Developing a transition scan to evaluate the transition process from home to nursing home for older people with dementia through the eyes of loved ones

DEDICATED
Desired dementia care towards end of life

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Abstract

Background: Dementia is a life-limiting disease with increasing prevalence and incidence. Palliative care plays an important role in improving the quality of life for both people with dementia and their families. Most people with dementia move to a nursing home when they have complex and severe needs. A transition of an older person with dementia from home to a nursing home is a challenging life experience, and due to a fragmented healthcare system, transitions are often poorly coordinated, resulting in high burden for informal caregivers and the person with dementia. There are already some studies focusing on interventions to improve the transitional care process, but most studies only on focus on a specific phase of the transition. This emphasizes the added value of this study as this study involves the entire pathway to improve transitional care initiatives pro-actively throughout the process.

Aims and objectives: The aim of this study is to develop a feasible theory based transition scan from the informal caregivers point of view to evaluate the transition process and to identify positive points and points of improvement for the transition process from home to a nursing home for people with dementia. This insight is needed in order to improve the future quality of the transition process to the needs of older people with dementia and their informal caregivers.

Aim of step 1: To develop a transition scan based on the TRANSCIT model and guidance Moving DEDICATED together.

Aim of step 2: To use interviews with experts involved in the transitional care process of older persons with dementia to test the transition scan for feasibility and to identify implementation elements that are needed to implement the scan in practice.

Methods: This study focuses on the first three steps of Vet et al.'s (2011) method for developing a measurement instrument to develop the transition scan. In the first step, the construct was defined, in the second step the measurement method was selected, and in the third step, the items of the measurement instrument were selected. This step is divided into two stages:

Step 1: The themes and questions of the transition scan were derived from the theoretical transition models (TRANSCIT model and guidance Moving DEDICATED) using thematic analysis by Clarke and Brown (2017) and by discussing the questions with the research group to get consensus.

Step 2: Interviews with family members, a home care nurse, a client advisor, managers in the home care setting and nursing home chain directors for dementia, as well as policy makers were performed in Limburg, the Netherlands. The interview topics were: (1) the first impression and usefulness of the transition scan, (2) revisions of the questions, (3) readability, (4) structure, (5) implementation elements. The transcripts were analyzed using content analysis.

Results:

Step 1: Five overarching themes derived from the thematic analysis were as follows: (1) the people involved in the transition, (2) needs/wishes of the person with dementia, (3) information provision, (4) support, and (5) collaboration and time. Using the method of de Vet et al., a first draft of the questionnaire has been developed.

Step 2: The results of the nine in-depth semi-structured interviews emphasize that the transition scan will be a useful tool that provides insight on how to improve the future transition care. To make it a feasible tool, adjustments regarding the content, structure and readability need to be considered for the revision of the first draft transition scan, and recommendations for implementation need to be taken into account. The content and the structure of the transition scan (divided into three phases: Before the move, Moving day, Feeling at home in the nursing home) were found to be favorable, but the scan should be shortened and made simpler to be readable and feasible in practice.

Conclusions: The transition scan will be a useful tool for informal caregivers to evaluate the transition from home to a nursing homes of older people with dementia and provide indications of improvement points for future transition care. To make it a feasible tool and implement it in practice, some adjustments need to be made and the next steps of the method of de Vet et al. (2011) need to be followed.

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1. Introduction

Dementia is a life-limiting disease for which there is no cure yet, and as the population is aging, the prevalence of dementia is increasing (Raz et al., 2016; van der Steen et al., 2014). Palliative care is generalist and specialized care for people facing serious diseases such as dementia (Mc Veigh et al., 2018; Sampson, 2010). It addresses the concerns and needs of patients and their families, and early access to palliative care can improve the quality of life for both people with dementia and their families (van der Steen et al., 2014). Older people with dementia are often cared for in their homes by family caregivers. Under the new reform of the Long Term Care Act (Wlz) in the Netherlands from 2015, older people are to be cared for in their own homes for as long as possible (Verbeek et al., 2012). The reliance on informal care is rising and informal caregivers play an important role in caring for the older person with dementia and for their quality of life as their health status declines (Hainstock, 2017; Kraijo, 2014). Older people may only move to a nursing home when they have complex and severe care needs or if there is an overburden of family members/informal caregivers (Kelders & de Vaan, 2018). A report from the Dutch National Health Care Institute shows that the number of people moving from their homes to a nursing home has decreased between 2013 and 2016 (from 48,267 in 2013 to 40,984 in 2016) since the new reform of the Long Term Care Act has entered into force (Kelders & de Vaan, 2018). A consequence of this change is that there are more acute transitions from home to nursing homes (Sampson, 2010). These transitions are often more stressful and traumatic for the person with dementia and their family members and it is questionable whether this policy is beneficial for older people with dementia, as the transition to a nursing home can be more acute, complex and decision making more time consuming (Sampson, 2010; Verbeek et al. 2012).

Transitioning from home to a nursing home is a challenging life experience and associated with changes in autonomy, daily routines, social status, and contacts for older people with dementia (Groenvynck et al., 2020b). They often show more behavioral and neuropsychiatric challenges during the transition period, “associated with a lower quality of life, lower general well-being, anxiety and/or depression” (Müller et al., 2017). However, in general, it is not only the person with dementia who is affected, but the entire family is involved in the transition process (Graneheim et al., 2014). The experience of relinquishing the care of a person with dementia to a nursing home is often associated with feelings of stress and anxiety for informal caregivers, as they feel unprepared for the transition and receive insufficient information and support (Graneheim et al., 2014).

Studies have shown that a good relationship with the formal caregiver in the nursing home is important for the person with dementia to adjust well to life in the nursing home (Müller et al., 2014). The transition from home to a nursing home is often poorly coordinated and does not follow a comprehensive approach, leading to fragmentation (Groenvynck et al., 2020a). There is a lack of confidence and competence of nurses and caregivers in caring for people with dementia (Sury et al., 2013). Poorly managed transfers of care can lead to adverse outcomes for all involved (Groenvynck et al., 2020b; Verbeek et al., 2012). Therefore, good collaboration between formal and informal caregivers and older people with dementia is needed (van der Steen et al., 2014). It is important to incorporate the care needs of older people as well as their family members and empower formal caregivers about caring for older people with dementia to improve the transitional care process, leading to a better quality of care (Colemann, 2003; van der Steen et al., 2014). Integrated care and interprofessional collaboration among the care triad (older persons with dementia, informal caregiver, and formal caregivers), as well as shared decision-making are important incentives toward a better transitional care process (Groenvynck et al., 2020b). Despite the growing number of older people with dementia, the transition process from home to nursing home is still fragmented and research about this period is scarce. Research about interventions to improve transitional care often do not focus on the entire pathway from home to a nursing home, but rather only on improving a specific stage of the transition pathway (Groenvynck et al., 2020b). An example is the multi method pilot evaluation by Gaugler, Reese and Sauld from 2015 which has examined the effectiveness of a Residential Care Transition Modul (RCTM), 4-month psychosocial intervention designed to help families manage their emotional and psychological distress after a loved one with dementia has moved to a nursing home. The results show that the provision of skilled psychosocial support can help families manage emotional distress and crises in the months following a family members admission to a nursing home (Gaugler et al. 2015). This intervention only focuses on the post-transition phase, where the person with dementia already moved to the nursing home. It is important to look at the entire pathway in a study to improve transitional care initiatives pro-actively throughout the process (Groenvynck et al., 2020b). There is a need for further research on the impact of interventions in all transition phases from home to a nursing home that targets the care triad. The limited scientific research on this topic supports the added value of this work with the aim of developing a transition scan from the informal caregivers point of view to identify positive points and points of improvement for the transition process from home to nursing home for people with dementia. This insight is needed in order to improve the quality of the transition process to the needs of older people with dementia and their informal caregivers.

The present study addresses the research question:

"How can a theoretical based, feasible transitional care scan be developed that will give insight in the current transition process and challenges and eventually will improve future transition care from home to nursing of older persons with dementia?"

In order to answer the main research question and develop a transition scan that is feasible the following sub-questions were formulated:

1. What and how can theories/models, practical tools be integrated in the development of the transition scan?

2. Is the developed transition scan a valid (face)/ feasible tool for (informal) caregivers to give insight in challenges of the transition process from home to a nursing home for older people with dementia
3. What are important implementation elements that need to be taken into account to implemented a transition scan from (informal) caregiver point of view?

The objectives of this work are addressed through a mixed methods approach. First theories/models and practical tools are used for the development of the ‘concept ‘transition scan. In the second step interviews with (in)formal caregivers that are part of this transition process will be held: family members, a home care nurse, a client advisor, managers in the home care setting and nursing home chain directors for dementia, as well as policy makers will be asked to give their point of view on the developed concept scan to identify if the scan includes all vital elements to capture experiences of the transition process from the view of the informal caregivers, and to provide recommendations for implementation. The results of these interviews are used in the further development of the transition scan (questionnaire), and to guide implementation.

2. Theoretical Framework

This chapter elaborates on the theories and key concepts that will be used in this study. The background and theories regarding the research question will be explained firstly, followed by a brief explanation supported by a visual representation of the concept model that encompasses these theories.

2.1 DEDICATED project and TRANS-SENIOR project

This study is part of the Desired Dementia Care Towards End of Life (DEDICATED) project (Website DEDICATED, 2020). It aims at increasing the quality of palliative care for people at home and in nursing home settings during the transition.

This project is divided into two subprojects: Subproject 1 addresses the improvement of basic palliative care for people with dementia by implementing a toolkit that focusses on end-of-life communication, knowledge on symptom control and patient-centered palliative care. The second subproject aims at improving interprofessional and transmural collaboration between (in)formal and people with dementia (Website DEDICATED, 2020). The DEDICATED project works in cooperation with the /TRANS-SENIOR project, which stands for 'Transitional Care Innovation in Senior Citizens'. It is a European project which intends to investigate where transitions can be prevented and how they can be improved (Website TRANS-SENIOR, 2020). The scoping review which is developed by the TRANS-SENIOR project is used for this work (Groenvynck et al., 2020a). This study is part of the second subproject of the DEDICATED project and the TRANS-SENIOR project and reveals insights into the transition from home to a nursing home for older people with dementia by developing and evaluating a transition scan for informal caregivers.

2.2 TRANSCIT model

The TRANSCIT model (figure 1) provides an approach aiming to improve the transition process from home to nursing home for older persons and informal caregivers (Groenvynck et al., 2020a). It has identified key components in the transition process and aims at avoiding fragmentation and promote continuity of transitional care. The TRANSCIT model is a first step towards a monitoring system by providing a guideline to optimize transitional care. It identifies four key components: support, communication, information, and time, as well as the importance of a successful partnership between the informal caregiver, the formal caregiver, and older people in the pre-, mid-, and post-transition phase. Support must be continuous and easily accessible by the informal and formal caregiver throughout the transition. Another component is communication: Open, complete and timely communication with all stakeholders is important so that knowledge, feelings, and expectations can be shared to facilitate the transition process. Not only communication, but also person-centered information is needed in all three transition phases. Furthermore, it is important to have continuity care, enough time to prepare for the transition, get in contact with everyone involved, share knowledge and get answers to possible questions. The arrows in the model show a cycle, indicating that the four key components are interrelated and interdependent in a successful transitional care process (Groenvynck et al., 2020a).

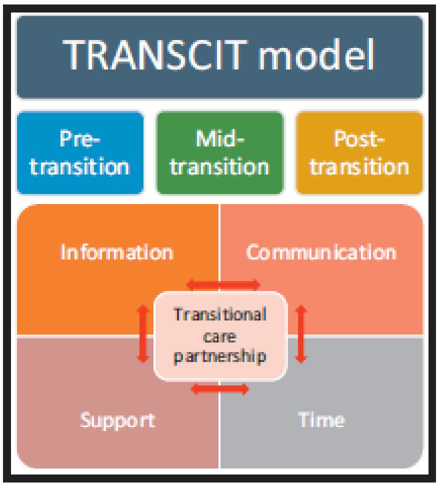


Figure 1: TRANSCIT model

2.3 Guidance Moving DEDICATED together

The second building block, which is used to develop the transition scan in step three of the method of how to develop a measurement instrument by de Vet et al., is the guidance Moving DEDICATED together (appendix 4). The transition route picture can be seen in figure 2. For further information, an infographic of the guidance is added in the appendix 5. The guidance functions as an advice document for primary care and nursing home care professionals who work with people with dementia, as it guides the three transitions phases from home to nursing home:

In all phases, designating a central point of contact, a caregiver who acts as a confidential advisor and contact person for the older person with dementia and informal caregiver(s) and coordinates the transition, is important.

1. *Looking ahead together at home (before the move (at home)/ pre-transition phase)*

At home, it is important to familiarize with the person with dementia and their family members, assess the living situation of the person with dementia and communicate about, make shared-decisions and prepare with all involved parties a possible future transition. Familiarizing with the person with dementia and their family members refers to asking them about their wishes, needs and preferences regarding daily life, a possible transition and end-of-life care. Assessing the living situation means to identify and monitor the overall situation of the person with dementia and her or his (informal and formal) caregivers. Continuous monitoring is pivotal to anticipate on time and thereby provide adequate information and make the transition decision together.

2. *Preparing a warm welcome together (moving day/ mid-transition phase)*

The period after making the transition decision and the moving day is crucial to prepare a warm welcome and this include providing emotional and practical support to the person with dementia and their family members (i.e. paying attention to the emotional process), preparing the person with dementia and their family members, making (i.e. home or nursing home visits), making practical arrangements (i.e. waiting list arrangements), exchanging (person-centered) information with the contact person from the other setting, and planning the moving day. Home and nursing home visits, which should take place at least two weeks before the move so that the FRC get an idea of how the person with dementia lives to make the move to the nursing home more personal and the person with dementia and their loved one get an first impression from the nursing home.

3. *<u>Feeling at home together in the nursing home (feeling at home in the nursing home/post-transition phase)</u>*

After the transition, caregivers should focus more on gradually reducing contact with caregivers from the home setting, giving the person a feeling of home for the person with dementia (i.e. maintaining previous routines and creating valuable activities), providing holistic care with all involved caregivers to the person with dementia, performing advance care planning with and treating the family members as part of the team.

Figure 2: transition route picture

2.4 The method for developing a measurement instrument

The theoretical framework for this work is presented by Hencrica C.W. de Vet et al.'s method for developing a measurement instrument (de Vet et al., 2011). This method is used as a foundation to develop the transition scan for informal caregivers and includes the building blocks: TRANSCIT model and guidance Moving DEDICATED together, which serve as the basis for this work.

In the scientific work "Measurement in Medicine" de Vet et al. (2011) explains the method for developing a measurement instrument. It consists of 6 steps (see concept model-figure 2). The first step concerns the construct, which answers the questions "what do we want to measure?", in "which target population?" and for "which purpose?". The instrument should be tailored to the target population and be well defined. In the second step, the choice of the measurement method, it is important to note, that the type of the measurement instrument corresponds closely to the construct. This step involves deciding whether it is more appropriate to use a multi-item measurement instrument or a single-item instrument. When measuring with multiple items, the content of the items is often more specific, which can reduce interpretation bias. Complex constructs are best measured with multi-item measurement instruments, while single-item instruments are more likely to be used when the construct is not the main focus. Since this study aims to develop and evaluate the transition scan the focus of this study is on a multi-item measurement instrument. The third step contains the selection of the items, often questionnaires. To get input for the items of a questionnaire literature and knowledge from experts are used. By examining similar instruments in literature, the construct can be clarified and potentially relevant items can be selected. This step also includes the formulating of the items for the first draft.

When formulating the items for the questionnaire, the following rules should be followed: Items should be comprehensible to the entire target population, terms with multiple meanings should be avoided, and items should be specific. Each item should contain only one question, and negative wording in questions should be avoided, as this can make it more difficult to answer. When formulating the items a distinction is made between a reflective model and a formative model. In the reflective model, the items correlate with each other; in a formative model, each item contributes a part of the construct and cannot be replaced by another. In this study, more of a reflective model is used because each item builds on another and the correct order of the items is very important. However, each item stands on its own and cannot be replaced by another. In the developmental phase it is important to come up with as many items as possible regardless of the choice of model. For this step the building blocks: the TRANSCIT model and the guidance Moving DEDICATED together and interviews with family members, a home care nurse, a client advisor, managers in the home care setting and nursing home (NH), chain directors for dementia, as well as policy makers in the nursing home organization are used to develop the questionnaire. The fourth step of the model is the scoring of the items. This step describes the level (nominal, ordinal or at interval or ratio level) at which the response to an item is expressed. The decision of which scoring to use for the items depends on how many categories are relevant to answering the question. For this study, it is also important to consider that the questionnaire will contain quantitative and qualitative questions. The fifth step is pilot-testing. This is an iterative testing process in which the first draft of the measurement is tested in a small sample, followed by adjustments. “Pilot-testing is intended to test the comprehensibility, relevance, and acceptability and face validity of the measurement instrument” (de Vet et al., 2011). In pilot testing, it is important to ask participants about their understanding of the questions and their overall experience completing the questionnaire and their added value (de Vet et al., 2011). The final step in developing a measurement instrument is field testing. After pilot-testing, the measurement instrument is applied to a larger sample. In this step, items are selected and reduced and insight into the structure of the data is gained.

This study focuses on steps one to four of the method of de Vet et al. The development of a measurement instrument is an iterative process as all steps are intertwined. This is illustrated in the conceptual model (figure 2) (de Vet et al., 2011).

2.5 Concept model

Combining those theoretical aspects of how to develop a measurement instrument with the research question of this study, a concept model is created (figure 3). The concept model shows the different steps for developing the transition scan with a particular focus on step 3, which is part of the development phase of the transition scan.

