The transition from home to a nursing home

Lindsay Groenvynck

THE TRANSITION FROM HOME TO A NURSING HOME:

The perspectives and experiences of older people with dementia, informal caregivers and professional caregivers

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The research presented in this dissertation was conducted at CAPHRI Care and Public Health Research Institute, Department of Health Services Research, Maastricht University. CAPHRI participates in the Netherlands School of Public Health and Care Research CaRe.

This research is part of the TRANS-SENIOR Marie-Curie International Innovative Training network; an EU funded project designed to train healthcare innovators who will shape future care for senior citizens. Funding was provided by the European Union’s Horizon 2020 research, an innovation programme under the Marie Sklodowska-Curie grant agreement No 812656, more information is available at https://www.trans-senior.eu.

This dissertation titled ‘The transition from home to a nursing home: the perspectives of older people with dementia, informal caregivers and professional caregivers’ is part of a double degree with Katholieke Universiteit Leuven (KU Leuven).

Cover Tinne Hoskens en Lindsay Groenvynck
Layout Renate Siebes | Proefschrift.nu
Printed by Proefschriftmaken.nl | www.proefschriftmaken.nl
ISBN 978-94-6469-952-4

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PROEFSCHRIFT

ter verkrijging van de graad van Doctor aan de Universiteit Maastricht,
op gezag van de Rector Magnificus, Prof. Dr. Pamela Habibović,
en de graad van doctor in de biomedische wetenschappen aan de KU Leuven,
op gezag van de Rector, Prof. Dr. Luc Sels,
overeenkomstig met het besluit van het College van Decanen,
in het openbaar te verdedigen op maandag 3 juni 2024, om 16.00 uur

door

Lindsay Groenvynck

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Chapter 1

General introduction

General introduction

The transition from home to a nursing home is an emotionally challenging event for everyone involved (1, 2). Older people prefer to spend their days enjoying the comfort of their homes (3, 4), given that many have been living in the same place for years (3). For them, home represents their past, present, future, and identity (3, 5). Nonetheless, the reality of increasing lifespans introduces a correlation with cognitive and physical decline, potentially compromising individual independence (6, 7). This correlation is particularly pronounced among the older people diagnosed with dementia. Home care, supported by both formal and informal caregivers, is initially established to enable people with dementia to maintain their residence in familiar surroundings despite the impact of their diagnosis. However, as the disease advances, providing care at home can become progressively challenging (8– 12). Informal caregivers may experience a significant care burden (13–15) and this can lead to older people and their families having to make the difficult decision to start a transitional care journey from home to a nursing home (16).

This dissertation aims to examine the needs and experiences of older people with dementia, informal caregivers and professional caregivers during the transition from home to a nursing home. The study aspires to contribute to the theoretical understanding of transitional care processes and give directions for improving transitional care.

Dementia

Dementia is a progressive brain disease that affects more than 14.1 million people in Europe (17). It stands as the leading cause of care dependency and disability in older age (18), significantly impacting the healthcare system in the Netherlands, as it ranks as the most expensive disease (19). Alzheimer’s disease is the most prevalent form of dementia, contributing to approximately 60–70% of dementia cases (20, 21). Other forms of dementia include vascular dementia, Lewy bodies, and frontotemporal dementia. The prevalence of dementia is projected to rise by 80% by 2050, indicating that 25 million people will be diagnosed with dementia (17). Age remains the primary risk factor associated with the disease. Three per cent of people between the ages of 65 and 74 years old have dementia. The prevalence increases to 30% among individuals aged 85 and above (22).

Older people with dementia experience both cognitive and physical decline. Cognitive decline, stemming from changing brain function, manifests as memory loss, challenges in planning and problem-solving, disorientation, and linguistic barriers (20, 23). Physical disabilities and symptoms such as incontinence (24), risk of falling (25), and the inability to perform activities of daily life (e.g. getting dressed) are prevalent (26). These symptoms, resulting from dementia, are the leading cause of care dependency and disability.

Furthermore, older people with dementia also experience personality and behavioural changes collectively known as Behavioural and Psychological Symptoms of Dementia (BPSD) (27). They affect about 90% of people with dementia throughout their illness (28). Examples of BPSD include aggression, apathy, anxiety, sleep disorders, agitation, and delusions (27–29). BPSD significantly contribute to burnout among informal caregivers (30). In particular, instances of aggression directed at caregivers during intimate care tasks like bathing can impact the home situation (29). These signs and symptoms profoundly affect the quality of life of older people and their informal caregivers (31, 32), thereby contributing to a broader societal impact (17, 21).

Informal caregivers play an important role in compensating for these losses in daily life. However, their caregiving role also affects their daily life and functioning (40, 41). The 24–hour job demands constant vigilance, affecting work–life balance, relationships, and everyday life (41–43). Moreover, research shows that informal caregivers can experience feelings of anxiety as they have to take on care responsibilities without formal training (41). This can lead to social isolation and disconnection from the environment (43). When informal caregivers experience a loss of social contact, freedom, and independence, it can negatively affect their quality of life (43–47).

The cognitive and physical decline associated with dementia can necessitate older people with dementia to undergo various transitional care processes across different healthcare settings, including respite care, hospitals, and nursing homes (17, 23, 48, 49).

Transitional care

The research included in this dissertation is part of TRANS-SENIOR, a European Union-funded project. TRANS-SENIOR stands for Transitional Care Innovation in Senior Citizens and focuses on avoiding unnecessary care transitions and improving necessary care transitions. The American Geriatrics Society defines transitional care as '*a set of actions that are designed to ensure the coordination and continuity of care as people transfer between different locations or levels of care within the same location*' (50). Different transitional care directions exist, including the move from hospital to home, from hospital to nursing home, and from nursing home to hospital, among others. Older people often undergo multiple care transitions. However, studies indicate that care transitions are more prevalent among older people living with dementia compared to those without dementia (51).

The need for multiple care transitions can be related to the cognitive and physical decline of older people and the related care burden for informal caregivers (33, 40, 41). This deterioration can result in the care needs of older people surpassing the care provided in the home situation, making a move to a nursing home unavoidable. Therefore, a common transition experienced by older people with dementia is the transition from home to a nursing home, and it is the focus of this PhD dissertation.

The term ‘nursing home’ refers to a long-term care facility that provides 24–hour care, room and board while simultaneously managing chronic medical conditions by providing constant assistance with activities of daily living for people facing cognitive and/or physical challenges (52).

The transition from home to a nursing home within the Dutch healthcare system

The transitional care pathway from home to a nursing home is a common and often unavoidable care process. Approximately 38% of older people with dementia living in the Netherlands ultimately reside in nursing homes (23, 53). It is a long, emotionally challenging (54, 55), and very complex care transition significantly impacting both older people and informal caregivers (56).

The transition process can be divided into three distinct phases (57). The pre-transition phase initiates when a possible move to a nursing home is discussed for the first time. In this phase, older people live at home, receiving care from a general practitioner who provides medical care to the general population. Home care staff, including nurses and care assistants, deliver support when necessary. Once the care at home exceeds the care possibilities, the decision can be made to transition from home to a nursing home. The pre-transition phase concludes upon the decision to transition and the selection of a preferred nursing home (58–61). The mid-transition encompasses the waiting period on the nursing home’s list and the phase ends on the day of the move. During this phase, older people and their informal caregivers prepare for the move (60–62). Finally, the post-transition commences when older people take up residence in the nursing home, with care now provided by nursing home staff (e.g. nurses and physiotherapists). Both older people and informal caregivers focus on adapting and adjusting to their new living situations (58, 60–62).

The home care setting and the nursing home setting are organizationally and financially separate, each operating under distinct care systems. In the Netherlands, the Social Support Act and Regular Health Insurance Act fund the home care setting. Municipalities are responsible for care provision under the Social Support Act, offering non-medical support such as domestic help and home modifications. Health insurers, accountable for home care under the Health Insurance Act, provide medical and nursing care at home (63). In 2021, the Dutch government introduced the ‘Longer at Home’ programme (64, 65), emphasizing the objective of enabling older people to stay at home ‘as long as possible’. The initiative aims to offer support and care at home, assistance for informal caregivers/volunteers, and suitable housing that meets older people’s care needs (64). Older people with dementia and their families receive additional care and support through the appointment of dementia case managers (66). These professional caregivers assist older people and their families in navigating through the rules and possibilities for care at home. Dementia case managers are independent professional caregivers who provide information, support, and advice until the older person either passes away or for up to 6 weeks following their move into a nursing home (66).

When the care needs of community-dwelling older people with dementia surpass the capacities of home care, the Long-term Care Act becomes applicable. This act ensures that the cost of long-term care is covered for frail Dutch residents with standard health insurance. The older people may have to pay a fixed premium that is based on their income. Eligibility for this act and residency in a nursing home require assessment by the Needs Assessment Centre (CIZ), which determines eligibility through an in-person interview and data collection on health and household (67). Three conditions need to be met before older people are permitted to move to a nursing home: 1) the older individuals have a chronic condition or disability; 2) they need 24–hour care or supervision; and, 3) they have high and permanent care needs (68).

This organizational and financial segregation between governing home and nursing home care may result in a fragmented and discontinuous care process (50, 69, 70), potentially impacting the quality of care for the various people within the care triad (50).

The impact of the transition on the care triad

The care triad comprises the older person living with dementia, informal caregivers, and professional caregivers involved in the transition process (71) (see Figure 1). Each participant in the care triad has a distinct role that can impact the care process (72, 73). Transitioning to a nursing home is a difficult and stigmatized care process that is often associated with negative outcomes (74, 75).

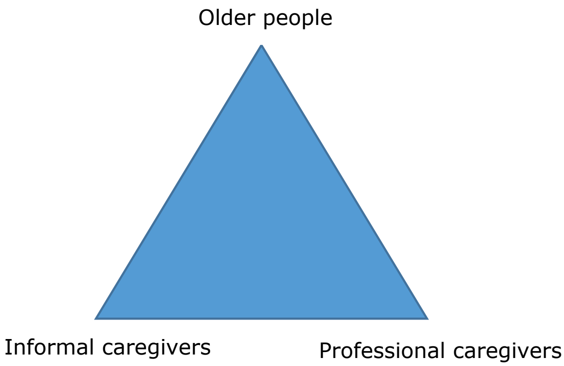

Figure 1: The care triad.

For older people, moving to a nursing home is an emotional and stressful event that can have consequences for their physical and mental health. The transition is associated with increased mortality. A study by Li et al. 2018 found that 16% of older people died within the first 100 days after moving into a nursing home (74). Braggion et al. (2020) corroborated this, reporting increased mortality in the first four months of a resident's life in a nursing home, primarily due to cardio-cerebrovascular diseases, dementia, respiratory diseases, and infections (76). Additionally, the move can confront older people with their physical and/or cognitive decline preceding the transition (77). However, some older people may experience a sense of relief as a nursing home often provides a secure environment (77).

Informal caregivers find the transition very difficult and distressing. Before the move, informal caregivers strive to care for their loved ones until their care abilities no longer meet with the care needs (78–81). Consequently, informal caregivers often bear a significant burden that impacts their own lives and relationships (78). They feel responsible for the decision to move, expressing feelings of guilt, anxiety, and shame (58, 71, 82). Constant worry about the well-being of older people regarding the transitional care decision is common (82). Once the older person resides in the nursing home, informal caregivers often assume many care responsibilities (83, 84). Moreover, as the older person no longer lives at home, informal caregivers may experience loneliness (79).

Professional caregivers perceive care transitions to be complex and stressful (85). Transitional care requires collaboration among different professionals to provide efficient and high-quality care in different settings (86, 87). However, due to gaps in the healthcare system, primary care professionals often feel their efforts are redundant as quality care cannot always be guaranteed in the next care setting (88, 89). As a result, professionals describe transitions as chaotic and unstandardized (88). Poor communication between different professional caregivers from different settings is prevalent, leading to inefficient care (e.g. incomplete discharge forms) (71, 90). These challenges are compounded by professional caregivers already experiencing a high care burden due to time constraints and staff shortages, potentially impeding care for older people (91, 92). This can lead to increased costs for the healthcare setting due to the duplication of services (93–97).

While negative consequences and perceptions associated with the transitional care process are well-documented, the underlying mechanisms contributing to these negative emotions, adverse health outcomes, and quality of life, remain elusive. Current literature lacks comprehensive identification of barriers during the transition process and initiatives to improve this fragmented care pathway. Most research on care transitions focuses on the transition from hospital to home (50, 98). The underlying mechanisms related to the discontinued and fragmented care process from home to a nursing home are still unknown. Understanding these mechanisms is crucial for developing and implementing effective transitional care interventions that could enhance care outcomes (99, 100). Existing studies mostly capture the experiences of older people, informal caregivers, and professional caregivers in the post-transition phase (1, 101, 102), focusing on the adjustment to and acceptance of living in a nursing home. A comprehensive overview of the care triads' experiences throughout the transition from home to a nursing home is missing from the literature.

Research aim

Current research highlights the negative impact and outcomes of the transition process from home to nursing home on the care triad. However, there is a pressing need for more comprehensive research to better understand the experiences and needs of the care triad. This understanding is crucial for enabling the development and implementation of effective transitional care initiatives. Therefore, this dissertation aims to contribute to the understanding of transitional care processes and give directions to improve the transitional care process during the transition from home to a nursing home by capturing the transitional care perspectives, experiences, and needs of older people with dementia, informal caregivers, and professional caregivers throughout the transition. Additionally, the dissertation offers preliminary insights into ways to enhance the transitional care process from home to a nursing home.

