Study protocol for ‘we DECide’: implementation of advance care planning for nursing home residents with dementia.

Abstract

Aim

To evaluate the effects of ‘we DECide’, an educational intervention for nursing home staff on shared decision making in the context of advance care planning for residents with dementia.

Background

Advance care planning (preparing care choices for when persons no longer have decision making capacity) is of utmost importance for nursing home residents with dementia, but is mostly not realized for this group. Advance care planning consists of discussing care choices and making decisions and corresponds to shared decision making (the involvement of persons and their families in care and treatment decisions).

Design

This quasi-experimental pretest-posttest study is conducted in 19 nursing homes (Belgium). Participants are nursing home staff.

Methods

‘We DECide’ focuses on three crucial moments for discussing advance care planning: the time of admission, crisis situations and everyday conversations. The ‘ACP-audit’ assesses participants’ views on the organization of advance care planning (organizational level), the ‘OPTION-scale’ evaluates the degree of shared decision making in individual conversations (clinical level) and the ‘IFC-SDM Questionnaire’ assesses participants’ views on Importance, Frequency and Competence of realizing shared decision making (clinical level). (Project funded: July 2010).

Discussion

The study hypothesis is that ‘we DECide’ results in a higher realization of shared decision making in individual conversations on advance care planning. A better implementation of advance care planning will lead to a higher quality of end-of-life care and more person-

centred care. We believe our study will be of interest to researchers and to professional nursing home caregivers as well as policy makers.

Keywords advance care planning, decision making, shared, dementia, care choices, end of life, education, residential facilities, nursing

Summary statement

Why is this research needed?

- Advance care planning, preparing care choices for when persons no longer have decision making capacity, is of utmost importance for nursing home residents with dementia, but is mostly not realized for this group.
- Education for nursing home staff in communication skills and shared decision making is needed to improve advance care planning.
- Better implementation of advance care planning will result in a higher quality of end-of-life care and in a more person-centred care.

INTRODUCTION

Advance care planning (ACP) aims to discuss and prepare care choices for the stage in life when people no longer have the capacity to make decisions (Scott *et al*. 2013). ACP is a way to improve the quality of end-of-life care and to provide person-centred care by focusing on individual preferences (Brinkman-Stoppelenburg *et al*. 2014, Piers *et al*. 2013). ACP is especially important for people with dementia, as this disease is characterized by the gradual loss of cognitive abilities (Robinson *et al*. 2012). Therefore, ACP discussions with people with dementia should start when they still have sufficient communicative and cognitive abilities to express personal preferences.

BACKGROUND

Despite the growing number of studies on ACP in the last decade, there is a limited number of ACP interventions for people with dementia that positively influence care outcomes (Dening *et al*. 2011, Robinson *et al*. 2012). Furthermore, for nursing home residents with dementia, ACP is mostly not realized (Mitchell *et al*. 2004, Vandervoort *et al*. 2012).

In Western Europe, the majority of people with advanced dementia spend the last period of their life in a nursing home (Houttekier *et al*. 2010). In that case, care choices and ACP should be coordinated with nursing home staff. Staff from both the organizational level (i.e. nursing home management) and the clinical level (i.e. nursing home caregivers) should be involved in the ACP process. First of all, continuous motivation by the management is important for the long-term implementation of ACP (Casey *et al*. 2011, Kuhn & Forrest 2012, Seymour *et al*. 2010). Secondly, the nursing home caregivers are key figures for taking up ACP in (in)formal conversations with residents and their families throughout their stay and for making and passing on significant observations.

In essence, the process of ACP consists of three key elements: introducing choice between care and treatment options; balancing these options and investigating personal

preferences of key persons (patients and families); and making the most appropriate decision, together with patients, families and healthcare professionals. Accordingly, ACP is basically a form of shared decision making (Coulter and Collins 2011, Teno *et al*. 2004, Waldrop & Meeker 2012). Shared decision making (SDM) is 'a process where clinicians and patients work together to clarify treatment goals, sharing information about options and preferred outcomes, with the aim of reaching mutual agreement on the best course of action' (Coulter & Collins 2011). Since practical guidelines on how to implement SDM in daily practice are lacking, Elwyn *et al*. (2012) proposed a three-step model for SDM. The three steps are the 'Choice Talk' (introducing choice between options), the 'Option Talk' (describing options) and the 'Decision Talk' (making a final decision).

Education in SDM and related communication skills is recommended for nursing home staff, to improve ACP (Galushko *et al*. 2012, Scott *et al*. 2013, Skills for Care 2008, Street & Ottman 2006). Consequently, we developed 'we DECide' (Discussing End-of-life Choices), an educational intervention for nursing home staff in applying SDM in conversations about ACP for residents with dementia. The three-step model for SDM guided the development of 'we DECide' and the assessment instruments. 'We DECide' is designed to teach competences necessary to apply the three-step model for SDM in ACP-conversations with nursing home residents with dementia and their families.

THE STUDY

Aims

The principal aim of this study is to evaluate the effects of 'we DECide', in a pretest-posttest design, using instruments for assessment at the organizational level and clinical level. The hypothesis is that 'we DECide' will result in increased competences for realizing SDM and ACP. Consequently, as a result of the increased competences of nursing home staff, 'we

DECide' will also result in a higher implementation of SDM in conversations about ACP for residents with dementia and eventually in a more person-centred care approach.

Design

The study uses a quasi-experimental pretest-posttest design. 'We DECide' is implemented in an intervention group, while a control group receives no intervention. The main difference between both groups is the baseline level of the realization of ACP and SDM in the nursing home.

Data are collected in both groups before and after the implementation of 'we DECide'. Assessments take place at the organizational level and at the clinical level. The study timeline contains following time points: T1 – baseline measurement at the organizational level, two months prior to 'we DECide'; T2 – baseline measurement at the clinical level, at the start of 'we DECide'; intervention – implementation of 'we DECide'; T3 – posttest measurement at the clinical level, immediately after 'we DECide'; and T4 – posttest measurement at both the clinical and the organizational level, three months after 'we DECide' (see also: *Figure 1. Study timeline*). Measurements in the intervention group take place at time points T1, T2, T3 and T4; measurements in the control group take place at time points T1 and T4.

Sample

The study is conducted in 19 nursing homes in Flanders, Belgium. Calls for participation were sent out by e-mail to the four umbrella organizations for nursing homes (i.e. the federation for care for older people, the federation for care homes in Belgium, the association of Flemish cities and municipalities and the Flanders care network). The study was also announced during a local conference.

Nursing homes could enrol on a voluntary basis. They had to meet three inclusion criteria: the presence of a special care unit for persons with dementia, a positive attitude

towards communication training and ACP and a willingness to further participate in the research.

Nursing homes in the intervention group are asked to delegate approximately five staff members to the training sessions, from both the nursing home management (organizational level) and the caregiver staff (clinical level). Nursing homes in the control group are guaranteed that they will also receive 'we DECide' when all data is collected (after time point T4). The group composition is described in more detail below (see section *ACP-Audit*).

Practice guidelines

Before the start of this study, the authors developed practice guidelines with recommendations on the communication on end-of-life issues for persons with dementia in nursing homes (Communication at the end of life of nursing home residents with dementia: Recommendations for conversations with residents and caregivers. Unpublished manuscript by the authors). These practice guidelines were based on literature review, expert interviews and focus groups with nursing home staff. The results of the literature review and the qualitative analysis of the expert interviews on the topic 'communication about end of life issues for persons with dementia in nursing homes' guided the development of the first draft. Focus groups were composed with multidisciplinary nursing home staff, who gave substantive feedback at different times during the process of the guideline development.

The practice guidelines are structured according to the crucial moments for introducing and discussing ACP during the nursing home stay of persons with dementia: formal conversations at the time of admission, informal conversations during the first weeks and months, conversations in crisis situations and conversations at the start of and during the palliative care phase. For each of these moments, the practice guidelines contain recommendations and examples for talking about ACP, care choices and personal preferences.

The three-step model for SDM was used as framework to formulate practical tips for conducting conversations.

Intervention

'We DECide' (Discussing End-of-life Choices) is a training program for nursing home staff. It was developed for this study, based on earlier work of the research group (Van Audenhove & Vertommen 2000). The objective is to teach 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.* (2012) (Figure 2). For each of the three steps in this model, a separate training module was designed, each module aiming at training specific competences for the corresponding step. 'Choice Talk' is covered in a first workshop, 'Option Talk' is practiced in a homework assignment and 'Decision Talk' is covered in a second workshop. Furthermore, the modules correspond to three types of conversations that are crucial for talking about ACP in the nursing home: conversations at the time of admission, conversations about end-of-life issues in daily informal contexts and conversations in case of crisis situations.

Participants receive 'we DECide' in small groups to optimize active participation. An experienced trainer conducts both workshops and coaches participants in role play exercises. One of the authors is co-trainer (SA). The training is given five times to five separate participant groups. The intervention modules are described below (Figure 3).

Workshop 1: 'Choice Talk' – Talk about the fact that different care options exist

The first workshop, a four-hour session, aims to increase the competences needed to apply step 1 of the three-step model, the 'Choice Talk'. In this step, professionals should talk about the fact that different (care) options exist, explain that all options are of equal value and check whether the resident and/or family caregiver understands that different options exist and what options are available. The workshop starts with theory on the three-step model for SDM and its application in ACP. Training in communication skills needed for the 'Choice Talk' is

elaborated in a role play exercise, a conversation at the time of admission of a resident with dementia. Persons with dementia may already have decreased communication abilities at this moment (Robinson *et al*. 2012), so it is considered as a crucial moment for starting or updating ACP (Alzheimer's Association 2007).

All participants are involved in the exercise, either by re-enacting a case, or by performing a specific observation task (Table 1). During the role play exercise, participants are coached closely by the trainer, making them aware of communication pitfalls and good SDM interventions. The workshop ends with a discussion about lessons learned from the exercise and with more information on the homework assignment. Workshop 1 was piloted at a local conference with multidisciplinary nursing home staff (n=60) before the start of the baseline measurement. This resulted in minor changes.

Homework assignment: 'Option Talk' – Talk about the different care options and choices

In between workshop 1 and workshop 2 (3-4 weeks), all participants are assigned homework concerning informal conversations about end-of-life issues. Because of their declining communication abilities, it is very important to recognize and seize opportunities that arise in day-to-day situations, for talking about personal preferences about end-of-life issues with persons with dementia.

The specific aim of the homework assignment is to focus on step 2 of the three-step model, the 'Option Talk': talking about the options and choices. In applying the 'Option Talk', professionals should be able to sum up all options regarding (end-of-life) care, discuss (dis)advantages and possible risks of each option and explore residents' and/or family caregivers' preferences.

Participants are instructed to engage conversations about end-of-life choices in their own nursing home facility with residents with dementia and family caregivers. They are asked

to send in their cases one week before workshop 2, together with an account of their experiences and perceived barriers and facilitators for the implementation of the three-step model for SDM in ACP-conversations. The homework cases are aggregated and summarized for discussion in workshop 2.

Workshop 2: 'Decision Talk' – Talk about the final decision

Workshop 2, a four-hour session, takes place three to four weeks after workshop 1. Workshop 2 focuses on the 'Decision Talk': talking about the final decision (step 3 of the three-step model). It includes: determining if and to what extent residents and/or family caregivers want to be involved in the care planning and decision making process, guiding them to a final decision and indicating that it is possible to revise the decision later.

Workshop 2 starts with sharing experiences with the three-step model in practice. Homework cases, strengths and alternative suggestions are discussed. After a short repetition of the theory of ACP and SDM, two prototypical cases are presented as new role play exercises. This first case represents a prototypical conversation about end-of-life issues in a daily context (in conformity with the homework assignment). The second case represents a formal conversation at the time of a crisis situation, which is a critical moment for making decisions and updating ACP. In both cases (Table 1), talking about options and making decisions is inevitable and SDM should be applied.

Participants are involved in the exercises as an actor or observer, taking into account that each participant is an actor at least one time in workshop 1 or in workshop 2 to ensure everyone has the same learning experience. During the role play exercises, actors and observers are stimulated by the trainer, by asking them to reflect on pitfalls and good or alternative communication- and SDM-interventions. Workshop 2 ends with a discussion on the lessons learned from the exercises.

Supporting materials

Presentation: Workshop 1 and workshop 2 are guided with a PowerPoint presentation.

Documents: Participants receive the three-step model as a reminder in poster- and in pocket-size.

Contacts: Contact details of the researchers are provided, should participants have questions during the homework assignment, or afterwards.

Practice guidelines: The practice guidelines on applying SDM in ACP-conversations (unpublished manuscript) are provided at the time of the second session.

Data collection

Three instruments are used to measure and evaluate the effects of 'we DECide'. One of these instruments assesses effects at the organizational level and two instruments assess effects at the clinical level.

Assessment at the organizational level

For pretest- and posttest-assessment at the organizational level, one instrument is used: the ACP-audit, for evaluation of nursing home staff's views on the organization of ACP in the nursing home.

1. ACP-audit

Description The ACP-audit was developed to evaluate the views of nursing home staff on the organization of ACP in the nursing home and was based on the practice guidelines for communication on end-of-life issues for persons with dementia in nursing home that were previously developed by the authors (unpublished manuscript).

The format of the ACP-audit was based on an existing method to evaluate the implementation of evidence based programs (Bond *et al*. 2011, Knaeps *et al*. 2012). In this case, the ACP-audit evaluates the implementation of the practice guidelines in the

organization. It consists of a structured questionnaire with nine sections, each of which represents an important moment in the ACP process, from admission to the nursing home up to the palliative care phase (corresponding to the structure of the practice guidelines). Per section, five criteria for the optimal organization of ACP are described, with 45 criteria in total. The more criteria are met, the higher the score on the ACP-audit (range between 0 and 45). An overview of the sections and corresponding criteria can be found in *Table 2. ACP-audit: Sections & criteria*. The questionnaire is designed for oral questioning of a group of nursing home staff members.

Pilot test The ACP-audit was piloted in cooperation with one independent nursing home, six months before the actual start of the baseline measurements. The structured questionnaire was administered in a group interview to three nursing home staff members. Afterwards, the questionnaire was evaluated and adapted in such a way that all necessary information could be obtained in an acceptable time span and that the questions were clear and comprehensible.

Data collection The ACP-audit is administered in a group interview with eight to twelve nursing home staff members, with a duration of approximately 1.5 hours per nursing home. The group of participants is multidisciplinary and consists of staff from the organizational level (management staff) as well as the clinical level (caregiver staff), which allows for obtaining information from different perspectives. The interviews are taped with a voice recorder and transcribed afterwards. The participating nursing homes are audited at time points T1 and T4.

Rationale and group composition It is our purpose to teach ‘we DECide’ to participants with comparable starting levels of competence, along with sufficient learning opportunities. Therefore, prior to the selection of the intervention group, the 19 nursing homes are ranked on their scores on the ACP-audit. The nine lowest scoring nursing homes are

invited for participation in ‘we DECide’ and are grouped in pairs. To compose groups of equal size, one of the control nursing homes was dropped from the control group and also invited to participate in the intervention group. Hence, a total of ten nursing homes received the ‘we DECide’, grouped into five pairs. Data obtained from the additional tenth nursing home were omitted in the study, since that nursing home did not belong to the nine lowest scoring nursing homes. Consequently, the control group consists of nine nursing homes, the intervention group consists of nine nursing homes and one nursing home is excluded from further analyses from this point on.

Assessment at the clinical level

For assessment at the clinical level, two instruments are used: 1) the OPTION scale, a validated instrument to evaluate patient involvement in conversations with clinicians (Elwyn *et al*. 2003) and 2) the IFC-SDM Questionnaire, that was developed for this study, to assess participants’ views on importance, degree of realization in practice and the degree to which they think they have the required competences for realizing SDM.

2. OPTION scale

Description The Observing Patient Involvement (OPTION) scale is one of the few validated instruments to measure SDM in practice (Elwyn *et al*. 2003). This tool assesses the extent to which clinicians involve patients in the decision making process regarding care options. It consists of 12 specific aspects of realizing SDM, to be scored by an independent observer.

Data collection The participating nursing homes receive a voice recorder at T1 and are asked to make audio recordings of two types of conversations: one conversation with residents and/or family caregivers at the time of admission to the nursing home (or in the first few weeks after admission) and one conversation with family caregivers in a crisis situation (i.e. a deterioration in the health situation of a resident). It is a formal requirement that staff

member(s) who conduct and record the conversations at time point T1, also conduct and record the conversations at time point T4 and actively participate in 'we DECide' in case their organization is part of the intervention group. Informed consent forms for residents and their family caregivers are provided, which need to be completed and signed before the recording starts.

Rationale The time of admission is a crucial moment for introducing ACP in the nursing home stay of residents with dementia. This moment usually requires a formal conversation with the new resident and/or family caregivers, which is the starting point for all future (formal) communication about ACP during the nursing home stay. Moreover, this is the type of conversation that is the focus in workshop 1 of 'we DECide'. This is why we ask to record this type of conversation. Another critical moment for talking about ACP is at the time a crisis situation occurs. In such situations, talking about care options and making a decision cannot be avoided and ACP should be updated, or at least initiated. This type of conversation is the focus in workshop 2. Hence, we will also analyse to what extent SDM is applied in this type of conversation. We do not ask to record the third type of conversation that 'we DECide' covers, conversations about end-of-life issues in daily contexts (homework assignment). Since these are mostly informal, unplanned conversations, asking permission to record them would be difficult and could affect the spontaneity of the conversation.

3. IFC-SDM Questionnaire

Description The IFC-SDM Questionnaire (assessing views on Importance, Frequency and Competence in Shared Decision Making) was developed for this study and was based on the three-step model for SDM (Elwyn *et al*. 2012). It consists of nine behavioural aspects needed for realizing SDM, each referring to one step of the model: items 1-3 refer to competences needed for the 'Choice Talk', items 4 to 6 refer to the 'Option Talk' and items 7-9 refer to the 'Decision Talk'. The IFC-SDM Questionnaire assesses participants' views on

'importance' of behaviours, 'frequency' of putting these behaviours into practice and *competence* in performing these behaviours. This format is based on earlier work of the research group (Van Audenhove *et al*. 2001). Views are assessed for three types of conversations: conversations with residents and/or family caregivers at the time of admission to the nursing home; conversations with family caregivers in the case of crisis situations; and conversations on end-of-life issues in daily contexts. The format of the questionnaire can be found in Table 3.