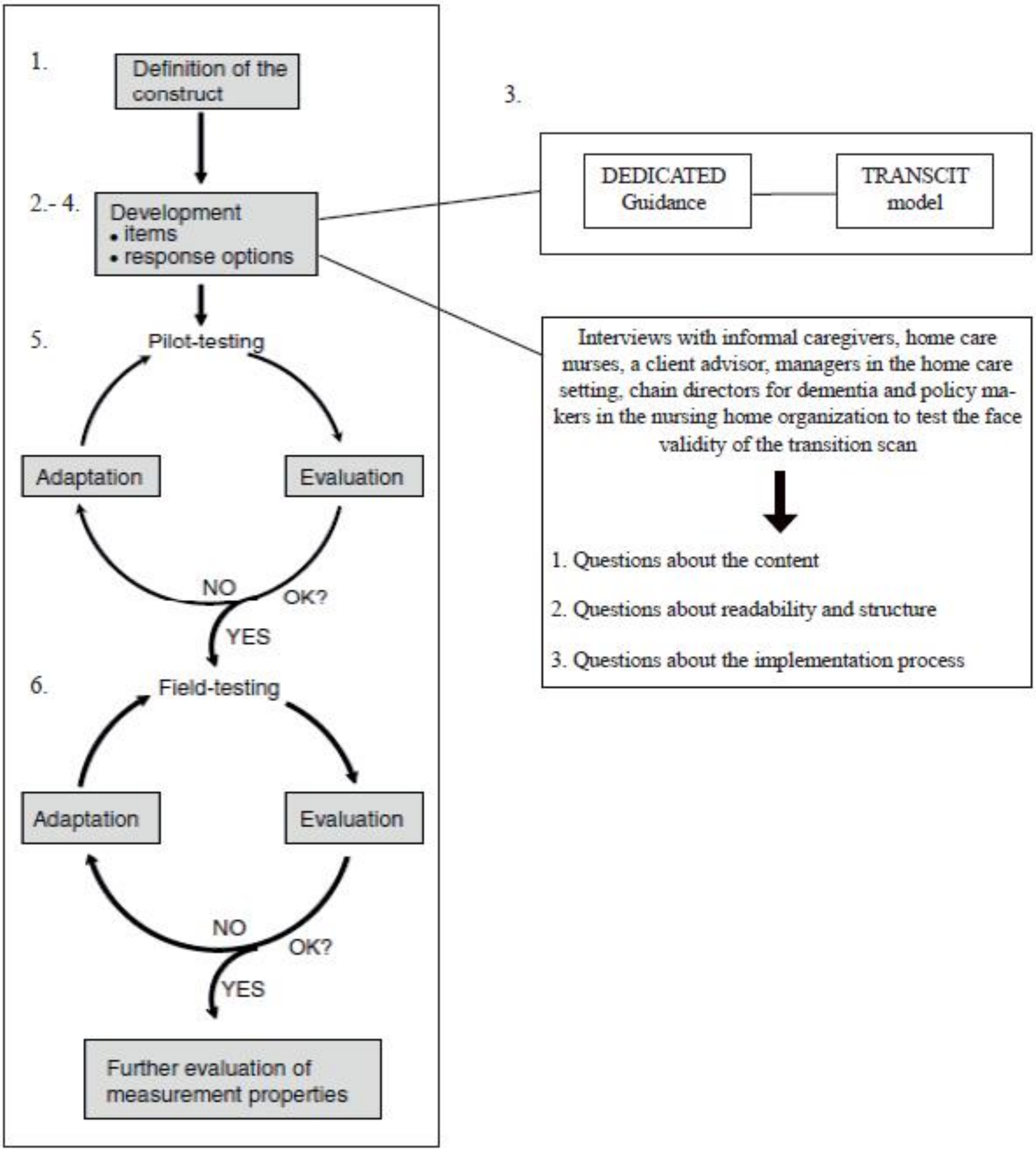


Figure 3: concept model: the six steps of developing the transition scan

3. Methodology

The methodology is divided into two steps. The first step focuses on the development of the transition scan by using theory/models and practical tools and the second step focuses on measuring the face validity of the transition scan by conducting interviews.

3.1 Research nature, type and design

To develop a measurement instrument for informal caregivers that improves the transition process from home to a nursing home for older people with dementia, a mixed methods approach is used. Mixed methods research is an approach to knowledge (theory and practice) that attempts to consider multiple perspectives (Hesse-Biber, 2015). In this study the method of de Vet et al. (2011) is being used for the development of the transition scan. This study focuses on the definition of the construct and the development of the measurement instruments, which is divided into two steps:

In the first step the transition scan is developed using the TRANSCIT model and guidance Moving DEDICATED together using thematic analysis by Clarke and Brown (2017).

The second step of the study uses a participatory action research (PAR). A PAR is a "collaborative research, education and action used to gather information to use for change on social or environmental issues" (Pain et al., 2007). In a PAR, the researcher enters into a collaborative partnership with participants to facilitate improved practice. The research design in a PAR consists of three stages: inquiry, action and reflection, which transition and evolve in an iterative cycle (Mackenzie, 2012; Khan & Chovanec, 2010). This study focuses on the first stage of the PAR, the inquiry, which is performed by using a qualitative research method namely semi-structured interviews (Mackenzie, 2012). In the inquiry, the researcher and participants identify a problem and methods to address that problem (Mackenzie, 2012). In-depth interviews with informal caregivers, home care nurses, a client advisor, managers in home care setting, chain directors for dementia and policy makers in the nursing home organization are used to test face validity and first feasibility items that need for further adjustments of the transition scan. The participants take an active role as co-creator, helping to develop and construct the transition scan by sharing their understanding and opinions of the items and structure/ readability of the questionnaire (Bryman, 2016). They also give insight into how the transition scan can be implemented and what needs to be considered. In depth interviews are used in order to gather the data needed to develop the transition scan and answer the research question. The interviews are semi-structured as this provides answers that the research is based on, but allows the interview process to be more flexible. The interviewer has the scope to change questions and adapt them to the interviewee's answers (Adam, 2015). It also allows the interviewer to provide additional information if the interviewee does not understand the question (Maxwell, 2012). The interviewer is not too intrusive, allowing the participant to speak freely and reveal information that might have remained hidden otherwise (Bryman, 2016). In addition, the use of open-ended questions allow the interviewees to explain their experience, thoughts and feelings about the transition process to gain more insight into the rationale of their answers

(Maxwell, 2012 & Bryman, 2016). The think-aloud and probing method will be used to capture participants' experiences and help to assess whether the questions of the transition scan are readable and clear (de Vet et al., 2011). In the think-aloud method, participants are asked to say what their first thought is when they read the transition scan. They are also asked if they think that scan is useful from their point of view. In the probing method, participants are asked about the interpretation of the items. The method is used to generate further explanations, e.g. how to interpret certain words and how they should be phrased to obtain what you intend to know. These methods are used to get insight in whether the questions were comprehensible, relevant and complete and will help to develop the transition scan (de Vet et al., 2011; Twohig et al., 2018). It therefore measures if the questions are appropriate for the specific population and the intervention (de Vet et al., 2011).

The knowledge and experience from the perspectives of multiple individuals who are involved in the care of older people with dementia will be used for the development of the transition scan for informal caregiver.

3.2 Data collection

The data of this study is collected by using the method of de Vet et al. (2011) on how to develop a measurement instrument. Step 1 focuses on the steps one, two and the first part of step three of de method of de Vet and step 2 on the second part of step 3 and step 4 of the method of de Vet et al. Figure 4 indicates the entire procedure of how the transition scan is developed.

Step 1: Development of the scan by using theories/models and practical tools

For the first step in the development of the transition scan for informal caregivers the construct that is being measured needs to be defined and elaborated (de Vet et al., 2011). The construct must be appropriate for informal caregivers and measure their experiences of the entire transition process from home to a nursing home of their loved one with dementia with the aim to evaluate the process and reveal positive points and improvements points. To be applicable for informal caregivers the age and education level needs to be considered. As informal caregivers are a broad group, it must be ensured that the measurement instrument can be used by everyone who belongs to this group. Taking this into account, the second step is to select the type of the measurement instrument (de Vet et al., 2011). A multi-item questionnaire is used for this study, as these consists of several items that measure one construct (ibid). The multi item questionnaire allows to obtain as much and precise information as possible, which also facilitates the analysis of the data. For the first part of step three, the selecting of the items for the questionnaire, thematic analysis by Clarke and Braun (2017) has been applied and different themes were formulated by considering key elements of the TRANSCIT model and guidance Moving DEDICATED together. The themes were guided by the research question and used for the development of the questions. Guidelines such as from de Vet et al. (2011) and Bryman (2016) have been used for the formulation of the questions. In the method of the Vet et al. she emphasizes the importance to make items comprehensible to the total target population, avoid multiple meanings, be specific and avoid negative wording in questions. Bryman (2016) mentions several rules that should be considered when designing questions. When developing a questionnaire, the question should always be aimed at what one want to know from the participants. An approach to formulate the questions is to ask the question yourself and try to figure out how to answer it. These rules were taken into account when developing the transition scan. To discuss the questions and the correct formulation of the questions, several meetings were held with the research team to obtain opinions and views from different people. These meetings supported the process with the aim of developing an adequate first draft of the transition scan that could be used for the interviews. The concept analysis of how the questions are developed can be found in the data analysis.

Step 2: Measuring feasibility by conducting semi structured interviews

For further development of the transition scan, data was collected from expert interviews conducted between May 19 and June 4, 2021.

Sampling: For the collection of these interviewees convenience sampling will be used. Participants in the study are recruited from Zuyderland, Vivantes and Envida which are participating in the DEDICATED project. Participants have been contacted when they are part of the care team for older people with dementia and have insight in transition processes. It is important to include everyone involved in the transition process to capture each step of the pathway and the information flow from home to a nursing home as well as to gather their different experiences. The people who have been contacted include informal caregivers, a client-representatives, a GP, a home care nurse and a nurse in the nursing home, chain directors for dementia, managers in the home care setting and nursing home, an physician and professor, client-advisors, case-managers and policy makers in the home care and the nursing home setting.. They were contacted by e-mail to participate in the study. After they have confirmed their participation, an appointment has been made for the interviews. The interviews have been taken place online via the platform Zoom.

The interviews were conducted by one interviewer, who would ask the questions and record the interviews. In some interviews, a facilitator was present to provide assistance if the interviewee wished to express him- or herself in Dutch, as the interviews were conducted in English due to the researcher background. The facilitator translated if needed and asked additional questions. At the start of the interviews, the transition scan has been briefly explained and the aim and approach of the interview were stated. The aim of the interviews with experts working in the transition process from home to a nursing home for older people with dementia is to test the first draft of the transition scan by asking participants whether all elements of the transition are covered, whether the questions in the draft are understandable, whether the scan is feasible in practice, and whether there are implementation issues. The participant have extensive expertise about the process and the measurement instrument should be therefore developed in close cooperation with these experts (de Vet et al. 2011). The interviews will be used to determine whether the transition scan is feasible in providing insight in informal caregivers experiences in the transition process and whether it helps identifying positive points and improvement points for the transition process for older people with dementia moving from home to nursing home.

Topic list for the interviews step 2:

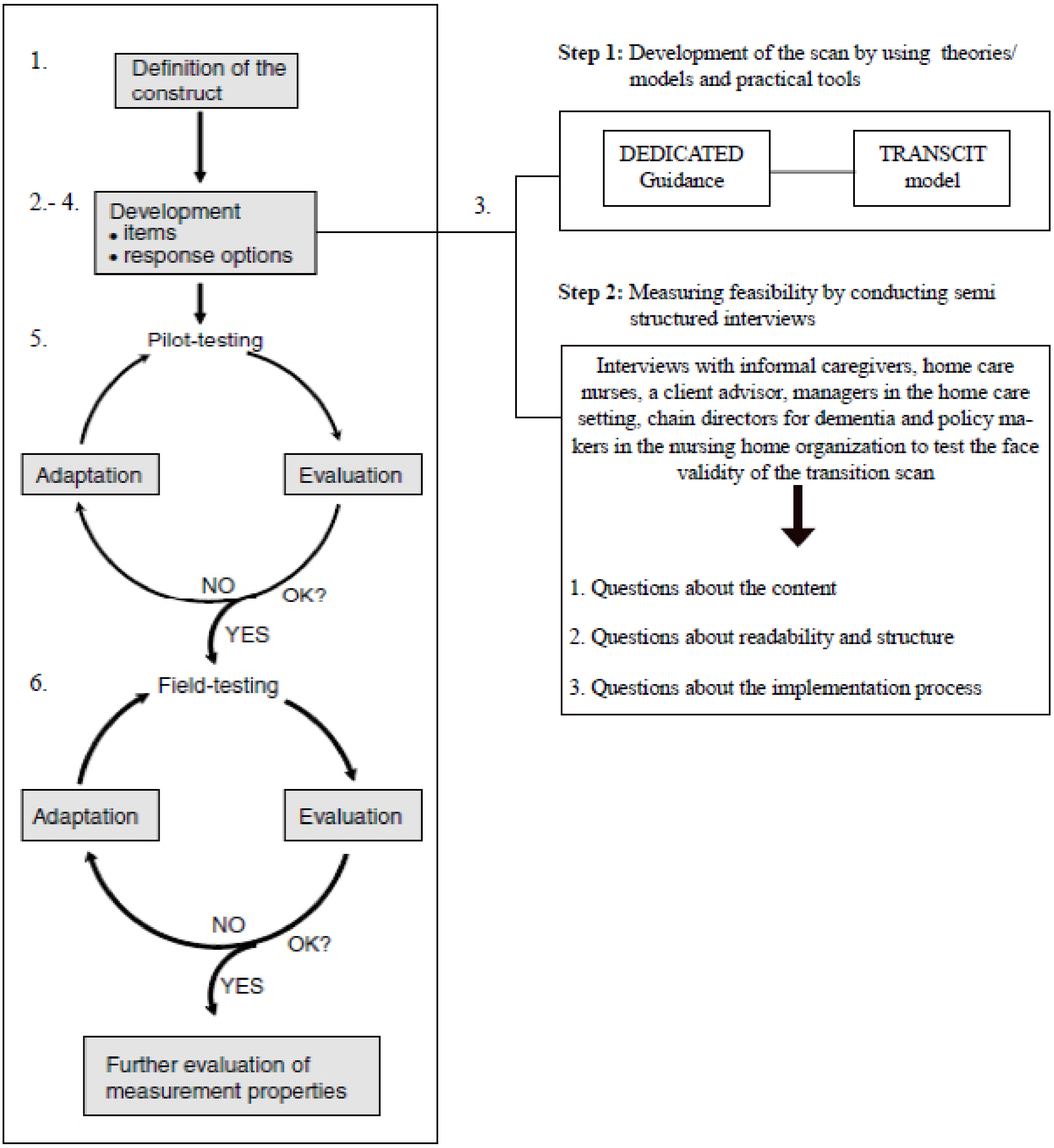
To test the feasibility in the interviews a topic list was created (appendix 1), which function as a guide throughout the interviews. It was used to maintain consistency with the multiple interviewees and allows the interviews to be structured and ensure everything is covered (Bryman, 2016). Using Bryman's approach for constructing an interview guide, topics to answer the main research question and sub-questions were identified. It includes questions about the content of the transition scan, questions about readability and structure, and questions about implementation. The topics were laid out in this order so that the questions flowed in a reasonable manner.

As an opening question participants were asked about their first impression of the transition scan. To test face validity, they were asked if they think the transition scan is useful and could add value to the current transition process from home to nursing home for older people with dementia. To get a precise idea of their opinion on the questions of the transition scan, the participants were asked about the content of the questions and whether anything was missing or should be added.

The second part of the topic list focuses on the readability and structure of the scan and includes questions about the clarity, relevance, and comprehensibility of the questions. Feasibility depends on a good structure, the difficulty and length of the questionnaire. If the questionnaire is too long, there is a risk that participants lose concentration or motivation before the end of the questionnaire (de Vet et al., 2011).

The last part contains questions about how to implement the transition scan in a nursing home. This part includes questions about the way informal caregiver should receive the transition scan, in what time frame, and who should receive the results of the scan to make quality changes.

Recommendations from Bryman were used to formulate interview questions. Simple language was used and questions were kept as short as possible to make them easy for each participant to understand (Bryman, 2016). Only open-ended questions were asked to elicit descriptive answers. Follow-up questions such as “What do you mean by that?” and probing question such as “Could you say some more about that” were used to gain more insight into a person’s answer. All questions were discussed with the research team and revised several times.



Step 1: Development of the scan by using theories/ models and practical tools

Step 2: Measuring feasibility by conducting semi structured interviews

Interviews with informal caregivers, home care nurses, a client advisor, managers in the home care setting, chain directors for dementia and policy makers in the nursing home organization to test the face validity of the transition scan

1. Questions about the content
2. Questions about readability and structure
3. Questions about the implementation process

Figure 4: Development procedure of the transition scan

3.3 Data analysis

The data analysis is divided into the two steps: first, the analysis of key elements of the TRANSCIT model and the guidance Moving DEDICATED together has been analyzed, and then in the second step data from the interviews have been analyzed.

Step 1: Analysis of the theory/models and practical tools to develop the transition scan

To capture the key elements of the TRANSCIT model and the guidance Moving DEDICATED, the first step of the analysis was to read both papers thoroughly to understand their essence and structure. Similarities in their structure, namely the three different steps of the transition process (pre-, mid- and post-transition), have been marked in the same colors in both documents, which facilitates comparison of the information. Focusing on the key elements of the model and the guidance, Braun and Clarke's (2017) thematic analysis was applied to come up with different themes and subthemes. A table was created in excel that included all three different steps, general themes, subthemes, and references from the TRANSCIT model and the guidance Moving DEDICATED together. The different themes are: the people involved in the transition, needs/wishes of the person with dementia, information provision, support and collaboration and time. The themes and several subthemes have been used to develop and formulate the questions of the transition scan. According to de Vet the first draft should contain as many items as possible and in the next steps item are reduced and reconsidered. Continuous reflection meetings were held with the research group to get consensus on the various questions and the first draft of the transition scan which was used for the interviews (appendix 3).