The overarching research question guiding this dissertation is: What are the perspectives, experiences, and needs of older people with dementia, informal caregivers, and professional caregivers during the transition from home to a nursing home?

Chapters

To address the research question, this dissertation commences with a literature review **(Chapter 2)**. This review focuses on identifying the care needs of older people and informal caregivers throughout the transition from home to a nursing home, with the overarching goal of avoiding fragmented care and improving transitional care. Based on the results, the comprehensive and theory-based TRANSCIT model is developed. To better understand these needs of older individuals and informal caregivers, two additional studies were conducted aiming to understand their experiences during the transition process. More specifically, the second study adopts a phenomenological approach to explore how older people with dementia perceive a potential future move to a nursing home **(Chapter 3)**. The study delves into the perspective of older people regarding current and future care provision to discern anticipated care wishes if the older people were to reside in a nursing home. Additionally, a third study explores the retrospective experiences of informal caregivers throughout the transition process from home to a nursing home **(Chapter 4)**. The results of these studies reveal negative and paradoxical perspectives regarding transitional care. Therefore, a fourth study aims to offer a comprehensive overview of interventions designed to improve the transition from home to a nursing home **(Chapter 5)**. This scoping review summarizes the existing interventions by identifying their key components and evaluating their effectiveness. Considering the retrospective nature of prior studies and the lack of comprehensive transitional care interventions, the concluding study adopts a prospective, multiple-case study utilizing a patient journey mapping methodology **(Chapter 6)**. The study aims to identify the experiences of the care triad, encompassing older people with dementia, informal caregivers, and professional caregivers, throughout the transition from home to a nursing home. The final chapter synthesizes the main findings **(Chapter 7)**, followed by a discussion on the key methodological and theoretical considerations. Furthermore, the chapter provides implications for practice, policy, and avenues for future research.

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2

Chapter 2

The TRANSCIT model

This chapter was published as:
Groenvynck, L., de Boer, B., Hamers, J. P. H., van Achterberg, T., van Rossum, E., & Verbeek, H. (2021). Toward a Partnership in the Transition from Home to a Nursing Home: The TRANSCIT Model. J Am Med Dir Assoc, 22(2), 351-356. doi:10.1016/j.jamda.2020.09.041

Abstract

The transition from home to a nursing home can be stressful and traumatic for both older people and informal caregivers and is often associated with negative outcomes. Additionally, transitional care interventions often lack a comprehensive approach, possibly leading to fragmented care. To avoid this fragmentation and to optimize transitional care, a comprehensive and theory-based model is fundamental. It should include the needs of both older people and informal caregivers. Therefore, this study, conducted within the European TRANS-SENIOR research consortium, proposes a model to optimize the transition from home to a nursing home, based on the experiences of older people and informal caregivers. These experiences were captured by conducting a literature review with relevant literature retrieved from the databases CINAHL and PubMed. Studies were included if older people and/or informal caregivers identified the experiences, needs, barriers, or facilitators during the transition from home to a nursing home. Subsequently, the data extracted from the included studies were mapped to the different stages of transition (pre-transition, mid-transition, and post-transition), creating the TRANSCIT model. Finally, results were discussed with an expert panel, leading to a final proposed TRANSCIT model. The TRANSCIT model identified that older people and informal caregivers expressed an overall need for partnership during the transition from home to a nursing home. Moreover, it identified 4 key components throughout the transition trajectory (i.e., pre-, mid-, and post-transition): 1) support; 2) communication; 3) information; and, 4) time. The TRANSCIT model could advise policymakers, practitioners, and researchers on the development and evaluation of (future) transitional care interventions. It can be a guideline reckoning the needs of older people and their informal caregivers, emphasizing the need for a partnership, consequently reducing fragmentation in transitional care and optimizing the transition from home to a nursing home.

Introduction

Transitional care is defined as the integration of a set of actions designed to ensure the coordination and continuity of care as a patient makes a transition within or between healthcare setting(s) or healthcare providers (1–2). A common care transition experienced by older people and informal caregivers is the relocation from home to a nursing home. This transition can be divided into 3 phases (3). The first phase is the pre-transition phase in which a possible move to a nursing home is discussed, a transition decision is made, and a nursing home is chosen (4–7). The mid-transition is the time on the waiting list of the chosen nursing home, which ends on the day the older person relocates (6–8). The third phase is the post-transition phase, which focuses on the adjustment and acceptance of the new living situation (4, 6–8).

Despite this being a complex and precarious transitional pathway, interventions aiming at improving the transition from home to a nursing home often solely focus on one phase of the transition process (9). Furthermore, recent evidence suggests that transitional care interventions and theories primarily concentrate on the transition from and to the hospital (10, 11).

A comprehensive and theory-based framework of the transition process from home to a nursing home is lacking, possibly leading to fragmented care. This has a significant impact on older people and informal caregivers, who are at the center of this transition (12). For older people, it can lead to complications such as deterioration of pre-existing conditions and falls (10, 13, 14). Informal caregivers, conversely, are confronted with feelings of guilt, sadness, and failure (15–17). Therefore, developing a comprehensive model is crucial. The model should identify key components to avoid fragmentation and optimize care. Additionally, it should include the care needs of older people and informal caregivers as these are associated with better quality and active participation in transitional care (18–20). Therefore, this article proposes a model to optimize transitional care from home to a nursing home.

Methods

Three steps were taken to construct the model: 1) a review of the literature; 2) mapping of identified needs; and, 3) preliminarily validation of the model.

1. A literature review was performed based on two assumptions. First, studies were included that explored the experiences of older people and/or informal caregivers, (in)advertently identifying their needs throughout the transition process. Second,

these needs were formulated as barriers/facilitators or problems (4). The assumptions guided the search string, which used the key terms ‘*experiences*’, ‘*needs*’, ‘*barriers/problems*’, ‘*older person/dementia*’, ‘*transition*’, ‘*(nursing) home*’, and synonyms hereof. The CINAHL and PubMed databases were used, and the bibliographies of the included articles were searched for additional references. Publications were included when published in 2000 or later and when they identified the needs of older people and/or informal caregivers during the transition from home to a nursing home.

2. Articles matching the inclusion and exclusion criteria were thoroughly read and analyzed by the lead author and discussed within the research team. Each need cited in the included articles was extracted to a separate file, leading to a list of identified needs. The articles were read until no new needs were identified. Next, the list of needs was mapped onto the pre-, mid-, or post- transition phases. Next, per phase, the needs were categorized thematically focusing on commonalities between these needs. Based on these commonalities, the key components were identified. The whole process was conducted by the first author and verified by the second author. Finally, they looked at all the needs together to see if overall themes could be identified throughout the transition from home to a nursing home. As a result, the TRANSCIT model was developed. This whole process was regularly discussed and verified by the research team.

3. Experts in research and practice preliminarily validated the TRANSCIT model at three separate meetings. First, the model was presented to the research team encompassing a professor in care of older people, a professor in long-term care environments, a professor in quality of care, a postdoctoral researcher in long-term care innovation, and an associate professor in healthcare and well-being. Moreover, approximately fifteen researchers and (associate) professors in aging and long-term care, as well as around 20 PhD students and professors from an international transitional care network, preliminarily validated the model at a colloquium meeting. Finally, sixteen experts in practice were found through the network of the research team. They were different professionals from care organizations, a coordinator of palliative care, a representative of the Dutch Alzheimer’s Society, a patient representative, a lecturer and a physician in geriatrics. Fidelity and recognizability were verified by probing questions of the first author (L.G.). For instance, ‘Do you recognize the key components and their persistence throughout each transition phase?’ and ‘Are there components missing?’ This led to a constructive discussion and the proposed TRANSCIT model.

Results

The proposed TRANSCIT model was developed to optimize the transition (Figure 1). TRANSCIT is the abbreviation for TRANsition Support, Communication, Information, and Time. The model, identifying the four key components and an overall need for a partnership throughout the transition process, is based on the thematic analysis of 20 articles (Appendix 2A). The final model was preliminarily validated and approved by the experts in research and practice, who agreed with the key components and the overall need identified.

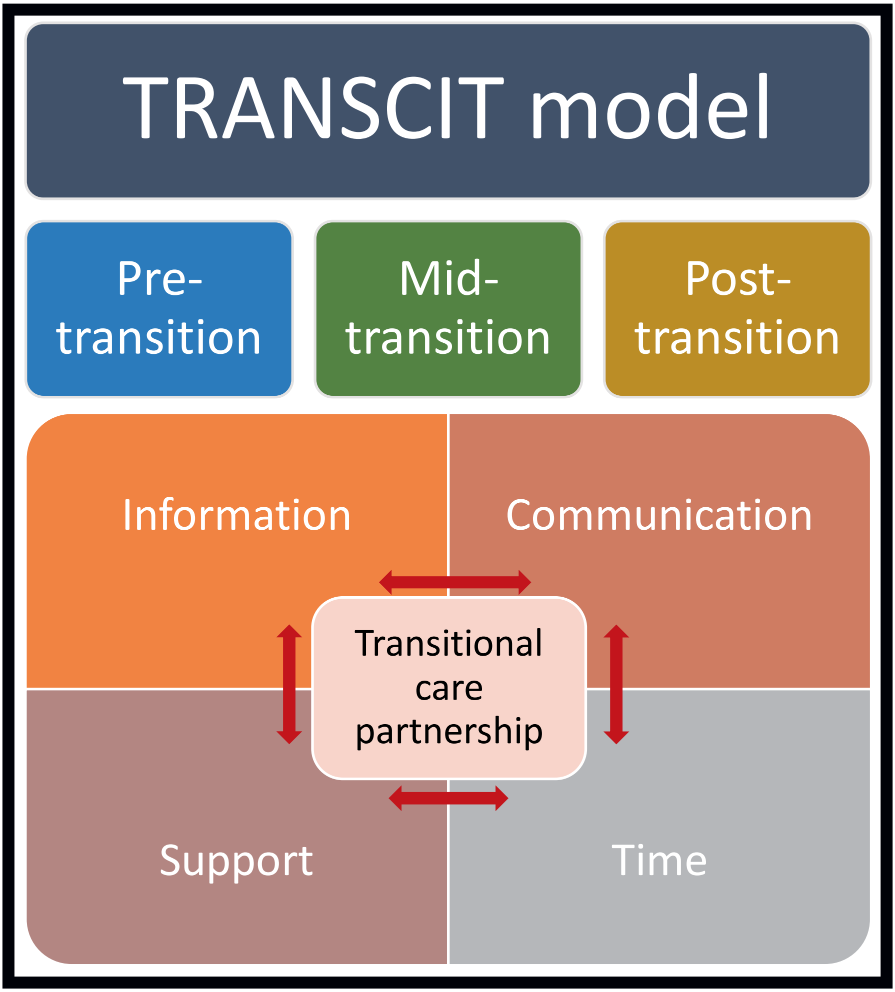

Figure 1: TRANSCIT model. The model presents the three phases in transitional care (the pre-transition, mid- transition, and post-transition phase). Additionally, it identifies the interrelated and interdependent key components of information, communication, support, and time. Finally, the authors identified an overall need for a partnership throughout the transition from home to a nursing home.

The TRANSCIT model

The TRANSCIT model was structured according to the three transition phases (pre-, mid-, and post- transition) (6–8). The model identified the overall need for a partnership throughout the transition process, which is reflected in all four key components identified: support, communication, information, and time. A detailed description of the TRANSCIT model is provided in Table 1.

Key components

The four key components identified are interrelated and interdependent. For instance: effective communication is necessary to provide good information and offer support. However, effective communication and good information require an adequate amount of time (4, 21).

Support

(In)formal support was crucial in the transition process (4, 22). Older people and informal caregivers defined support as continuous and easily accessible. It could range from emotional to practical support (4, 5, 8). Some studies emphasized the desire for a supportive network (family, professional caregivers, and peers) (4, 16, 18, 23). Additionally, specific support should have been offered to informal caregivers taking on miscellaneous care roles (e.g., advocating, expert, or a visitor role) (4, 8, 16, 24).

In the pre-transition phase, older people and informal caregivers preferred support from family and professional caregivers to make a shared decision rather than them making that decision (4, 5, 8, 14, 16, 21, 25). Studies, moreover, recommended the professional caregiver to confirm the necessity of this transition while also offering practical support (4–6).

The mid-transition phase focused on the preparations and the actual move (23). Here, older people and informal caregivers communicated the importance of supportive peers who had already experienced the transition process (7, 23). They also expressed their need for support from professional caregivers in packing belongings and saying farewell to their house (7, 23, 26).

The literature showed that feeling at home is central in the post-transition phase (25). The evidence indicated the need to feel supported and to receive compassion from professional caregivers and peers (6, 8, 21). More specifically, older people needed support to adjust to the daily routine and to meet other residents (7, 25). Informal caregivers seek support to stay connected with the older person. They, therefore, should have been offered a place in the care team (6, 14, 16, 21, 23).