Pilot test The first version of the IFC-SDM Questionnaire was administered at the same conference where workshop 1 of 'we DECide' was piloted. No changes were made to the final version.

Data collection Filling out the questionnaire takes about 15 minutes. The questionnaires are filled out by the participants in the intervention group immediately before the start of 'we DECide' (T2) and immediately after 'we DECide' (T3). Three months after the intervention, questionnaires are filled out again by the participants in the intervention group (T4).

Rationale The three types of conversations in the IFC-SDM Questionnaire are the same that are covered in 'we DECide': a conversation at the time of admission to a nursing home is exercised in workshop 1, a conversation in a crisis situation is exercised in workshop 2 and informal conversations about end-of-life issues in daily contexts are the focus in the homework assignment.

Data analysis

The **ACP-audit** scores on a total of 45 criteria. Per criterion that is met, one point is added to the total score, with a maximum of 45. The criteria are scored independently by two researchers. The researchers then confer with each other to assign a consensus score per nursing home. Comparisons of audit scores are made before and after the intervention and between the intervention and the control group.

With the OPTION scale (the instrument and manual are available online), an independent observer evaluates the extent to which clinicians initiate behaviour to involve patients during the consultation in the process of decision making. Twelve items are used to score the consultation. Item scores can vary from 0 – 4, with a total score between 0 and 48. All recorded conversations are initially analysed by one researcher. A random sample of these conversations is rated by an independent researcher, for inter-rater reliability. Comparisons are made before and after the intervention and between the intervention and control group.

On the IFC-SDM Questionnaire, participants indicate to which extent they agree with the items on a five-point scale, from 1 (low) - 5 (high). Answers are analysed by assessing the degrees of two types of discrepancies: 1) the difference between perceived importance and perceived frequency of performing a behaviour; and 2) the difference between perceived importance and perceived competence in performing a behaviour. Especially if importance is perceived 'high' (>3) AND frequency or competence is perceived 'low' (<3), it is an indication that applying SDM is compromised (Van Audenhove *et al*. 2001). It means that a particular intervention is regarded as (very) important, but is barely present in practice or participants do not feel competent enough to do this intervention. A high discrepancy score is therefore an indication of a need for training. For example, when a participant thinks 'Talking about the fact that different (care) options exist' is very important (= score 5) and thinks that he/she rarely does this, or that he/she feels incompetent to do this (= score 2), training in SDM is relevant for this person. The results of the IFC-SDM Questionnaire are compared before and after the intervention in the intervention group only (within group analysis).

Ethical considerations

The study was approved by the governmental Privacy Commission and ethics approval was received from the Medical Ethical Committee of the researchers' university. Written informed

consents are completed by all participants of the intervention and by all persons whose conversations are recorded.

Validity and reliability

The intervention and control group are formed based on the baseline ACP-audit scores instead of an at random distribution. In an ideal situation we would prefer involvement of a larger group of nursing homes so that a random sample of lower scoring nursing homes could be distributed over the intervention and the control group. In the current study, the audit-scores of half of the participating nursing homes indicated that the competences that would be the focus of the learning process in 'we DECide' were already required. According to their assessment there was no room for improvement through training. It makes no sense to participate in a learning process that covers competences that are already mastered. Therefore, we are convinced that the nursing homes in our intervention group represent the real life target group of our intervention. After the completion of this study, a randomized trial with a larger study sample will take place, including a follow-up over a longer time period to evaluate the sustainability of the effects.

Evaluation questionnaires, with open questions assessing barriers and facilitators to implement SDM in the clinical practice, are completed by the participants after each workshop. The purpose is to gain insight in hindering and helping factors for implementing 'we DECide' in practice.

Researchers or organizations wanting to use 'we DECide' in other countries, may have to take account of the fact that the target groups for the training (management and clinical) may slightly differ according to the organization of care in that particular country. This however does not change the content of the training.

DISCUSSION

In this paper we described ‘we DECide’, an educational intervention on SDM in ACP-conversations for residents with dementia. We also described how it is implemented in a group of nursing home staff members and how its effects are assessed on the organizational and the clinical level. Assessments are made before and after the implementation of ‘we DECide’.

This study has several strengths. To our knowledge ‘we DECide’ is the first educational intervention for nursing home staff on ACP for residents with dementia, that is based on the three-step model for SDM. For each step a training module was developed focused the competences needed to accomplish SDM: Workshop 1 was designed to practice the ‘Choice Talk’; the homework assignment was designed to practice the ‘Option Talk’; and workshop 2 was designed to practice the ‘Decision Talk’. Furthermore, each training module focuses on one of three crucial moments during the nursing home stay for talking about ACP: at the time of admission, at the time of a crisis situation and in daily contexts.

The underlying assumption is that ‘we DECide’ results in a higher realization of SDM in ACP-conversations with residents with dementia and family caregivers as a result of the professionals’ increased competences in SDM. This in turn will positively influence the ACP communication process in the nursing home. As described in the introduction, a better implementation of ACP will lead to an improved quality of end-of-life care and a more person-centred care. Another strength of this study is that evaluations of the intervention are made at both the organizational level and the clinical level. Two instruments were developed for this purpose: the ACP-audit for the organizational level and the IFC-SDM Questionnaire for the clinical level. A third instrument, the OPTION scale measures the extent of SDM in individual conversations (clinical level). The involvement of nursing home staff from both the organizational and the clinical level and the fact that effects at both those levels are measured, which may have important implications for policy.

Assessments are also made of perceived practice as well as actual practice. Views on the realization of ACP are assessed with the ACP-audit, views on the realization of SDM with the IFC-SDM Questionnaire and actual behaviours for realizing SDM in individual conversations are evaluated with OPTION. Results of comparisons between perceived and actual practice will be relevant to researchers and policy makers when new educational interventions with a focus on changing attitudes and/or behaviours are implemented.