Step 2: Analysis of the results of the interviews and changes needed in the scan

Data obtained from the interviews are recorded and transcribed. This study uses the intelligent transcript, which aims to communicate the meaning of the speech in the most natural way possible. The transcript may not accurately match the audio in terms of speech uttered, but focuses on the meaning of what has been said (Smith, 2019). The transcripts are analyzed through content analysis by using excel to code and track themes of the qualitative data. Content analysis allows the researcher to explore theoretical issues to enhance understanding of the data and provides a method for making replicable and valid inferences from the data to its context with the purpose of providing knowledge, new insights and practical guidance for action (Elo & Kyngäs, 2008; Krippendorff, 1980).

The results of the interviews provide indications of the face validity of the transition scan. The themes that emerged from coding the interviews in excel are structure, readability, usefulness, implementation and recommendation for the revision of the draft transition scan. Words, phrases and the like that share the same meaning are classified in the same category to capture whether all participants have similar or different opinions (Elo & Kyngäs, 2008).

Another table is created that functions as a checklist, showing what needs to be changed in the scan questions and how many participants share the same opinion. An overview of how the questions should be changed or if a question should be removed or added to the transition scan can be seen in table 1. Content analysis is a reflective process and the identification of meaning units is a continuous process to obtain all information about their experiences to develop a transition scan for informal caregivers of older people with dementia that will enable home care and nursing home care to improve practice.

3.4 Validity and reliability

This study focuses on the face validity which is the degree to which a measurement instrument adequately reflects the construct being measured (Mokkink et al., 2010). Interviews are used to measure the face validity of the questionnaire. Participants are asked about their experiences and thoughts and whether the measurement instrument appears to reflect the concept concerned. In addition, validity will be guaranteed in this study through triangulation. Triangulation will lead to improved study outcomes by looking at a problem from more perspectives (Heale & Forbes, 2013). Triangulation is used in the interviews in this study as different perspectives are used from different people involved in the transition process for older people with dementia.

3.5 Ethical considerations

The research proposal is reviewed by the FHML research ethics committee by evaluating the FHMLREC form in the Appendix. There are several ethical considerations that must be taken into account for this study. The interviews are anonymous to protect the privacy of the participants (Bryman, 2016). Prior to the start of the interviews, participants are asked to sign the consent form accepting the anonymity and confidentiality of the discussion (appendix 2). Confidentiality and the voluntary nature of participation in all study activities, as well as the ability to withdraw participation at any time have been explained to the participants. Recordings will be deleted after this study is completed.

4. Results

The following section aims at presenting the results of the study. The results are divided into the results of the first step of the development of the measurement by using theories/models and practical tool and the second step of the development, the first feasibility check by using interviews with experts.

4. 1 Step 1: Results of the analysis of theory/models and practical tools for the development of the transition scan

Applying the method of the Vet et al. (2011), a first draft of the transition scan has been developed by using the TRANSCIT model and the guidance Moving DEDICATED together. The results of the analysis of the model and practical tool are divided into three parts. The first part focuses on the key elements from the TRANSCIT model and the guidance Moving DEDICATED together, the second part includes the structure of the transition scan and the third part the type and amount of questions.

Key elements from the TRANSCIT model and the guidance Moving DEDICATED together.

The key elements that were extracted from the model and guidance using thematic analysis are: (1) the people involved in the transition, (2) needs/wants of the person with dementia, (3) information provision, (4) support and collaboration, and (5) time:

It is important to consider everyone involved in the transition process when developing the questions. The transition scan is addressed to informal caregivers and asks from their perspective what role they had and from whom they received guidance, support and information during the transition of the older person with dementia. The second key element highlights the importance of focusing on what the needs, wishes, and preferences of the person with dementia are and whether all of this was considered and continuously discussed during the transition. The third key element involves the need for sufficient information provision so that the informal caregiver is educated about dementia and knows all possible options to make the right decision with and for the person with dementia. As mentioned in the TRANSCIT model, the characteristics of a good partnership between the care triad (older persons with dementia, informal caregiver, and formal caregivers) must also be considered in the development of the transition scan. In addition the right timing of information, support etc., needs to be addressed in the transition scan.

Structure

The structure of the TRANSCIT model and the guidance Moving DEDICATED together guidance are applied in the transition scan. The transition scan is divided into the three transition phases. The first part focuses on questions related to the pre-transition phase (before the move), the second part on questions to the mid-transition phase (moving day), following by questions about the post-transition phase (feeling at home in the nursing home) in the third part. Before question related to the three phases are asked the informal caregiver is informed about the goal of the scan, which is to identify the informal caregiver's experiences throughout the moving process and to capture their view on the new living situation of the person with dementia in the nursing home. In addition, some general information about the informal caregiver and the move is collected. Characteristics such as age, gender, highest level of education, relationship to the person with dementia, and the name and location of the care organization, as well as some general information focusing on the overall transition process, are asked.

Questions

The transition scan combines quantitative measures and open-ended questions to explain why the participants choose a specific answer category. For closed-ended questions, 3 point, 4 point or a 10 point Likert scale is being used. The transition scan consists of 7 questions about the pre-transition phase (Before the move), three questions about the mid-transition phase (Moving day) and 7 questions about the post-transition phase (Feeling at home in the nursing home). The questions can be seen in table 1.

4.2 Step 2: Results from experts interviews

The results follow the themes that derived from the analysis of the interviews, i.e., structure, readability, usefulness, implementation and recommendation for the revision of the draft transition scan are used to test the feasibility of the transition scan. In order to have an overview of who had which opinion, the demographic data of the participants of this study are first presented (figure 5).

Demographics

From the 16 persons that have been contacted, 10 persons participated in this study. When persons refused to participate, the most common reason was a lack of time. The mean age of the participants was 40 years and about 60% was female and 40% was male. 50% worked in the home care, 20% in the nursing home organization and 30% had overall experiences with the transition process from home to the nursing home. An overview about the functions of the participants and in which setting they work is shown in figure 5.

Demographics of the participants

Home care

1. Home care manager (participant number 1)
2. Home care policy maker (participant number 2)
3. Home care nurse (participant number 3)
4. & 5: 2 x Chain directors dementia (participant number 4&5)

Nursing home

6. Client advisor from NH (participant number 6)
7. Policy maker NH organization (participant number 7)

Family member/ other

8. Physician/medical director/professor (participant number 8)
9. 1 x family member (participant number 9)
10. 1 x family member and coordinator of network palliative care (participant number 10)

Figure 5: Demographics of the participants

Structure

All participants are in favor of the structure of the transition scan. The majority agrees that the division into the three transition phases plus the general information makes it easier for the reader to follow. An family member proposes to add some general information about the person with dementia before filling in the questionnaire (participant 9). Both family members and the client advisor suggest to include an introduction explaining the three different phases of the transition (participant 4, 9 & 10). It is important to *"explain the structure and provide a guidance on what the content is"* as well as what is being targeted with the results so that the informal caregiver has a starting point as to why he or she should complete this questionnaire (participant 4). The goal of the transition scan should be adjusted, as it should be a *"goal that encourages the informal caregiver to participate in this survey not only to explore their experiences throughout the moving process, but also to improve practice by providing advice to the nursing home"* (participant 10). Although the overall structure is viewed as favorable by the majority of participants in this study, one policy advisor criticized that having different parts can make the questionnaire seem long. Furthermore, it is questionable whether the different parts are necessary if the questionnaire is shortened. "*If you have maybe two questions left, it's not necessary to have separate parts*" (participant 5).

Readability

A criticism made by the majority of the participants is that some questions might be too difficult as not all informal caregivers are well- educated and some have low health literacy (participants 3 & 9). From the experience of a physician, the answer options for some closed questions could be made simpler to increase the response rate. For instance, for question 22, he recommends only giving the option to tick that it has been discussed or not and omitting the part where it was discussed but not always taken into account (participant 10). The combination of open and closed questions has been considered beneficial by all participants. Most of the participants share the opinion that it is a good idea to first use a closed question, because these are easier and answered more often, but to also give the possibility to motivate the answer (participant 3 and 5). Closed questions will be filled in more often, but “you will miss information if you just use closed questions” (participant 3). An option would also be to combine the questionnaire with a qualitative dialogue with the informal caregiver and healthcare professional, who can support the person. In this case, the transition scan may be slightly longer (participant 10).

Usefulness/added value of the transition scan in practice

All participants’ first impression of the content of the transition scan is positive. The majority agrees that the transition scan will add value to the current care process, as it makes healthcare professionals, who are involved in the transition process, aware of the high impact of their work around transition (participant 4) and could potentially improve the collaboration between informal caregivers, the home care and the nursing home in the future (participant 3). A Chain director mentions that healthcare professionals often forget to support the emotions of informal caregivers, who often feel guilty that they can no longer care for their loved one and the transition scan gave insight into their challenges.

All participants indicated that the transition scan is very useful to get insight into the transitional care process from home to a nursing home for older people with dementia. Six out of ten participants emphasize that it is very useful for the nursing home because they can use the information to improve the care for new nursing home residents (participant 3 & 7). The manager of the admission department in the nursing home can use the results of the transition scan to reveal what is done adequately and how to improve practice (participant 8). In addition, the results can be used to see trends or differences between departments or locations and see where changes are needed in policy (participant 7). The nursing home can make use of this in-depth information “to improve the alignment with persons with dementia, their loved ones and healthcare professionals within the nursing home”, and ensure that everyone is well informed about the situation (participant 4).

The home care nurse (participant 3), who has experience working in both nursing home and home care, and a chain director (participant 4) mentioned that they perceived a lack of information transfer that prevents home care professionals and nursing home professionals to adequately work together. This shows that the transitional care is fragmented and one approach to overcome fragmentation is for home care nurses and nurses at the nursing home, case managers, and care coordinators to also use the transition scan as a checklist to ensure that both nursing home and home care have all necessary information to care for the person with dementia. The transition scan can provide insight about the importance of certain elements in the transitional process and improve practice by integrating changes into work when negative experiences have occurred (participant 4).

In the interviews, many participants criticized the length of the scan, which has an impact on its usefulness. To make the scan feasible in practice, the majority of participants recommend shortening it to a maximum of three pages. The physician and professor distinguishes between using the scan in practice or for research: "It's too long for daily practice, but for research specifically focusing on transition it's a good instrument" (participant 6). A policy advisor, who has experience with surveys in practice, emphasizes that "two pages are the best portion to have a lot of response" (participant 5). A shorter scan increases the chance that it will be completed by the informal caregivers and also makes it easier to analyze the data (participant 5). The transition scan must capture everything of the process, however, the majority agrees that some questions are overlapping and could be removed so that everything is only asked once (participant 10). An example is the overlap between questions 9 and 18, both of which ask if there was a specific/central medical professional who supported the informal caregiver on the moving day. Therefore, one of these questions can be deleted (participant 5, 9). Six out of the ten participants have said that the transition scan might be too long, but when specifically asking what should be removed, it was often difficult to point out specific questions as all seemed somehow relevant. The right length of the scan should be further tested in a pilot phase to determine how many pages the participants are willing to fill in.

The transitions scan might even add further value for informal caregivers, as it would be an opportunity to use another version of this tool as a guide to prepare for a possible future move of their loved one with dementia to a nursing home, and not only just as an evaluation tool (participant 8). When asking whether this scan could be useful in the case of a crisis transition, the majority has agreed, but suggested either using a second scan for people who have experienced a crisis transition or indicate which questions can be omitted. "It's also relevant when an emergency movement takes place, that there is the support, maybe not on beforehand but on the moving day itself to feel welcome at the nursing home" (participant 8). This shows that the transition scan can be very useful for everyone who is involved in the transition process and leads to better care of the person with dementia.

Implementation

All participants have been interested in how, where, and when the transition scan will be implemented and some have shared their opinions and experiences they have had with similar instruments in the past. Especially the policy advisors and managers in the home care and the nursing home setting as well as the two chain managers had many recommendations for the implementation of the transition scan.

In terms of how the informal caregiver should receive the transition scan, the manager and policy maker at the home care setting suggest to use a digital version, but also give the possibility to use paper in case that is preferred (participant 1,2). The nursing home policy advisor recommends the use of tablets, as it is important to already take into account how the data will be analyzed and the advantage of tablets is that data can be easily extracted to an excel file (participant 5). All participants agree that the informal caregiver should be approached in the nursing home, as this allows to offer support in completing the questionnaire and could lead to a higher response rate (participant 5). It is useful to inform the informal caregiver about the questionnaire in advance and to mention it in the flyer of the nursing home or to send them the information by e-mail (participant 10). When asked whether the transition scan should be filled in individually or together in a consultation, the majority concludes that the best way to obtain meaningful results from the questionnaire is to assist the informal caregiver in completing this form. Opinions on how this should be done vary among participants. Three participants prefer to have the informal caregiver complete the questionnaire themselves, but then discuss the answers in a consultation. Three other participants mention that the entire transition scan can be completed together in a consultation. Two participants suggest to let the informal caregiver decide what they prefer and to give them the opportunity to support the person if needed. These different opinions show that there are multiple ways and it would be best to test this in a small pilot study with a few informal caregivers. There has been no agreement on which specific person should discuss the scan with the informal caregiver. The majority of participants suggest the case manager or a healthcare professional from the nursing home should discuss this. The home care nurse recommends a person that knows the older person with dementia and his or her family, so it is someone they trust (participant 3). Other possible people who can conduct the interview with the informal caregiver include the care coordinator or a manager. One participant points out that the risk of consulting with the informal caregiver is that the person who leads the interview may influence the informal caregiver's responses and thus the response will be very subjective (participant 7). The results indicate that there is no preferred person and this should also be tested in a pilot study.

There has been an intensive discussion with participants about the right timing of when the transition scan should be filled in by the informal caregiver. In average, most of the participants recommend to set the date after four weeks. Two weeks are too early, because "*usually the first two weeks are really hectic for patients and the family, […] they have a lot of things they have to take care of, so this would be a a bit too much* (participant 3)." Persons with dementia need time to adjust to the nursing home, but the transition scan should not be filled in too late either, because by then they may have already forgotten how they have experienced the transition (participant 3 & 4). The policy advisor and the physician have mentioned that a good time to discuss the transition scan would be at the first evaluation in the nursing home after four weeks, as this can be easily be combined and no other appointment has to be made (participant 5 & 6).

Once the questionnaire has been implemented in the nursing home, it is also important to consider who should receive the information of the results of the transition scan to be able to make quality changes. Everyone agrees that all people involved in the transition process should be informed about the outcomes, i.e. from macro to meso to micro level. At first the outcomes should be shared with the policy advisors and managers within an organization, and then a meeting should be arranged to share the outcomes with people from the home care and the nursing home organization (participant 5 & 9). In the end, each ward in the nursing home, the coordinating nurse (werkverpleegkundige), the home care nurses, the case manager, the trajectbegleider, and the general practitioners should have access to the data in order to be able to use the results to improve their daily work and collaboration between all stakeholders to provide the best possible care to older person with dementia and their loved ones. It is important to "look at micro level what is the questionnaire saying and then combine the different results after a while, talk about it with the team, if they see some trends, […] not only the trends but also the problems and experiences with filling this in, some practical issues, and whether the family members are willing to fill it in" (participant 5). It must also be decided to what extent the questionnaire will be used and evaluated. One suggestion from a chain leader is to evaluate the transition scan every two years with a new sample and check whether everything is going well or what needs to be done differently (participant 8).The manager of the home care organization has mentioned that her role in the implementation would be to receive the results of the questionnaire and discuss it with the nurses in the home care (participant 1). For the home care nurse, the results of the transition scan are useful in ensuring that everyone receives the care they need (participant 3). The role of the chain directors would be to share the results with the case managers and make them aware of how they can improve if there are negative experiences, but also to encourage the nursing home to improve practice (participant 7 & 8). The case managers' tasks are to integrate it in their work and motivate informal caregivers to participate in this questionnaire.

The participants are open to test the scan in a further stage of the development. To receive significant results from the transition scan and be able to use it to make improvements in the current care process, the policy advisor and the chain director suggest to start with a pilot phase to get some experience and then make an implementation plan about how it should be done in practice (participant 5 & 7).

Recommendation for the revision of the questions of the current draft transition scan

All participants have emphasized that the questions cover the most important aspects of the transition process from home to a nursing home for older people with dementia. However, the participants indicate which questions can be removed, need to be changed or what should be added to the transition scan, which is shown in table 1. The analysis of the data shows that people in different settings and with different functions vary in their focus on the phases in the transition process and have remarks in different phases of the transition process.

General information

Looking at the comments on the items of the transition scan, it becomes clear that the majority is not entirely content with the questions about the general information about the move. Most of the questions in the general information have been criticized and should be changed or removed (see table). It is important to start the questionnaire with a rather general and simple question, such as "could you briefly explain the transition from a nursing home in your own words or something" (participant 2 & 9). Question 7: "Did you feel that the move from home to the nursing home was rushed?", is criticized by the majority as the word "rushed" contains a negative connotation and should not be asked as the first question on their experience of the move. A chain director suggested to rather use a closed question and then give three answer options to explain how they felt about the transition process. Another question that needs to be changed in the general information about the move is question 10, which is an open question that asks about the role of the informal caregiver during the move from home to nursing home. Six out of ten participants state that the word "role" is too broad and therefore too difficult for informal caregivers to answer. Suggestions for this question are to either remove it as it overlaps with question 14, which asks about the involvement of the informal caregiver, or rephrase it as: "What were your activities/tasks during the move to the nursing home?" This question specifically asks about what the informal caregiver has done for the loved one during the move to the nursing home, and is easier to grasp.

Before the Move

For the phase before the move, the majority agreed to include the perspective of the loved one with dementia not only in question 14, which asks about involvement from the perspective of the informal caregiver and the person with dementia, but also in subsequent questions 15, 16, and 17 when asking about whether they received enough information, whether they felt prepared for the move, and whether emotions/feelings have been addressed. Four participants have mentioned that it is rather difficult to have the person with dementia complete the transition scan by themselves, as the dementia is often advanced by the time they need to move to a nursing home (participant 2,3,7 & 8). However, all agree that it is a good addition. In case the older person with dementia is not able to fill in the questionnaire it can also be filled in by the informal caregiver on behalf of the older person with dementia. Referring to that a recommendation of a family member has been to shift the focus of the informal caregiver to the person with dementia, as they are the central person in the transition process (participant 10).