Table 1: The needs of older people and informal caregivers throughout the transition from home to a nursing home

Pre-transition	Key factors → There is an expressed need for …
Information	(In)formal and personalized information on the transition (decision) process.
	Information about the healthcare system and financing.
	Information on the dementia process and health declines of older people.
	Information on the perspectives of family members and professional caregivers to make a shared decision.
	Information on care alternatives/different nursing homes and how to access them.
	Recommendations and information on the future nursing home (e.g., visiting a nursing home).
	Information on the registration process of the nursing home.
Communication	Older people, family, informal caregivers, and professional caregivers to be included and involved in a shared decision process.
	A shared and constructive decision regarding the move.
	Older people to feel in control and be involved in the transitional care plan. The older person needs autonomy.
	A professional caregiver to initiate and guide the transition process.
	Communication on expectations and perceptions of the transition.
	Communicating on the conflicting emotions and stigma surrounding an admission.
	Expressing insecurities and anxieties regarding the transition.
	Acknowledging/understanding the sense of loss and grief some older people experience with leaving their home.
	Older people and informal caregivers to acquire communicative skills (e.g. on assertive communication).
Support	Emotional support during the transition process.
	Older people and informal caregivers to be supported by, ideally, a network (family and professional caregivers).
	Older people to be supported in the decision rather than making the decision.
	Support from family and professional caregivers to make a shared decision to transition.
	Informal caregivers to receive confirmation that a transition is necessary.
	Practical support with decision-making.
	Informal caregivers to receive support taking on new roles: info seeking, advocating, navigating.
	Support to process insecurities.
Time	***Timeliness*** • A professional caregiver to coordinate care. • To feel prepared and in control during the transition process. ***A care plan*** • A timely transitional care plan. • A crisis plan to be in place. • To know the right time for placement.

Table 1 continues on next page.

Table 1: *Continued*

Mid-transition	Key factors → There is an expressed need for …
Information	***Older person/informal caregivers → Professional caregiver at a nursing home*** • Information on the habits and course of life of the older person. • Information on the needs of both the older people and informal caregivers. • Information on the family situation of the older person. • Information on the process of admission and the items required for the move. • Detailed information on the habits and regulations of the nursing home. ***Nursing home → home care*** • Information on the situation at home and medical information. • Information on the profile of the older person, how he/she fits in the nursing home. ***Day of the move*** • Information on what is needed to be prepared for the admission process. • Information on what happens on the day of the move.
Communication	Communication between the different professional caregivers involved to efficiently prepare for the move (a partnership between home care and nursing home care). To communicate and share experiences with peers. Communication on the negative feelings regarding the healthcare system. Older people and informal caregivers to be included in the admission process. ***Day of the move*** • Communication on the experience of the older person's first day in the nursing home. • A formal introduction between the older people/informal caregivers and professional caregivers/other residents.
Support	Informal caregivers to receive support in the adaptation to their new roles as advocates for the older person. Support during the grieving process. Support from friends or peers and family members who have had a similar experience. Support for informal caregivers when informing the older person on the planned move. ***Day of the move*** • Support or help from family and friends on the day of the move. • A warm welcome. • The establishment of a sense of home for the older person. • Immediate support on arrival at the nursing home.
Time	***A transition plan*** • A checklist to plan the actual transition. ***Timeliness*** • Time to pack belongings. • Updates regarding the place on the waiting list. The waiting time needs to be acceptable. • Time to anticipate the move and accept the proposed place in the nursing home. • To prepare and plan the admission procedure. Administrative work or other preparations should be done beforehand.

Table 1 continues on next page.

Table 1: *Continued*

Mid-transition	**Key factors → There is an expressed need for …**
	Day of the move • Time to unpack. • Professional caregivers to make time to offer support and information.
POST-TRANSITION	**Key factors → There is an expressed need for …**
Information	***Older people/ informal caregivers to professional caregivers*** • Information on the role of the informal caregiver and the professional caregiver in the nursing home. • Information on how to be active in the life and care of the older person. • Information on the daily routine of the nursing home. • Information on the routine, expectations, and preferences of the older people and informal caregivers. • Informal caregivers to receive information on the daily life, routines, care, and health of the older person. ***Professional caregivers to older people/informal caregivers*** • Information on the habits and regulations of the nursing home. ***Nursing home to home care*** • Information on the transition pathway and critical points of the care transition. ***General*** • Navigation and self-care skills. • Training to build a relationship with professional caregivers.
Communication	Communication with the informal caregiver and staff about the experience of the older person living in the nursing home. Informal caregivers to be recognized as a care partner where each other's roles are clear and where they are encouraged to be involved in care. To be heard by professional caregivers (questions, opinions, and expectations are taken seriously). Older people to feel in control. Positive interaction and relationship with professional caregivers. A regular contact person at the nursing home. Communication with the informal caregiver and professional caregivers on the experience of transitional care. Communication of negative feelings regarding the nursing home and feelings of losing control. Communication skills to efficiently communicate with professional caregivers.
Support	Support from a social environment. Informal caregivers to be supported when taking on different roles: quality monitor, lawyer, visitor, and link to the outside world. Informal caregivers to be supported by a professional caregiver to terminate home care but also to discuss insecurities or uncertainties. Older people to receive support in creating their own space in the nursing home. Support to stay connected to the older person. Support from family, friends, and other residents residing in the nursing home.
Time	Contact with the outside via family/friends to create continuity of care. The creation of time by professional caregivers to listen. To create continuity and to remain connected (e.g., by regular visits, business as usual, and meaningful activities of the past).

Communication

Studies outlined the importance of an open, complete, and timely dialogue. This dialogue ideally, according to older people and informal caregivers, should have been initiated by a professional caregiver (6, 22, 24). These constructive discussions aimed to exchange knowledge, feelings, and expectations from all involved and they could be facilitated by acquiring the necessary communication skills (3–7, 14, 16, 18, 22, 24, 27–29). Moreover, a professional caregiver should have coordinated the transition process and defined the responsibilities of those involved (7, 16, 22, 27, 30).

There was an identified need for a shared transition decision in the pre-transition phase (4, 16, 22, 23). It was pivotal during these conversations that the older person felt in control and for his/her autonomy to be respected (5, 7, 24–26). This need to feel in control entailed acknowledging conflicting emotions and feelings of bereavement associated with the move (6, 23, 26–28).

In the mid-transition phase, communication between older people, informal caregivers, and professional caregivers was paramount (7, 22). This started with a formal introduction of the older person and informal caregivers to professional caregivers and peers, and vice versa (6, 18). These interactions should be respectful, positive, and create mutual understanding (4, 6, 7, 23). Furthermore, research expressed the need to familiarize oneself with the future home by exchanging experiences with other residents and by exchanging knowledge and demands with professional caregivers (4, 21, 22).

In the post-transition phase, older people and informal caregivers asked for contact moments with the assigned professional caregiver (5, 14, 29). In these moments, opinions, expectations, and questions should have been heard (4, 7, 16, 18, 27). It allowed informal caregivers to start a partnership with the professional caregiver and for both to elaborate on their transition experience (4, 6, 16, 21, 23, 24, 27).

Information

The studies analysed highlighted the need for person-centred information in educating older individuals and informal caregivers on the transition process (8, 22–24). Here, information is defined as more than classic knowledge provision. It also includes education and skills training.

In the pre-transition phase, information was gathered to make an informed and shared transition decision (5, 6, 8, 14). Several studies described the information requested by older people and informal caregivers. First, there was a need for information on the dementia process or general health decline in frail people (4, 8, 23). Second, information on care alternatives and the legislation and finances of nursing home admission should have been made available to make an informed decision (4, 8, 22, 24). The latter decision then announced the need for information and recommendations concerning different nursing homes (e.g. the need to visit a nursing home) (6–8, 14, 18).

In the mid-transition phase, the evidence addressed the importance of transferring the information on the older person's needs, life story, and family situation to the nursing home (14, 21, 23, 27). At the same time, studies indicated the need for detailed information on first the admission process and second the future nursing home. The latter should have been provided by professional caregivers and peers at the nursing home (7, 18, 26).

The evidence regarding the post-transition phase suggested that information should be individualized. Informal caregivers wanted to stay involved and, therefore, their knowledge should have been acknowledged and information on the care plan and the older person's health provided (21, 22, 27). The older person, conversely, requested information on the routine, habits, and rules of the nursing home and vice versa (4, 6, 14, 23, 26, 27).

Time

Overall, the studies highlighted the need for continuity of care and sufficient time to prepare for the transition. This allowed the professional caregiver to organize the transition and plan regular contacts. It could improve the feeling of preparedness necessary during this process (3, 4, 6, 7, 14, 22).

In the pre-transition phase, the need for a multidisciplinary team to set up a timely transitional care plan was expressed (7, 27). Older people and informal caregivers wanted a plan that aims to continue and efficiently coordinate care (8). Furthermore, they needed a care plan that anticipated a crisis moment and defined the right placement time (5).

During the mid-transition phase, studies indicated that an acceptable waiting time, with the provision of regular updates, allowed older people and informal caregivers to anticipate the move (4, 7, 8). This anticipation was needed to sort through belongings and plan a timely meeting with the professional caregivers of the nursing home (6, 7, 18, 26). Finally, older people and informal caregivers requested a flexible and simple admission procedure where administrative work was filled out beforehand (6, 7).

In the post-transition phase, time was related to persistence and flexibility (6–8, 14, 18). This flexibility, according to multiple studies, should have been created by allowing older individuals to establish previous routines, habits, and the creation of valuable activities (7, 23, 27). The persistence could have been created by allowing older people to stay connected to their communities and former homes (6, 14, 18, 26). For informal caregivers, the latter meant continuing their lives while remaining close to the older person (14, 21).

A transitional care partnership

Together, the included studies provided important insights into the overall need of older people and informal caregivers to form a partnership with professional caregivers throughout the transition process (4, 6, 16, 21–23, 27). Within this partnership, they expressed the importance of being an autonomous person who feels in control throughout the transition process. Moreover, they wanted to add knowledge, experiences, and opinions to facilitate the transition (5, 7, 21, 26). Inadvertently, the four key components promoted the need for involvement and a partnership. In other words, clear communication, accurate information, ongoing support, and sufficient time are crucial ingredients to a successful partnership.

Discussion

The TRANSCIT model identified four key components support, communication, information, and time, and one overall need for a partnership to optimize the transition from home to a nursing home. The TRANSCIT model is, to our knowledge, the first model based on the needs of older people and informal caregivers making the transition from home to a nursing home. This perspective is important as the WHO encourages practices to include their needs into care (20). Furthermore, the TRANSCIT model and consistency of the key components throughout the transition verifies the need for consistency throughout the transition process. In other words, the TRANSCIT model validates the necessity to see the transition from home to a nursing home as an entity. This is an important implication for intervention development and evaluation as current transitional care interventions mostly focus on only one phase or one key component of the transition process (31). Finally, the TRANSCIT model provides important information on the resources necessary to improve care. More specifically, the four key components, although initially recognized as important needs, can be interpreted as resources necessary to meet other needs identified (e.g., the need for control and autonomy), ultimately leading toward the optimization of transitional care (32, 33).

Implications for practice and policy

First, the TRANSCIT model aims to defragmentize the transition from home to a nursing home. The defragmentation and therefore optimization of care is associated with reduced healthcare costs. More specifically, defragmentation of care is associated with a higher quality of care, which inadvertently means the reduction of transition-related negative outcomes such as preventable hospital admissions (34). This cost reduction can be used to reimburse professional caregivers guarding the continuity of transitional care from living at home to moving into a nursing home. This is important considering the current lack of reimbursement systems for professional caregivers in transitional care (35).

A second implication for policymaking is that the TRANSCIT model can promote the continuity of transitional care, which can decrease the workload of professional caregivers. This promotion of care continuity avoids duplication of services and therefore reduces additional work, which remains a reoccurring problem within the long-term care continuum (36, 37).

Third, a standardized quality-monitoring system for transitional care is missing in the transition from home to a nursing home. This makes efforts to improve or validate the transitional care pathway difficult, as there is no standard of care (35). The TRANSCIT model could be the first step toward such a monitoring system. The model provides a comprehensive overview of the transition process as well as the most prominent components that should be present during transitional care according to both the older person and the informal caregiver. Healthcare organizations could use this model to compare the provided care with the TRANSCIT model and optimize where necessary. The proposed TRANSCIT model can thus be used as a guideline to provide optimal transitional care reckoning the care needs of older people and informal caregivers. Future research should present the TRANSCIT model to both older people and informal caregivers as a means to further validate the model. Once validated, the focus should shift to the applicability of the model as a tool to develop and evaluate transitional care interventions.

Finally, the TRANSCIT model not only presents overarching components of transitional care, it also specifies the care needs of older people and informal caregivers per transition phase and key component. These specifications could help the alignment of care to the needs identified by the key stakeholders. Moreover, the specification of those needs can help professional caregivers to improve care in daily practice (20). Specifically, it can facilitate communication with the older person and informal caregivers regarding their care needs, subsequently identifying the best transitional care plan.

Limitations

Despite the comprehensiveness of this article, a few limitations need to be addressed. First, the literature review was conducted by the lead author only. However, potential confirmation bias was reduced by validating the results with both the research team and geriatric and palliative care experts in research and practice. Second, the authors only searched in the databases PubMed and CINAHL. However, the researchers felt that the most valuable search engines were covered and all relevant articles, necessary to build the model, were identified. Finally, despite it being a conceptual model, aiming at the defragmentation of the transitional care process, empirical data verifying its value are missing. Therefore, future research is necessary to assess the model's ability to defragmentize and optimize transitional care from home to a nursing home.

Conclusions and implications

The TRANSCIT model is a proposed model with the goal of defragmentizing and optimizing the transition from home to a nursing home. Future studies should assess the TRANSCIT model as a tool to develop and evaluate transitional care interventions. Finally, with the TRANSCIT model, the first step is taken toward optimizing care for older people and informal caregivers throughout the transition from home to a nursing home.

