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Advance care planning for nursing home residents with dementia: Influence of 'we DECide' on policy and practice

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ABSTRACT

Objectives: (1) To pilot 'we DECide' in terms of influence on advance care planning policy and practice in nursing home dementia care units. (2) To investigate barriers and facilitators for implementing 'we DECide'.
Methods: This was a pre-test—post-test study in 18 nursing homes. Measurements included: compliance with best practice of advance care planning policy (ACP-audit); advance care planning practice (ACP criteria: degree to which advance care planning was discussed, and OPTION scale: degree of involvement of residents and families in conversations).
Results: Advance care planning policy was significantly more compliant with best practice after 'we DECide'; policy in the control group was not. Advance care planning was not discussed more frequently, nor were residents and families involved to a higher degree in conversations after 'we DECide'. Barriers to realizing advance care planning included staff's limited responsibilities; facilitators included support by management staff, and involvement of the whole organization.
Conclusion: 'We DECide' had a positive influence on advance care planning policy. Daily practice, however, did not change. Future studies should pay more attention to long-term implementation strategies.
Practice implications: Long-term implementation of advance care planning requires involvement of the whole organization and a continuing support system for health care professionals.
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1. Introduction

Advance care planning (ACP) is the communication process in which future (care) choices are discussed with healthcare professionals, patients, and their family caregivers, in anticipation of reduced decision-making capacity [1,2]. In the case of dementia, a disease that is characterized by a gradual loss of cognitive competencies, ACP is therefore of undeniable importance [3]. ACP in this case is not a single discussion. It is rather a process that should start early, at the latest at the time of diagnosis, and is initiated by the general practitioner (GP) [4]. In most cases, however, preferences for end-of-life care are not addressed in the GP practice [5]. Another important occasion to discuss end-of-life planning is at the moment of admission to a nursing home [6,7].

When it comes to *how* ACP should be discussed, different aspects of "making choices" should be addressed: talking about the possibility of choosing, talking about the available options, and talking about the final decision. The concept of shared decision-making (SDM), when healthcare professionals and patients share information in order to reach agreement on the most appropriate decision about care, is best suited to characterize this process of communication [8]. SDM is a communication model for involving patients in decisions about care and treatments, especially when these decisions highly depend on values and personal preferences [9,10]. Research shows that SDM is not yet common practice in clinical settings [11,12]. In order to realize this, healthcare professionals should be trained in SDM skills, more specifically in the context of ACP [13,14].

This study had two aims. The first aim was to evaluate the influence of the intervention 'we DECide – Discussing End-of-life

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Choices' on the policy and actual practice of ACP in nursing home dementia care units. More specifically this study aimed at piloting the 'we DECide' intervention with respect to its influence on nursing home staff's views on the policy of ACP in the dementia care unit, and on the involvement of residents with dementia and their families in ACP. The second aim of the study was to investigate the nursing home management and clinical staff's perceived barriers and facilitators for the implementation of SDM in ACP conversations.

1.1. 'We DECide – Discussing End-of-life Choices'

'We DECide' was a communication intervention for nursing home staff working in dementia care units, in which competences were trained for realizing SDM in ACP conversations with residents with dementia and their families [15]. It was developed for this study and aimed at practising how to conduct ACP conversations with residents with dementia and their family caregivers, by applying the three-step model for SDM by Elwyn et al. [16]. This model describes the three steps that are necessary for realizing SDM in a clinician-patient encounter: the 'Choice talk', talking about the fact that different choices exist; the 'Option talk', talking about the different options and choices; and the 'Decision talk', talking about a final decision. 'We DECide' consisted of three modules (two 4h-workshops and a homework assignment) that were based on the three steps of the model for SDM. Each module was designed to train the specific competences that are necessary to complete the corresponding step. Three types of conversations that are crucial for talking about ACP in the nursing home were used for practising SDM. Conversations at the time of admission were used as a prototype for the 'Choice talk' in the first workshop, since these conversations are crucial for indicating that certain choices for care exist. As a homework assignment participants were to practise the 'Option talk' by engaging in conversations with residents about preferences in routine care situations, and thus to talk about the different care options. Conversations in crisis situations were used as a prototype for the 'Decision talk' in the second workshop (which took place after the homework assignment), since the urgency of crisis situations require that certain decisions have to be made. The overview of the 'we DECide'-modules are represented in Fig. 1.

'We DECide' was taught in small groups (approximately 10 participants per session) by an experienced communication trainer, in order to ensure active participation of each participant. The intervention took place in a time span of maximum 4 weeks.