Moving day

The home care manager and the policy advisor from the home care have focused more on the preparation and the moving day. They have noticed that especially on the moving day some aspects are missing in the transition scan. It is important to ask the informal caregiver if they and their loved one with dementia felt warm welcomed in the nursing home. Not only should it be asked how prepared the nursing home was for their arrival, but also how welcome they felt and whether the nursing home staff took time to answer any questions they had. The home care manager has mentioned another important question to add under moving day, which is whether the older person with dementia could bring personal belongings from home. “I always ask myself but the people are going out of their environment where they live about 50 years mostly. To feel like home in the nursing home the furniture can be crucial” (participant 1). A comment of a chain director can be added here. She emphasizes that it could be useful to get more insight into how the older person with dementia has experienced the transfer, whether they know that there is no coming back and if there has been any resistance (participant 8). “You walk out of the house with the suitcase and close the door behind you and knowing you will not be here again” (participant 8).

Feeling at home in the nursing home

The analysis of the interviews has shown that the part about feeling at home in the nursing home was the clearest and most complete and therefore fewer comments have been mentioned. With regard to the feeling at home in the nursing home phase, the physician and professor emphasizes that it is very important to ask the informal caregiver if he or she can care for the person with dementia in the same way as he or she did before the move to the nursing home, in order to determine whether sufficient attention is given to the informal caregiver and his or her role in the care for the person with dementia (participant 6). Furthermore, question 23 should be changed and asked whether there is attention for the informal caregiver in the nursing home than whether the informal caregiver feels acknowledged in his or her role as an informal caregiver, as this question can be uncomfortable for the informal caregiver to answer (participant 6).

End of the transition scan

To have a proper end of the transition scan, the majority recommends moving questions 11 and 12, about how the informal caregiver would grade the entire moving process and how they experienced it, to the end, as they can then adequately answer the questions with an overview of how the transition went. Free space to leave the option to add something else, such as question 24, should also be included here.

More details on how the items of the transition scan should be changed and what should be removed or added can be found in table 1. The results show that there are different opinions and comments about the transition scan regarding the function of the participants, but overall most comments align.

Table 1: Adjustments of the items of the transition scan

	Current question:	**Change/add/remove**	**New question/ changes**
	Introduction	➔ add ➔ change goal	- Add that transition scan entails all three phases, - Goal: should be filled in for the higher goal to give advice to nursing home
	Question 1: *Age* **Question 2:** *Gender* **Question 3:** *Highest level of education* **Question 4:** *What is the relationship with your loved one residing in the nursing home?* **Question 5:** *At what care organization is your loved one staying at and at which location?* **Question 6:** *Date of nursing home move*	-	-
General information about the move	**Question 7:** *Did you feel that the move from home to the nursing home was rushed?*	- negative connotated - rather closed question ➔ change/ remove	How did you experience the moving process? - relaxed/smooth - well-prepared - rushed already asked
	Question 8: *What was the reason for the move to the nursing home of your loved one?*	Question 7 and 8 similar ➔ remove	
	Crisis situation	Add second scan for crisis situations or skip questions ➔ add	Did you experience an acute transition to the nursing home of your loved with dementia? If yes, you can leave out the following questions…
	Question 9 A: *Was there a specific/-central healthcare professional you could always contact for information, guidance, or support and what was her/his function?*	similar to question 18, remove question 18	
	Question 9 B: *Did you receive sufficient support from this healthcare professional/these healthcare professionals?*	-	-
	Question 10 A:	too complicated, too broad ➔ change	What were your activities/tasks during the move to the nursing home?

	What was your role during the move from home to nursing home? **Question 10 B:** *Did your role change during the moving process? (was it different at home, on moving day or at the nursing home)?*		
	Question 11: *How would you grade (0-10 line) the entire moving process?* **Question 12:** *How did you experience the transition?*	- Question 11 to difficult - Move question 11 and 12 to the beginning or end ➔ change	explain scale of question 11, good – bad opening or ending questions
	Question 13 A: *When was a possible move discussed for the first time?*	-	-
1 phase (question 13- 17)	**Question 13 B:** *Who started this first conversation about the move to the nursing home?*	add to answer options ➔ add	- it was not discussed - I forgot that it was discussed
	Question 14: *What was the level of involvement of your loved one and what was your involvement?*	Make answer options easier ➔ change	only involved/not involved
	Question 15: *Did you receive sufficient information regarding?* **Question 16 A:** *Overall, did you feel prepared for the move?* **Question 17:** *Were your feelings/emotions addressed due to the nursing home move by the healthcare prof?*	Include involvement of person with dementia in question 15 to 17 ➔ change	**Question 15**: Did you and your loved one with dementia feel like that you received enough information regarding..? **Question 16 A:** Did you and your loved one with dementia feel prepared for the move? **Question 17:** Were your and your loved ones feelings/emotions addressed due to the nursing home move by the healthcare prof?
	Question 16 B: *How was the move to the nursing home prepared?*	-	-
2 phase (question 18-19)	**Question 18:** *Was there a familiar central contact person who welcomed and supported you at the day of the move?*	Similar to question 9 ➔ remove	

	Question 19: *How well was the nursing home staff prepared for your arrival?*	Should be asked earlier Add answer options Add questions ➔ change place ➔ add	Ask in before the move: discussion about care needs is already before Add answer options: - I was able to take personal stuff from my home - The people at the NH took time for me and answered all my questions Add questions: - How did you experience the transfer? - Was there resistance from the person with dementia?
3 phase (question 20 – 24)	**Question 20:** *What is the level of feeling at home of your loved one in the nursing home?*	Motivate your answer ➔ add	Add possibility to motivate the answer
	Question 21: *Do/did you notice any behavioral changes in your loved one/family member?*	Already answered in question 20 ➔ remove	
	Question 22 A: *Did the healthcare professionals take into account the needs, preferences and wishes of your loved one?*	Should be asked earlier ➔ change place	Should be asked in phase 1: Before the move
	Question 22 B: What of the following examples were discussed?	- Make question more simple, - include more answer options ➔ change ➔ add	- only discussed/ not discussed - add: care plan; levensfragen
	Question 23: *Do you feel acknowledged in your role as an informal caregiver?*	Rather ask if there was attention for informal caregiver in the nursing home ➔ change	- Was there attention for me in the nursing home? Or: - Could I still carry out the things for my loved one in the NH as I did before?
	Question 24: *Is there anything that you would like to add?*	-	-

5. Discussion

In the following section the significance of the results of the interviews are further discussed with regard to the theoretical background and research question. First, the main findings are presented and discussed with previous studies. Then, policy and practical implications as well as future recommendations for the transition scan are given. The final section focuses on limitations of the study.

5.1 Main findings

This study developed a theory based feasible transition scan, that can give insight in the current transition process from home to the nursing home of older people with dementia and will eventually improve future transition care. The first part of the present study examined how the TRANSCIT model and the guidance Moving DEDICATED together can be used to develop an evaluation tool in the transitional care using the method of the Vet et al. (2011). The model and guidance provided a useful foundation for extracting key elements (needs/wants of the person with dementia, information provision, support and collaboration, time) that were used for developing the questions and building the structure of the transition scan. The second part of the study examined perceptions of persons with different functions about the transition scan in terms of development and feasibility. The core results of the interviews focus on content, readability, structure and implementation strategies. Regarding the content of the transition scan the overall perspective was positive as the transition scan was seen as a useful tool to gain insight into the current transitional care process and reveal positive points and improvement points. The scan can be used to make health care professionals aware of the impact of their work around transition and emphasizes the importance of a successful collaboration between everyone involved in the transition process. However, some recommendations for small adjustments about the content were provided to improve the feasibility of the transition scan. Points of improvement relate to the begin of the questionnaire, which should include more information about the purpose and aim of the scan. Further improvements include focusing more on the person with dementia and paying more attention to how the person with dementia and the informal caregiver felt welcome on the moving day by the nursing home staff. The majority of participants mentioned that the structure of the transition scan is favorable, but it needs to be shortened and some questions need to be simplified to make it a readable and feasible tool in practice. Regarding the implementation of the transition scan, the results show that the transition scan should be discussed in a consultation, possibly involving the person with dementia. Most participants recommend having the scan completed about four weeks after the transition. The results of the scan should first be shared with managers and policy advisors of the home care and nursing home care and then discussed with all those involved in the transition process to make quality changes.

The findings of the study align with the results of previous studies and reviews which emphasize the importance of interventions to improve transitional care (Gaugler et al., 2015; Müller et al., 2014). For instance the study of Gaugler et al. (2015) focuses on improving the post-transition phase for the informal caregivers, by using a Residential Care Transition Modul (RCTM), which includes six sessions with a transition counselor to talk about how they feel and how they adapted to their new role after the transition of their loved one. This is also content of the transition scan, however to a lesser extent, as the transition scan includes all three phases of the transition. There is little evidence on evaluation tools that investigate the entire transition process from home care to a nursing home for older people with dementia. Given the different methodological approaches taken, the comparability of results reported in other studies with our own results is limited.

Looking at literature about how to develop a feasible questionnaire Young (2016) advises in Zhu Hua's Practical Guide that it is beneficial for questionnaires to use a standard format that includes a title, some general information about the research project, and instructions or guidance for completion. This will increase the response rate as the format is likely to be familiar to the participants. To make the transition scan a feasible tool for practice, it is important to render it readable for informal caregivers (de Vet et al., 2011). The transition scan should therefore include an introduction with an explanation of the different parts of the questionnaire and the goal, why the transition scan should be filled in. It should also be considered to start the questionnaire with a simple opening question (Kabir, 2016). "The first question is crucial because it is the respondent's first exposure to the interview and sets the tone for the nature of the task to be performed. If they find the first question difficult to understand […] they are likely to break off immediately" (ibid). It is important that the transition scan uses simple questions that are comprehensible to the total target population (de Vet et al., 2011). In addition, a shorter scan should be used, as literature shows that long questionnaires are often filled in superficially (Kabir, 2016).

To implement the transition scan in practice some important elements need to be considered: The majority of interview participants recommend approaching the informal caregiver in the nursing home and handing over the transition scan in person, as approaching participants personally can motivate them to complete the questionnaire and increase the response rate (Bowling, 2005). Taking into account the opinions from the interviews, the best way to obtain useful results is to assist the informal caregiver in completing the questionnaire, as this provides more in-depth answers and the opportunity to discuss the questions if needed. However, there were some differences in opinions among participants when it comes to who should support the informal caregiver. The majority of participants indicated that this person could be the case manager or someone from the nursing home. Participants from the home care setting emphasized that it is important that the informal caregiver can discuss the questions with someone he or she knows and trusts. However, the chain directors mentioned that support from both the case manager or someone from the nursing home can lead to socially preferential responses from the informal caregiver. As noted in the findings, the informal caregiver knows the case manager and may not feel comfortable sharing information about something that also involves the case manager's duties. If it's someone from the nursing home, they may not want to say anything negative because they are afraid it could have consequences for the person with dementia in the nursing home. The right person to assist the informal caregiver in completing the questionnaire should be tested in a pilot study. Training and education are needed to equip healthcare professionals to discuss the questions with the informal caregiver.

The findings of the interviews revealed that the focus should not only be on the informal caregiver, but also the older person with dementia should be included in the discussion of the questions, as it is important to take the view of the person him or herself. Family members and the home care nurse mentioned that there may be added value in including the person with dementia in the discussion. The majority agreed, but stressed that it is rather difficult as the person is already in the advanced stages of dementia when he or she moves to the nursing home. In a study from Bolt et al. (2021), which aims at investigating the perspectives of people with dementia on being cared for by others and their capability and willingness of having conversations about the future and end of life. The study emphasizes that it is important to treat people with dementia as equal and worthy human, who have a desire to stay an active member of society and be valued by others as an individual. It is important to reduce stigma that a person with dementia can no longer express him- or herself. Depending on the stage of dementia and whether the person with dementia is capable and open to be part of the discussion, he or she should be included. It would be useful to test this in a pilot study.

In addition it is essential to have the discussion about the transition scan at the right time. The average of the results of this study concluded that four weeks after the person with dementia moved to the nursing home is a good time, as by then the first emotions have settled, but the informal caregiver can still remember how the transition went and how he or she felt. This is in line with the literature, which suggests that an initial evaluation should be conducted after four weeks after transition (Reibnitz et al., 2015).

5.2 Implications for Practice and Policy

This study holds particular value by demonstrating an measurement instrument aiming at evaluating the entire transition pathway from home to the nursing home of older people with dementia. Interventions that focus on the entire transition process from home to the nursing home are scarce as most studies only focus on a specific time of the transition phase (Groenvynck et al., 2020b). This could be due to the fact that the transitional care process is known to be fragmented (ibid). The transition scan adds value to the current transition process by evaluating points of improvement in all three transition phases and thus helping to overcome fragmentation in the long term. However, the fragmented healthcare system is a challenge and makes it questionable to what extend the home care and the nursing home are able to improve practice by using the transition scan. The transition scan looks back at the transition, but some changes need to be made beforehand to improve practice.

A second implication is that the transition scan provides a first step towards a quality monitoring system, since a standardized quality-monitoring system in the transition process from home to a nursing home is still missing (Hinshaw & Grady, 2010). There is no standard of care for the transition process, which makes it difficult to improve the transitional pathway (ibid). The transition scan provides a comprehensive overview of informal caregivers’ experiences of the transition of their loved one and allows to obtain and analyze data to improve the quality of care. It shows the ideal situation of how a transition from home to the nursing home should occur for older people with dementia. By completing the transition scan, informal caregivers begin to think about what could have been done better, what is not normal, and share their new knowledge with other people and give feedback to healthcare professionals.

Third, an implication is that the transition scan or a deviated version of the scan could also be transformed into a guideline that informal caregivers can use to inform informal caregivers about the three phases of the transition and make them aware of everything that needs to be considered for a future transition of a person with dementia to a nursing home. There is already a similar study in which a decision aid (the DECIDE manual) has been developed to help healthcare professionals support dementia informal caregivers in making decisions about living arrangements and future place of care (Lord, 2016). The results show promising results and the majority of informal caregivers in the study mentioned that the tool has helped them in the decision-making process to get an overview of the available options for the person with dementia and an opportunity to discuss them (ibid).

An additional implication is to also use the transition scan for crisis admissions of older persons with dementia. The majority of the participants mentioned that the current version is not suitable for these cases as many questions such as the preparation for the move would not be applicable then. Rather, another version of the transition scan might be useful that is shorter and only focuses on the moving day and the adjustment in the nursing home. Crisis admissions are particularly hectic and stressful for the person with dementia and the loved one, and the transition scan should focus on how they were approached and supported by healthcare professionals (American Medical Directors Association, 2010).

To make policy changes in the transition process, it is important to determine who will receive the results of the transition scan. In a guidance from O’Cathain et al. (2019) on how to develop interventions to improve healthcare it is mentioned that it is important to involve stakeholders official bodies or policy makers who endorse or accredit an intervention. Results of the transition scan should be shared on national level as health policy from the government is relevant for the care standard of dementia care. At the meso level, nursing home and home care managers and policy makers should receive the results of the transition scan to analyze the data and determine what is done well in the transition process and what needs to be done differently to make organizational changes and thus improve transitional care. It is their responsibility to share the results with the micro level to raise awareness among healthcare professionals about what they need to pay more attention to. There is no standardized transition protocol used in nursing homes (American Medical Directors Association, 2010). Healthcare professionals from the nursing home fill out an admission form when a new person with dementia moves to the nursing home. These protocols focus on assessing the physical, psychological, emotional and social needs of the residents in nursing homes (Tan, 2002). Managers and policy makers can improve these protocols by evaluating the transition process with the transitions scan.

5.3 Recommendations for the transition scan

This study uses the first three steps of de Vet et al.'s (2011) method to develop a feasible instrument for informal caregivers to measure their experience of the transition process of their loved one with dementia from home to a nursing home (figure 5). The first three steps of the development phase are not yet complete, as the questions still need to be modified with the new input from the expert interviews. Recommendations from the interview participants for using the transition scan in daily practice are to shorten it and make some questions easier to answer. The changes should be discussed with the research group and a new version of the transition scan should be developed. It should also be noted that the transition scan is intended for informal caregivers, but only two informal caregivers are included in this study, so the scan should be tested in a larger group of informal caregivers to ensure that it is feasible for informal caregivers. Another recommendation is to broaden the target group as we now only focus on informal caregivers in our study. In the future, the focus should also be on older persons with dementia and healthcare professionals from the home care and the nursing home to capture the experiences of all stakeholders involved in the transition process. After the first three steps of the development of the questionnaire are completed, the next step of de Vet method (2011) is to test the transition scan in a pilot to explore the results of the use of this transition scan. The pilot should include a small sample of participants (e.g. 5 loved ones), after which adjustments will follow (de Vet et al. 2011). When the transition scan is considered satisfactory regarding the content, readability and structure after one or more rounds of pilot testing, a recommendation from the interviews is to establish an implementation plan that includes where, how, and when the transition scan will be implemented in practice and how and from whom the results will be used to change practice. It should then be tested in a larger sample of the target population (field testing) (de Vet et al., 2011).

5.4 Limitations

There are some limitations of the study that need to be addressed. One limitation is the method of data collection. The results of this study are based on a diverse sample that includes researchers and various individuals involved in the transition process from home to a nursing home for older people with dementia. However, the sample size is rather small (10 participants from the interviews and 4 participants from the research group), which affects reliability, and the data analysis of the study may produce biased results as some factors may not been taken into account. A second limitation is that the interviews were conducted in English as the interviewer does not speak Dutch. Some participants had some difficulty expressing themselves in English, which might have led to some communication issues and misunderstandings. They might not were fully expressing themselves or felt limited due to language challenges. Furthermore, by conducting the interviews online on the zoom platform, there are limitations related to distractions caused by technical problems such as poor internet connections.

6. Conclusion

We have developed a theory-based transition scan using the de Vet method for informal caregivers of older persons with dementia that will be used to evaluate the transition from home to nursing homes. According to a diverse group of stakeholders our transition scan, appears to be right in content and structure regarding the preparation before the move, the moving day and the feeling at home in the nursing home. It is highly useful for the nursing home and home care organization, and adds value to the current transition process. However, some changes regarding the content, length and difficulty of questions are required, as well as strategies for implementation need to be established before it is a feasible tool for informal caregivers and can be put into practice. Future research is needed to explore the usefulness of evaluation tools of the transition process and to compare results between different disciplines involved in the transition from home to nursing home of older people with dementia. This is needed to identify point of improvement from different perspectives and uncover differences that can be used to improve transitional care.

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Appendices

Appendix 1: Topic list

Interview	Topics
Introduction	- Introduce myself - Aim and approach of interview (explain on what the transition scan is based on) - Emphasize anonymity - Recording and duration - Ask for short introduction of interviewee o What context do you use to answer the questions?
Experience with transition scan overall -> face validity	<u>Content</u> - When you read the transition scan what was the first thing that came to your mind? - Is the scan useful and why would it be useful for you? - What is in your opinion the added value of the scan? - Mention goal of the scan and ask: Is the scan focused on testing this?: o *Does it help to identify positive points and improvement points of the transition process for older people with dementia moving from home to nursing home from an informal caregiver point of view?* o *Does it inform healthcare professionals in the nursing home on how the transition process is being experienced and how it can be improved?* - Does the transition scan cover all important steps for the move? o Would you add something in the pre- transition phase (time before the move); mid-transition phase (moving day) or post-transition phase (familiarization with the new living situation) o Is something missing in the 3 phases? - Do you think this scan can also be used in case the transition was an emergency? <u>Questions about readability and structure</u> - Is the scan readable? - Are questions clear and understandable? - Are questions comprehensible? - Are questions relevant and complete? - Do you like the structure of the transition scan? (divided into three steps of the moving process) - Are the questions and the structure of the scan logical? - How much time did it take you to answer the questions? o Is the length of the transition scan favorable or is it too short/too long?
Closing	- Does the interviewee want to add something? ➔ Ask additional questions about how they (and who else) can be part of the implementation of the transition scan: o How/in what way should the informal care giver receive this scan? o Should the answers of the scan be discussed verbally as well and with whom should it be discussed? o In what time frame after the move should the scan be filled in? o Who should receive the information of the scan to be able to make quality changes (meso and macro level). o Is there a team/working group responsible for moving policy in your institution? o what could be your possible role in the implementation? o Can we ask you for testing the scan in the further stage of the development?

	○ Would you use the results of the transition scan and how would you use them? - Mention the ability to receive thesis after completion - Thank interviewee for their time and effort

Appendix 2: Interview Participation Consent Form

I volunteer to participate in a research project conducted by Judith Meijers, Chaan Khemai and all members of the DEDICATED team. I understand that the project is designed to gather information for academic purposes and further development of the DEDICATED project only.

1. I had sufficient time to consider my participation in this study and I am fully aware that my participation in the study is voluntary.

2. I know that I can decide not to participate or stop my participation at any time without giving any reason for this decision.

3. I agree to my interview being audio-recorded.

4. I understand that the researcher will not identify me by name in any report using information obtained from this study, and that my confidentiality as a participant in this study will remain secure.

5. Data collected for this study become property of the Maastricht University, and will not be shared with external parties. They will only be used for the DEDICATED project and related research.

6. I have read and understand the document provided to me. I have had all my questions answered to my satisfaction, and I voluntarily agree to participate in this study.

If you cannot obtain satisfactory answers to your questions, or have comments or complaints about your treatment in this study, contact: Dr. Judith Meijers, project leader of the DEDICATED project, j.meijers@maastrichtuniversity.nl.

________________________	________________________	____________
Name (Participant)	Signature	Date

Appendix 3: Transition scan

Date *(filled in by loved one):………/………/…………*

Transition scan

Your experience of the past transition process and your view on the new living situation of your loved one in the nursing home

<u>The goals of this transition scan are to</u>:
- Identify your experiences during the entire moving process.
- Capture your view on the new living situation in the nursing home

<u>General information about you</u>

1. **Age:** …………………..

2. **Gender:** ☐ male ☐ female

3. **Highest level of education:** ☐ mbo ☐ hbo ☐ wo ☐ other………………………..

4. **What is the relationship with your loved one residing in the nursing home?**
   ☐ daughter
   ☐ son
   ☐ partner
   ☐ friend
   ☐ neighbor
   ☐ other, namely………………………..

5. **At what care organisation is your loved one staying at and at which location?**
   ……………………………………………………………………………………………………

<u>General information about the move</u>

6. **Date of nursing home move:** ………/………/…………

7. **Did you feel that the move from home to the nursing home was rushed?**

☐ 1	☐ 2	☐ 3	☐ 4
No, not at all	A little bit	Yes	Yes, extremely

Please motivate your answer:

……………………………………………………..……………………………………………

8. **What was the reason for the move to the nursing home of your loved one?**

   ………………..………………………………………………………………………………
   ……………………………………………………………………………………………..
   …………………………………………………………………………………………….

9. A. Was there a specific/-central healthcare professional you could always contact for information, guidance, or support and what was her/his function?

	Yes	no	Function of the healthcare professional
At home	☐	☐	……………………………………....
Moving day	☐	☐	………………………………….......
At the nursing home	☐	☐	……………………………………..

B. Did you receive sufficient support from this healthcare professional/these healthcare professionals?

☐ Yes, I felt sufficiently supported

☐ No, I did not feel sufficiently supported because…………………………………………
………………………………………………………………………………………………..

10. A: What was your role during the move from home to nursing home?
………………………………………………………………………………………………

10. B: Did your role change during the moving process? *(was it different at home, on moving day or at the nursing home)?*

…………………………………………………………………………………………
…………………………………………………………………………………………

11. How would you grade (0-10 line) the entire moving process?

1 2 3 4 5 6 7 8 9 10

Could you please motivate your grading?
....
....
....

12. How did you experience the transition?

A: What were positive experiences during the total moving process?
………………………………………………………………………………………………

B: What could be improved during the total moving process?
……………………………………………………………………………………………..

Before the move (at home)

13. A. When was a possible move discussed for the first time?
- ☐ < 3 months before the transition
- ☐ 3-6 months before the transition
- ☐ 6-12 months before the transition

☐ > 1 year before the transition

13.B. Who started this first conversation about the move to the nursing home?

☐ Loved one/family member
☐ Myself
☐ Healthcare professional, namely……………………………………………………
☐ Others, namely………………………………………………………………………..

14. What was the level of involvement of your loved one and what was your involvement?

	Involved	*Partially involved*	*Not involved*	Please motive your answer. Also, clarify if the level of involvement sufficed?
Your involvement				
When deciding to live in a nursing home?				
When choosing a nursing home?				
The preparation for the move?				
Your loved one's involvement				
When deciding to live in a nursing home?				
When choosing a nursing home?				
The preparation for the move?				

15. Did you receive sufficient information regarding?

	Yes	**No**	**In case the answer is no, please motivate your answer**
The place on the waiting list (and expected day of move to the nursing home)			
The day of the move to the nursing home			
The daily life at the nursing home			

16. A: Overall, did you feel prepared for the move?

☐ No, I was not prepared at all**.**

☐ I was somewhat prepared.

☐ I was sufficiently prepared**.**

Please motivate your answer:

……………………………………………………………………………..

16. B: How was the move to the nursing home prepared?

	Yes	**No**	**Please motivate your answer**
I visited the nursing home in advance (with family/loved one).			
The healthcare professional from the nursing home visited me at home.			
The healthcare professional from the community informed me.			
Practically support for the move was arranged.			
Your role has been discussed with the healthcare professionals.			
Other………………………………………… ………………………………………………..			

17. Were your feelings/emotions addressed due to the nursing home move by the healthcare prof? *(Multiple answers are possible)*

	Yes	**No**	**Please motivate your answer**
My concerns and fears were heard/seen and addressed.			
My questions were answered			
My opinion was taken into account.			
My expectations were heard and discussed			

Moving day

18. Was there a familiar central contact person who welcomed and supported you at the day of the move?

☐ Yes ☐ no

a) Was she/he available when you arrived?

☐ Yes ☐ no

19. How well was the nursing home staff prepared for your arrival? *(more answers are possible)*

☐ The nursing home was informed about the care needs of my loved one/family member

☐ The nursing home staff was informed about the needs, wishes and personal preferences of my loved one/family member

☐ The room was prepared and personalized by the nursing home staff (e.g.with name tag/picture).

☐ The nursing home staff gave you a walk-through the nursing home.

☐ The nursing home staff prepared a warm welcome (e.g. friendly, cup coffee was offered…)

☐ Others, namely……………………………………………………………………………

Feeling at home in the nursing home

20. What is the level of feeling at home of your loved one in the nursing home?

☐ He/she does not feel at home in the nursing home.

☐ He/she is starting to feel at home in the nursing home.

☐ He/she feels at home in the nursing home.

a) Which actions (if any) were undertaken by the nursing home staff to make your loved one feel (more) at home?

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…………………………………………………………………………………………

21. Do/did you notice any behavioral changes in your loved one/family member?

☐ Yes, please indicate what kind of behavioral changes

……………………………………………………………………………………………
……………………………………………………………………………………………
…………………………………………………………………………..

☐ No

22. A: Did the healthcare professionals take into account the needs, preferences and wishes of your loved one?

☐ Yes ☐ no

Please motivate your answer……………………………………………………………..

22. B: What of the following examples were discussed?

	They were not discussed.	*They were discussed but <u>not</u> always taken into account.*	*They were discussed and always taken into account.*	*Motivate your answer*
Care provision (bathing, wound care…)				
Daily activities				
Routines (e.g. bed time hour)				
Food/drinks preferences				
Social activities				
Spiritual/ religious				
Treatment/medication				
End of life care				
Other………………… ………………………				

23. Do you feel aknowledged in your role as an informal caregiver? *(please indicate the reason)*

☐ Yes, because
………………………………………………………………………………………
………………………………………………………………………………………
………………………………………………………………………………………
☐ No, because
………………………………………………………………………………………
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………………………………………………………………………………………

24. Room for comments: Is there anything that you would like to add?

……………………………………………………………………………………………………

Appendix 4: Guidance Moving DEDICATED together

Moving DEDICATED together

A guide for working together when people with dementia move from home to a nursing home

DEDICATED
Desired dementia care towards end of life

Introduction

Why is interprofessional collaboration important during a move?

Dementia is a collective term for symptoms and signs that are caused by the deterioration or death of nerve cells. As a result, people with dementia experience problems in at least two cognitive domains (memory, executive functions, seeing and processing an observation in space, language functions and personality and behavior) and it is difficult for them to perform daily activities independently. In addition, dementia is an incurable disease with an uncertain prognosis, whereby the average life expectancy can vary from 3 to 12 years. That is why it is important to think about *palliative care* after the diagnosis of dementia. The goal of palliative care is to improve quality of life by preventing and alleviating suffering through early recognition, assessment and treatment of the needs or problems that may arise on four dimensions (physical, social, psychological and spiritual). Since palliative care looks at the person with dementia with a holistic view (four dimensions), the collaboration between various care professionals (from various fields) themselves, but also with people with dementia, loved ones (i.e. blood relatives, partners, relatives and/or adoptees) and informal caregivers (i.e. family members, acquaintances, friends, local residents and/or volunteers) are important for maintaining and improving the quality of life. We call this *interprofessional collaboration*.

Interprofessional collaboration in dementia care is important within care settings, but also during transitions between care settings. Since about 90% of people with dementia die in a nursing home, interprofessional collaboration when moving to a nursing home is a point of attention. Various studies have shown that a move to a nursing home often unintentionally still has an unpleasant course, due to for instance not having questioned and/or complied with the preferences of people with dementia at an early stage. This can result in negative effects on for example cognition, behavior, mental well-being, functioning and the resident's overall quality of life. In addition, crisis relocations to a nursing home in dementia care also occur because people wait until the last moment to arrange a move, the move is postponed or because an acute event (such as a hospitalization) occurs. Although anticipating a move is crucial, some people with dementia, their loved ones and/or informal caregivers find it difficult to start a conversation about a move at an early stage if they do not yet have a need for it or do not want it at the time being, but then indicate afterwards after the move that it would have been more convenient to discuss the move earlier. That is why it is very important that healthcare professionals involved with people with dementia receive advice/tips on how to work in a forward-looking and person-centered way, and to involve the person with dementia, their loved ones and/or informal caregivers in a move as much as possible and in time.

What is this guide about?

The guide consists of a central theme *'Working together with attention for the person with dementia, loved ones and/or informal caregivers during a move'* and describes three steps in the move that run parallel to the phases of the move:

1. Looking ahead together at home (phase before the move)
2. Prepare a warm welcome together (phase during the move and the adjustment phase)
3. Feeling at home together in the nursing home (phase after the move)

What is the purpose of this guide?

The purpose of this guide is to provide guidance throughout the entire move (before, during and after the move) to healthcare professionals who work with people with dementia, to work with each other as healthcare professionals, people with dementia and their loved ones and/or informal caregivers forwardlooking towards a person-oriented and warm move. The guide is an advice document for the involved healthcare professionals to check whether they have gone through all the essential steps in the relocation and have addressed all important (discussion) topics step by step. In addition, the guide increases awareness of interprofessional collaboration during a relocation. Since the topics and discussion topics of the core steps are described in general terms, this guide can possibly also be used for a move to other intramural forms of housing, such as the hospice, the care apartment, the nursing home and the care farm.

Overview key steps *Moving DEDICATED together with people with dementia from home to a nursing home*

Central theme: Working together with attention for the person with dementia, loved ones and/or informal caregivers (at home, during the move and in the nursing home)

It is important that the care professionals involved before, during and after the move:

- *Demonstrate an understanding of the health situation, the dementia process and the palliative care approach by i.e. explaining this to the person with dementia, their loved ones and/or informal care providers and to deal with the person with dementia in a person-oriented way*
- *Start from the wishes and preferences of the person with dementia, the loved ones and/or informal caregivers in the care process, choosing a nursing home and providing end-of-life care*
- *Involve loved ones and/or informal caregivers actively in representing the wishes and preferences of the person with dementia (if the loved ones and/or informal caregivers are willing to do so)*
- *Ask loved ones and/or informal caregivers which role in the care process they would like to have (expectation management) and how the involved care professionals can support them in this*
- *Ask loved ones and/or informal caregivers (if they are willing to do so) and people with dementia (to what extent this is possible and if they are willing to do so) to give their perspective and opinion and to include these in order to reach a joint decision-making*

Step 1. Looking ahead together at home

Directly involved care professionals in the home setting:

Carers/Nurses
Paramedics (occupational therapist, speech therapist, physiotherapist and/or dietician)
Spiritual caregiver
Social worker or other welfare professionals
Case manager dementia
Client advisora
General practitioner

Looking ahead together at home is the preliminary phase before the move in which living at home is mapped out, wishes and preferences regarding advanced care planning are discussed (daily life, a possible move and end of life), joint coordination takes place and all involved (person with dementia, loved ones and/or informal caregivers and all involved care professionals) reach a joint decision-making. ***This phase starts with conversations in the home setting (about living at home, monitoring the care burden and living in a nursing home) and ends when there is a preference for a nursing home or when a nursing home has been selected.***

a Client advisor, also referred to as a care pathway counselor, customer advisor or care mediator (depending on the region and care organization) works at the nursing home and arranges the practical matters regarding the move to a nursing home.

Looking ahead together at home, how do you do that?

- *As a directly involved care professional, regularly talk with the person with dementia, their loved ones and/or informal caregivers to check how living at home is progressing in order to anticipate a (possible) future move*
    - You can use tools on the website of Care for better (Zorg voor beter) to initiate or improve communication with people with dementia.
    - Support the person with dementia, loved ones and/or informal caregivers in creating an overview of which formal and informal care professionals are involved in the care of the person with dementia. By making an overview, one can see at a glance whether all important care professionals are involved in the care process for the person with dementia, who is still missing and who will be the most suitable central point of contact for the person with dementia.
        - Example tool for this is *'Who is who in dementia' (Wie is wie bij dementie)*
    - Regularly here means on average every six weeks (more often if necessary)
        - Depending per organization and/or case. Also consider signals that the person with dementia, loved ones and informal caregivers give and, if they wish, discuss this more often with them.
    - Begin the conversation with the general question *'How are you?'* to get a picture of how the person with dementia experiences life themselves.
        - For this, use for example the infographic *Getting started with Positive Health (Aan de slag met Positieve Gezondheid)* to see how you can start this conversation and pay attention the four dimensions.
    - During the conversation ask a couple of key questions like:
        - *'How is living at home going?'*
        - *'What makes it more difficult to live at home?'*
        - *'What support and help from healthcare professionals do you miss while living at home?'*
        - *'How is living at home now for you as (a) loved one(s) and/or informal caregivers?'*
        - *'When do you, as a loved one (s), think that it is too much for you?'*
- *As care professionals, timely discuss and map out the expectations, wishes and preferences of the person with dementia, loved ones and informal caregivers regarding advanced care planning.*
    - During this conversation don't use professional jargon, but use simple language.
    - During this conversation consider the following topics:
        - *Who is the person with dementia and what are his or her wishes in daily life?*
            - The life history of the person with dementia. Consider questions like the following:
                - *'What do you find important in life?'*
                - *'What are the most beautiful moments in your life?'*
                - *'What important events have occurred in your life?'*
                - *'What occupation did you have?'*

- Four dimensions. Consider questions like the following:
  - *'What does your day look like?'*
  - *'What are your daily activities and hobbies?'*
  - *'In which social activities would you like to participate?'*
  - *'In which spiritual, religious or cultural activities would you like to participate?'*
- The ways of handling (communication and actions) or forms of activities that contribute to the preservation of the autonomy and identity of the person with dementia. Consider the following:
  - The way in which you address the person with dementia. For example, the sentence "*Come on, Mrs. X, let's take a shower*" has a paternalistic character, which can lead to problematic behavior and less understanding in the person with dementia.
  - The wishes and preferences of the person with dementia in care. For example, the time at which the person with dementia prefers to get up or sleep or which food preferences he or she has.
  - The ways to calm the future resident. For example, the ways to calmly approach and soothe the person with dementia exhibiting agitation.
- Document the personal information
  - This can be in the form of a life book or life poster, for example. Ask the loved ones and/or informal caregivers whether they want to play a role in this and, if so, whether they can and want to fill in the life book or life poster. For this, u can use the DEDICATED-method life book or the DEDICATED-method life poster (go to https://dedicatedwerkwijze.nl/materialen/)
- You can for example use the questions from the model Care living plan (Zorgleefplan) of Actiz to initiate this conversation.
- *What are his or her wishes and preferences for a (possible) move?*
  - As an involved care professional in the home setting talk to the person with dementia, the loved loves and/ or informal caregivers and his/her loved ones about a possible future place to live. Take the following aspects into account before starting the conversation:
  - The cognitive ability of the person with dementia to realize his/her deterioration
    - It is possible that the person with dementia does not want or is unable to realize the deterioration but does not resist a possible move.
      - It is important not to mention the deterioration of the person with dementia in the conversation with the person with dementia, but to discuss it with loved ones and/ or informal caregivers.