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Appendices

Appendix 2A. The reference list upon which the TRANSCIT model was built

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3

Chapter 3

The perspectives of older people with dementia regarding future care

This chapter was published as:
Groenvynck, L., Khemai C, de Boer B, Beaulen A, Hamers JPH, van Achterberg T, van Rossum E, Meijers JMM, Verbeek H. The perspectives of older people living with dementia regarding a possible move to a nursing home. Aging Ment Health. 2023 Nov-Dec;27(12):2377-2385. doi: 10.1080/13607863.2023.2203693. Epub 2023 Apr 26. PMID: 37099667.

Abstract

Background/Objectives: Moving into a nursing home is often an unavoidable life event for older people living with dementia. It is associated with negative emotions and outcomes. Research capturing their perspectives is scarce. This study aims to identify how older people living with dementia perceive a potential life in a nursing home and to understand their (future) care wishes.

Materials and methods: This study is part of the European TRANS-SENIOR research network. The study followed a qualitative phenomenological methodology. Semi-structured interviews with eighteen community-dwelling older people living with dementia were conducted between August 2018 and October 2019 (METCZ20180085). A stepwise interpretive phenomenological analysis was performed.

Results: The majority of community-dwelling older people feared the idea of potentially moving to a nursing home. The participants associated a possible move with negative perceptions and emotions. Additionally, this study emphasized the importance of knowledge of current and past experiences with care when identifying the participant's wishes. They wanted to remain (a) individuals, who are (b) autonomous, and have (c) social contacts if they would move to a nursing home.

Discussion/Implications: This study showed how past and current care experiences can educate/ inform professional caregivers on the future care wishes of older people living with dementia. The results indicated that listening to the wishes, and life stories of people living with dementia could be a way of identifying 'a suitable time' to suggest a move to a nursing home. This could improve the transitional care process and adjustment to living in a nursing home.

Background

The transition from home to a nursing home is a common care transition that significantly impacts the lives of older people living with dementia. Although, hospital admission often precedes the move to a nursing home (1). A substantial group of older people move directly from home to a nursing home. Here, a nursing home is defined as a long-term care facility (LTC) providing room and board, as well as management of chronic medical conditions and 24–h assistance with Activities of Daily Living (ADL) in residents who are physically and/or cognitively impaired (2).

Moving to a nursing home is often viewed as a last resort and is associated with negative feelings and emotions for both older people and their family caregivers (3, 4). Statements such as ‘locking people up’ and ‘the place where you die’ are often related to nursing homes (3). The study by Oosterveld-Vlug et al. (2013) found that nurses and physicians employed at a nursing home hoped they would never have to move to a nursing home themselves (5). They associated moving to a nursing home with the loss of dignity and independence.

To counter the prejudices and avoid negative outcomes recent studies aimed to understand how older people can feel more ‘at home’ in a nursing home (6, 7). According to the WHO, nursing homes need to create a home-like environment for older people (8). Feeling ‘at home’ in a nursing home is important as it can create independence and personhood. It is also associated with quality of life, being acknowledged, having autonomy, having a relationship with other residents and staff and, having an environment that allows for privacy and personal belongings (9–11). Feeling ‘at home’ is crucial, especially for older people, as it supports activities of daily living and social contact (e.g. by participating in leisure activities with other residents) (10, 12, 13).

Understanding older people’s wishes for future nursing home care is crucial as a recent study by Cater et al. (2022) found that only 31% of nursing home residents felt at home in their nursing homes. A possible explanation for this is that nursing homes may not sufficiently prioritize the needs and wishes of their residents (7, 14). More specifically, a recent study by Groenvynck et al. (2021) found that older people and family caregivers need information, communication, support, time and a partnership with professional caregivers involved throughout the transition process from home to a nursing home (15). However, when comparing those needs to existing transition interventions, services addressing these needs are not well represented (16). Considering these needs throughout the transition process can positively influence the ‘feeling at home’ once the older person resides in a nursing home (12, 17–19). Additionally, the needs, wishes, and expectations concerning a move to a nursing home are very personal. This implies that older people’s expectations can influence their initial adaption and long-term experiences with those nursing homes (14, 20, 21). Despite the upcoming research in this area, research capturing the perspectives of older people living with dementia is still scarce (22, 23). Older people living with dementia are often excluded from data collection due to ethical reasons (24). In spite of the indications that older people living with dementia are still able to share their perspectives and wishes on care provision (25, 26).

This study focuses on identifying how older people living with dementia perceive a potential move to a nursing home and how they wish to receive care in the future while residing in a nursing home. The main research question is: 'What are the perspectives of community-dwelling older people living with dementia regarding a possible move to a nursing home and what are their wishes for future care if they would move to a nursing home?'

Materials and methods

Study design

A phenomenological research methodology was used (27). The design focused on understanding the perspectives of participants and interpreting the meaning (28–30). The phenomenon under study was the perspectives of older people regarding current and future care provision. By analyzing these perspectives, the researchers aimed to understand the anticipated care wishes if older people would move to a nursing home. Data was collected through in-depth interviews conducted within Desired Dementia Care Towards End of Life (DEDICATED) project (31). The 'Standards for Reporting Qualitative Research' (SRQR) checklist was used to report this study (32).

Participants and setting

A purposive, criterion-based sampling technique was used to recruit participants living in the south of the Netherlands. In the Netherlands, both home care and nursing home care are funded by health insurance/the government. The care receiver only needs to pay a small contribution based on their financial situation. However, the government focuses on letting older people remain at home for as long as possible. Therefore, older people should require 24–h care and supervision before they are allowed to move to a nursing home. The decision to move to a nursing home is, therefore, mostly dependent on the health status of the person rather than financial considerations (33). Different professional caregivers (e.g., dementia case managers, community care nurses, and a geriatrician) recruited the participants they cared for. The professional caregivers made a clinical judgement regarding the cognitive abilities of the potential participants. This assessment was based on their expertise as professional caregivers and their direct knowledge of the older person. The researcher did not use a scale to assess cognitive abilities as these scales often do not accurately reflect the communicative skills of older people. The professional caregivers selected participants based on a set of eligibility criteria set up by the researchers. Participants were eligible if: 1) they were 65 years or older and still lived at home; 2) they had a formal dementia diagnosis and were aware of their illness; and, 3) they were able and willing to participate. Potential participants received information regarding the study and were asked if they were interested to participate. Twenty-two older people living with dementia were approached. Those interested in participating gave their consent to being contacted by one of the researchers. A week later, the researcher contacted the participants by phone and provided them with the opportunity to ask additional questions. Finally, an interview date was scheduled.

Ethical considerations

All participants were informed about the study and were asked to give consent. Those who were capable to sign gave written informed consent. For those who could not give written consent, a legal representative signed the informed consent. In addition, all participants gave verbal assent to participate in the study (34). The researcher clarified that the participants could stop the interview at any time and they could decline to answer certain questions without the need for an explanation. The participants were allowed to invite their family members or legal guardian to support them through the interview. The Research Ethics Committee of Zuyderland and Zuyd University of Applied Sciences (METCZ20180085) approved the study.

Data collection

The topic guide of the interviews within the DEDICATED project, addressed the following topics: 1) transitional care for a possible move to a nursing home; 2) receiving care from others; 3) interprofessional collaboration; and, 4) future and end-of-life care (Appendix 3A). To optimize the topic guide, professional caregivers (e.g. dementia case managers) and family caregivers of people living with dementia were consulted and relevant literature was searched (31, 35). Additionally, a pilot interview was conducted after which the topic guide was finalized. The focus of the current study is on transitional care. Examples of questions related to the transitional care process included: ‘If in the future you had to reside elsewhere, where would you like to live?’, and ‘What would you need in a nursing home to feel “at home”?’ However, the other three topics were also analyzed as the literature showed that older people find it difficult to talk about care transitions (36). Therefore, their experiences with current care and their perspectives on future care could provide insight into what older people's care wishes could be if they would move to a nursing home. Moreover, it could help them to consider and discuss transitional care. Examples of questions regarding current and future care were: 'What do you find important when offered care?' and 'If you needed more care in the future, what would be important?'.

Demographic characteristics (e.g. age and gender) were gathered before the start of the interviews. The interviews were conducted between August 2018 and October 2019. The interviews took place at the participants' homes. Three researchers (CK, SB and LG) conducted the interviews, of whom two researchers (CK and SB) were trained and had experience with qualitative research and interviewing older people living with dementia. One researcher (LG) was an expert on the subject of transitional care from home to a nursing home. An observer (LD, CK, SB or LG), present at each interview, took notes and asked clarifying questions. The interviews were audio-recorded.

Data analysis

To increase dependability, two researchers (LG and AB) undertook the data analysis. This process started with transcribing the interviews according to the verbatim methodology (37). Excel was used to analyze participant characteristics. The researchers followed seven iterative steps of the Interpretative Phenomenological Analysis approach (IPA): 1) coding the data; 2) developing themes; 3) searching for meaning; 4-5) organizing and structuring the data; 6) auditing the findings with the research team; and, 7) narrating of the findings (38). In the first step, both researchers (LG and AB) read the data thoroughly and separately. Line-by-line, codes were added that summarized the fragments relevant to the subject of transitional care and (future) nursing home care. Examples of codes found were 'remaining independent gives satisfaction' and, 'the older person wants to visit his/her future nursing home beforehand'. In the second step, the researchers (LG and AB) evaluated the different codes until a consensus was reached. Together, they analyzed the commonalities and differences between the codes until overarching themes were formed. Examples of themes that were found were 'transition-related experiences and perspectives' and 'older people's view on the future'. In the third step, the authors started analyzing the themes more in-depth. They suspected that the current care experiences and perspectives of the older people at home might be linked to their potential, future care wishes. Therefore, in the fourth and fifth steps, the lead author analyzed the identified themes to further define and support this hypothesis. Through analysis and interpretation with the research team, overarching themes were formed that described the assumed link between the current care experiences and potential, future care wishes. The sixth step existed of an audit. The audit existed of multiple peer debriefings throughout all steps of the analysis with the research team (HV, BdB, TvA, JPH, JM, CK, and EvR). Any disagreements were resolved and a consensus was reached through joint discussion (39). Finally (step 7), the results of the analysis were written down, narrating and defining each of the overarching themes identified in this study. Participants' quotes were added throughout the paper to recite the perspectives and experiences of the participants (38). By analyzing the data separately and discussing mismatches in coding, investigator triangulation was applied (40).

Results

Eighteen older people living with dementia participated in the study. Table 1 shows the participant characteristics. Four participants declined to participate. Of those four, one person living with dementia and one family caregiver declined participation. The two other participants cancelled last minute. It was unclear whether the cancellation was initiated by the person living with dementia, the family caregiver, or both. The majority of the participants (*n* = 13) had a relative that accompanied them during the interview. The family members did not participate in the interview. The interviews lasted 53 minutes on average, with a range of 31–108 min. One person resided at home during recruitment but moved to a nursing home when the interview took place. The participant was included in the study as he was still able to provide insight into his experiences with care and his perspective on moving to a nursing home. Two people lived in an assisted living facility. However, in the Netherlands, an assisted living facility is considered living at home as the care is provided by home care organisations. Finally, saturation was reached as the final interviews merely confirmed the existing codes (41).

Table 1: Participant characteristics

Age, mean (range)	82 (77–93)
Gender, number (%)	
Male	11 (61%)
Female	7 (39%)
The current living situation of the participant, number (%)	
At home	15 (83%)
In an assisted living facility	2 (11%)
In a nursing home	1 (6%)

The results were divided into two parts: 1) Future life in a nursing home: an idea that was feared by the majority of community-dwelling older people; and, 2) The care wishes of potential, future nursing home residents were focused on individuality, autonomy, and contact with others. The three wishes are described by the subthemes of (a) Individuality:

the wish for personalized care while continuing routines and hobbies, (b) Autonomy: the wish for respect regarding preferences and choices while enabling independence, and (c) Social contacts: the wish to no longer be alone while remaining close to friends and family.

Future life in a nursing home: an idea that was feared by the majority of community-dwelling older people

The results showed that the majority of the participants focused on remaining at home for as long as possible and feared the idea of moving into a nursing home. Several participants specifically stated that they did not want to move. Two of these participants said that thinking about that possible scenario frightened them. Negative associations with nursing homes, expressed by most participants, could be related to feelings of anxiety and fear. More specifically, a few participants recalled negative experiences with family/friends residing in a nursing home.

> *[**Quote D17, Living at home:** 'Well, like, I found that some people, it is sad when they are sitting there. They don't look happy.']*

Several older people associated nursing homes with loss. They linked moving to a nursing home with declining health or serious life events (e.g. breaking a hip). One person was scared of losing her dearest possessions due to the limited space a nursing home room has, while another person was scared of losing her hobbies. One person was scared of losing his identity and becoming one of many.

> *[**Quote D1, Living at home:** 'Yeah, that you lose yourself. You just sit together with a group of people who have the same illness and are surrounded by the same nurses.']*

Despite the ever-returning wish of wanting to remain at home, a great number of the participants stated that a further decline in their health, resulting from their illness, could lead to a nursing home move. Two people said that they would be open to residing in a nursing home. It would allow them to stop fighting a losing battle against dependency and they would be able to rely on others for help. The interviews revealed that older people considered moving to decrease the burden experienced by their family members/friends. Conversely, some older people did not have negative experiences with nursing homes. They described the beautiful environment in which the nursing home was built or the good/friendly staff that provided the necessary care.

> *[**Quote D15, Living at home:** 'Most exasperating? It is not exasperating for me. I think it is a good institution. Why? People in need of care receive the necessary care.']*

The participant who had already moved to a nursing home and the two participants who moved to an assisted living facility indicated being relieved and referred to the long-term care facility as 'their home'. The participants' choice to move was mostly a combination of being alone, a loss of independence, and having a home that no longer fitted their needs. The person who had recently moved to a nursing home liked his new home, where he had company. In his own house, he felt unsafe and locked up, unable to go out. He described the nursing home as his new home where he could participate in various activities and continue his habits of drinking a glass of wine and enjoying his afternoon siesta.

