46 (60,5)		

<sup>2</sup> A limitation with the GEE approach is a non-acceptance of zero and decimals. Three of our variables had a count of zero in one of the cells, which made a statistical analysis impossible. To enable statistical analysis we inserted the value 1 in the cell with the value 0. By doing this in the “zero-cells”, the reported P values for these three variables are all somewhat higher than they would have been if we could use e.g. 0,0001 as the added value. That is, the changes on these three variables were actually somewhat bigger than the reported P value indicate.

## Highlights

- Improved participation in advance care planning among nursing home patients
- Advance care planning is possible also when cognitively impaired
- Next of kin may play important role in supported decision-making
- Concordance between patient preferences and provided treatment increased
- Improved patient participation is achievable using a whole-ward approach



## CRedit author statement

**Trygve Johannes Lereim Sævareid:** Conceptualization, Methodology, Software, Formal Analysis, Investigation, Writing – Original Draft, Writing – Review & Editing. **Lisbeth Thoresen:** Conceptualization, Methodology, Writing – Review & Editing, Supervision. **Elisabeth Gjerberg:** Conceptualization, Methodology, Software, Writing – Review & Editing. **Lillian Lillemoen:** Conceptualization, Methodology, Writing – Review & Editing, Project Administration. **Reidar Pedersen:** Conceptualization, Methodology, Writing – Review & Editing, Supervision, Project Administration.

## Documenting Advance Care Planning

Present in the conversation:

**The patient's capacity to consent** regarding these question (ie. Yes, no, not assessed):

Comments:

**Anything the patient wishes to experience?**

**Does the patient have any worries for the future?**

**Any other needs or requests the patient has for the future?**

**The patient's wishes regarding information about themselves** (ie. Knowing as much as possible, limited information, does not want to know, unclear, cannot decide now – revisit question later):

**The patient's request for proxy if she/he cannot speak for her/himself:** (ie. Unclear, cannot decide now – revisit question later):

**The patient's wishes regarding participation in decisions about future treatment** (ie. wants to make decisions themselves, discuss and make decisions along with family, physician informs thoroughly and helps with decision, physician makes decision, unclear, cannot decide now – revisit question later):

**The patient's wishes regarding information given to next of kin** (ie. Knowing as much as possible, limited information, does not want to know, unclear, cannot decide now – revisit question later):

**The patient's wishes regarding future treatment intensity** (ie. Less or more extensive treatment, palliative treatment, unclear, cannot decide now – revisit question later):

**The patient's wish for future hospitalization** (ie. Yes, no, unclear, cannot decide now – revisit later):

Comments:

Date:

Signature:

**Other** (ie. next of kin's comments, living will etc.):

## Data collection form

Form number

Nursing home / Date of admittance

Date of registration

Age / Gender: Male / Female / Diagnoses (fill inn) / Religion: Christian / Muslim / Other / None / Unknown

During the past 12 months:

1. Has a conversation with the patient regarding end-of-life treatment been documented in the patient's chart?  
If yes: Was the patient's competence to consent in this conversation assessed? If yes: was the patient found to be competent?  
Is the following documented in the patient's chart?
2. Anything the patient wants or wishes to experience in the future?
3. Anything the patient is worried about for the future?
4. Who is the patient's chosen proxy?
5. What information does the patient want regarding him/herself?
6. What does the patient want next of kin /proxy to know about?
7. The patient's wishes about participating in decision making regarding future treatment
8. Wishes regarding future treatment intensity (life-prolonging treatment<sup>1</sup>)

If yes for question 8, what is documented:

- Wishes expressed by patient
- Wishes of next of kin
- Next of kin's knowledge of patient's wishes
- Was the wish positive or negative to life-prolonging treatment?
- Other....

9. Wishes for future hospitalization

If yes for question 9, what is documented?

- Wishes expressed by patient
- Wishes of next of kin
- Next of kin's knowledge of patient's wishes
- Was the wish positive or negative to hospitalization?
- Other....

Is documentation regarding questions 1-9 readily available?

<sup>1</sup> Here life-prolonging treatment refers to all treatment and measures taken to postpone the patient's death. Examples of this could be resuscitation, other breathing help or heart-stimulating medication, fluids and nutrition treatment (intravenous or through tubes), dialysis, antibiotics or chemotherapy.

Written advance care planning/ Advance directive, filled out by patient him/herself

1. Does the patient have a living will that deals with treatment choices?

Decisions about treatment

1. Has the patient been given life-prolonging treatment in the nursing home in the last 12 months? / If yes, was competence to consent assessed? / Was the patient competent? / Was the treatment in line with the patient's wishes? / Number of treatments: / Other:
2. Has the nursing home had the patient hospitalized in the last 12 months? / If yes, was competence assessed? / Was the patient competent? / Was the hospitalization in line with the patient's wishes? / Number of hospitalizations: / Other:
3. Has life-prolonging treatment been withheld from the patient in the nursing home over the last 12 months? / If yes, was competence assessed? / Was the patient competent? / Was the decision in line with the patient's wishes? / Number: / Other:
4. Has the nursing home decided not to hospitalize the patient in the last 12 months? If yes, was competence assessed? / Was the patient competent? / Was the decision in line with the patient's wishes? / Number: / Other:

Comments: