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Original Article

## Improving advance care planning in patients with dementia: the effect of training nurses to engage in ACP-related conversations

\*Maartje Wils<sup>1</sup>, Jan Verbakel<sup>2</sup>, Jo Lisaerde<sup>2</sup>

<sup>1</sup>Department of geriatrics, University Hospital Leuven, Herestraat 49, 3000 Leuven, Belgium

<sup>2</sup>ACHG, KU Leuven, Kapucijnenvoer 33, blok J, PB 7001, 3000 Leuven, Belgium

### ABSTRACT

**Background:** Advance care planning consists of an individual approach to anticipate the decisions on treatment during the course of illness and at the end of life. In a nursing home setting there is a pressing need for advance care planning, especially for residents with dementia. Timely discussion of the treatment goals may help to increase the resident's autonomy and the quality of life and care.

**Objectives:** The aim of the study is to assess the effect of an education program for nurses on the registration of care goals in a nursing home with a population of elderly residents suffering from dementia. Another objective was to explore the views of nursing home staff on advance care planning in patients with dementia.

**Methods:** This quantitative study is a pre- and post-intervention evaluation in a nursing home in Flanders, Belgium, providing care for a population of 124 residents diagnosed with dementia. The intervention consisted of a 12-month program for nursing staff (n=13) including training in theoretical and communication skills. This group was asked to complete a structured 10-item-questionnaire (type Likert) at 0 and 12 months between January 2011 and January 2012 exploring their views on facilitating and obstructing factors concerning the implementation of ACP. At the same time a pre- and post-measurement of all ACP-related registrations, based on a novel care goals model in the electronic medical record was done.

**Results:** The intervention included all 124 residents diagnosed with dementia. 13 members of the nursing staff participated in the training and completed the questionnaire at point 0 and 12 months. At 12 months we noticed a significant increase in the number of interviews regarding ACP held with the residents, and also a significant increase in the number of care goals documented. We identified several facilitating factors and barriers for the ACP process. Furthermore we saw significant changes in caregiver's views on ACP at the end of the intervention period.

**Conclusions:** Prior to the intervention the members of the nursing staff presented some resistance towards the implementation of ACP, supported the ACP process afterwards. ACP was said to help raise the dignity and autonomy of the residents, and was especially useful in improving clarity for medical decision making. The number of successfully recorded information on ACP was increased significantly. Special attention should be given to the barriers that obstruct the implementation of ACP in the nursing home setting.

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### \*Correspondence

Miss Maartje Wils  
Universitaire Ziekenhuizen Leuven,  
Geriatrics, Herestraat 49, 3000  
Leuven, Belgium.  
Email: maartje.wils@triamant.be

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### INTRODUCTION

Advance care planning (ACP) is a personalized care approach encouraging decisions on issues of care that are to be expected in a patient's near future.<sup>1</sup> ACP consists of a communication process between the patient and the professional caregivers. Repeated conversations concerning the patient's views on life, care, illness and issues regarding the end of life are part of the ACP-process.

Planning care in advance can help to avoid unnecessary transitions of care at the end of life. Agreeing on specific

care-goals with the patient can improve medical decision-making in an urgent situation.<sup>2</sup> ACP can help to timely switch the focus from cure to care.<sup>3</sup> Using written directives on end of life care or appointing a representative who will advocate the premorbid wishes of the resident can enhance this process.<sup>4</sup>

ACP is especially important in patients living with dementia, a condition in which physical and cognitive capacity deteriorates over a period of several years. These patients often feel a great need to discuss their wishes for the future.<sup>5</sup>

However, there is little consensus on how ACP should be implemented in the nursing home setting and which professional caregivers should be appointed as guardian of this process. Nurses and doctors often feel a reluctance to engage in end-of-life care discussions especially in residents living with dementia. There is limited evidence for the effect of the ACP-process in people with cognitive impairment.<sup>5</sup> Previous studies have described the effectiveness of instruments such as guidelines for implementing ACP in long term care facilities<sup>6</sup> but in most of these instruments a cut-off score for the MMSE: 16/30 is used to decide if a person still has mental capacity to engage in ACP related conversations.<sup>7</sup> However if decisional capacity is inadequate a personal understanding relationship with the residents might facilitate patient centered decision making by the health care professional<sup>8</sup> and ACP could be possible.