1.1.1. Rationale for 'we DECide – Discussing End-of-life Choices'

In order to introduce an important change in clinical practice that requires a multidisciplinary team effort, the whole organization has to be involved. This includes not only the clinical staff but also the management [6,17–21]. That is why staff from both the management and clinical level were involved in 'we DECide'.

A typical characteristic of dementia is that although the disease implies a degeneration of the cognitive functions, there are moments when a person with dementia functions well and can indicate their preferences for (end-of-life) care [22]. The resident with dementia should be able to express personal preferences and discuss them with a healthcare professional, who then has the responsibility to articulate their wishes and take them into account should the moment come to make a final decision about care or treatment and the resident no longer has the capacity for making choices. Nursing home healthcare teams consist of healthcare professionals from various disciplines (i.e. nurses, nursing auxiliaries, occupational therapists . . .), all of which were included in 'we DECide'.

The management staff was included in the intervention, firstly because the management usually conducts the formal conversations at the time of admission. In these conversations the 'Choice talk' occurs, i.e. talking about the fact that choices exist (i.e. the choice to discuss ACP), the critical first step to realizing SDM. Secondly, the management's vision on ACP has an influence on the policy and on the conditions that permit implementation in practice [17–19,23], whereas the clinical staff discuss ACP with the residents and families in practice. If management staff do not believe in the importance of ACP, the clinical staff will not receive the proper support, time and resources for this. It is therefore important to assess to what extent ACP policy is compliant with best practice, in addition to assessing daily practice.

Therefore, 'we DECide' was designed to include healthcare professionals from various disciplines and levels.

2. Methods

This was a quasi-experimental pre-test–post-test study with an intervention and a control group. Assessments were performed twice, with a six-month interval. Mixed methods were used to evaluate the influences of 'we DECide' on the policy (i.e. compliance with best practice) and the actual practice of ACP (i.e. involvement of residents and families in conversations). Results of the pre-test are reported in a previous paper [24]. This paper describes the results from the post-test measurement.

2.1. Setting & participants

The study took place in eighteen dementia care units from eighteen different nursing homes in Belgium. Participants were nursing home staff from both the management and the clinical level. Originally, twenty dementia care units were enrolled at pre-test, of which one unit dropped out after pre-test measurements, because they were no longer interested to participate due to time constraints. Prior to the selection of the intervention group, the 19 remaining nursing homes were ranked on their pre-test ACP-audit scores. A difference was found between a 'high score' (n = 10) and a 'low score' group (n = 9) (see also: Fig. 2). The audit scores of the high score group indicated that there was little room for improvement through training. Therefore, because 'we DECide' was designed for participants with sufficient learning opportunities, the nine care units with the lowest scores were included in

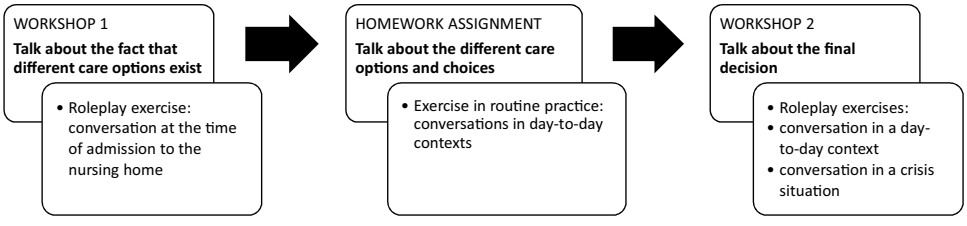

Fig. 1. 'We DECide': Training modules (from: Ampe et al., 2015 [15]) provides details on the three modules that constitute the 'we DECide'-intervention.

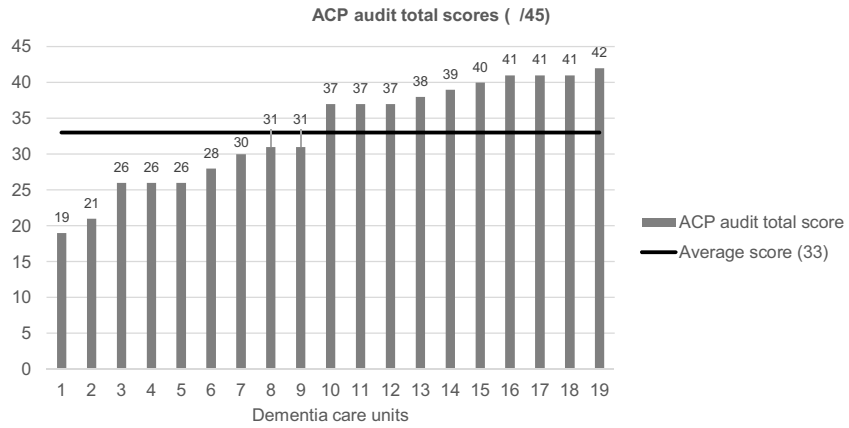

Fig. 2. Pre-test ACP audit scores represents the ranking of the dementia care units, based on the pre-test ACP-audit scores; the horizontal line represents the average score.

the intervention group. Moreover, these units all had comparable starting levels of competence.