    - Thoughts, visions and attitudes of the person with dementia and his/her loved ones and/ or informal caregivers about moving to a nursing home
        - Moving can be seen as a threat by people with dementia on various levels: physical (losing their 'own' house with their own things and known neighborhood and being fully dependent on the care provided by the care professionals), social (losing contacts with family, neighbors, friends and acquaintances), emotional (no longer being able to feel the memories built up in the house with family members) and psychological (the feeling of losing freedom, privacy and autonomy). As a result, people with dementia can resist the move.
    - The proactive ability of the person with dementia, their loved ones and/or informal caregivers to anticipate the deterioration in living at home
        - People with dementia who want to stay at home for as long as possible, but do recognize the deterioration and want to facilitate living at home for the current and future living situation, can take actions such as writing down information if they forget it at a later time, adjusting the house to be able to live at home longer or to already look for existing 24-hour supporting forms of housing.
- Discuss living at home with the person with dementia, loved ones and/ or informal caregivers
    - Ask how they experience living at home (such as performing daily activities), what they appreciate about living at home, what they enjoy and what they experience as pleasant and as less pleasant.
    - Also check how daily life is structured on a social/activity level such as practicing hobbies and getting together with companions, acquaintances, friends or family. Depending on the case, propose to participate in organized day activities and check at which location/environment the person with dementia would like to participate in day activities. Map the wishes and preferences regarding the location of day activities.
    - Provide support for the person with dementia to live at home longer (if this is still possible). For example, consider the question: *How can we help you or what aids do you need to live at home longer?*
    - Also refer them to existing information documents such as the brochure ‘Living at home with dementia’ (Thuiswonen met dementie) or ‘What if living is not possible anymore’ (Wat als thuis wonen niet meer mogelijk is)
    - Talk about the wishes and preferences regarding residence in general ○ Identify the wishes and preferences of the person with

    dementia regarding a place to live. Example questions: *What do you find important in a place of residence?* or *What do you need to feel at home?*

- Identify the care burden of the loved ones and/or informal caregivers
    - For working together with loved ones you can for example use the Toolkit Working together with informal caregivers: this is how it works! (Samenwerken met mantelzorgers: zo werkt het!) or the Toolkit caresupport for homecare workers (mantelzorgondersteuning voor thuiszorgmedewerkers).
    - Have a separate conversation with loved ones (where the person with dementia is not present) and ask how they experience the living at home and the (increased) care burden or informal care provision (and for how long they want to and are able to continue to do so). The overall situation of the loved ones needs to be monitored regularly. For this you can use instruments that visually display the lives of informal caregivers such as the MantelScan.
    - Provide support to loved ones and/or informal caregivers in performing the informal care function in a healthy and balanced manner. Provide them with information about what overburden entails and refer them to information about how caregivers can be supported, such as how to arrange respite care. Refer loved ones to organizations or institutions where information is provided on informal care support is provided (e.g. MEE Plus, 24uursloket, MantelzorgNL, of Omzorg) such as providing respite care in the form of lodging care (click here for more information on lodging care). In particular, check which organizations are active within your own region and/or care organization.
- Find out what loved ones and/ or informal caregivers think about a nursing home and a possible move
    - If loved ones are willing to discuss a move, ask them how their loved one (according to them) can adapt best in the nursing home and what is needed for this. Also refer loved ones to information about the choices that can be made when selecting a nursing home, as explained on dementie.nl
    - If the loved ones themselves also resist a move, it is important to engage other care professionals such as the general practitioner, as a central point of contact, for a personal discussion about the use of respite care (to support loved ones) and the likelihood and consequences of an acute move (to make loved ones aware of the consequences of overburden and acute or sudden moves). Refer them to, for example, the website of Zorg en Beter
    - As a healthcare professional, be aware of the state of mind of the loved ones before and during the move, and the differences in wishes between loved ones. Record this as well and as the central point of contact coordinate with the contact person in the nursing home.

- If the person with dementia resists the conversation about moving, consider the following:
  - Map out the wishes and preferences of the person with dementia in their current place of residence. Example questions are:
    - *'What do you find important in a place of residence?'* or '*What do you need to feel at home?'*
    - *'What are your fears and concerns regarding the nursing home and a possible move?'*
    - *'How do you think about alternative forms of living such as the care farm, care apartments or care homes?'*
  - If living at home is no longer possible due to the increased care needs and there is an overburden in the home care and loved ones, it is important to talk to loved ones about compulsory admissions and their various forms. Provide loved ones with an explanation of Article 21 of the Care and Duress Act (WZD). Explain to loved ones what this law entails and where they can find more information about it. Refer loved ones for example to websites about compulsory admissions such as CIZ, dementie.nl and Care for better (zorg voor beter)
- If the person with dementia and loved ones are open to the discussion about the move, then also consider the following:
  - Offer the possibility to explain what is involved in arranging a relocation to the nursing home if the person with dementia and/or loved ones are open to this. For example, refer them to dementie.nl
  - Discuss the wishes and preferences of the person with dementia, loved ones and/ or informal caregivers regarding a move. Consider the following questions:
    - *'Do you envision a move in the future and where would you like to move to?'*
    - *'What is your preferred location and have you already taken a tour there?'*
- Think of the daycare location or known environment/neighborhood of the person with dementia
    - *'Suppose it is not possible for you to move to the preferred location, what is your second option and have you already had a tour there?'*
    - *'What is the distance between the nursing home (first and second preference) and the home address of loved ones?'*
    - *'Do you have any preferences regarding size, layout and atmosphere of the nursing home?'*
      - Consider the presence of a garden in the nursing home and the organization of (daily) activities within the nursing home
    - *'With whom do you want to maintain social contact (contacts from the home situation) and come in contact with (new contacts in the nursing home)?'*

    - *'How do you want to remain active in everyday life in the nursing home?'*
  - Conduct this conversation on average once a quarter of a year, in line with the willingness of the person with dementia, loved ones and/ or informal caregivers to have this conversation.
- *What are the wishes and preferences for future care and treatments in the end-of-life phase?*
  - As an involved care professional in the home setting, have (recurring) conversations about proactive care planning (also referred to as early care planning or advanced care planning). Important topics of conversation are:
  - Communication and involvement. You can think of the following:
    - Provide information about dementia, palliative care and proactive care planning
    - Giving a voice to the person with dementia, loved ones and/or informal caregivers
    - Need of the person with dementia (depends on the mental competency) and loved ones and/or informal caregivers to participate in joint decision-making
  - Ethical/legal aspects. You can think of the following:
    - Need and mental competency of the person with dementia to think and decide for themselves
    - Appoint a representative, witness or confidant (explain the difference between these legal terms)
    - Mapping ongoing legal matters
  - Psychological/mental needs. You can think of the following:
    - Discussing emotions and support during difficult moments (both for the person with dementia, loved ones and/or informal caregivers)
    - Execution of expectation management (i.e. expressing expectations of the person with dementia, loved ones and/or informal caregivers and involved core care professionals)
  - Spiritual and existential needs. You can discuss the following:
    - Meaning of the person with dementia ○ Support to make the life of the person with dementia meaningful or more meaningful
    - Beliefs about the illness, life and death of the person with dementia
    - Need for conversation about life questions, moments of reflection, guided rituals (whether or not religious in nature)
  - Decisions about (life-extending) treatments. You can discuss the following:
    - Declarations of will/ power of attorney ○ Declarations of treatment (such as resuscitation, admissions, surgeries, administration of food and fluids, administration of antibiotics and artificial respiration)
    - Euthanasia statement
    - Donation statement
  - Wishes and preferences for a warm farewell. You can discuss the following:
    - Desired rituals just before dying
    - Desired attire

        - Need for the presence of specific persons
        - Desired place for saying goodbye
        - Desired procedure and location of the funeral
    - Wishes and preferences for aftercare. You can discuss the following:
        - Questions or comments from loved ones about the period surrounding the death
        - Talking about supporting bereavement
        - Evaluating the care process
- What tools can you use to inform the person with dementia, loved ones and/or informal caregivers regarding proactive care planning?
    - Conversation assistance the later life phase in dementia (Gesprekshulp de latere levensfase bij dementie)
    - Talking in time about you end of life (Praten op tijd over uw levenseinde)
- What tools can you use for having conversations about proactive care planning?
    - DEDICATED manual talking stones and talking cards (handleiding praatstenen en praatkaarten)
    - Toolkit Advance care planning regarding end-of-life
    - Conversation guide for proactive care planning (Gesprekswijzer voor proactieve zorgplanning)
    - Booklet end-of-life conversations
    - Guide Eye in Eye (Oog in Oog)
    - Handle discussion with vulnerable patients (Handvat gespreksvoering met kwetsbare patiënten)
- Use existing proactive care planning formats during the conversation and add this information to the file.
    - Guideline on proactive care planning (Leidraad proactieve zorgplanning)
    - Declarations of will regarding my health care and end-of-life (Wilsverklaringen inzake mijn gezondheidszorg en levenseinde)
- What tool can you use for having the aftercare conversation with loved ones and/or informal caregivers?
    - Guide to aftercare consultation after death (Handreiking nazorggesprek na overlijden)

Consult and coordinate regularly with the care professionals involved to jointly monitor the home situation

- Discuss the current home situation of the person with dementia with the involved care professional. Think about:
    - Neuropsychiatric symptoms and increase in their display *(neuropsychiatric symptoms are symptoms that affect behavior and cognitive functioning and include apathy, anxiety, agitation, depression, uninhibited behavior, hallucinations and appetite changes)*
    - Feedback about the conversations held regarding proactive care planning (daily life, a possible move and the end of life)
    - Use of home automation or other auxiliary means in the house

- Agree mutually with the person with dementia, loved ones and/or informal caregivers which care professional from the home setting will take on which task and record this. Consider the following tasks:
    - Act as a central point of contact during the move for the person with dementia, loved ones and/or informal caregivers and the care providers involved. This means that the central point of contact:
        - Is a confidential advisor and contact person for the person with dementia, loved ones and/or informal caregivers
        - Provides information about the disease process and the current health situation to the person with dementia, loved ones and/or informal caregivers
        - Stays informed about all important communication regarding this process with the person with dementia, loved ones and/or informal caregivers, keeps an overview/status of the move and approaches the client advisor* of the nursing home.
        - Collects information regarding proactive care planning
        - Coordinates with the client advisor[a]
        - Provides emotional support to the person with dementia when leaving his or her home and support for loved ones and/or informal caregivers to deal with feelings of guilt
    - Guiding in familiarizing with living in a nursing home. Consider the following tasks
        - Informing the person with dementia, loved ones and/or informal caregivers about living in a nursing home
        - Arranging administrative matters and coordination such as applying for a CIZ indication, keeping an eye on the waiting list and informing the person with dementia, loved ones and/or informal caregivers when a place becomes available
        - Familiarizing with the procedures on the way to the nursing home, such as explaining what a care office is and what WZD Article 21 entails
- Tools for conducting the multidisciplinary meetings
    - See Appendix 1. Step-by-step plan discussing MDM Zuyderland
    - See Appendix 2. Form interprofessional team meeting MDM Zuyderland
- Tool to communicate with each other
    - Practical guide for communication with people with dementia, their informal caregivers and involved care professionals
- Some good examples of collaboration on palliative care in primary care:
    - PaTz-methodolgy
    - Care path dying phase (Zorgpad stervensfase)

Joint decision-making on relocation

- Important actions performed in this process:
- As the central point of contact, determine together with the involved care professionals in the home setting, the person with dementia (as far as this is possible), loved ones and/or informal caregivers when it is the right time to move.

    - As a central point of contact during the move, take into account the preferences of the person with dementia, loved ones and/or informal caregivers as discussed earlier
    - As a central point of contact, also ask the person with dementia, loved ones and/or informal caregivers whether they or one of them want to participate in multidisciplinary consultations
    - As the central point of contact for the person with dementia, loved ones and/or informal caregivers, timely engage the client advisor[a] (*clear mutual agreements must be made about this*)
    - As the central point of contact for the person with dementia, loved ones and/or informal caregivers, agree with the client advisor[a] to make a home visit together
      (*Optional and depending on the wishes of the future resident and loved ones*)
- Some tools to make decisions together:
    - Toolbox shared decision-making in dementia
    - Steps of joint decision-making

Step 2. Prepare a warm welcome together

Directly involved care professionals in the home setting and nursing home:

Carers/nurses in the home setting and nursing home
Paramedics (Occupational therapist, speech therapist, physiotherapist and/or dietician) from the home setting and nursing home
Case manager dementia from the home setting
Client advisora from the home setting
General practitioner from the home setting
Specialist geriatrics from the nursing home

Preparing a warm welcome is the intermediate phase/ bridging phase in which coordination takes place between the central contact points from the home setting and the nursing home, the person with dementia, loved ones and/or informal care providers are transferred (through conversations and / or nursing home visits and home visits), information about the person with dementia is transferred and discussed, information about how the loved ones and/or informal caregivers want to be involved is transferred and discussed, the moving day (including the way in which the person with dementia would like to be welcomed) is prepared and contact with the involved care professionals from the home setting is gradually being phased out. This phase begins when the person with dementia is on the waiting list and ends one or two weeks after the move (adjustment phase in the nursing home).

<u>Preparing a warm welcome together, how do you do that?</u>

- *Mutually agree which care provider in the nursing home will be the central point of contact (usually the First Responsible Carer (FRC[1]) or care coordinator (CC)) for the person with dementia, loved ones and/or informal caregivers*
    - This central point of contact has the following tasks:
        - Has direct contact with the central point of contact in the home setting
        - Is a confidential counselor and contact person for the person with dementia, loved ones and/or informal caregivers
        - Receives relevant personal information about the person with dementia
        - Makes a home visit to the person with dementia
        - Guides the person with dementia, loved ones and/or informal caregivers during the nursing home visit
        - Receives the person with dementia, loved ones and/or informal caregivers on the moving day
- *Discuss with the person with dementia, loved ones and/or informal caregivers that the central contact person from the home setting will collect, document and pass on the expectations, wishes and preferences regarding proactive care planning to the central contact person in the nursing home.*
- *As an involved caregiver in the home setting, transfer the collected information about proactive care planning (including written statements/documents) to the central point of contact in the nursing home.*
    - As an involved healthcare professional, send the collected personal information to the nursing home workers <u>at least one week before the moving day</u> (if possible, earlier)
        - The dementia case manager, district nurse and client advisor[a] must mutually agree who will pass on the person-oriented information and the admission report to the FRC[b] and geriatrics specialist (GS)
        - The GP sends the medical file (including documents about "Your wishes for the future") to the GS
    - As an involved care professional in the home setting, possibly schedule a call or physical appointment with the FRC[b] to discuss the personal information
- *Keep the involved care professionals in the nursing home informed* ○ As an FRC[b], document the personal information in the file ○ As an FRC[b], ensure that the involved nurses, carers and helpers of the resident have access to the personal information and keep them informed of changes in the file
    - As an FRC[b], request that the involved/assigned nurses, carers and helpers of the resident have read the file before the move day
    - As an FRC[b], also pass on the collected personal information to other disciplines (e.g. doctors and paramedics) that are involved in the care provision of the resident

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[1] EVV’er wordt ook wel Eerst Verantwoordelijke Contactverzorgende (EVC’er) genoemd (afhankelijk van de zorgorganisatie).