It's a challenge to summarize all the information received during the ACP-process into directions and guidelines to provide appropriate care for a specific patient with chronic illness in case of sudden deterioration of health. One option is to try and translate this information into care goals.<sup>9</sup> A more detailed description of the care goals commonly used in nursing homes in Flanders, Belgium today can be found in box 1.

**Box 1.** The model of care goals commonly used in nursing homes in Belgium

Code A: prolongation of life  
Code B: sustaining current physical possibilities  
Code C: care for comfort  
Code Ct: care for comfort in a terminal stage

In this study we aimed to improve communication about the ACP-process and we expected theoretical and communicational training of nurses to change the amount of successful registrations on ACP-related issues.

## METHODS

### Design

This quantitative pilot study consisted of a pre- and post-intervention evaluation. The intervention was an educational program for nursing staff (n=13) including training on theoretical aspects of ACP and communication skills. Over a period of 12 months, four debriefing moments were organized for the nursing staff. A baseline and a 12-month measurement of all ACP-related registrations in the electronic patient files were done.

Prior to data collection, the study protocol was reviewed and approved by the multidisciplinary ethical board of the institution Vzw Dijleland, Leuven, Flanders, Belgium on December 10<sup>th</sup> 2011. Informed consent was provided by the resident and/or by the legal representative of the resident. The family-members were informed of the content of this study during several informative sessions. The nurses that agreed to participate in the study were also asked to provide informed consent.

### Setting and Population

The study was done in a nursing home (WZC De Wingerd, Wingerdstraat 14, 3000 Leuven, Belgium) in Flanders, Belgium with a population of 124 elderly patients all diagnosed with dementia. All 124 residents were included in the study as a convenience sample. During the 12 months of the intervention period 20 residents died and 1 patient was discharged. The 21 residents who were newly admitted to the nursing home during the intervention period were also included in the study.

Participants represented a range of diagnoses of dementia including Alzheimer's disease, Lewy Body dementia, vascular dementia, and mixed type (Alzheimer's disease and Vascular dementia). More women with dementia were included (n=90) than men (n=34). The intervention group consisted of registered nurses (RN) from different wards (n=13). Nurses were women (n=11) and men (n=2). People with dementia ranged in age from 68 to 95 years and nurses ranged in age from 22 to 55 years. Nurses were asked to participate and if they declined, another nurse was randomly selected from the staff lists and asked to participate.

### Study Protocol and Measures

To design the study protocol the Conceptual Framework for Implementation of Advance Care Planning<sup>1</sup> was used as guideline. During the 12-month study-period the participating nurses were offered two educational training sessions and four debriefing moments, all sessions lasted two hours each. The first educational session was a theoretical one that addressed the legal and ethical issues on ACP. Concepts such as advanced directives, legal representatives and care goals were explained by an independent expert in law. The second session consisted of communication training. This session was given by one of the researchers who had been trained in this matter. Participants were taught how to engage in an ACP-related conversation by using examples and role play. They were provided with interview guidelines containing questions that might be useful to ask in an ACP related conversation. Over the course of the next months the nurses were asked to engage in ACP conversations with the residents during everyday care. Four sessions of debriefing were organized for the nursing staff participating in the study. The content and manner of these conversations were discussed during the debriefing moments. As debriefing strategy video learning was used: a number of conversations with the residents were filmed and discussed in the intervention group.

### Outcomes

The primary outcome was the successful recording of ACP in the electronic medical patient file. In January 2011 the researchers reviewed the 124 medical records to identify the amount of registrations on ACP. In January 2012 this search was conducted a second time.

Collected data in the medical files can be found in box 2. These questions describe the data collected by the researchers seen as information related to ACP. The choice

for these particular questions was based upon the current guidelines on ACP in Belgium as provided by the Federation of Palliative Care in Flanders, to be found on [www.pallialine.be](http://www.pallialine.be).

**Box 2.**

1. Does the resident have an advanced directive concerning ACP?
2. Did the resident appoint a representative?
3. Was care goal A,B, C or Ct documented?
4. What are the resident's current wishes for care?
5. Has a conversation about ACP been recorded:
  - a. With the resident present?
  - b. With the representative present?
  - c. With the family present?