Limitations

Inevitably, this study also has some limitations. First, nursing homes have been recruited on a voluntary basis, implying that participants are not representative for all nursing home staff in Flanders. However, a basic requirement for learning is that people are motivated to gain new insights and have a positive attitude towards the subject of the training. 'We DECide' also requires active participation in the education and learning activities. Therefore, we believe that voluntary participants are the real target group of the intervention and the 19 participating nursing homes reflect this population better than an at random invited sample could. A second limitation concerns the non-equivalent control group, which may limit the validity of study findings.

CONCLUSION

We believe our study will make a significant contribution to the field of research in ACP and SDM. This topic is also relevant to the continuing education in clinical practice and the data resulting from this study will be of importance to professional caregivers in nursing homes as well as policy makers. Furthermore, results from this study will inform the design of a randomized trial with a larger study sample.

References

Alzheimer's Association (2007) Dementia care practice: recommendations for assisted living residences and nursing homes. Phase 3: End-of-Life Care. Alzheimer's Association, Chicago.

Bond GR, Becker DR, Drake RE (2011) Measurement of Fidelity of Implementation of Evidence-Based Practices: Case Example of the IPS Fidelity Scale. Clin Psychol-Sci Pr 18(2):126-141. doi: 10.1111/j.1468-2850.2011.01244.x

Brinkman-Stoppelenburg A, Rietjens JAC, van der Heide A (2014) The effects of advance care planning on end-of-life care: a systematic review. Palliat Med 25:1000-1025. doi: 10.1177/0269216314526272

Casey D, Murphy K, Leime AN, Larkin P, Payne S, Froggatt KA, O'Shea E (2011) 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(13-14):1824-1833. doi: 10.1111/j.1365-2702.2010.03628.x

Coulter A, Collins A (2011) Making shared decision making a reality. No decision about me, without me. The King's Fund, London.

Dening KH, Jones L, Sampson EL (2011) Advance care planning for people with dementia: a review. Int Psychogeriatr 23(10):1535-1551. doi: 10.1017/S1041610211001608

Elwyn G, Edwards A, Wensing M, Hood K, Atwell C, Grol R (2003) Shared decision making: developing the OPTION scale for measuring patient involvement. Qual Saf Health Care 12(2):93-99. doi: 10.1136/qhc.12.2.93

Elwyn G, Frosch D, Thomson R, Joseph-Williams N, Lloyd A, Kinnersley P, Cording E, Tomson D, Dodd C, Rollnick S, Edwards A, Barry M (2012) Shared decision making: a model for clinical practice. J Gen Intern Med 27(10):1361-1367. doi: 10.1007/s11606-012-2077-6

Galushko M, Romotzky V, Voltz R (2012) Challenges in end-of-life communication. Curr Opin Support Palliat Care 6:355-364. doi: 10.1097/SPC.0b013e328356ab72

Houttekier D, Cohen J, Bilsen J, Addington-Hall J, Onwuteaka-Philipsen BD, Deliens L (2010) Place of Death of Older Persons with Dementia. A Study in Five European Countries. J Am Geriatr Soc 58(4):751-756. doi: 10.1111/j.1532-5415.2010.02771.x

Knaeps J, DeSmet A, Van Audenhove Ch (2012) The IPS fidelity scale as a guideline to implement Supported Employment. Journal of Vocational Rehabilitation 37:13-23.

Kuhn DR, Forrest JM (2012) Palliative care for advanced dementia: a pilot project in 2 nursing homes. Am J Alzheimers Dis Other Demen 27(1):33-40. doi: 10.1177/1533317511432732

Mitchell SL, Kiely DK, Hamel MB (2004) Dying with advanced dementia in the nursing home. Arch Intern Med 164(3):321-326. doi:10.1001/archinte.164.3.321. doi:10.1001/archinte.164.3.321

Piers RD, van Eechoud IJ, Van Camp S, Grypdonck M, Deveugele M, Verbeke NC, Van den Noortgate NJ (2013) Advance Care Planning in terminally ill and frail older persons. Patient Educ Couns 90(3):323-329. doi: 10.1016/j.pec.2011.07.008

Robinson L, Dickinson C, Rousseau N, Beyer F, Clark A, Hughes J, Howel D, Exley C (2012) A systematic review of the effectiveness of advance care planning interventions for people with cognitive impairment and dementia. Age Ageing 41(2):263-269. doi: 10.1093/ageing/afr148

Scott IA, Mitchell GK, Reymond EJ, Daly MP (2013) Difficult but necessary conversations - the case for advance care planning. Med J Aust 199(10):662-666. doi: 10.5694/mja13.10158

Seymour J, Almack K, Kennedy S (2010) Implementing advance care planning: a qualitative study of community nurses' views and experiences. BMC Palliat Care 9:4. doi: 10.1186/1472-684X-9-4

Skills for Care (2008) Common core competences and principles for health and social care workers working with adults at the end of life to support the National End of Life Care Strategy. Skills for Care, Leeds.

Street AF, Ottman G (2006) State of the Science Review of Advance Care Planning Models. La Trobe University, Victoria.

Teno JM, Clarridge BR, Casey V, Welch LC, Wetle T, Shield R, Mor V (2004) Family perspectives on end-of-life care at the last place of care. JAMA, 291, (1) 88-93. doi:10.1001/jama.291.1.88

Van Audenhove C, Van Humbeeck G, Spruytte N, Storms G, De Hert M, Heyrman J, Peuskens J, Pieters G, Vertommen H (2001) The Care Perception Questionnaire - An instrument for the assessment of the perspective of patients, family members and professionals on psychiatric rehabilitation. Eur J Psychol Assess 17(2):120-129.

Van Audenhove C, Vertommen H (2000) A negotiation approach to intake and treatment choice. J Psychother Integr 10(3):287-299.