To increase standardisation of the intervention, we created participant groups of comparable size and composition. In order to make groups with staff from two nursing home units, we chose to include a unit from the control group. In this way, the training could be offered to five small groups separately, each of which contained staff from two different nursing home units. Post-test data from this unit were excluded from further analyses, since they did not have comparable baseline scores to the other units in the intervention group.

The dementia care units in the control group (n = 9 dementia care units) were offered the training after all data were collected.

2.2. Data collection and assessment tools

Three months before 'we DECide' started, the pre-test data were collected [15]. Three months after 'we DECide' ended, the post-test data were collected. The same elements were assessed both during pre-test and at post-test, i.e. the policy of ACP and the actual practice of ACP. At post-test, views of participants on barriers and facilitators for the implementation of SDM in ACP conversations were also examined. We expected ACP policy to be more compliant with best practice after 'we DECide'. Moreover, we expected residents with dementia and their families to be involved in ACP conversations to a greater extent in units from the intervention group. The assessment procedures are described below. Data at post-test were collected between January and March 2014.

2.2.1. Views on the policy of ACP

The policy of ACP was evaluated with the ACP-audit. This instrument assessed management and clinical staff's views on pre-defined criteria related to the policy of ACP in the dementia care unit [15]. The ACP-audit was based on best practices for ACP for nursing home residents with dementia, which were previously developed by the authors. Several crucial moments in the nursing home stay of persons with dementia are addressed. For each of these moments, recommendations and examples for talking about ACP, care choices and personal preferences are offered [15]. The ACP-audit evaluates the extent to which the policy of ACP is compliant with best practices. It consists of a structured questionnaire with nine sections, each of which contains five criteria. Consequently, the total number of criteria for best practices that are evaluated with the ACP-audit sums up to 45. For an overview of the ACP-audit items and scoring criteria see Supplementary information S1.

The validity of the scale was ensured by integrating the state-of-the-art literature review and expert interviews. Furthermore, the ACP-audit was validated by expert panels with multidisciplinary nursing home staff from different levels. Cronbach's alpha of the ACP-audit was calculated at pre-test, in order to evaluate the internal consistency, which resulted in 0.79 [24]. At post-test Cronbach's alpha resulted in 0.52. At pre-test, inter-rater reliability of the audit scorings of two independent raters was statistically significant ($r = 0.95$, $p < 0.05$). Cohen's Kappa for the item scores was 0.80. At post-test the ACP-audits were evaluated by one rater only.

2.2.2. Involvement of residents and families in ACP

The involvement of residents and families in ACP, i.e. the actual practice of ACP, was evaluated with ACP criteria and the OPTION (Observing Patient Involvement). ACP criteria were used for assessing the degree to which ACP was discussed, and the OPTION was used for assessing the degree of involvement of residents and families in the conversations.

Participants were asked to record two types of conversations: conversations at the time of admission and conversations at the time of a crisis situation, the two conversations that are practiced in the 'we DECide' workshops [15]. We asked that the same persons would conduct and record the conversations as at pre-test.

2.2.2.1. Degree to which ACP was discussed. The degree to which ACP was discussed in the recorded conversations was evaluated with ACP criteria. Conversations were categorized in one of five levels: 0–no ACP discussion; 1–short introduction of ACP; 2–introduction and short explanation of ACP; 3–explanation of ACP with substantive discussion; 4–substantive ACP discussion including discussion of emotions.

2.2.2.2. Degree of involvement of residents and families. The actual involvement of residents with dementia and their families in conversations was evaluated with OPTION [25]. The OPTION consists of twelve items, each of which is scored on a five-point scale ranging from 0 ('the behaviour is not observed') to 4 ('the behaviour is performed to a high standard'). The scale items refer to the necessary clinician skills that are needed to realize SDM in a conversation with patients. The total score is calculated by adding the twelve item scores (with a maximum of 48) and is standardized by transforming this to a score between 0 and 100. Conversations were analysed by one researcher. The scale items and scoring categories are provided in Supplementary information S2.