**Statistical Analyses**

We compared the outcome and significance of the number of ACP related registrations in all residents with a baseline and 12 months measurement. Because our data included repeated measures on the same subjects, analysis of variance (ANOVA) was used. Statistical differences between the pre- and post-intervention groups were determined, through calculation of the F-statistic. The  $\alpha$  level of significance was set at  $p < 0.05$ . All analyses were performed with Stata software (version 11.2; Stata Corp., College Station, TX, USA).

**RESULTS**

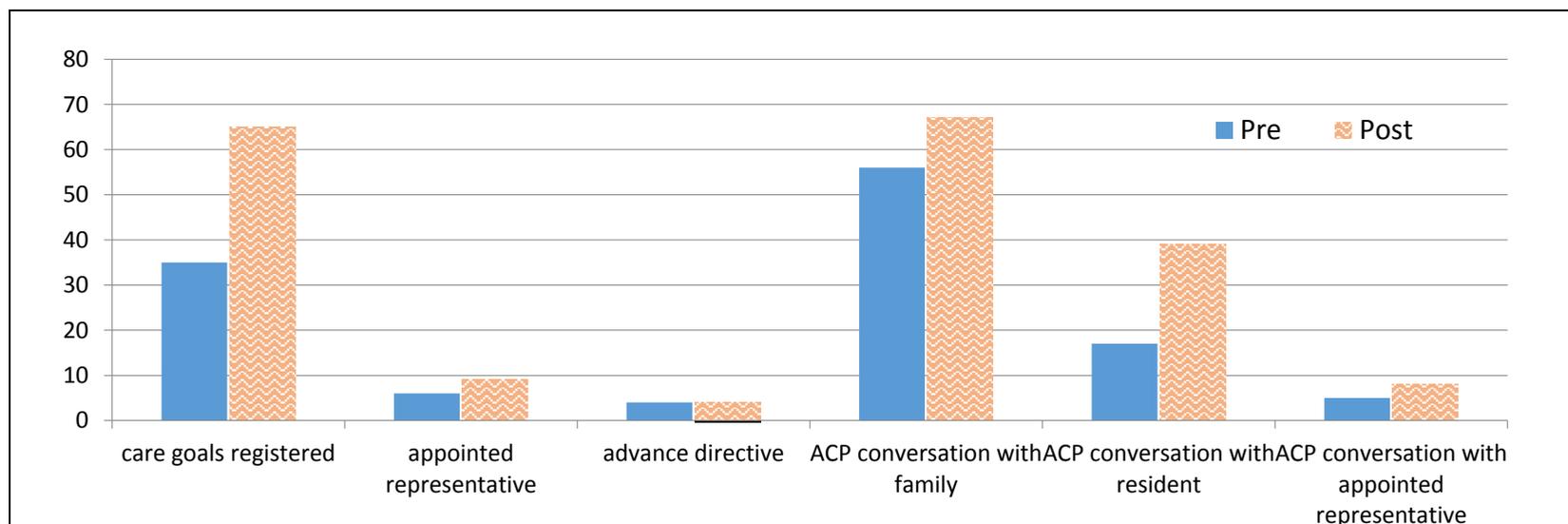
Figure 1 shows the frequency of each of the 5 essential data items collected from the medical files registered in the pre- and post-intervention time period.

Apart from the number of advanced directives ( $p=1.00$ ) and appointed representatives ( $p=0.08$ ), all items increased significantly in all residents still alive after the registration period ( $p<0.05$ ), providing repeated measurements of these crucial items. (Table 1) The overall number of ACP related items registered in the electronic medical record was even larger (73 at 12 months versus 39 at baseline), taking into account that 20 residents died, 1 resident was discharged and 21 new residents were admitted during the study period.