> *[**Quote D13, Living at a care facility:** 'Agreed, agreed, yes, I could no longer live there alone… I find it much better here.']*

The care wishes of potential, future nursing home residents are focused on individuality, autonomy and contact with others

In general, older people living with dementia were able to express their care wishes. The analysis of their stories about the present, past and future identified that the potential, future nursing home residents wished for care that enables them to remain (a) individuals; (b) who were autonomous; and, (c) in contact with others.

Individuality: the wish for personalized care while continuing routines and hobbies

All interviews led to the older people talking about their past lives and who they were as individuals. The participants stated the importance of keeping their individuality and continuing life regardless of their diagnosis, level of care, or place of residence.

More specifically, the participants felt it was important that professional caregivers provided personalized care. They defined the latter as having time for an informal chat and listening to their stories.

> *[**Quote D18, An assisted living facility:** 'They are really, very nice. It is as if… he is my son, we talk about the weather, the kids…']*

The results showed that when older people felt comfortable enough to talk about a possible move to a nursing home, they expressed the importance of having an environment and living space where they could continue their routines and hobbies. Several participants specifically mentioned that their future nursing home should facilitate the continuation of their previous hobbies and routines.

> *[**Quote D19, Living at home:** 'Music is my passion. So if you could have similar opportunities in the nursing home that would be ideal, yes.']*

The wish to continue previous hobbies and routines, once residing in a nursing home, could possibly be explained by the fact that the majority of participants stated that they were happy with the life they were currently living. The majority of participants told the interviewers that they had a fixed routine consisting of visiting friends and practising hobbies or religion. They wanted to remain active and fill in the free time they had with enjoying life. Many of the participants had hobbies. The most common hobbies were walking and going out. Three people specifically mentioned the importance of staying up to date with global news. Religious participants also actively practised their beliefs (e.g., they went to church or prayed).

> *[**Quote D20, Living at home:** 'If I sit inside or if it rains or something, it is not right. Normally, I am always outside. Alternatively, I go for a walk or I take my bike if I have nothing to do. I cannot sit inside.']*

Autonomy: the wish for respect regarding preferences and choices while enabling independence

To maintain their individuality, almost all older people stressed the importance of autonomy, in all phases of life. The analysis showed that this wish for autonomy determined older people's preferences concerning their future housing. Older people felt the idea of moving into an assisted living facility less threatening compared to the idea of moving into a nursing home. An assisted living facility would allow them to remain more autonomous.

> *[**Quote D7:** 'With an assisted living facility, you cannot get it much better, right? Living autonomously and knowing that…' Interviewer: "You can still receive the necessary care?" Participant: 'Yes, that is amazing. I am very pleased.']*

Once in the LTC facility, the older people felt it was important that they could participate in activities of their choice. Negative feelings were expressed when a fixed routine had to be followed. The participants expressed the wish for autonomy regardless of their place of residence or declining health status.

> *[**Quote D1, Living at home:** 'It was just that management arranged everything. That is when I think: I cannot feel at home like this.']*

The majority of the older people stated being aware of the implications that a declining health status would have on who they were and what they were able to do. The possibility of having to receive care from family/friends was one of the concerns expressed by some older people, as they felt it impeded their independence. Moreover, a few participants associated receiving care with losing their dignity and feeling exposed. They felt submitted to care and associated it with losing their privacy.

> *[**Quote D17, Living at home:** 'You do not have anything anymore. You are naked. In the end, you don't know, you do it and you say come. However, your self-esteem disappears.']*

Participants coped with a declining health status differently. Despite all the different coping strategies, the participants stressed the importance of being a part of life. They changed their plans in a way that allowed them to participate in activities of daily living independently and making their own decisions. More specifically, some older people had friends they saw regularly and when their disease made them unable to visit, changes would be made to accommodate the older people's wish to meet his/her friends. Another participant followed a church service on television when she could no longer attend in person.

> *[**Quote D1, Living at home:** Interviewer: 'And the garden right?' Participant: 'Yes, I can still do that and that is nice. Because then you got something to do and you feel of value.']*

The professional caregivers' encouragement of autonomy during care, currently provided to participants, influenced the older people's perspectives on receiving care in the future (e.g. at a nursing home). More specifically, the older people stated they did not want any help if it was not strictly necessary. They perceived receiving (unnecessary) help, given by professional caregivers, as negative or difficult. Moreover, almost all participants stated the importance of respect for their wishes, preferences and choices in life and care. When it came to care provision, several older people defined respect for their wishes/ preferences as respecting their autonomy, for instance, enabling them to participate in open and honest conversations, being listened to and being taken seriously.

> *[**Quote D14, Living at home:** 'To start they have to speak with you on the same level. That is something I appreciate.']*

When these wishes, preferences, and choices were ignored, older people felt unheard by professional caregivers. An example hereof is how two participants felt they had to prove their independence.

> *[**Quote D22, Living at home:** How do you prove to someone that you took a shower if that person does not believe you, especially when you have been showering for 80 years? That is very difficult.']*

Although some negative emotions were expressed concerning care provision, the results showed that some of the participants' negative experiences could also be associated with a sense of loss resulting from their disease. An example was how two older people linked their negative feelings towards care provision to being dependent on that care.

> *[**Quote D4, Living at home:** Participant: 'I did not like the different professional caregivers.' Interviewer: "Why?" Participant: "If it is easy to answer their questions then it is not a problem. However, when it gets harder then it is not so nice." Interviewer: "They asked you difficult questions?" Participant: "Yes, beyond my capabilities."]*

Social contacts: the wish to no longer be alone while remaining close to friends and family

Throughout the interviews, it became clear that for the participants, social contact remained pivotal despite their diagnosis. This could also be reflected in their needs and wishes regarding possible, future nursing home care. The older people who had already moved or were planning to move lived alone. They all indicated that one of the reasons for the (future) move was to avoid being alone. Moreover, older people's preferences regarding the location of the nursing home were based on their wish for social contact. They defined a nice environment/living space as having a nice view, being in a familiar neighbourhood and being able to go outside while having sufficient space inside (e.g. to invite family), allowing them to remain connected. A clear example is how one older person, who moved to a nursing home after recruitment, no longer feels lonely now that he resides in a nursing home.

> *[**Quote D13, Living at a care facility:** 'Good, definitely good. Because where I lived previously, I was alone the whole day.']*

The results revealed that the wish for social contact is also reflected in the important role of (future) nursing home staff. Several older people stressed the importance of having friendly, loving staff available to offer a helping hand. Other older people expressed the importance of connecting with other residents and making friends.

> *[**Quote D19, Living at home:** 'I already spoke about having good contact. You need to have competent staff, also concerning personal contact with patients and not just technical aspects.']*

The importance of social contact was reflected in the older people's definition of good (future) care. Most participants associated good care with the interaction and contact they had with professional caregivers who cared for them at home (e.g., home care nurses, the general practitioner) in addition to adequate care provision. Good care was defined as having satisfactory contact with the professional caregivers and perceiving them as being friendly, trustworthy, hardworking, and available. They stated the importance of having a 'click' with the professional caregiver.

> *[**Quote D23, Living at home:** 'We make it very gregarious; I always have coffee for when they come… Yes, it has come to a point that they walk towards the kitchen and turn on the water… That is nice, is it not?']*

Consequently, negative care experiences could be related to impersonal care. More concretely, due to the complexity of their illness and the schedules of professional caregivers, different professional caregivers cared for the same older person. For one person this was too hectic. For others, it took some time to get used to the different professional caregivers. One older person was, after an adjustment period, grateful for the diversity of people visiting her. It allowed her to interact with different personalities.

> *[**Quote D22, Living at home:** 'You come across very feisty people, but also very wise people. The next day a more upbeat person can walk in, which is nice.']*

Finally, the results indicated that older people enjoyed spending time with friends and family. According to the older people, friends and family provided them with good company, humorous conversations, and memories of the past. The participants who mentioned the importance of friends and family were happy when they came for a visit. The older people indicated that family gave them meaning in life.

> *[**Quote D17, Living at home:** 'My family does. I do not care where I live as long as my daughter and the kids are surrounding me.']*

Discussion

This study aimed to identify how older people living with dementia perceive future life in a nursing home and what their future care wishes could be if they would ever move to a nursing home. The majority of older people living with dementia feared the idea of having to move. Nevertheless, they were able to express their needs and wishes concerning a potential move to a nursing home. They had a clear view of how they perceived current care and what made their life meaningful. If they were to move to a nursing home, they wanted to be perceived as autonomous individuals who remain in contact with others.

Regarding older people's fear of a possible move to a nursing home and their preference to remain at home, Tse et al. (2007) found similar results. Only 15% of their sample of 118 older people would consider moving to a nursing home. A possible explanation could be the negative feelings (e.g. feelings of loss) that are often associated with a move to a nursing home (6, 12). For example, older people feared that they will lose their autonomy and control when moving into a nursing home (12). These fears might be reasonable, as a qualitative study by Walker et al. (2016) indicated that nursing home residents felt they traded their autonomy and individuality, in exchange for a safe environment and assistance from professional caregivers (42). Moreover, studies found that professional caregivers rarely engaged their residents in activities of daily life (e.g. cooking meals) (43, 44). This suggests that some nursing homes are not able to tailor care to older people's needs and wishes.

Our findings suggested that older people living with dementia have the same wishes and needs concerning their future care as older people without cognitive decline. More specifically, a good number of studies focused on defining the meaning of 'home' in a nursing home from the perspective of older people without cognitive decline. Similar to this study, those studies found that older people felt at home in a nursing home when they experienced autonomy, which allowed them to feel in control and make choices. Additionally, they stated the importance of involvement and engagement with other residents and staff and the importance of personalization (6, 7, 11, 14, 45, 46).

The older people living with dementia in our study identified three anticipated care wishes. These wishes were similar to those reported in the study by Rijnaard et al. (2016) who found that fifteen factors, divided into three overarching themes, influenced the sense of home for older people residing in a nursing home. Two of the three themes, psychological (e.g., autonomy and being acknowledged as an individual) and social factors were directly in line with the results of this study. Additionally, previous studies identifying the meaning of home for older people in the community found similar care needs (6, 7, 14, 20, 47, 48). This suggests that older people's anticipated care needs, if they were to move into a nursing home, are similar to the needs of older people residing in the community (49–52). This could confirm the earlier assumption that led to the data-analysis process.

The participants who positively considered or experienced the move to a long-term care facility in our study felt that they could no longer live an individualistic, autonomous, and social life in the community. This suggests that older people might accept a nursing home move more easily when their needs for individuality, autonomy, or social contact could be met in nursing homes. This insight is crucial, as research showed that older people's involvement in the decision-making process regarding a care transition is pivotal to nursing home adjustment (12).

Practice, policy and research implications

Both the methodology used to collect the data and the results of this study have important implications for policy and practice. First, collecting data on/or listening to wishes and needs in the life history when performing home-based care visits, could be a way of identifying a suitable time to suggest a move to a nursing home. By focusing on older people’s past lives and current care provision, this study was able to create a deeper understanding of older people’s perspectives of potential, future nursing home care. This is paramount as similar questions could help professional caregivers to involve older people living with dementia actively in their transitional care process (12). However, simply having information about a person’s life history, hobbies and preferences does not always lead to a comprehensive transitional care process. Future research should focus on identifying additional contextual factors that can improve the transition from home to a nursing home.

Second, this paper also confirms results from previous studies that signalled the influence of the transitional care process on older people feeling ‘at home’ in a nursing home (12, 18, 53). More specifically, this paper showed that having significant information on an older person’s life, hobbies, habits and social contacts can contribute to helping an older person adjust to living in a nursing home. Therefore, it could be important for professional caregivers to prepare for this transition process together with the older person by organizing nursing home visits, assembling information about past life experiences and current hobbies/routines at home and helping the older person become acquainted with the professional caregivers and residents of the nursing home (15). The latter might be crucial as older people’s relationships with other residents, staff and family also influenced their nursing home experiences (6, 7, 11, 14, 47, 54). Therefore, in both in-home care and nursing home care, policymakers and management could educate their staff on providing relationship-centred care (47, 55). Relationship-centred care is a framework to aid the conceptualization of the healthcare system. Central within this framework are the quality and nature of the relationships. More specifically, it focuses on the relationship between the patient and the professional caregiver while taking into account the community surrounding them (56). Following the results, policymakers and management should employ innovations and strategies that would allow the older person to stay autonomous and in contact with others while remaining unique. Such strategies should be employed at the start of the transition process, as research found that a timely initiated transition process positively affects older people’s outcomes and adjustment when moving to a nursing home (57–60).

Next to implementing relationship-centred care practices on time, professional caregivers need to facilitate residents’ ability to remain autonomous when making decisions about care provision and activities of daily life if they would ever move to a nursing home. It requires professional caregivers to be flexible and provide tailored care. More specifically, they should adjust their care according to the older people’s hobbies and routines in such a way that older people can continue their life autonomously once they reside in a nursing home. This care may vary between residents, and over time (e.g. If a resident wants to participate in a certain activity, it does not mean he/she would like to participate again a week later). Furthermore, staff needs to be able to get a clear view of a resident's social network, and should be able to facilitate maintaining this social network when an older person moves to a nursing home.