2.2.3. Perceived barriers and facilitators

At the time of the post-test administration of the ACP-audit, we asked the participants from both the intervention and control group, about barriers and facilitators for implementing ACP in daily practice. Because this questioning followed the ACP-audit, the answers about barriers and facilitators were collected in group. No differences were found between the answers of the management and clinical staff. Consequently, the responses of the clinical level and the management level were combined. We asked two open-ended questions: "What are the barriers to implementing ACP?" and: "What would help you to implement ACP in your daily practice?" Results were analysed using a thematic approach (i.e. the identification of implicit and explicit ideas within the qualitative data).

2.3. Data analysis

Descriptive statistics were used to evaluate the policy and the actual practice of ACP in the dementia care units at post-test. The normal distributions of all data were confirmed with the Shapiro-Wilks test ($p > 0.05$). The ACP-audit scores and the OPTION scores were compared between the intervention and control group with *t*-tests for independent samples. Within-group comparisons were made in order to compare the policy and the actual practice at pre-test and post-test. Within-group comparisons between pre-test and post-test results were made for the intervention and control group separately, using *t*-tests for dependent samples. The significance levels for statistical analyses were set at $\alpha = 0.05$.

Analyses were conducted using STATISTICA software, version 12 (StatSoft, Inc. (2013) STATISTICA (data analysis software system), version 12. www.statsoft.com).

2.4. Ethical considerations

Informed consent forms for residents and their families were provided and needed to be signed before conversations were recorded. If a resident with dementia was not able to sign the document, the resident's representative was always asked for consent. The study was approved by the national Privacy Commission and ethics approval was received from the Medical Ethical Committee of the University of Leuven. Written informed consents were completed by all participants and by all persons whose conversations were recorded.

3. Results

3.1. Views on the policy of ACP

Ninety nursing home staff members from various disciplines, working on one of the 18 dementia care units, participated in the ACP-audit (see Table 1). On average, five nursing home staff per organization participated (range: 3–7). Twenty-five staff members from the management level (nursing home managers: n = 5; or department managers: n = 20), and 65 from the clinical level participated. (Head) nurses accounted for the best represented discipline (n = 30), followed by nursing auxiliaries (n = 12).

The average ACP-audit score for the **intervention group** was 33/45 (*SD* 4.69), and for the **control group** 38/45 (*SD* 3.46).

3.1.1. Comparison with pre-test scores

Pre-test and post-test total scores were compared for the intervention and control group separately (see Table 2). A statistically significant difference was found for the intervention group (average pre-test score: 27/45, *SD* 3.81), but not for the control group (average pre-test score: 40/45, *SD* 1.88). This means that for dementia care units that participated in 'we DECide', the policy of ACP was more compliant with best practice after the intervention.

3.2. Involvement of residents and families in ACP

Thirteen units recorded one or more conversations (seven from the intervention group, and six from the control group). Five units (two from the intervention group) did not record any conversations, due to one of the following reasons: no admission of new residents with dementia due to relocation of the care unit to a new building, or absence of staff members due to illness.

A total of 21 conversations were analysed. The intervention group provided 11 conversations; the control group provided 10 conversations. Five of the conversations involved a discussion in a crisis situation, i.e.: a general deterioration in the health condition of the resident; aggressive behaviour of a resident who refused treatment; a resident approaching the end-of-life; and a resident with a recently discovered medical problem.

A total of 30 staff members were involved in the conversations, most of which were head nurses. Participants are represented in Table 3. Thirteen residents with dementia were involved. Five of the conversations were conducted with residents alone. In 16 conversations one or more family members were involved.

3.2.1. Degree to which ACP was discussed

ACP was addressed in seven of the 11 conversations from the **intervention group**. In the four other conversations, routine care issues were discussed without addressing future care options. Each conversation was categorized in one of four levels of *ACP criteria*. One conversation was categorized in the first level: introduction of ACP without further explanation. Two conversations were categorized in the third level, explanation of ACP with substantive discussion of all aspects. Four conversations were categorized in

Table 1
ACP-audit: participants per dementia care unit.

ACP audit Total no of participants:	Nursing home manager	Head of department/ coordinator	Nurse	Head nurse	Nursing auxiliary	Occupational therapist/animation	Physical therapist	Social worker	Pastoral staff	Pedagogue
90	5	20	18	12	12	10	5	4	3	1

Table 2
ACP audit: Comparison of average pre-test and post-test scores (t-tests for dependent samples).

Average ACP audit score (/45)	Pre-test	*SD*	Post-test	*SD*	*p*-value	t-value	Confidence interval −95% – +95%
Intervention group	26.67	3.81	32.56	4.70	*.013*	−3.1931	−10.1417– −1.6361
Control group	39.56	1.88	37.67	3.46	*.086*	1.9597	−0.3338–4.1115

Table 3
Conversation participants.