- *As an involved care professional, give the person with dementia, loved ones and/or informal caregivers a warm feeling when you talk about the nursing home*
    - Try to give a warm and personal feeling to the person with dementia, loved ones and/or informal caregivers by using simple and recognizable terms. Examples are:
        - 'Move' instead of 'Transition' or 'admission'
        - 'Residents' instead of 'Patients' or 'Clients'
        - 'Your wishes for the future' instead of 'Advance care planning'
- *As a client advisor*[a] *give the person with dementia, loved ones and/or informal caregivers an indication of the waiting time until the moving day*
    - As a client advisor[a] contact *the person with dementia, loved ones and/or informal caregivers)* and clearly indicate where the person with dementia is on the waiting list
- *As a central point of contact in the home setting, support the person with dementia, loved ones and/or informal caregivers with the home and nursing home visits (these preliminary visits are of course not feasible for ad hoc or acute nursing home admissions)*
    - Home visit
        - It is not a requirement to make a home visit, as it depends on the home situation and the wish of the person with dementia and/or informal caregivers.
        - As an FRC[b], visit the person with dementia, loved ones and/or informal caregivers at least two weeks before the moving day, at home to get an idea of how the person with dementia lives at home and to make the move to the nursing home more personal. Examples of topics to discuss during this introductory meeting are:
            - *'What makes you feel at home?'*
            - *'What personal items do you consider important to bring to the nursing home?'*
                - Think of items for daily care such as a toothbrush, comb and creams, other necessities such as clothes, shoes, flip flops and/or slippers, items that give a familiar feeling such as photos, statues, paintings, posters and/or trophies, furniture that is recognizable such as an armchair, cupboard and table and things that provide relaxation such as a TV, CD player, radio and books.
            - *'What do we was care professionals need to know in order to take good care of you?'*

- As an FRC[b], discuss with the loved ones and/or informal caregivers their involvement in the care process. Consider the following:
    - Inform how loved ones and/or informal caregivers can view information about the person with dementia

    - Inform loved ones and/or informal caregivers about who their central point of contact is in the nursing home (ideally it is the FRC[b] who was present during the home visit
    - Ask loved ones and/or informal caregivers how they would like to be informed about changes in the medication or health situation of the person with dementia, how they would like to be involved in decision-making processes and whether they would like to participate in meetings between the involved care providers (such as visits or multidisciplinary meetings (MDM))

- Nursing home visit
  - It is not a requirement to make a nursing home visit, as it depends on the home situation and the wish of the person with dementia and/or informal caregivers.
  - As a central point of contact from the home setting, discuss with the person with dementia, loved ones and/or informal caregivers whether they want to visit the nursing home. Schedule a nursing home visit at least two weeks before the moving day
    - Ask the person with dementia, loved ones and/or informal caregivers whether they want you to be present as a central point of contact during the nursing home visit (*Depending on the wishes of the person with dementia, loved ones and/or informal caregivers and the workload of the central contact point from the home setting)*
  - As a central point of contact in the home setting, contact the FRC[b] prior to the home visit to give a tour of the nursing home

As the central point of contact from the home setting (dementia case manager, general practitioner, GP assistant elderly care or community nurse), transfer the person with dementia, loved ones and/or informal caregivers to the new central point of contact in the nursing home (usually the FRC[b] or care coordinator)

- As a central point of contact from the home setting, have a personal conversation with the person with dementia, loved ones and/or informal caregivers at least one week before the moving day (if possible, sooner) to indicate that your role is gradually ending after the move and that a new central point of contact in the nursing home takes over your role
  - This transfer can take place verbally via a conversation (by telephone or an online appointment) or physically by being present on the moving day or by meeting before the moving day (*Depending on the wishes of the person with dementia, loved ones and/or informal caregivers and the workload of the central contact point from the home setting*).
- As the central point of contact from the home setting, contact the FRC[b] of the person with dementia at least one week before the moving day to transfer the personal information
  - Consult with the FRC[b] when and how you will transfer the personal information
  - Schedule an appointment with the FRC[b] to discuss personal information (by telephone or physically)

As a primary care professional, gradually reduce contact with the person with dementia, loved ones and/or informal caregivers

- As a central point of contact from the home setting, ask the person with dementia, loved ones and/or informal caregivers at least six weeks before the moving day whether they still need a (telephone) conversation and gradually reduce the contact

As an FRC[b], schedule the moving day

- Make the planning for the moving day at least one week in advance, as an FRC[b], and take the following steps:

    - Reception with drinks and snacks/sweets and (if possible and desired) welcome music (by, for example, a music therapist). Discuss this in advance with the person with dementia, loved ones and/or informal caregivers.
    - Try to discuss as few administrative matters as possible on the moving day itself (it is advisable to discuss this as much as possible during the (nursing) home visit).
    - Escort the person with dementia, loved ones and/or informal caregivers to the room and give them space to recover and say goodbye to each other. Discuss this in advance with the person with dementia, loved ones and/or informal caregivers.
- Discuss the planning of the moving day with the person with dementia, loved ones and/or informal caregivers on how they prefer to be welcomed and how they prefer to say goodbye to each other. Support them from within the organization by using, for example:
    - Appendix 3. the procedure of a warm welcome that is used by care organization Vivantes
    - Step 2 Warm welcome from the personal care method at Vivantes (https://www.waardigheidentrots.nl/wp-content/uploads/2020/06/2019-WerkwijzePGZ-bij-Vivantes.pdf)
    - Phase 5. The moving day from the guide worthily moving to the nursing home of Pieter van Foreest (https://www.waardigheidentrots.nl/wpcontent/uploads/2017/02/Handreiking-Waardig-verhuizen-van-thuis-naarverpleeghuis-DEF.pdf)
    - Preparation for the move from the guide from home to the nursing home of the Knowledge Center for Care Innovation of the University of Applied Sciences Rotterdam (http://www.invoorzorg.nl/docs/ivz/informatiecentrum/ketenzorg/21110.pdf)

As an involved care professional in the nursing home, make sure that you are aware of personal information before the resident arrives (before the move)

- As an FRC^b, carer and assistant read through all transferred documents before speaking to the resident
- As a Specialist in Geriatrics (GS), read the admission report and the transferred documents about person-related information before speaking to the resident

As FRC^b and GS, pay attention to the emotional process of the loved ones and/or informal caregivers (before, during and after the move)

- As an FRC^b, discuss with the contact person from the home setting what role he or she played in providing emotional support the loved ones and/or informal caregivers and take over his or her role in this
- As FRC^b and GS, if the loved ones and/or informal caregivers needs this, engage other disciplines (such as a social worker) to provide emotional support

Step 3. Creating a feeling of home together

Directly involved healthcare professionals in the nursing home:

Carers /Nurses
Paramedics (occupational therapist, speech therapist, physiotherapist and/or dietician) Spiritual caregiver
Professional therapists (music therapist, drama therapist, psychomotor therapist and/or visual therapist)

Social worker or other welfare professionals

Specialist Geriatrics

Creating a sense of home is the phase after the move in which healthcare professionals pay attention to the adjustment phase, have regular discussions about early care planning and regularly evaluate the cooperation between and the care provision with all parties involved. This phase overlaps with preparing for a warm welcome because this phase starts with the move day and ends with the death of the resident in the nursing home.

Creating a feeling of home together, how do you do that?

- *Pay attention to the adjustment phase (conduct the conversations 2 weeks after the move)*
    - As an FRC[b], start a conversation with the resident about how he/ she has experienced the move and living in the nursing home
        - Consider the following:
            - Feeling of whether the resident feels at home in the nursing home
            - Experience of the resident about participation in (social) activities in the nursing home
        - As an FRC[b], keep an eye on changes that occur in the resident. Consider, for example, the following:

        - Behavioral changes
        - Changes in daily patterns/activities
        - Changes in eating patterns or eating preferences
  - As an FRC[b], talk to the loved ones and/or informal caregivers about how they have experienced the move and the involvement in the nursing home
    - Make clear that the role(s) that the loved ones and/or informal caregivers had in the home setting don't stop after the move, but that they can still fulfill their roles if they want to and are able to do so.
    - Consider the following the following questions:
      - 'How do you feel after your loved one has moved?'
      - 'How do you experience your involvement in the nursing home?'
    - As FRC[b], keep an eye out for changes occurring in the loved ones and/or informal caregivers
      - Role or involvement in the care process
      - Emotional health
      - Satisfaction with the care process
  - As an FRC[b], talk to the central contact person from the home setting
    - Consider the following question:

      'Have you had contact with the resident and loved ones after the move? If so, how often and have these conversations revealed action points/points for change in healthcare for us?'
    - In case you or your colleagues observe a change in the resident, you could ask the following:
      - <Describe the behavioral change> *'Have you noticed this behavioral change in the resident before?'* and *'How do you think we can best deal with this and what handling advices do you have for us?'*
- *Consider the person with dementia, loved ones and/or informal caregivers ("holistic care")*
    - Regularly (during weekly visits, behavioral visits and MDMs) discuss the various health domains with the relevant care professionals, loved ones and/or informal caregivers and resident (if he or she wants to and is able to do so)
      - Think of the following domains: Housing and living conditions (feeling at home, safety and daily rhythm and moving possibilities), Participation (daytime activities, social life and contact with the community) Mental well-being and autonomy (own identity and meaning of life, mood and respect) and Physical well-being and health (e.g. drinks and nutrition, rest and exercise, health risks, mobility and physical hygiene).
      - Integrate the different perspectives of the involved healthcare professionals

            - Include the directly involved care professionals in the care for the person with dementia
            - As an involved care professional in the nursing home, clearly indicate what you have observed in the resident, which area of life it involves that exactly needs to be improved and how (with medication or via non-pharmacological interventions) it can be improved.
        - As a moderator, aim to integrate the different perspectives during the meetings and to come to a balanced decision
        - As a note-taker (usually FRC[b]), write down the different perspectives during the meetings, document the final decision and note down the (amended/adjusted) action points (and state which care professional will take care of this)
        - Make sure that the resident is feeling at home in the nursing home.
            - Performing meaningful activities can improve the well-being of people with dementia, the sense of connection with themselves, others and the environment for people with dementia, and the sense of preserving the personality of the person with dementia. It is important here that involved healthcare professionals pay attention to and awareness of the subject of meaningful activities, the personalization of meaningful activities and the practical organization of meaningful activities. For example, you can use the inspiration booklet of care centers De Betuwe and the manual of Rotterdam University of Applied Sciences.
            - Consider e.g. the following factors:
                - Psychological factors (sense of recognition, maintaining habits (such as taking into account personal preferences when eating and drinking) and values, maintaining autonomy and control and handling/coping style with/from the move).
                - Socials factors (interaction and relationship with the care professionals, interaction with other residents, interaction with family and friends/acquaintances, interaction with (pets) animals and the performance activities).
                - Environmental factors (availability of a private space, layout of the public space, taking personal belongings with you, use of technological aids (such as an alarm button), thinking about the interior and the possibility to go outside).
    - Involve the loved ones and/or informal caregivers
        - As the FRC[b], take the perspective of the loved ones and/or informal caregivers into account to check whether the loved ones and/or informal caregivers observe the same changes and/or have also identified new changes
        - As an FRC[b], ask for the opinion of the loved ones and/or informal caregivers about the (changed/adjusted) action points and provide the involved the care providers with the feedback

- Make sure that loved ones and/or informal caregivers feel involved and part of the nursing home (if they so wish). Consider, among other things, the following:
  - Pay attention to their coping style for coping with the move and getting a different role in the nursing home (compared to home)
  - Ask loved ones and/or informal caregivers what the resident would like to eat and drink (if the resident can no longer indicate this himself)
  - Include their voice in decorating the room
  - Ask if they want to be involved to participate in activities (indoor or outdoor) together with the resident
  - Ask loved ones and/or informal caregivers if they want to be involved in the care or other matters (such as combing the resident's hair)
  - Ask the loved ones and/or informal caregiver how they experience autonomy and control in the care and life of the resident
- Support the resident, loved ones and/or informal caregivers in making choices and decisions. You can for example use the Toolbox deciding together
- *Have regular discussions about proactive care planning*
  - Take into account the wishes and preferences of the resident and informal caregiver(s) (these are central at all times)
    - As care professionals, discuss who takes the lead in discussions (about proactive care planning) with the resident loved ones and/or informal caregivers.
      - Remember that the FRC[b] can fulfill this role as a discussion partner because he or she has already built up a relationship (of trust) with the resident, loved ones and/or informal caregivers.
      - Remember that the GS, in addition to the FRC[b] conducting the conversations, also conducts conversations with the resident, loved ones and/or informal caregivers regarding proactive care planning. It is important that input collected by the FRC[b], GS and other disciplines who also have discussions with the resident, loved ones and/or informal caregivers about proactive care planning are being fed back.
      - The discussion partner will also provide an update of these conversations to the other involved care professionals
  - Also respect the willingness of the resident, loved ones and/or informal caregivers
    - As a discussion partner, ask the resident, loved ones and/or informal caregivers if they want to talk about the future and respect their opinion if they prefer not to. In the latter case, explain the added value of discussing wishes for the future in a timely manner.
  - Integrate the different perspectives of the involved parties
    - As an involved care provider, discuss the wishes and preferences of the resident, loved ones and/or informal caregivers regarding proactive care planning with the other involved care professionals and jointly consider how the future care can be shaped.

Consider, for example, the following:

        - Medication or non-pharmacological interventions
        - Action points/treatment goals are described in the care-living plan and the involvement of core disciplines
        - Storage and notification of advance directives and treatment decisions
        - Recording and passing on decisions regarding resuscitation, hospitalization, nutrition and fluids, etc.
        - Preparation for the dying process (at the moment the resident enters the terminal/dying phase). For this you can use for example the procedure a warm farewell from the care organization Vivantes (see Appendix 4).
    - ○ Pay attention to the cooperation process. For this, you can use the process description *Using proactive care planning together DEDICATED* (https://dedicatedwerkwijze.nl/materialen/)

- *Schedule regular reflection/evaluation moments with the involved care professionals, the resident, loved ones and/or informal caregivers (conduct the conversations 3-6 weeks after the move)*
    - By regularly we mean once a month during doctor, behavioral/handling visits and family meetings and after every MDM, but is also dependent on the events and personal wishes such as wanting to evaluate sooner or more frequent.
    - As care professionals, evaluate the 'joint decision' process regarding the provision of holistic care and discuss future wishes
        - Discuss e.g. the following questions:
            - *'Is my expertise and advice taken into account when making decisions?'*
            - *'Are we all aligned when we make decisions?'*
            - *'Are the agreements/advices that are made or given also fulfilled? If not, what is the cause of this and how can we improve compliance with the agreements/follow-up of the advice?'*
            - *'As committed care providers, do we treat residents in the same way as they wish? If not, what is the cause of this and how can we ensure that we apply a uniform approach to this?'*
            - *'Do we facilitate meaningful activities for the resident? If not, what is the cause of this and how can we do this from now on?'*
            - *'What could we improve in collaboration with each other and how can we achieve that improvement?'* Document these points for improvement and come back to them during the next reflection moment.
        - For this you can use for example the translated Questionnaire about the functioning of a team of Bronstein, Appendix 5, and Quickscan.
    - As the FRC[b] of the resident, loved ones and informal caregivers, evaluate the collaboration with each other and the care process.
        - Discuss e.g. the following questions:

- *'To what extent do you feel heard?'*
- *'To what extent do you feel that we take your wishes and preferences into account?'*
- *'To what extent do you feel as a part of the resident's life?' Why?*
- *'To what extent do you feel you have a say in making decisions?'*
- *'Do you feel your loved one is in the right place? If so, why? And if not, because of what and what could we do about it?'*
- *'What could we improve in our collaboration with you and how do you envision that?'* Document these points for improvement and come back to them during the next reflection moment.

▪ For this, you can use for example the Checklist of Sting de National professional association, the Teamscan of V&CN and OPTION observation list.

Appendix 1. Step-by-step plan discussing MDM Zuyderland

1	2	3	4
Description situation of the resident	Question	Personal goals and preferences	Formulating concrete (care) agreements
What is the background of the resident? *What is the situation like for the resident (and their loved ones)?*	*What is the reason for this contribution?* *What is the question for this meeting?* *What result do we want to reach?*	*Wat are the goals, wishes and preferences for the resident?* *What is the perspective of the team on the goals of the resident?*	*What can we concretely recommend the resident and their loved ones to do in order to reach the goal? (actions)* *What actions best suit the preference of the resident?* *What concrete (care) agreements are we making?* *Who will take on what?*

Goal	Person-oriented way of working together around residents with complex care needs.
Why?	This way we ensure that the perspective of the resident is central continuously.
Solution	The 4-steps plan. To promote awareness of these steps, we recommend positioning the "placemat" on the table. Both the chairman and contributor are asked to follow these steps actively.
Result	Agreed actions and the care plan do not properly match the resident's personal wishes and interests.

Appendix 2. Form interprofessional team meeting MDM Zuyderland

Discussing residents with complex care needs together is not always easy. In order for the meeting to be as efficient and person-oriented as possible, it is important that every participant in the MDM is well prepared. The “Interprofessional team meeting form” can be used as an aid.

How does it work?

1. The team member who brings in a resident for discussion (the contributor) finds out the residents' goals and wishes and completes the “Interprofessional Team Meeting form”. This may also (preferably) be completed together with the resident / family members.
2. The contributor asks the resident for permission to discuss his personal goals and wishes in an interprofessional team meeting.
3. The contributor sends the completed form to the chairman one week before the interprofessional team meeting takes place.
4. The chairman collects the forms from all residents and then distributes them to the team members in preparation for the discussion. It goes without saying that the other team members treat the information about the resident confidentially.
5. During the team meeting, the form is used as a starting point and concrete (care) agreements are ultimately formulated on page two.

Why the form “Interprofessional Team meeting”?

- During the discussion, the resident's situation only needs to be briefly explained. The other team members can add additional information if necessary. In this way, the situation is clear from the start and can be discussed efficiently. At first glance, filling in this form may seem like a lot of work, but in practice this turns out to be less than expected.
- By completing the form, the purpose of the resident and the question are clear to everyone from the start of the meeting. The team can then jointly try to approach the goal as closely as possible and tailor care accordingly.

Tips:

- Try to describe the resident's goal and the research question derived from it as concretely as possible. For example: the resident's goal is to be able to go to the store independently again. The derived question from this for the team is: "*How can we support this*?"
- Briefly and succinctly describe the situation and background of the resident
- Only include information that is necessary to be able to discuss the purpose and the question

Form Interprofessional Team meeting

Date meeting ...

Name & birth date resident ...

Name contributor ...

Involved disciplines ...

Goal or question of the resident ...

Concrete question or reason of contribution to the team

...

Background information on the situation of the resident

...

Mapping the functioning of the resident

(based on the core values Care Living plan (Zorgleefplan) Zuyderland)

Physical wellbeing and health (PW)

Physical functioning (current complaints, medication, doctor appointments/examinations) Mental functioning (cognition, emotion, behavior)

...

Participation (PT)

Daytime activities, social life, contact with the community, hobbies, grocery shopping, household

...