Finally, future research should focus on confirming the outcomes of this study by prospectively following older people living with dementia during the transition from their home to a nursing home, thus facilitating a comprehensive overview of the transitional care process. This is crucial as existing research only focused on the perspectives of older people before or after the move to a nursing home.

Limitations

Firstly, the data collection was performed by researchers from the DEDICATED project, a study on palliative care for older people living with dementia. Therefore, not all questions focused on transitional care and future nursing home living. However, the additional questions on older people's daily lives and current care provision enriched the results of this study. Secondly, one older person was interviewed while residing in a nursing home. This was because the older person had moved to a nursing home after recruitment. The researchers felt that his experiences added to the understanding and enriched the results. Nevertheless, the older person's living situation was taken into account when analysing and reporting the results of this study. Moreover, sufficient amounts of interviews were conducted for saturation to be reached. Finally, it were the professional caregivers, who cared for the older individuals, that recruited them for the study. They judged their willingness and ability to participate based on their knowledge of the potential participants. It could bias the results of this paper as the older people who were not considered willing or able to participate may have different perspectives. However, the results of this paper are in line with previous studies, which suggests that this recruitment method has not affected the results.

Conclusion

Older people living with dementia preferred to live at home for as long as possible and they feared the idea of having to move to a nursing home. Nevertheless, the questions asked throughout the interviews allowed older people to express their perspectives regarding potential, future care wishes. The results of this study suggest that older people want to be seen as individuals, who are autonomous, and remain in contact with others. The study showed that information on past and current care experiences can educate and inform professional caregivers on the importance of incorporating these care wishes when involving older people in the transitional care process. Simultaneously, discussing these wishes could help to identify ‘a suitable time’ for a transition from home to a nursing home.

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Appendices

Appendix 3A. Topic list: the perspectives of older people with dementia

Topic 1: Transitional care into a nursing home

1. How do you experience living at home at this moment?
   - What would make it difficult for you to stay at home?
   - What would help you to stay at home as long as possible?
   - What are your thoughts regarding living somewhere else?
2. What is your perspective on moving to a nursing home?
   - What are your thoughts regarding a nursing home?
   - What would you need in a nursing home to feel ’at home’?
   - Who needs to prepare you for a possible nursing home transition?

Topic 2: Receiving care from others (in the future)

1. Do (or did) you receive help or care from other people?
   - What do they do for you?
   - How do you feel about them caring for you?
   - What is important to you when other people are caring for you?
   - What are things you like or dislike when other people are caring for you?
2. Do you usually receive care from the same individuals?
   - How do you feel about that?
3. How do the people that care for you, approach you?
   - How do you feel about that?
   - How should they approach you?
4. Are you concerned with faith/religion/giving meaning?
   - How do you engage in these topics?
   - Do you discuss these topics with professional caregivers?
     - (Yes) How are these topics discussed?
     - (Yes) How do you feel about that?
     - (No) How does that make you feel?
     - (No) Would you like to discuss these matters with them? Why (not)?
5. Can you imagine being (fully) cared for by other people?
   - What comes to your mind then?
   - What makes the thought (un)pleasant?
   - What would help you to accept such help/care from others?
6. What do others need to know about you, to care for you properly?

Topic 3: Interprofessional collaboration

1. Do you receive support from anyone?
   - Which type of professional caregivers were involved in the care process?
   - How did you experience the involvement of these professional caregivers?
   - How do these professional caregivers support you?
   - How do you experience their support?
   - Do you receive support from your loved ones? How do they support you?
2. How do you perceive collaboration among professional caregivers?
   - Why do you think their collaboration is important for you?
   - Are you able to say anything regarding their communication with one another?
     - (Yes) How do they communicate with each other?
     - (No) Why can't you say anything about their communication?
   - Do you know if they are up-to-date with everything?
   - Do you need to repeat the information given to the professional caregivers?
     - (Yes) Could you explain or describe what you mean?
     - (No) Would you like to know how they discuss your care? Why or why not?

Topic 4: Future and end-of-life care

1. Do you ever think about the future?
   - What comes to your mind?
   - Why is this thought (pleasant/unpleasant/confronting…)?
2. Do you ever think about the end of life?
   - What comes to your mind?
   - Why is this thought (pleasant/unpleasant/confronting…)?
     - (No) What could be the reason for that?
3. Did you ever talk about particular wishes regarding the end-of-life?
   - (Yes) With whom did you discuss this?
   - (Yes) How did you feel about discussing the end-of-life?
     - What is the reason that it was (easy/difficult/confronting/…) for you to discuss this?
   - (No) How do you feel about discussing the end of life?
   - (No) Would you like to discuss this with someone (a professional caregiver)?
     - (Yes) with whom?
     - What would make it easier to discuss the future?
     - What would you need to discuss in the future?
4. Have your wishes regarding end-of-life care been documented?
   - Do you have a living will?
5. Who will decide for you, if you cannot decide for yourself?
   - Have you ever been asked that question before?
   - Did you ever discuss this with the GP or notary, for instance?
     - Has this been documented?
6. What do you hope for in the future?

A positive wrap-up:

1. With all your life experience, I am really curious …
   - What do you think is important in life?
   - What is a life lesson that you would teach to a young person?
   - What is your motto?

4

Chapter 4

The paradoxical experiences of informal caregivers

This chapter was published as:
Groenvynck, L., de Boer, B., Beaulen, A., de Vries, E., Hamers, J. P. H., van Achterberg, T., . . . Verbeek, H. (2022). The paradoxes experienced by informal caregivers of people with dementia during the transition from home to a nursing home. Age and Ageing, 51(2). doi:10.1093/ageing/afab241

Abstract

Background: The transition from home to a nursing home is a common care process experienced by older people with dementia and their informal caregivers. This transition process is often experienced as fragmented and is paired with negative outcomes for both older people (e.g. mortality) and informal caregivers (e.g. grief). Due to the central role that informal caregivers play, it is crucial to capture their experiences throughout all phases of the transition.

Methods: A secondary data analysis was conducted using an interpretative phenomenological design. A total of 24 informal caregivers of older people with dementia, moving to a nursing home, participated in in-depth interviews. Data were collected between February 2018 and July 2018 in the Netherlands. Data were analysed using Interpretative Phenomenological Analysis.

Results: The transition experiences are characterised by three paradoxes: 1) contradicting emotions during the transition process; 2) the need for a timely transition versus the need to postpone the transition process; and, 3) the need for involvement versus the need for distance. All paradoxes are influenced by the healthcare system.

Conclusions: The identified paradoxes show the impact of the healthcare system and the importance of timely planning/preparing for this transition on the experiences of informal caregivers. In addition, it provides professional caregivers insight into the thought processes of informal caregivers. Future research can use these paradoxes as a foundation to develop innovations aiming to improve the transition process from home to a nursing home for informal caregivers and consequently, older people.

Introduction

Nursing home admission is a common care transition, especially for older people diagnosed with dementia. In Europe, about 80% of nursing home residents are diagnosed with dementia (1–3). The transition from home to a nursing home can be divided into three phases: pre-, mid-, and post-transition (4).

The pre-transition phase commences when a nursing home move is discussed for the first time and the phase is terminated when the decision for nursing home admission is made (5–8). The mid-transition phase focuses on the preparation for the move as the older person receives a place on a nursing home waiting list. The phase ends when the older person resides at the nursing home (7–9). Lastly, the post-transition phase starts after the move and it includes the time for the older person and informal caregivers to accept and adjust to the new living situation (5, 7–9). In the Netherlands, the possibility to move into a nursing home is based on a standardized need assessment carried out by a government agency while following the older people's and informal caregivers' wishes.

The World Health Organization encourages that the needs and preferences of older people are prioritized during the transition process, as this is a very complex and emotionally challenging process (10–13). However, the majority of future nursing home residents are diagnosed with dementia. Therefore, their informal caregivers will often take on a more active and central role during the transition process (14, 15). Often, informal caregivers tend to postpone nursing home admission until the older person is no longer safe at home and they or other informal caregivers are mentally and physically drained (6, 12, 16–19). This can cause a crisis to unfold, possibly leading to urgent, uncoordinated, and fragmented transitions, which in turn can lead to outcomes that are even more negative for both older people (e.g., mortality and morbidity) and informal caregivers (e.g., higher mortality due to grief) (18, 20–23). Despite these negative emotions, studies indicate that a nursing home admission can also reduce the burden for informal caregivers (24–26).

Some studies have focused on describing the experiences and needs of informal caregivers (4, 5, 7, 11, 18, 19, 27, 28). Nevertheless, the majority of these studies either examined only the period before the transition or after the transition. A description of the entire transition process (pre-, mid-, and post-transition), as experienced by informal caregivers is missing from the literature (10–12). Moreover, a comprehensive understanding of why informal caregivers experience transitional care as being very complex, and the thoughts, emotions, and perceptions of informal caregivers during this transition are still unknown.

Therefore, the research question is: What are the experiences of informal caregivers of older people with dementia during all phases of the transition from home to a nursing home? To answer this question, interview data from a large-scale research project DEDICATED, into palliative care for people with dementia, was used. The DEDICATED project aimed to examine the interprofessional collaboration between professional caregivers and informal caregivers, both intra- and transmural, as experienced by informal caregivers during the palliative care process in the Netherlands.

Methods

Study design

A secondary data analysis study was conducted using an interpretative phenomenological design. This design was chosen as it allows the identification of the personal lived experiences of informal caregivers during the transition from home to a nursing home (29). This study was reported according to the Standards for Reporting Qualitative Research (SRQR) to ensure rigor (30).

Participants and setting

Nurses employed from the three partner organizations in the DEDICATED project identified participants, using a purposive sampling technique (31). The recruitment was based on a predetermined list of inclusion criteria provided to the nurses. Participants with varying characteristics, such as gender, age, level of education and years residing in the nursing home, were recruited. Participants were included in the study if: 1) they were informal caregivers whose partner/loved one received care at the partner nursing home organization; 2) the person with dementia was 65 years of age or older and had made the transition to a nursing home; and, 3) the older person had died between six weeks and six months ago. A significant amount of participants was approached, as the researchers needed a heterogeneous sample of participants. These sampling methods were chosen to accommodate the aim of the original study.

Informal caregivers matching the inclusion criteria were asked to participate by a professional caregiver. If they agreed, the researchers from the DEDICATED project contacted potential participants, and a face-to-face meeting was scheduled. Participants were free to choose where the interviews took place, either at their residence, a university building, or one of the participating care organizations.

Participants provided written informed consent before starting the interviews. The Medical Ethics Committee of Zuyderland confirmed that the rules of Medical Research involving Human Subjects Acts were not applicable (registration number METCZ20180026).

Data collection

Semi-structured, face-to-face interviews were conducted between February 2018 and July 2018. A topic list was designed based on existing literature and guidelines (32–34). The topic list consisted of four themes relevant to the DEDICATED project: 1) symptom management; 2) interprofessional collaboration; 3) collaboration between home and nursing home care; and, 4) end-of-life communication (see Appendix 4A). This study focused on capturing the experiences of informal caregivers concerning the transition to a nursing home mentioned most extensively in the third topic. Two researchers (SB and SP) from the DEDICATED project conducted the interviews together. One interviewer asked the questions. The second interviewer noted relevant observations and asked additional questions when necessary. Both researchers received training on conducting interviews. Moreover, both were experts on dementia and palliative care. All interviews started by obtaining the demographic characteristics of participants. The interview ended by asking participants if they had additional comments. The interviews were recorded using an audio recorder or mobile phone.

Data analysis

The demographic factors were descriptively analysed. The recorded interviews were transcribed according to the clean-read verbatim method. Only the fragments focusing on transitional care were analysed in this study. The Interpretative Phenomenological Analysis method was used. It consisted of three consecutive steps: 1) develop a list of significant statements; 2) develop themes; and, 3) writing the essence (35). The first step was developing a list of statements related to transitional care. Each of these statements was given a code. Examples of codes were ’feeling like imprisoning a loved one’ or ’relief due to unsustainability at home’. The codes used were closely related to the words of the participants. The codes analysed in the first step were then clustered leading to the development of themes, such as ‘negative transition feelings’ or ’positive transition feelings’. Initially, the themes seemed contradictory to one another. However, upon further analysis, the authors found a common mechanism that linked the different themes to one another. These links were defined as paradoxes. A paradox entails a statement or opinion that seems contradictory as it contains opposite facts or characteristics (36). For example, codes related to the theme of both ’negative transition feelings’ and ’positive transition feelings’ were found in almost all transcripts. This indicates that informal caregivers felt conflicted during the transition period, leading to paradoxical emotions. The different steps were realized consecutively and iteratively throughout the whole analysis (37, 38).

Three different researchers analysed the data together (LG, AB and EdV). Two researchers had extensive experience with qualitative research (AB and EdV), and one researcher was an expert on the subject (LG). The quality of this analysis was ensured in several ways. First, investigator triangulation was adopted as three researchers analysed the data separately, followed by a discussion to reduce decision bias (39). Moreover, these researchers reflected on their backgrounds and their knowledge of the subject and how this could interfere with data analysis. Uncertainties regarding possible bias were discussed within the research team. Finally, peer debriefings were held on multiple occasions to discuss the preliminary and final results within the research team.

Results

Sample characteristics

In total, 24 interviews were conducted, lasting for 94 minutes on average (range: 66–139 minutes). The loved ones of the informal caregivers had passed away at the time of the interview. The length between nursing home admission and the interviews varied significantly. Data saturation was reached as the final interviews did not lead to additional codes or significant changes in the results. Participants were on average 62 years old. Although heterogeneity was obtained for educational and aging characteristics, the majority of participants were women (*n* = 17) and daughters (Table 1).