	Intervention group		Control group	
	Admission	Crisis	Admission	Crisis
Head nurse	5	2	2	1
Social worker	2		2	1
Nursing home manager			3	
Reference person palliative care			1	
Nursing auxiliary	2			
Coordinating and advisory physician of the nursing home	1			2
Head of department/coordinator	1		3	1
Pastoral staff				1
Resident	7	1	5	
Family (= at least one family member)	7	1	5	3

the fourth level, where ACP was explained and discussed substantively, and emotions regarding ACP were also addressed.

All ten conversations from the **control group** addressed ACP to a certain level. One conversation was categorized in the first level (introduction of ACP), and another one in the second level (introduction of ACP and explanation of what it means). Five conversations were categorized in the third level. Three conversations were categorized in the fourth level.

3.2.2. Degree of involvement of residents and families

The average OPTION score for admission conversations was not statistically different from the average OPTION score for crisis conversations (see Table 4). Consequently, a general OPTION score per dementia care unit in the intervention and control group was calculated in order to evaluate the overall involvement of residents and/or families (i.e. one average OPTION score per dementia care unit).

Average OPTION scores in the intervention group, 38.82/100 (*SD* 14.01) did not differ significantly from those in the control group, 40.10/100 (*SD* 9.46) (see Table 5). From the **intervention group**, seven units provided 11 conversations. From the **control group**, six units provided 10 conversations.

3.2.3. Comparison with pre-test scores

Generally (for the intervention and control group separately), ACP was not discussed more frequently or at a significantly higher level after 'we DECide' than before (comparison of the ACP criteria levels). There was also no significant difference between the intervention and control group in this area.

When OPTION scores at pre-test and post-test were compared, no statistically significant differences were found for the intervention group (average pre-test score: 41.32/100, *SD* 10.84), nor the control group (average pre-test score: 47.61/100, *SD* 20.54) (see Table 6). The ACP communication in practice remained at the same level in all participating dementia care units.

3.3. Perceived barriers and facilitators

Both management and clinical staff were asked for barriers to and facilitators for the implementation of SDM in ACP practice. The themes that emerged from the qualitative analysis of the answers at the time of the ACP-audit administration are represented in Table 7. The barriers and the facilitators that were reported by the control group were the same as those reported by the intervention group. The intervention group reported some extra barriers and facilitators. The most important barriers to realizing ACP in practice reported by the participants were the limited responsibilities of the staff, the hierarchy in the organization related to ACP, and time and work pressure. Important facilitators included the support of direct supervisors and peers, and of the management level, involvement of all levels and disciplines, and education and training.

Table 4
OPTION scores: Comparison of average scores of admission conversations and crisis conversations at post-test (*t*-test for independent samples).

	Admission conversation	*SD*	Crisis conversation	*SD*	*p*-value	t-value
Average OPTION score (/100)	39.06	11.82	40.42	12.78	*.829*	−0.21890

Table 5
OPTION scores: Comparison of average total scores of intervention group and comparison group at post-test (t-test for independent samples).

	Intervention group	*SD*	Control group	*SD*	*p*-value	t-value
Average OPTION score (/100)	38.82	14.01	40.00	9.46	*.826*	−0.22259

Table 6
OPTION scores: Comparison pre-test and post-test (*t*-test for dependent samples).

Average OPTION score (/100)	Pre-test	*SD*	Post-test	*SD*	*p*-value	t-value	Confidence interval −95% – +95%
Intervention group	41.32	10.48	38.82	14.01	*0.973*	0.03548	−4.8545–4.9974
Control group	47.61	20.54	40.10	9.46	*0.061*	0.05452	−9.1841–14.1286

Table 7
Barriers and facilitators to implementing ACP in practice, as reported by participants from the intervention (n = 37) and control group (n = 53), and number of citations.