**Table 1.** Results from the ANOVA analysis of repeated measures on the ACP related items in the electronic medical record

Group 2 versus Group 1	ANOVA	
	F-statistic	p-value
Care goals	3.95	0.05
Appointed representative	3.05	0.08
Advance directive	0.00	1.00
ACP conversation with family	0.64	0.43
ACP conversation with resident	20.71	0.00
ACP conversation with appointed representative	5.53	0.02

During the debriefing moments we explored the views of the nurses concerning the facilitating factors and barriers experienced during the implementation of the ACP process. To do this we used semi-structured interviews. Communication training and theoretical education on the legal and ethical issues concerning ACP were considered to be very useful. Nurses asked to provide them with interview guidelines, suggesting very specifically which questions they should ask and how to do so. *As one nurse said "The most difficult part is to start the conversation. What words do you use, what do you say. Once you are talking, it isn't that difficult."* (Nurse, 24 y) Support from the head nurses and medical staff was needed to encourage nurses in getting involved in the ACP process. Nurses indicated a lack of time and space as a primary problem to implement ACP. *"Sometimes a patient would say something about how they feel, and you think 'I should sit down now, make time' but you know, you have other patients waiting for care..."* (Nurse, 37y) The ABC-model of care goals needed to be explained during the theoretical training to make it understandable for implementation. Also, dementia and cognitive decline also remain barriers in the ACP process. Difficulty to start an ACP-related conversation was perceived as a barrier before the intervention, however after the training intervention this was no longer the case. After the intervention nurses also did no longer experience resistance within themselves to engage in an ACP related conversation. *"It surprised me but I didn't get any negative reactions from the patients. This made me more confident about having this kind of conversations."* (Nurse, 41y) During the course of the intervention the electronic patient file was updated, creating specific space for the registration of ACP-related issues (as having nowhere to register accurately was considered a major barrier to nurses).



**Figure 1.** Changes in documentation between the pre- and post-intervention period

## DISCUSSION

Our results showed a significant increase in the number of ACP-related registrations after implementing the intervention of communication training. This specific nursing home already puts strong focus on ACP-related conversations with family members. After the intervention the number of this type of conversation increased significantly from 56/124 to 67/124. However, the number of conversations held with the resident with dementia present more than doubled from 17/124 to 39/124. This could mean that training nurses in having conversations concerning ACP might increase patient involvement and autonomy in care decision-making.

Previous studies have shown that ACP should be implemented early in the illness of dementia, while the patient still has the mental capacity to make decisions concerning his future preferences. Dementia and cognitive decline, as seen in our study, are major barriers towards ACP.<sup>5</sup> However, this study suggests that it is still possible to discuss certain issues concerning ACP with the patient even when dementia is progressing.

A limit to this study was that the convenience sample of residents was rather small (n=124), and we conducted the study in only one nursing home in Belgium, Flanders, therefore results can't be generalized as such. Power wasn't calculated in advance so this study should be seen as a pilot study for further research. This nursing home also specializes in care for people with dementia. Another limitation to this study was the lack of possibilities to question the patients thoroughly on their views on the concept of ACP; this was mainly due to a lack of cognitive capacity. This is described as a major lack of evidence in the current discussion on ACP.<sup>5</sup> It can also be argued that the intervention group of nurses was rather small (n=13). This is also a convenience sample of nurses working in this particular nursing home, of course this has a major impact on the generalizability of the results. However even with this small number of nurses receiving training we did see a significant impact on the number of ACP-related registrations.

Little research has been done concerning which professional caregivers should take part in the ACP process. It is said however that if decisional capacity has declined a personal understanding relationship with the patient might facilitate decision-making.<sup>8</sup> Nurses spend the majority of time as caregivers with the resident and therefore are most familiar with them. For this reason we focused our intervention on this group of care professionals.

We acknowledge that the qualitative part of this study, questioning the nurses was very brief and incomplete. Because of the small number of nurses involved (n=13) the information gathered from these interviews is purely descriptive and can't be generalized. It could however be of inspirational value for further research.

## CONCLUSIONS

The number of successfully recorded information on ACP increased significantly after the training of nurses on the subject, however special attention should be given to

the barriers and facilitating factors that obstruct the implementation of ACP in the nursing homes. Lack of time was considered a major barrier, being provided with a structured interview guideline was considered as facilitating the ACP-process. Further research addressing the implementation process of ACP remains necessary.

## CONFLICT OF INTEREST STATEMENT

No conflict of interest was declared among authors.

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