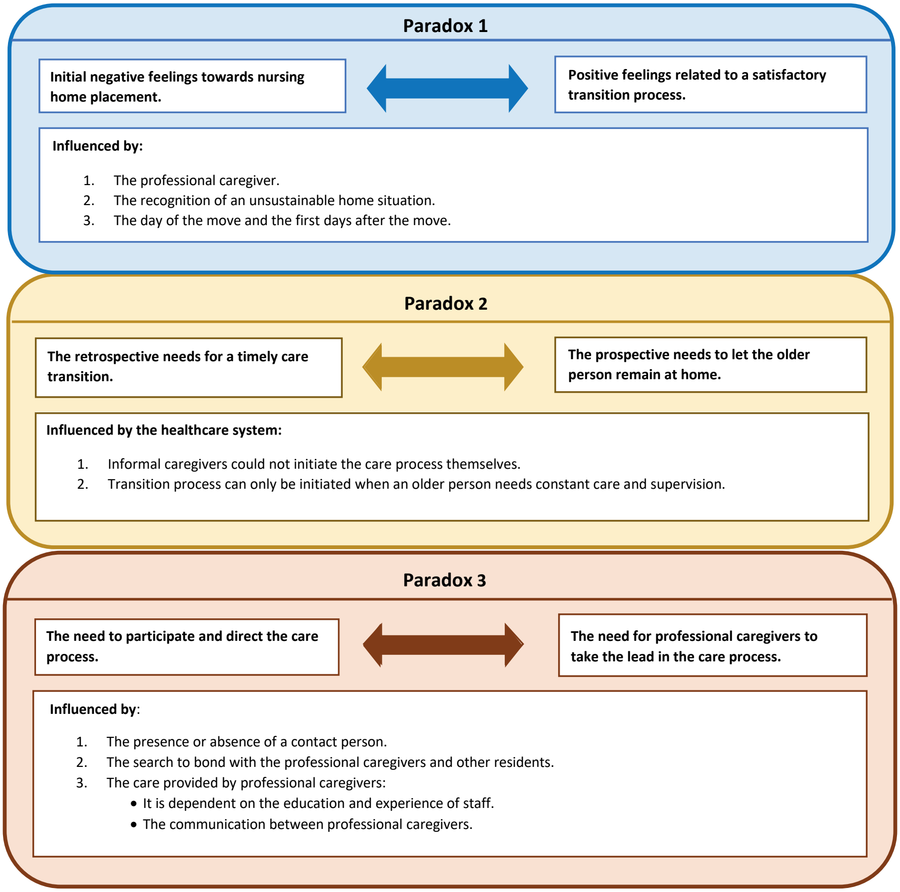
Table 1: Participant characteristics

Age, mean (range)	62 (44—85)
Gender, number (%)	
Male	7 (29%)
Female	17 (71%)
Connection to the older person with dementia, number (%)	
Son (in-law) or daughter (in-law)	18 (75%)
Brother (in-law) or sister (in-law)	1 (4%)
Niece or nephew	2 (8%)
(ex-) Partner	2 (8%)
A friend	1 (4%)
Highest level of education, number (%)	
Preparatory secondary vocational education	7 (29%)
Senior secondary vocational education and training	7 (29%)
Senior general secondary education and university preparatory education	4 (17%)
Bachelor or Master level	6 (25%)
Length of stay at the nursing home, number (%)	
0—6 months	7 (29%)
7—12 months	2 (8%)
1—2 years	9 (38%)
2—5 years	6 (25%)

The place before the transition to the nursing home varied—sixteen older people moved from home or another nursing home and eight moved from the hospital ($n = 2$) or another care facility ($n = 6$).

Key findings

Informal caregivers experienced the older person's transition to a nursing home as a complex care process characterized by paradoxes. The term paradoxes were used as the informal caregivers describe ostensibly, seemingly contradicting needs and emotions when relaying their transition experiences (Figure 1). Three overarching paradoxes were identified: 1) contradicting emotions during the transition process; 2) the need for a timely transition process versus the need to postpone the transition process; and, 3) the need to be involved versus the need for distance from care responsibilities. These paradoxes are influenced by how the healthcare system is organized and by how professional caregivers provide care.



Paradox 1

Initial negative feelings towards nursing home placement. ↔ **Positive feelings related to a satisfactory transition process.**

Influenced by:

1. The professional caregiver.
2. The recognition of an unsustainable home situation.
3. The day of the move and the first days after the move.

Paradox 2

The retrospective needs for a timely care transition. ↔ **The prospective needs to let the older person remain at home.**

Influenced by the healthcare system:

1. Informal caregivers could not initiate the care process themselves.
2. Transition process can only be initiated when an older person needs constant care and supervision.

Paradox 3

The need to participate and direct the care process. ↔ **The need for professional caregivers to take the lead in the care process.**

Influenced by:

1. The presence or absence of a contact person.
2. The search to bond with the professional caregivers and other residents.
3. The care provided by professional caregivers:
    - It is dependent on the education and experience of staff.
    - The communication between professional caregivers.

Figure 1: Three paradoxes as experienced by the informal caregivers.

Contradicting emotions during the transition process

The first paradox describes the initial negative feelings associated with nursing home placement, which is a paradox to the feelings of relief and acceptance related to a positive transitional care process afterward.

Initially, the participants indicated that the transition from home to a nursing home was a very emotionally challenging process. The majority of informal caregivers described the process of admitting their loved ones with negative emotions. They described it as a very difficult and painful process. Some informal caregivers even described it as imprisoning those they cared for.

> **(Daughter, 62, interview: Z1.04)** [*'I feel incredibly guilty and I said, under false pretences, we are going to have a nice sit down in the cosy living room…sitting down, and later on she will be imprisoned here, yes...'*.]

Paradoxical to the informal caregivers' predominately negative associations with transitional care, more than half of the participants also identified clear positive experiences throughout this process, such as feelings of relief and acceptance after nursing home admission. This was especially true for informal caregivers who described positive experiences related to the practical and emotional support offered by professional caregivers.

> **(Daughter, 60, interview: e1.07)** ['*On the one side, it is positive, a bit of safety that you know… She had been there for a year and a half because my father could no longer support her. It gave us a sense of security, and it resolved the reciprocal conflicts that we had*'.]

Moreover, the interviews showed that the emotions related to this transition process were strongly influenced by three factors. Firstly, the care provided by the professional caregivers had the strongest influence on the experiences of informal caregivers. Negative emotions were pronounced even stronger when the care process itself was experienced as being insufficient and/or when the move felt very sudden and/or the informal caregivers did not receive any (emotional) support from professional caregivers. One informal caregiver even spoke about the guilt she felt after being advised by professional caregivers to prepare the transition process behind her back.

On the other hand, professional caregivers could also positively influence the transition experience. For example, if the informal caregiver felt supported by professional caregivers and experienced that the older person was included in the decision-making process. The latter was not always feasible due to the older person's dementia or their unwillingness to move to a nursing home.

> **(Daughter-in-law, 55, interview: V1.05)** [‘*If I recognize that, yes, she has a central position and we are going for it, we are really striving for comfort and quality, yeah, you know, that is very soothing*’.]

Despite the practical support offered by professional caregivers to navigate through the different care organizations, the majority of informal caregivers indicated that professional caregivers, although much needed, did not offer emotional support. Moreover, more than two-thirds of the informal caregivers had to prepare the older people (emotionally) for the upcoming transition themselves.

> **(Wife, 75, interview: Z1.06** [‘*Because were you ever prepared for this? No, not at all. I thought, what is happening now…it was a real shock, yes*’.]

Secondly, most participants recognized the dangerous home situation for older people and their feelings of worry and burnout. They acknowledged that the former home situation was no longer homely and nursing home admission was inevitable. This was especially true for the five informal caregivers whose loved ones understood their illness or were positive about moving into a nursing home. When the older person acknowledged it was no longer safe to live at home and indicated to appreciate the secure environment of a nursing home, the participants themselves were more positive and accepted a move to a nursing home.

> **(Brother, 85, interview: Z1.05)** [‘*I thought she will be fine there. And she agreed. That was of course very nice for me, that she liked it there herself. Otherwise, it would have been a bit more difficult of course…I always left there feeling satisfied*’.]

Finally, the interviews showed that negative emotions regarding the transition (e.g., feelings of guilt and grief) were often related to the day of the move and the first days after the move. It was noticeable that the majority of informal caregivers coped with this emotional challenge by focusing on re-establishing routine and homeliness for the older person. This continuation of their lives seemed just as important for the informal caregiver’s well-being as for the older person’s adjustment to a new living situation (40). More specifically, for informal caregivers, it was paramount that their loved ones had a place that looked like home. Furniture from their previous residence was brought in to let the older person feel at home. Additionally, all informal caregivers indicated the importance of continuing routines and habits once the older person resided at the nursing home. Different examples were given, such as the importance of religion, eating habits, and care provision. If these habits were broken, informal caregivers often stepped up ensuring the proceedings of their routines.

> **(Daughter, 59, interview: e1.04)** [‘*So, I asked them like, wouldn’t you be able to place his chair on the ward as it can be tilted. He really can’t get out of his chair and they said: yeah, we could do that. And then another person said no, we have asked, but it is not allowed regarding the safety regulations…then maybe he would have been more comfortable in comparison to the wheelchair which was closed off and which he hated. Then, he would have felt more at home, I think*’.]

The need for a timely transition process versus the need to postpone the transition process

The second paradox showed that, at the moment of the transition, informal caregivers postponed a nursing home admission for as long as possible. In contrast, when looking back, informal caregivers would have preferred a timely transition plan. This shows the paradox between retrospective and prospective needs.

By analysing the interviews, it became clear that informal caregivers would have preferred sufficient time to prepare for the transition process. More specifically, about one-fourth of the informal caregivers specifically indicated the need for a timely organized care process, where sufficient time was taken to recognize, address and discuss a possible transition with family and, if possible, with the older people as well. Moreover, about three-fourths of informal caregivers had a clear idea of what an ideal nursing home would look like. Around half of the informal caregivers focused on location (e.g., a familiar neighbourhood for the older person) or the context of the nursing home (e.g., easy access to the outdoors). They would have preferred more time to visit some nursing homes to allow for careful consideration.

> **(Daughter, 67, interview: V1.09)** [‘*She had to be admitted within 14 days, at the first place available. It was absolutely horrible*’.]

However, the actions of the informal caregivers, at the time of transition, showed that they aimed at keeping the older people home for as long as possible. The negative emotions associated with a nursing home admission made informal caregivers postpone a nursing home admission and thus avoid transitional care until the home situation was unsustainable and dangerous.

> **(Son, 63, interview: Z1.02)** [‘*She then went home where she had to cross a very busy road. She would say: those cars will stop for me. However, we realized something needed to happen*’.]

The majority of informal caregivers waited too long to commence the admission process. They were mentally exhausted and/or the older person was no longer safe. However, this often led to an unsustainable home situation, requiring an immediate admission, which led to a hastened care transition. The older person and informal caregivers were no longer able to prepare for this challenging process. This led one-third of the informal caregivers to feel like the transition process was unexpected and hastened. They indicated feeling overloaded with tasks/information and they did not have the time or space to mentally process the upcoming move.

> **(Daughter, 59, interview: e1.10)** [‘*On Wednesday going to your mother and you sit with her and then your mother is being told that yes, you will be moving on Friday. Then, you have to support your mother and arrange everything, you have to start packing right away, arranging things and you don’t even have, you don’t even have the chance to adequately prepare yourself or straightening things out, this is lacking yes…that should have been prepared better, yes*’.]

Moreover, the few people who started the transition process on time were impeded by an inefficient healthcare system, which influenced the transition experiences. Firstly, it was almost impossible for informal caregivers to initiate this care process themselves. Five informal caregivers felt that they were not taken seriously when addressing the need for transition, and once informal caregivers started contacting the responsible professional caregivers, it was often a lengthy process. They indicated that they had to almost beg, insist, and use strong language. One informal caregiver even used a family friend to start up the transition process. Another informal caregiver was advised by professional caregivers to keep calling, repeatedly, to the responsible care organizations.

> **(Daughter, 44, interview: V1.10)** [‘*Interviewer: But how did you organize the transfer? Participant: …I made use of favouritism, what I mean is, in the nursing home works a girl who lives in our village and my aunt suggested, yeah, try to get in via her*’.]

Secondly, in the Netherlands, older people are only allowed to be put on a nursing home waiting list when they require 24–hour support and care. However, by the time the older person had reached this stage, the informal caregiver often felt burned out and a nursing home admission was required urgently.

> **(Daughter, 59, interview: e1.04)** [‘*However, the GP is much more focused on the medical aspect of care and he had all the medications, and then one time he had a TIA. It is waiting for the big blow, so to speak but that’s how it was told to us. Interviewer: Yes, yes, until the requirements are there to take another step into care. Participant: Yes*’.]

The need to be involved versus the need for distance from care responsibilities

The final paradox focuses on the internal struggle of informal caregivers, especially once the older person is residing at the nursing home. On the one hand, they wanted to be involved and monitor the care process, as they did at home. While, at the same time, they recognized their limitations and chose a nursing home when the care became too burdensome.

More than three-quarters of the participants felt the need to remain involved in the life of the older person after moving to the nursing home. They indicated a need to participate and help direct the care process. They strived to form some kind of partnership with professional caregivers. In this partnership, informal caregivers wanted to be acknowledged as a caregiver while searching for their new role in the nursing home.