BARRIERS	FACILITATORS
What are the barriers to implementing advance care planning according to you?	*What would help you to implement advance care planning in your daily practice?*
Reported by intervention and control group:	**Reported by intervention and control group:**
– Responsibilities/organization and hierarchy (n = 21)	– Support of direct supervisors and peers, and of the management level and nursing home management (n = 15)
"On my unit, the head nurse is responsible for advance care planning, this is not in my job description" *"Our unit is now convinced, but it will be hard to engage all units to implement this (program)"*	*"If I would have the chance to conduct these conversations, together with the person who is responsible for advance care planning (like the head nurse)"*
– Time and work pressure (n = 17)	– Involvement of all levels and disciplines/functions (n = 13)
"I do not have the time to sit down with residents and talk about these things" *"The time and work pressure are high in our organization"*	*"More attention for this subject during team meetings"* *"Make everyone responsible for these discussions/share responsibilities"* *"If all disciplines would receive the opportunity to follow training and education on advance care planning and shared decision making"*
	– (Continuous) education and training (n = 10)
	"Every staff member should be able to follow education and training on conducting these conversations" *"If the workshops are attended by staff from various disciplines, and not only nurses, it would increase the implementation in our unit"* *"The staff who did receive training should at least have the time or occasion to inform and teach their colleagues who did not attend the workshops"*
	– Creating more time by hiring extra staff (n = 7)
	"I need to make the time for preparing and conducting these conversations" *"If more staff were hired, we would have more time for preparing and conducting conversations"*
Reported by intervention group only:	**Reported by intervention group only:**
– Lack of confidence (n = 5)	– Implementation in a structured way (n = 10)
"Engaging in a conversation with a resident on this subject, at a certain moment . . . I still feel very insecure to actually do this in practice" *"I am still not sure how to start a conversation, I am afraid I will offend the resident"*	*"There is a need for a more systematic approach to introduce the topic of advance care planning, such as providing information at the time of intake"*
– Lack of knowledge and education (n = 4)	– Courage/confidence (n = 4)
"I lack the knowledge to discuss end-of-life decisions in detail"	*"You need the confidence to engage in these conversations, but I found that, once you do, residents do not react badly"* *"The three-step model for shared decision-making does give me the support to structure conversations"*
– Experience/competence in conducting conversations (n = 1)	
"I just don't have enough experience in conducting this type of conversations, so I do not feel competent to do so"	– Systematic documentation (n = 3)
– Organization's vision on ACP (n = 1)	*"We should have a shared document to write down our observations"*
"The nursing home management has a different vision on advance care planning, they are more medically oriented"	– Rooms/structural elements (n = 3)
	"A quiet room is needed for conducting conversations in a serene and quiet manner"

4. Discussion

4.1. Discussion

In this study we evaluated the influence of 'we DECide' on the policy and the practice of ACP in nursing home dementia care units, and perceived barriers and facilitators to implementing ACP. Although the policy improved significantly in dementia care units from the intervention group after 'we DECide', the actual practice did not. In the control group, neither the policy nor the practice improved at post-test.

In practice, ACP appeared not to be discussed more frequently or on a higher level than before 'we DECide', and residents and families were not involved in conversations to a greater extent. Although we expected this for the control group, we did not for the intervention group. We hypothesized that the policy as well as the actual practice would benefit from 'we DECide', because both management and clinical staff were involved, and because the intervention was a very practically oriented training.

One of the reported barriers to realizing ACP in practice concerns the hierarchy in the organization. When it is not someone's formal responsibility, this is considered to be a reason

not to conduct ACP conversations. However, ACP should be a joined responsibility of staff from various disciplines and levels. It is not because, for example, the head nurse is appointed for ACP that the nursing auxiliary should not engage in a conversation with a resident when the opportunity occurs. Moreover, some clinical staff have more informal contacts with residents and therefore are in a better position to pick up on signals that the resident is ready to discuss ACP. It is not practical, or desirable, to go and find the 'ACP responsible' when the topic occurs in an informal contact. It is indeed the responsibility of the designated staff members to stimulate their colleagues to pick up on conversations and communicate relevant information.

A positive finding is that in more than half of the recorded conversations, residents with dementia were involved. We advise to increase the involvement of residents with dementia even more, especially at the time of admission when communicative and cognitive capacity might still be sufficient [3,4].

Inevitably, this study has some limitations. Only a small number of conversation recordings was provided. Maybe a longer time period would have allowed dementia care units to conduct more conversations and to provide a more complete picture of resident involvement in ACP in the dementia care unit. No recordings of informal routine conversations were made which was the focus of the homework assignment in 'we DECide'.

'We DECide' was the first intervention that aimed to implement ACP for nursing home residents with dementia, by using the evidence-based communication model for SDM. Moreover, it included nursing home professionals from various disciplines and levels (i.e. the clinical and the organizational levels), in order to increase its implementation in practice.