Vandervoort A, van den Block L, van der Steen JT, Vander Stichele R, Bilsen J, Deliens L (2012) Advance directives and physicians' orders in nursing home residents with dementia in Flanders, Belgium: prevalence and associated outcomes. Int Psychogeriatr 24(7):1133-1143. doi: 10.1017/S1041610212000142

Waldrop DP, Meeker MA (2012) Communication and advanced care planning in palliative and end-of-life care. Nurs Outlook 60(6):365-369. doi: 10.1016/j.outlook.2012.08.012

Figure 1. Study timeline – Time points, instruments used and levels of measurement in the participant groups.

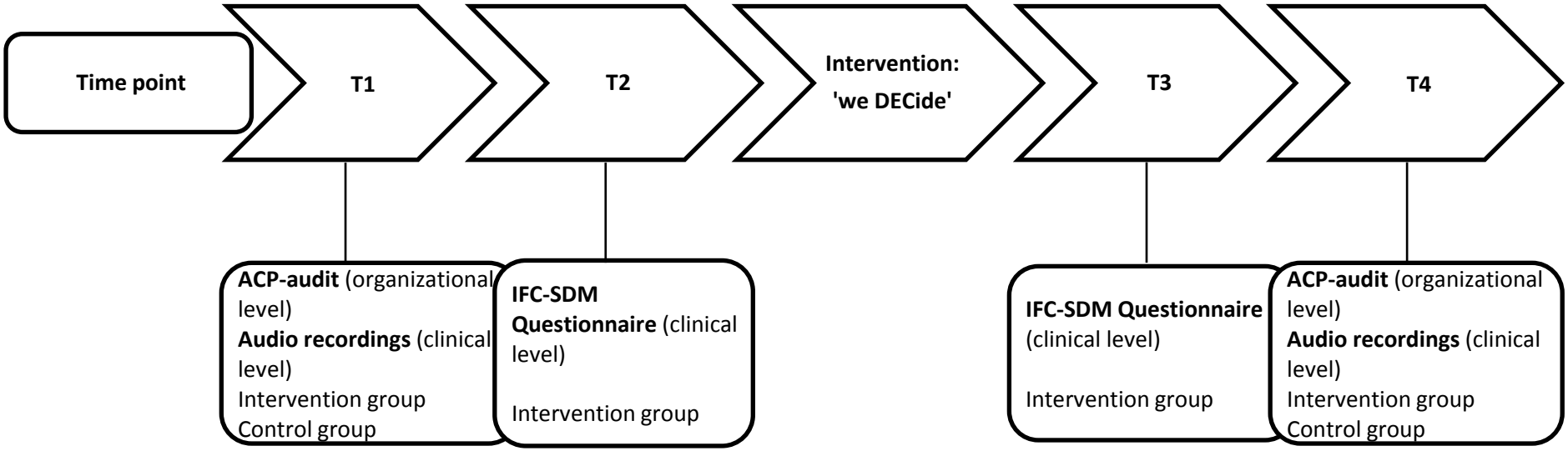

Figure 2. Three-step model for shared decision making – adapted for use in 'we DECide'