Housing and living conditions (LC)

Living space (decoration, cleaned up and tidy), feeling at home, safety, daily rhythm, moving possibilities (ease of use of furniture)

...

Mental wellbeing

Support meaning of life/identity (e.g. control + preferences), mood, respect (e.g. form of address), identity

...

Care agreements

(Description of the made (care)agreements)

Agreement	Action holder	Time path

Appendix 3. Warm welcome

Motivation

We want to give new residents and informal caregivers the feeling that they are welcome and ensure that the transition from home to Aelserhof is as pleasant as possible for new residents.

Goals

- New residents and informal caregivers feel welcome and experience a pleasant move to Aelserhof.
- New residents, informal caregivers and care providers get to know each other.
- New residents and informal caregivers experience the space to indicate what is important to them and where their wishes and needs lie.
- New residents and informal caregivers know what to expect from Aelserhof employees and who they can approach with questions.

Actions

1. When a new resident arrives, the customer advisor sends an email with details of the new resident to the location manager, Geriatrics Nurse (GN), Daytime Activities Coach (DAC) and the relevant department.
2. The GN and the day responsible person determine together who the contact person is for the new resident. In determining this, they look at the needs of the new resident. Depending, the contact person can be: FRC, DAC, a nurse or helper.
3. The GN and day responsible person ensure that this person is scheduled (as much as possible) in the first week that the new resident is at Aelserhof.
4. The contact person has the following tasks in the first week:

4.1. Meets the new resident and informal caregivers at the entrance of Aelserhof at the agreed time.

4.2. Introduces the new resident and informal caregivers to the inmates, staff and volunteers, adjusted to the resident's needs and capabilities. Not too many people at once. Getting acquainted can take place throughout the first week.

4.3. Shows the new resident and informal caregivers the way to Aelserhof by giving a small tour. This does not all have to take place on day 1 and can be spread over the first week. It is always adjusted to the needs and possibilities of the resident.

4.4. Accompanies the new resident at all meals, helps introduce the table companions, until the resident feels at home.

4.5. Offers the informal caregivers the opportunity to eat together with the resident on the first day

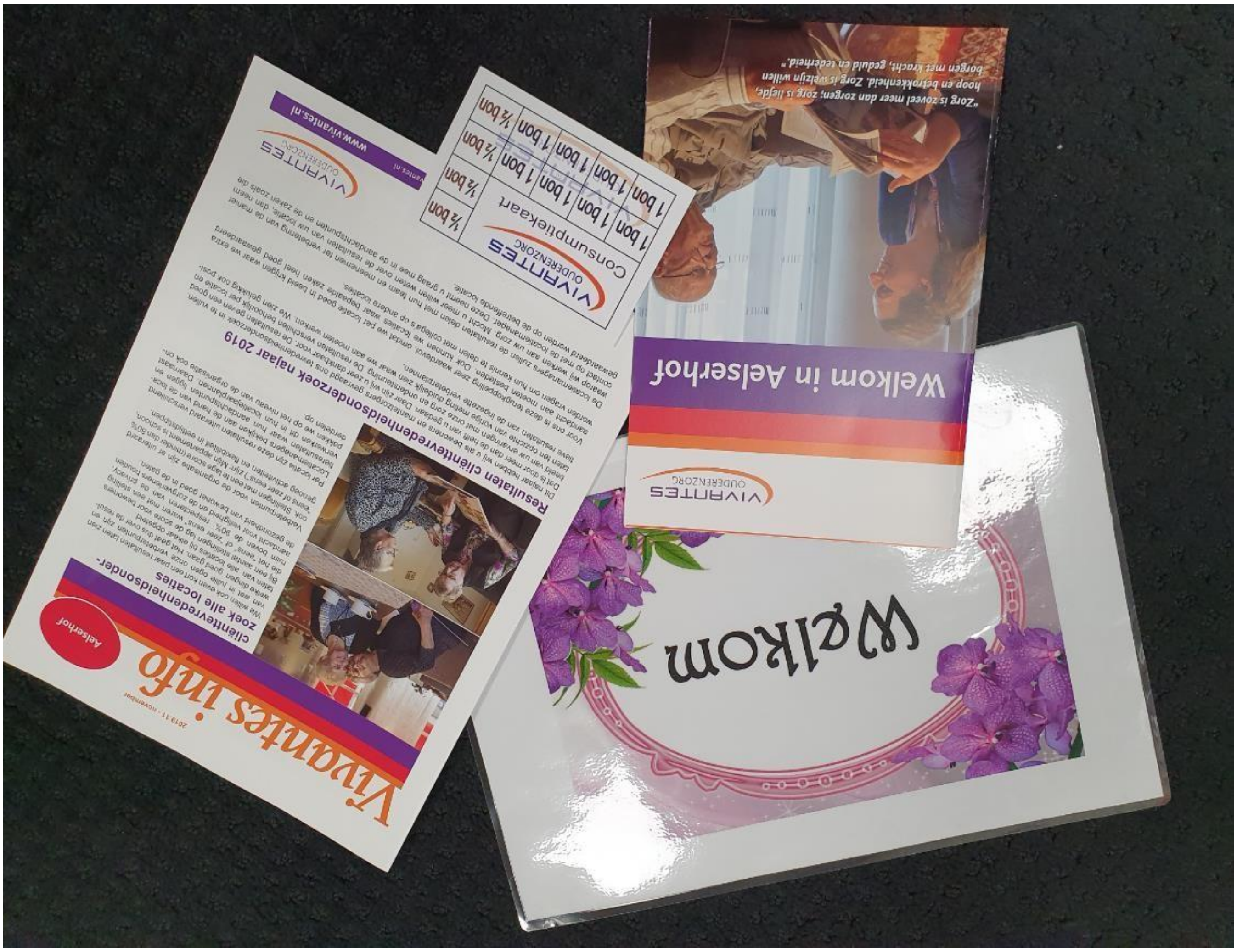
4.6. Involves the informal caregivers in everything that happens to the resident.

4.7. Informs informal caregivers that they can (continue to) participate in the care and support of the resident. Informal caregivers can indicate how they want to do this. The contact person organizes a discussion about this with the resident and the informal caregiver or only the informal caregiver, in the form of a coffee moment.

5. There will be a "welcome card" for the new resident and informal caregivers. This includes: information about Aelserhof, a map of the location, that the resident may bring his own belongings, whether there is a hairdresser/pedicure, whether someone can continue to visit his own hairdresser/pedicure, etc. Information that helps residents and informal caregivers to quickly feel at home at Aelserhof.

Welcome card at the resident’s door

Welcome box for the resident, loved ones and/or informal caregivers



Appendix 4. Procedure warm farewell (Vivantes)

We believe it is important that the final phase of life, regardless of how long it lasts, proceeds according to the wishes of the resident and the caregiver. As with the warm welcome, we also want to actively involve the caregiver, especially if the resident is no longer able to express his or her wishes.

During each MDM, the doctor discusses the resuscitation policy. This is an opportunity for the FRC to briefly discuss the palliative phase and its interpretation. The resident and/or informal caregiver can then think about this and come back to it at a later time. In principle, the FRC will take upon themselves, but of course other colleagues can also have this conversation. During that conversation, the resident and/or informal caregiver will receive extensive information about the possibilities within the Aelserhof. A selection of these: watching family members, the watch box/comfort box, aromatherapy, a chat with a spiritual caregiver, volunteer palliative care, lanterns at the door, realizing last wish, revelation and a final greeting to the departed. Naturally, residents can also express specific wishes themselves.

The details and wishes regarding the final phase are reported in the care plan and the life domains. The wishes may have been made known at an earlier stage, but may change during the final stage. It is important to report again and again in the care plan and the life domains.

When the final phase has arrived, the resident and informal caregiver will be checked to see whether the details of this phase are still in line with the wishes. In this phase it is important to keep informal caregivers and family well informed and to provide support where necessary. This could be offering coffee and tea or a sandwich or discussing the possibility of vigil and the burning candle in the lanterns at the door. Above all, it is important to listen carefully and observe the needs of the resident, informal caregiver and family. In this phase it is also important to inform other colleagues within Aelserhof about the expected death so that care support staff, for example, do not just walk in.

When the resident has died, a rose is hung on the door and lanterns with burning candles are placed at the door. This will continue until the resident leaves Aelserhof. The informal caregiver and family have the opportunity to take care of the resident together with a care worker. A memorial place has been created in the department, where when a resident dies, a candle is burned, a rose is placed and an obituary is placed with the consent of the family. At the request of the resident, informal caregiver and family, the resident in Aelserhof can be laid out in their own room. Family members are allowed to visit the resident as often as they wish. At official moments of farewell, family members are present to accompany this. As we welcome the resident upon entering Aelserhof, when leaving Aelserhof, a hedge of honor can form as a final greeting.

Palliative phase:

1. Ask during theMDM whether the resident and/or family has thought about palliative care, terminal care and aftercare in the event of death. Offering a life phase conversation and recording the wishes that arise from it in the life domains. This can be linked to the physician's request for policy. Guidelines for life phase conversation can be found in the palliative care folder
2. Deployment of a volunteer for palliative care when a resident is deteriorating, not just in the last few days.
3. When the residents are in the terminal phase, the care worker will send an e-mail to all disciplines for information.
4. During the vigil, lanterns are placed at the door so that it is clear to everyone that a resident is terminal and is being watched. Offer the watch box/comfort box and inquire if there is a need to approach the spiritual counselor. All necessities such as lanterns and watch box are on the cupboard at the reception. Warm farewell procedure and points for attention for life phase conversation can be found in the palliative care folder and in the farewell box, which is also on the cupboard at the reception.

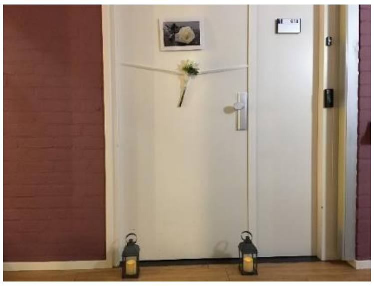
Upon death:

1. When the need arises, family can take care of the deceased together with care workers. Offering a listening ear and aftercare to family.
2. A rose hangs on the door of the deceased resident. When the resident has been laid out in the room, the lanterns remain at the door until the resident is escorted outside. In the ward there is a memorial place where a candle is burning and a condolence is placed upon the death of the resident. The candle will burn until after the funeral or cremation. After the cremation or funeral, the prayer print is placed in a glass case in the hall. On the nursing ward, the prayer print is placed on the appropriate plank in living room B.
3. Family receives a condolence card (standard Vivantes card) with a personal poem. In addition, a written statement of support is put on the map by hand. The care worker provides this card and sends it to the home address of the first contact person.
4. The nurse will hand over the plaid with flowers to the undertaker to put over the bier when leaving the house. If the resident is placed in a room, the plaid with flowers can be placed on the bed.
5. When the resident is picked up by the funeral home, the care worker will inform all colleagues in the house in good time at what time the resident will be leaving the house. Then, down in the hall, a hedge of honor is formed as a final greeting. Resident is escorted outside through the front door.

Aftercare:

1. Inform family about the possibility of a final meeting with a doctor and/or care worker. In the event of a positive conclusion, ask for a review to be placed on the Zorgkaart Netherland, inform about Adieu.
2. When a resident dies, a note is made in the agenda that the family will be called 6 weeks after bereavement. A care worker contacts family to inquire about how things are going and how care is experienced in Aelserhof. A report of this is made in the file of the resident. Attention palliative care officers review the evaluations every 3 months and identify points for attention. These points for attention are discussed in the team meetings. If you notice that there is a need for aftercare, you can inform family about the possibility to contact the center for life questions.

   levensvragen@zuyderland.nl



Appendix 5. Questionnaire interprofessional collaboration (Bronstein)

Questions	Strongly disagree	Disagree	Agree	Strongly disagree
I utilize other (non-social work) professionals for their particular expertise.				
I consistently give feedback to other professionals in my setting.				
Other (non social work) professionals in my setting utilize social workers for a range of tasks.				
Teamwork with professionals from other disciplines is not important in my ability to help clients.				
My colleagues from other professional disciplines and I rarely communicate.				
The colleagues from other disciplines with whom I work have a good understanding of the distinction between my role and their role(s).				
**7. I communicate in writing with my colleagues from other disciplines to verify information shared verbally.*				
My colleagues from other disciplines make inappropriate referrals to me.				
I can define those areas that are distinct in my professional role from that of professionals from other disciplines with whom I work.				
I view part of my professional role as supporting the role of others with whom I work.				
My colleagues from other disciplines refer to me often.				
Cooperative work with colleagues from other disciplines is not a part of my job description.				
I utilize informal methods of communication (i.e. social networks, lunchtime, etc.) to communicate with my colleagues from other disciplines.				
My colleagues from other professional disciplines do not treat me as an equal.				
**15. My colleagues from other disciplines believe that they could not do their jobs as well without the assistance of social workers.*				
Incorporating views of treatment held by my colleagues from other disciplines improves my ability to meet clients' needs.				
Distinct new programs emerge from the collective work of colleagues from different disciplines.				
Organizational protocols reflect the existence of cooperation between professionals from different disciplines.				
Formal procedures/mechanisms exist for facilitating dialogue between professionals from different disciplines (i.e., at staffings, inservice, rounds, etc.).				
I am not aware of situations in my agency in which a coalition, task force or committee has developed out of interdisciplinary efforts.				

**21. Some meetings, committees etc. in my agency/organization are consistently run jointly by social workers and other professionals.*				
22. Working with colleagues from other disciplines leads to outcomes that we could not achieve alone.				
23. Creative outcomes emerge from my work with colleagues from other professions that I could not have predicted.				
24. I am willing to take on tasks outside of my job description when that seems important.				
**25. I am not willing to sacrifice a degree of autonomy to support cooperative problem solving.*				
26. I utilize formal and informal procedures for problem-solving with my colleagues from other disciplines.				
27. The professional colleagues from other disciplines with whom I work stick rigidly to their job descriptions.				
28. My non-social work professional colleagues and I work together in many different ways.				
**29. Relationships with my colleagues sustain themselves despite external changes in the organization or outside environment.*				
**30. Decisions about approaches to treatment are made unilaterally by professionals from other disciplines*				
31. Professionals from other disciplines with whom I work encourage family members' participation in the treatment process.				
32. My colleagues from other disciplines are not committed to working together.				
33. My colleagues from other disciplines work through conflicts with me in efforts to resolve them.				
34. When colleagues from different disciplines make decisions together they go through a process of examining alternatives.				
35. My interactions with colleagues from other disciplines occurs in a climate where there is freedom to be different and to disagree.				
36. Clients/patients/students participate in interdisciplinary planning that concerns them.				
37. Colleagues from all professional disciplines take responsibility for developing treatment plans.				
38. Colleagues from all professional disciplines do not participate in implementing treatment plans.				
39. Professionals from different disciplines are straightforward when sharing information with clients/patients/students.				
40. My colleagues from other disciplines and I often discuss different strategies to improve our working relationships.				
41. My colleagues from other professions and I talk about ways to involve other professionals in our work together.				
**42. I work to create a positive climate in our organization.*				
43. My non-social work colleagues do not attempt to create a positive climate in our organization.				

44. I am optimistic about the ability of my colleagues from other disciplines to work with me to resolve problems.				
45. I help my non-social work colleagues to address conflicts with other professionals directly.				
46. My non-social work colleagues are as likely as I am to address obstacles to our successful collaboration.				
47. My colleagues from other disciplines and I talk together about our professional similarities and differences including role, competencies and stereotypes.				
48. My colleagues from other professions and I do not evaluate our work together.				
49. I discuss with professionals from other disciplines the degree to which each of us should be involved in a particular case.				

Colophon

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Appendix 5: Infographic: Moving together DEDICATED

Moving together DEDICATED

Collaborate with all those involved (the person with dementia, loved and/or informal caregivers and all healthcare professionals involved) before,during and after the move to a nursing home*.

Pay attention to the expectations, wishes and preferences of people with dementia, loved ones and/or informal caregivers.

1. Looking ahead together at home

Agree with everyone involved who will be the central point of contact in the home setting

As an involved healthcare professional, discuss:

- The wishes and preferences regarding advanced care planning (i.e. living at home, daily life, care and the end-of-life)
- The joint decision to move

Regularly discuss and evaluate the cooperation concerning living at home and advanced care planning with all involved

2. Preparing a warm welcome together

As an involved healthcare professional in the nursing home, agree who will be the central point of contact

Transfer the person with dementia and loved ones and/or informal caregivers

- Contact the central contact person of the other setting
- Collect, document, share and discuss wishes and preferences regarding advanced care planning with the central point of contact in the nursing home
- Indicate personally who the central point of contact in the nursing home is

As the central point of contact in the nursing home, perform the following:

- Inform the involved caregivers of the wishes and preferences regarding advanced care planning
- Discuss with all involved whether there is a need for a home visit, a nursing home visit and activities to promote adjustment in the nursing home.
- Give an indication of the waiting time until the moving day
- Plan the moving day with the warm welcome of the person with dementia and loved ones and/or informal caregivers as a point of attention
- Use personal instead of clinical words, such as "move" instead of "admission"
- Pay attention to the processing of relatives and/or informal caregivers

As an involved healthcare professional from the home setting, gradually reduce contact with the person with dementia and loved ones and/or informal caregivers

Discuss and evaluate the cooperation on the warm welcome with all involved

3. Creating a feeling of home together

As an involved healthcare professional perform the following:

- Perform the warm welcome
- Pay attention to familiarizing with the nursing home
- Offer holistic care (four dimensions)
- Have regular conversations about the wishes and preferences regarding advanced care planning (i.e. living at home, daily life, care and the end-of-life)

Regularly discuss and evaluate the cooperation concerning living at home and advanced care planning with all involved

**Our focus in the guidance moving together DEDICATED is the transition from home to nursing home, but these key steps can also be applied in the transitions to other intramural or residential care facilities such as the hospice and the care apartment.*

DEDICATED