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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.

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

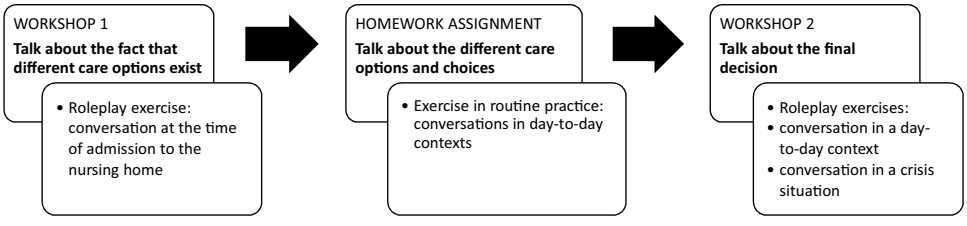

Fig. 1. 'We DECide': Training modules (from: Ampe et al., 2015 [15]) provides details on the three modules that constitute the 'we DECide'-intervention.

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