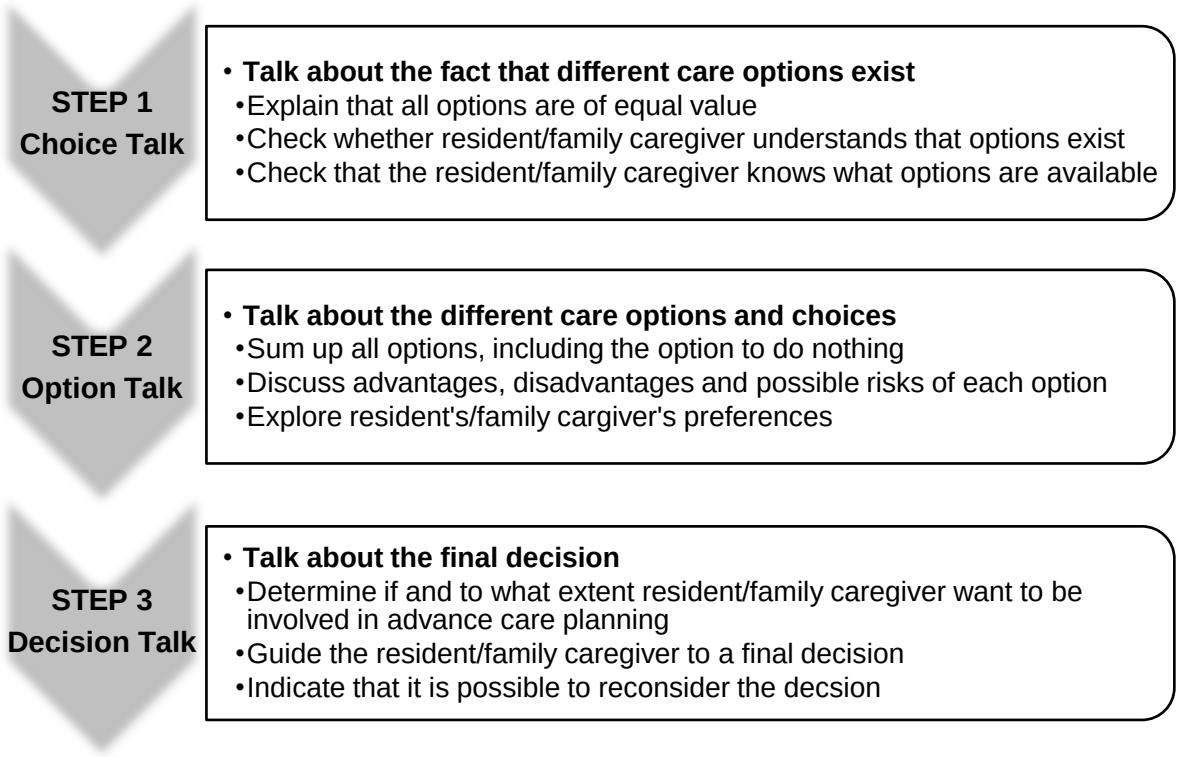

Figure 3. Intervention details

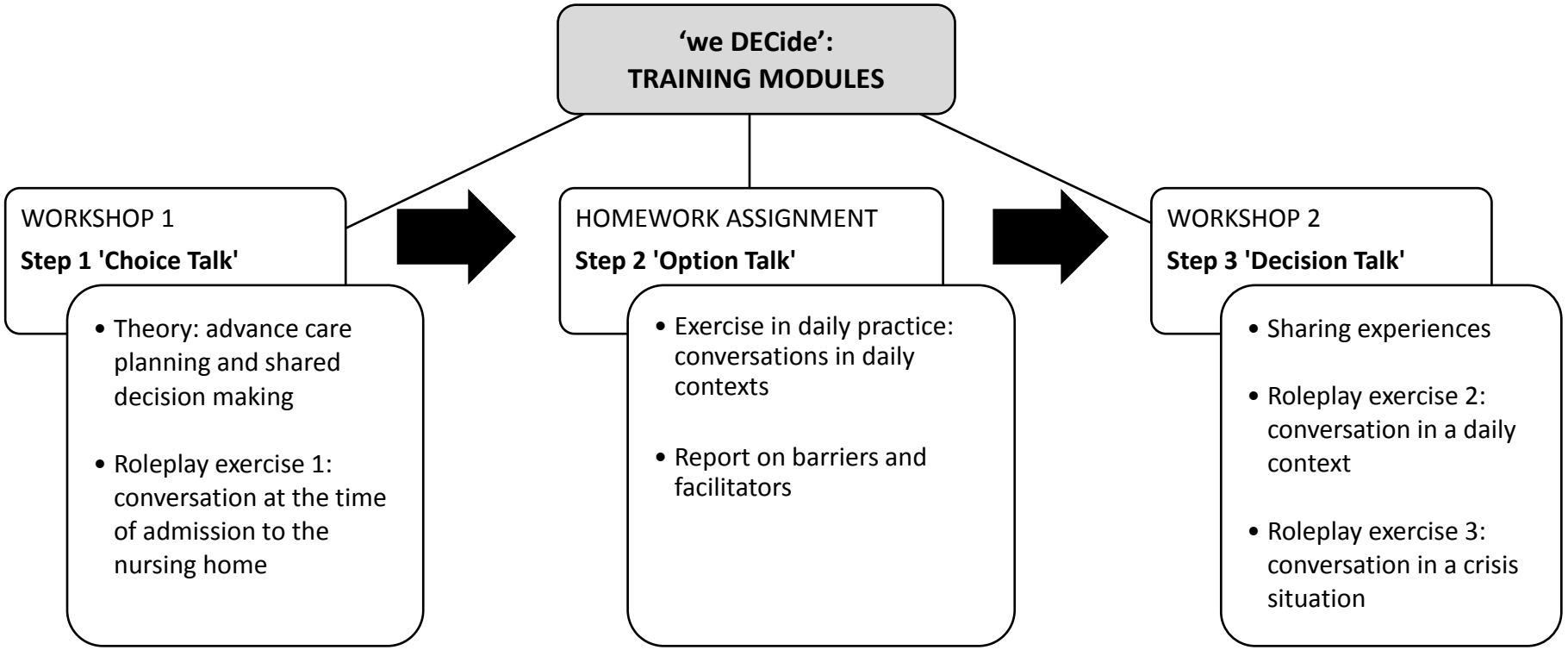

Table 1. Cases and roles used for the role play exercises in the workshops

	CASE	ROLES	OBSERVATION TASKS
Exercise workshop 1: **Formal conversation at the time of admission**	Two years ago, Mrs. Pieters was diagnosed with dementia. Because of increasing disorientation problems, she admitted to a nursing home. After an introductory meeting with Mrs. Pieters and her three children, the family is invited for a formal conversation about advance care planning.	1. Professional caregiver; responsible for discussing advance care planning; is instructed to focus on step 1 of the three-step model 2. Youngest daughter; thinks admission to the nursing home was the best solution 3. Oldest daughter; finds it emotionally difficult that her mother is admitted to the nursing home 4. Son; thinks the nursing home admission is too early, his main concern is the medical follow-up	1. Observe the professional caregiver's verbal and non-verbal listening skills 2. Observe what the professional caregiver says, focus on step 1 of the three-step model 3. Observe the structure and the course of the conversation 4. Observe one of the daughters / son and write down how the professional caregiver responds to him / her
Exercise workshop 2: **Informal conversation about end-of-life issues in a daily context**	A resident with early dementia receives a dialysis treatment, several times a week in the hospital. She is always very confused and tired after the dialysis. After another treatment session, she returns from the hospital with her daughter. The professional caregiver who guides her back to her room asks how she is feeling. She says she is fed up and does not want to undergo the dialysis anymore.	1. Professional caregiver; discusses with the resident and her daughter whether or not to stop the dialysis treatment; is instructed to focus on step 2 of the three-step model 2. Resident; is fed up with the dialysis treatment and wants to know about other options 3. Daughter; knows the treatment is exhausting for her mother and wants what is best for her	1. Observe the professional caregiver's verbal and non-verbal listening skills 2. Observe what the professional caregiver says, focus on step 2 of the three-step model 3. Observe the structure and the course of the conversation 4. Observe the daughter / resident and write down how the professional caregiver responds to him / her
Exercise workshop 2: **Formal conversation at the time of a crisis situation**	Mrs. Martens is a nursing home resident with early dementia. Six months ago her diet was adjusted because of mild dysphagia and since then the situation stabilized. Last week Mrs. Martens was admitted to the hospital due to food aspiration. Due to a low food intake in the hospital, tube feeding was started. When she returns to the nursing home, the feeding tube is still in place. A meeting is organized with Mrs. Martens, her husband and her son, to discuss care and treatment options (advance care planning was not yet discussed).	1. Professional caregiver; discusses the care and treatment options; is instructed to focus on step 3 of the three-step model 2. Resident; wants to stop the tube feeding 3. Husband; finds it difficult to see his wife in this condition, thinks it is useless to persist tube feeding if it does not increase her quality of life 4. Son; thinks that stopping tube feeding will cause his mother to deteriorate	1. Observe the professional caregiver's verbal and non-verbal listening skills 2. Observe what the professional caregiver says, focus on step 3 of the three-step model 3. Observe the structure and the course of the conversation 4. Observe the resident / husband / son and write down how the professional caregiver responds to him / her