4.2. Conclusion

'We DECide' had a positive influence on the policy of ACP in participating dementia care units. Nevertheless, the actual practice did not improve. Future studies should pay more attention to implementation strategies. For instance, a more intensive training may be required. We suggest engaging healthcare staff from the whole care unit and even the whole organization in long-term initiatives, in order to embed ACP in the organization. This could be achieved by a train-the-trainer approach in the training sessions, and by an intensive follow-up after the intervention. Participants should receive support when they are to transfer new knowledge and skills to their co-workers, for instance by means of regular meetings with the trainers and with supervisors, and evaluations of practice. Furthermore, interventions should focus more on strategies to activate residents as well as family caregivers to participate in ACP. Strategies could include raising public awareness about the importance of ACP and the possibility to participate in future care decisions; involving residents and families in training and information sessions; providing practical tips for conversations, with suggestions on what can be discussed or examples of questions that can be asked during the conversation.

4.3. Practice implications

Engaging healthcare staff from the whole care unit and even the whole organization, is essential for ACP. For ACP to be implemented on the long term, the engagement of staff from the whole organization is needed. Nursing homes need to develop implementation strategies, such as continuing education and a support system for health care professionals. Future studies on ACP in nursing homes should focus on a more intensive training and follow-up. Residents and families should also be involved in these initiatives, as equal partners in the ACP process.

Disclosure statement

I confirm all patient/personal identifiers have been removed or disguised so the patient/person(s) described are not identifiable and cannot be identified through the details of the story.

Conflict of interests statement

No conflict of interest has been declared by the authors.

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Contributions

All authors contributed equally to the conception and design of the study. SA collected and analyzed the data. All authors contributed to the interpretation of the data. SA drafted and wrote the paper. AS supervised the data collection and assisted with writing the paper. TS revised the paper critically for important intellectual content. AD and Ch.VA supervised the study and revised the paper critically for important intellectual content. All authors have approved the final version of the article.

Appendix A. Supplementary data

Supplementary data associated with this article can be found, in the online version, at http://dx.doi.org/10.1016/j.pec.2016.08.010.

References

[1] W. Europe, in: S. Hall, H. Petkova, A.D. Tsouros, M. Costantini, I.J. Higginson (Eds.), Palliative Care for Older People: Better Practices, Copenhagen, 2011.
[2] I.A. Scott, G.K. Mitchell, E.J. Reymond, M.P. Daly, Difficult but necessary conversations – the case for advance care planning, Med. J. Aust. 199 (2013) 662–666, doi:http://dx.doi.org/10.5694/mja13.10158.
[3] A. Vandervoort, D. Houttekier, R.V. Stichele, J.T. van der Steen, L. Van den Block, Quality of dying in nursing home residents dying with dementia: does advanced care planning matter? A nationwide postmortem study, PLoS One 9 (3) (2014) e91130, doi:http://dx.doi.org/10.1371/journal.pone.0091130.
[4] J.T. van der Steen, L. Radbruch, C.M. Hertogh, M.E. de Boer, J.C. Hughes, P. Larkin, 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. 28 (2014) 197–209, doi:http://dx.doi.org/10.1177/0269216313493685.
[5] A. De Vleminck, K. Pardon, K. Beernaert, R. Deschepper, D. Houttekier, C. Van Audenhove, et al., Barriers to advance care planning in cancer heart failure, and dementia patients: a focus group study on general practitioners' views and experiences, PLoS One 9 (1) (2014) e84905, doi:http://dx.doi.org/10.1371/journal.pone.0084905.
[6] J.T. van der Steen, M.C. van Soest-Poortvliet, M. Hallie-Heierman, B.D. Onwuteaka-Philipsen, L. Deliens, M.E. de Boer, et al., Factors associated with initiation of advance care planning in dementia: a systematic review, J. Alzheimers Dis. 40 (2014) 743–757, doi:http://dx.doi.org/10.3233/JAD-131967.
[7] L. Robinson, C. Dickinson, N. Rousseau, F. Beyer, A. Clark, J. Hughes, et al., A systematic review of the effectiveness of advance care planning interventions for people with cognitive impairment and dementia, Age Ageing 41 (2012) 263–269, doi:http://dx.doi.org/10.1093/ageing/afr148.
[8] A. Coulter, A. Collins, Making shared decision making a reality No decision about me, without me. Fund TKs, 2016 London 2011.
[9] E. Belanger, C. Rodriguez, D. Groleau, Shared decision-making in palliative care: a systematic mixed studies review using narrative synthesis, Palliat. Med. 25 (2011) 242–261, doi:http://dx.doi.org/10.1177/0269216310389348.
[10] G. Elwyn, M. Tsulukidze, A. Edwards, F. Legare, R. Newcombe, Using a 'talk' model of shared decision making to propose an observation-based measure:

observer OPTION5 Item, Patient Educ. Couns. 93 (2013) 265–271, doi:http://dx.doi.org/10.1016/j.pec.2013.08.005.
[11] N. Couët, S. Desroches, H. Robitaille, H. Vaillancourt, A. Leblanc, S. Turcotte, et al., Assessments of the extent to which health-care providers involve patients in decision making: a systematic review of studies using the OPTION instrument, Health Expect. (2013), doi:http://dx.doi.org/10.1111/hex.12054.
[12] F. Legare, S. Ratte, K. Gravel, I.D. Graham, Barriers and facilitators to implementing shared decision-making in clinical practice: update of a systematic review of health professionals' perceptions, Patient Educ. Couns. 73 (2008) 526–535, doi:http://dx.doi.org/10.1016/j.pec.2008.07.018.
[13] J.S. Weiner, S.A. Cole, Three principles to improve clinician communication for advance care planning: overcoming emotional, cognitive, and skill barriers, J. Palliat. Med. 7 (2004) 817–829, doi:http://dx.doi.org/10.1089/jpm.2004.7.817.
[14] J.S. Weiner, S.A. Cole, ACare a communication training program for shared decision making along a life-limiting illness, Palliat. Support. Care 2 (2004) 231–241, doi:http://dx.doi.org/10.10170/S1478951504040325.
[15] S. Ampe, A. Sevenants, E. Coppens, N. Spruytte, T. Smets, A. Declercq, et al., Study protocol for 'we DECide': implementation of advance care planning for nursing home residents with dementia, J. Adv. Nurs. 71 (5) (2015) 1156–1168, doi:http://dx.doi.org/10.1111/jan.12601.
[16] G. Elwyn, D. Frosch, R. Thomson, N. Joseph-Williams, A. Lloyd, P. Kinnersley, et al., Shared decision making: a model for clinical practice, J. Gen. Intern. Med. 27 (2012) 1361–1367, doi:http://dx.doi.org/10.1007/s11606-012-2077-6.
[17] J. Seymour, K. Almack, S. Kennedy, Implementing advance care planning: a qualitative study of community nurses' views and experiences, BMC Palliat. Care 9 (2010) 4, doi:http://dx.doi.org/10.1186/1472-684X-9-4.
[18] D. Casey, K. Murphy, A.N. Leime, P. Larkin, S. Payne, K.A. Froggatt, et al., Dying well: factors that influence the provision of good end-of-life care for older people in acute and long-stay care settings in Ireland, J. Clin. Nurs. 20 (2011) 1824–1833, doi:http://dx.doi.org/10.1111/j.1365-2702.2010.03628.
[19] D.R. Kuhn, J.M. Forrest, Palliative care for advanced dementia: a pilot project in 2 nursing homes, Am. J. Alzheimers Dis. Other Demen. 27 (2012) 33–40, doi:http://dx.doi.org/10.1177/1533317511432732.
[20] K. Froggatt, S. Vaughan, C. Bernard, D. Wild, Advance care planning in care homes for older people: an english perspective, Palliat. Med. 23 (2009) 332–338, doi:http://dx.doi.org/10.1177/0269216309103802.
[21] M. Galushko, V. Romotzky, R. Voltz, Challenges in end-of-life communication, Curr. Opin. Support Palliat. Care 6 (2012) 355–364, doi:http://dx.doi.org/10.1097/SPC.0b013e328356ab72.
[22] H.K. Normann, K. Asplund, S. Karlsson, P.O. Sandman, A. Norberg, People with severe dementia exhibit episodes of lucidity. A population-based study, J. Clin. Nurs. 15 (11) (2006) 1413–1417, doi:http://dx.doi.org/10.1111/j.1365-2702.2005.01505.x.
[23] M. Korner, H. Ehrhardt, A.K. Steger, J. Bengel, SDM Interprofessional train-the-trainer program fit for SDM: provider satisfaction and impact on participation, Patient Educ. Couns. 89 (2012) 122–128, doi:http://dx.doi.org/10.1016/j.pec.2012.04.008.
[24] S. Ampe, A. Sevenants, T. Smets, A. Declercq, C. Van Audenhove, Advance care planning for nursing home residents with dementia: policy vs. practice, J. Adv. Nurs. (November (12)) (2015), doi:http://dx.doi.org/10.1111/jan.12854 [Epub ahead of print].
[25] G. Elwyn, H. Hutchings, A. Edwards, F. Rapport, M. Wensing, W.Y. Cheung, et al., The OPTION scale: measuring the extent that clinicians involve patients in decision-making tasks, Health Expect. 8 (2005) 34–42, doi:http://dx.doi.org/10.1111/j.1369-7625.2004.00311.x.