Table 2. ACP-audit: Sections & criteria

SECTION	CRITERIA	SCORE
1. Conversations at the time of admission to the nursing home	• Information is provided on the existence of palliative care choices, including those at the end of life • Information is provided on the possibility of appointing a legal representative • Written information is provided on advance care planning • This information is provided during the first weeks of admission • This information is provided systematically to all new residents	…/ 5
2. Conversations about residents' preferences	• Preferences for participation in advance care planning are explored, systematically for all residents • Preferences about end-of-life issues are explored (such as: hospitalization, resuscitation, pain treatment and goals of care) • Preferences are assessed continuously (not at one time only) • Preferences for participation in advance care planning are respected • Findings are documented in the residents' files	…/ 5
3. Conversations about family caregivers' preferences	• Family caregivers' attitudes towards end-of-life issues are explored • This is done systematically, for family caregivers of all residents • The communication about end-of-life issues is open and honest, • There are frequent informal contacts between the nursing home staff and the family caregivers, facilitating communication about end-of-life issues • Family caregivers are allowed to ask questions about end-of-life issues at any time and they know who to turn to	…/ 5
4. Talking about end-of-life issues at team meetings	• End-of-life issues and topics are addressed at team meetings • Residents' preferences about end-of-life are addressed at team meetings • Family caregivers' preferences about end-of-life are discussed at team meetings • Important observations and significant changes are documented in resident files • Resident files are continuously updated	…/ 5
5. First formal meeting about advance care planning	• Family caregivers of all residents are systematically invited for a formal meeting about advance care planning • This meeting is organized maximum 3 months after the resident's admission to the nursing home • Advance care planning is discussed and information is provided on end-of-life decisions and treatment options (such as: hospitalization, resuscitation, pain treatment and use of medication, care goals and artificial nutrition and hydration) • Family caregivers' attitudes towards end-of-life issues and future care is explicitly asked • Decisions are documented in the resident's file	…/ 5
6. Team communication in crisis situations	• Whenever a resident's condition significantly deteriorates, a team meeting is organized • All significant deteriorations in a resident's condition are communicated to the resident's general practitioner	…/ 5

	• At the team meeting, treatment options are discussed • Residents' and family caregivers' preferences are taken into account, as well as any decisions that were previously made • Any deterioration in a resident's condition is communicated to the family caregivers	
7. Communications with families at the time of crisis situations	• Whenever a resident's condition significantly deteriorates, different treatment and care options are discussed with the family caregivers and information is provided on (dis)advantages and consequences of each option • Any previous treatment decisions as well as the resident's preferences are taken into account • Treatment decisions are evaluated and discussed and changed if necessary • The following end-of-life issues can be discussed: hospitalization, resuscitation, pain treatment and use of medication, care goals and artificial nutrition and hydration. • Decisions are always documented	…/ 5
8. Team communication in the palliative care phase	• The start of palliative care is always discussed at a multidisciplinary team meeting • The general practitioner is always involved in the decision to start palliative care • The start of palliative care is based on the consensus between all care professionals • When the team members have different but equal views on palliative care, they are discussed with the family caregivers • Multidisciplinary team meetings take place on a regular basis during the palliative care phase	…/ 5
9. Communications with families in the palliative care phase	• A formal meeting with family caregivers is organized at the start of the palliative care phase • (In)formal meetings with family caregivers take place on a regular basis during the palliative care phase • Treatment and care options and their (dis)advantages are discussed • The following options are discussed: artificial nutrition and hydration, hospitalization, resuscitation, pain treatment and medication use • The resident's comfort, well-being and quality of life are taken into account when decisions are made	…/ 5
	TOTAL SCORE:	… / 45

Table 3. IFC-SDM Questionnaire

The items below are to be filled out for each of the following conversation types:

1) *conversations with residents and/or family caregivers at the time of admission to the nursing home;*
2) *conversations with family caregivers in crisis situations; and*
3) *conversations with residents and/or family caregivers in everyday situations, about (care) preferences and end-of-life issues.*

		How **important** do you think this behaviour is?	How **often** do you perform this behaviour?	How **competent** do you feel to perform this behaviour?
		1= not important at all 2= not very important 3= neutral 4= important 5= extremely important ? = I don't know	1 = (almost) never 2 = seldom / rarely 3 = sometimes 4 = often 5 = (almost) always ? = I don't know	1 = not competent at all 2 = a little competent 3 = competent 4 = moderately competent 5 = very competent ? = I don't know
Step 1 Option Talk	1. Talking about the fact that different (care) options exist	**1 2 3 4 5 ?**	**1 2 3 4 5 ?**	**1 2 3 4 5 ?**
	2. Explaining that all options are equal	**1 2 3 4 5 ?**	**1 2 3 4 5 ?**	**1 2 3 4 5 ?**
	3. Checking if the resident and/or family caregiver understands that options exist	**1 2 3 4 5 ?**	**1 2 3 4 5 ?**	**1 2 3 4 5 ?**
Step 2 Choice Talk	4. Summing up all options, including the option to 'do nothing'	**1 2 3 4 5 ?**	**1 2 3 4 5 ?**	**1 2 3 4 5 ?**
	5. Discussing (dis)advantages and possible risks of each option	**1 2 3 4 5 ?**	**1 2 3 4 5 ?**	**1 2 3 4 5 ?**
	6. Exploring the resident's and/or family caregiver's preferences	**1 2 3 4 5 ?**	**1 2 3 4 5 ?**	**1 2 3 4 5 ?**
Step 3 Decision Talk	7. Determining if and to what extent the resident and/or caregiver wants to be involved in the care planning and decision making process	**1 2 3 4 5 ?**	**1 2 3 4 5 ?**	**1 2 3 4 5 ?**
	8. Guiding towards a final decision	**1 2 3 4 5 ?**	**1 2 3 4 5 ?**	**1 2 3 4 5 ?**
	9. Indicating that it is possible to revise the decision later	**1 2 3 4 5 ?**	**1 2 3 4 5 ?**	**1 2 3 4 5 ?**