> **(Daughter-in-law, 55, interview: V1.05)** [‘*My husband said at a certain moment: Gosh, don’t worry so much, she now lives over there and you need to let go, and I felt something was not right, I can’t let go when something isn’t right*’.]

Although almost all informal caregivers indicated they wanted to remain involved in the life of their loved ones, about half of them stated a need to alleviate the care burden. Some informal caregivers felt they were still burdened with care tasks, taking on care responsibilities normally executed by professional caregivers. Four participants said it was their job to lead the professional caregivers and felt they needed to resolve any issues that arose. While preferably, informal caregivers did not want to direct the care process. They wanted to trust the expertise and experience of the professional caregivers at the nursing home. Therefore, three-quarters of the informal caregivers indicated the importance of a contact person, as an influencing factor. Preferably, informal caregivers want to be introduced to him/her before or on the day of the move, and ideally, it was the same person throughout their stay at the nursing home. Eleven participants described the main responsibilities of these contact persons—to keep in contact with the informal caregiver and be available.

> **(Ex-husband, 72, interview: V1.04)** [‘*One contact person, even if it is a carpenter… Yes, I mean, if you go to the store and you can’t find a certain product, then you also go to the person wearing a blouse or jacket. Then, I think, “Oh, that person I can see.” And that person then has a boss to whom he/she has to answer. That is not my problem, is it?*’]

The search for that balance, between being involved and keeping some distance, was strongly influenced by the other residents residing at the nursing home and the perceived care provision. More specifically, about one-third of informal caregivers indicated having difficulties accepting the new home, if other residents were more cognitively impaired compared to their loved ones. They had more difficulties leaving the older person alone. This could be related to the older people themselves feeling less comfortable and experiencing more difficulties adapting to the new living situation. Moreover, if informal caregivers felt dissatisfied with the care provided, they tended to monitor care more closely. This dissatisfaction was, according to informal caregivers, often related to absenteeism and lack of educated staff. Informal caregivers often criticized the lack of personnel. Two participants specifically indicated the difference between highly educated staff compared to staff in training, which caused a decrease in the quality of care. Moreover, informal caregivers often felt that communication with and between professional caregivers was lacking. This made some informal caregivers intervene in this care process and take on the role of intermediator in the communication process. Informal caregivers defined good communication as being open and honest. They wanted to be able to express their experiences of care with the professional caregivers, and they felt they should be able and time should be made to ask questions. However, half of the participants noticed an inconsistency or a lack of communication between staff which, according to them, led to incomplete care provision.

> **(Daughter, 61, interview: V1.12)** [‘*Everyone should be on the same level of understanding. And that did not happen. Then you noticed that everyone who worked there is an individual with their approach, which I understand. However, there should be a certain, yes, equality, a sort of, yeah, basis, I would call it, which should be the same for everyone…And I missed this, certainly at the beginning*’.]

Discussion

This study aimed to capture the experiences of informal caregivers of older people with dementia throughout the transition process from home to moving into a nursing home. These experiences were characterized by the presence of three paradoxes: 1) contradicting emotions during the transition process; 2) the need for a timely transition process versus the avoidance of transitional care altogether; and, 3) the need to be involved versus the need for distance from care responsibilities. These paradoxes were influenced by the healthcare system, such as the inability to become familiar with a nursing home before receiving an official nursing home placement indication.

This study defined the transition from home to a nursing home as paradoxical. These paradoxes not only narrate the experiences but also provide a deeper understanding of the reasoning of informal caregivers during this process. It showed how fragile this care process is, identifying a fine line between an optimal and fragmented care transition.

To illustrate, while informal caregivers need time to accept the need for a transition, a simple delay at the start of the transition process can lead to a crisis admission. The study by Boots et al. (2015) identified that informal caregivers of individuals in an early stage of dementia had difficulty accepting help, and in later stages of dementia, they wished help would have been offered sooner.

Our results indicate that overall negative feelings associated with moving into a nursing home can be alleviated by a successful care transition. This is supported by the literature stating that the choices and steps made in the pre-transition phase strongly influence the experiences in the post- transition phase (e.g., good information about different nursing homes enables informal caregivers and older people to choose a nursing home that fits their needs) (7, 19). Additionally, different transitional care studies have emphasized the influence of professional caregivers on the transitional care experiences of informal caregivers (5, 7, 11, 19, 41). However, the importance of the social environment and the support of fellow informal caregivers, although strongly present in other studies (5–7, 9, 19, 41, 42), was not clearly stated by the participants in this study. This can be related to the focus of the interviews, which concentrated more on the relationship between the informal caregiver and professional caregivers.

Furthermore, we identified a clear mismatch between retrospective needs for a timely transition process versus the prospective desire of informal caregivers to enable the older person with dementia to remain at home for as long as possible. This paradox provides a possible explanation as to why care transitions are often associated with a crisis and critical events (e.g., hospitalization) (7, 19, 42). This highlights the importance of the nursing home placement occurring at the right time (6, 24).

Our results showed an internal dialogue of informal caregivers struggling to remain a part of the lives of older people while simultaneously letting go of the caregivers' responsibilities. Previous studies have indicated the difficulty for informal caregivers to distance themselves from their caregiver roles and take on new roles once in the nursing home (5, 6, 27, 43, 44). These new roles were described as those of an advocate, quality controller, and representative (9, 19, 43). This is in line with the current study, which identified the need for informal caregivers to remain involved, assure continuity of care, and re-establish previous routines (9, 11, 19, 43).

Finally, all paradoxes were influenced by the operationalization of the healthcare system and whether professional caregivers offered support (practical and emotional). More specifically, in some countries practical matters (e.g. financial burden) may significantly influence the transition process, possibly influencing the paradoxical experiences. However, in the Netherlands, the government finances nursing homes, decreasing the financial burden of informal caregivers and thus its impact on the transition experiences. Moreover, the need for support as expressed by informal caregivers indicates the importance of a partnership with the professional caregivers, preferably led by a contact person appointed on the day of the move. This was also confirmed by Groenvynck et al. (2020), who indicated the overall need of older people and informal caregivers was to form a partnership during the transition process (4).

Implications for research and practice

The results show that the transition from home to a nursing home is more than relocating. They identify the complexity of transitional care and signify the need for improvement. However, the question should be raised if such an improvement is possible. The paradoxes, as described by the informal caregivers, are mostly internal conflicts related to the emotional gravity of the care transition (10–12). This could mean that optimal transitional care simply should recognize and tie into these. Therefore, future research should enable professional caregivers to support informal caregivers in managing these paradoxes. Moreover, the relation of these paradoxes to the current healthcare system should be defined. It is paramount to understand the ability of professional caregivers and policymakers to improve the transition process.

Further insight into these existing paradoxes is important for both professional caregivers and informal caregivers. For informal caregivers, it can be motivating to start planning this care transition on time, and it can prepare them for this upcoming care process. For professional caregivers, it can provide insight into the thought processes of informal caregivers. This can help professional caregivers to better support informal caregivers. For both of them, it can create awareness of the current gaps within the healthcare system (27, 45). Moreover, the paradoxical feelings identified by the participants were found throughout all phases of the transition process (pre-, mid-, and post-transition). This can be confirmed by previous research that indicated that the needs of informal caregivers are constant throughout the entire transition process (4, 5). Future research should define the relationship between the paradoxes and the three transition phases as it would allow for more focused care innovations. Finally, throughout the analysis of the interviews, it became clear how strongly the identified paradoxes are interwoven with one another. One example hereof is how the negative emotions associated with the transition process led informal caregivers to postpone nursing home admission, which in turn led to negative transitional care experiences, followed by a need to more closely control the care environment. Future research should focus on further defining and analysing these interwoven paradoxes. This can be done by relaying these findings to the informal caregiver.

Limitations

Some limitations of the study should be considered. Firstly, the data collection was a secondary data analysis, part of the DEDICATED project focusing on palliative care. Therefore, data collection was started after the older person had passed away at the nursing home and a significant amount of time had passed between the interview and transition. For six participants, the transition thus occurred more than 2 years ago. This retrospective research may have led to recall bias that might have influenced the results. Alternatively, the time between the transition and the interviews may have allowed informal caregivers to rationalize their transition process, possibly providing a more distant recollection of the transitional care process. Secondly, some older people were admitted to a hospital or resided at a different care setting before making the transition to a nursing home. This may have led to different care experiences. However, although the transition pathways were different, the researchers did not find clear differences regarding the identified paradoxes.

Conclusion

The transition process, as experienced by informal caregivers, is defined by three paradoxes. They indicate the fragility of this transitional care process. Therefore, future research should focus on further defining these paradoxes and their link with the care system to determine if the transition from home to a nursing home can be optimized.

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APPENDICES

Appendix 3A. Topic guide: experiences of informal caregivers during the transition from home to a nursing home

General introduction of the project and researcher		
Did the informal caregivers read and understand the informed consent? • Repeat that participation is voluntary. • The data is kept confidential and anonymous. • The interview will be recorded.	**Practical information** • One interviewer/ one observer • Average of 1.5 hours • A break is always possible when necessary.	**The start: characteristics of the older people and informal caregivers.** • Sex (both) • Age (both) • The connection between the participant and the informal caregiver • Education • When did the loved one pass away?

Theme 1: Symptom management

1. What were your experiences with daily care?
   - Were the wishes and preferences of the loved ones noticed and anticipated? - Are the preferences of your loved one known? Please explain.
2. Were professional caregivers able to guarantee comfort?
   - Did the professional caregivers notice and anticipate/react to certain behaviours/signals (e.g. when he/she felt uncomfortable) of your loved one? Please explain.
   - Did the professional caregivers pay attention to your emotional well-being? Please explain.
3. Were the professional caregivers alert to spiritual or life questions? Please explain.
4. Did the professional caregivers have the knowledge to answer these end-of-life questions? Why or why not?"

Theme 2: Interprofessional collaboration

1. Which type of professional caregivers were involved in the care process and during the last months?
   - How did you experience the involvement of these professional caregivers?
2. How were you involved in the care process?
   - Did you feel that you had control in the care process? Why or why not?
   - Did you feel acknowledged as an informal caregiver? Please explain.
   - Did the professional caregivers ask for your experiences in the care process? Please explain.
   - Did the professional caregivers consider your advice? Please explain.
3. Did one person coordinate the care?
   - How did information transfer occur between professional caregivers?
   - Did you often have to repeat information to professional caregivers? Why or why not?
4. What was your general impression of the collaboration between professional caregivers?
   - How was the collaboration between the professional caregivers?
   - Did the professional caregivers know which tasks they had? Please explain.
   - How was the communication process between professional caregivers?
   - Are the collaboration agreements written down? Please explain.
   - Did all professional caregivers execute the collaboration agreements in the same way? Please explain.
5. What would you like to change in the collaboration process?
   - Do you have any advice?

Theme 3: Collaboration between home and nursing home care

1. How did you experience the nursing home transition?
    - How did you and your relative experience the admission day?
    - Were you and your relative prepared for the move to the nursing home? If yes, please explain in which way you were prepared.
    - Could the admission be prevented according to you? Please explain.
    - How were you as an informal caregiver involved with the admission?
2. Were the professional caregivers in the nursing home prepared for the admission of your loved one?
    - Did you have the impression that they were aware of the healthcare situation of your loved one at the nursing home? Please explain.
    - Did one person coordinate the transition process? Please explain.
    - Was it clear who your first contact person was? Why or why not?
    - Could you ask the first contact person the necessary questions? Please explain.
3. How did you experience the handover communication?
    - Who was responsible for the handover, according to you?
    - Did you experience the handover as warm, personal and complete?
    - Was there any information missing during this handover? Please explain.
4. What would you wish to change in the transition process?
    - Is there any advice that you would like to give to the professional caregivers?

Theme 4: End-of-life communication

1. Did you talk about future care needs?
    - How did you experience this dialogue?
    - When and who first addressed these future care needs?
    - Was the moment well-chosen or occurred it too early/late? Please explain.
    - Was your loved one comfortable discussing the care needs?
    - If not, what was the role of the legal representative?
    - Were future care needs documented? Please Explain.
    - Were future care needs met as intended? Please Explain.
2. How did you experience the overall communication?
    - Did the professional caregivers possess the necessary communication skills? Please explain.
    - Did you feel heard throughout the care process? Why or why not?
    - Did you receive emotional support when necessary? Why or why not?
3. What was the cause of death?
    - Was the death of your loved one expected or unexpected and why?
    - Did you receive care after your loved one passed away? How did you experience that?
4. How can the communication regarding end-of-life be improved according to you?
5. Do you have general suggestions for improvement? / Is there anything else you would like to add?

5

Chapter 5

Interventions to improve the transition from home to a nursing home: A scoping review

This chapter was published as:
Groenvynck, L., Fakha, A., de Boer, B., Hamers, J. P. H., van Achterberg, T.,
van Rossum, E., & Verbeek, H. (2022). Interventions to Improve the Transition From
Home to a Nursing Home: A Scoping Review. Gerontologist, 62(7), e369-e383.
doi:10.1093/geront/gnab036

Abstract

Background and Objectives: The transition from home to a nursing home is a stressful event for both older people and informal caregivers. Currently, this transition process is often fragmented, which can create a vicious cycle of healthcare-related events. Knowledge of existing care interventions can prevent or break this cycle. This project aims to summarize existing interventions for improving transitional care, identifying their effectiveness and key components.

Research Design and Methods: A scoping review was performed within the European TRANS-SENIOR consortium. The databases PubMed, EMBASE (Excerpta Medica Database), PsycINFO, Medline, and CINAHL (Cumulated Index to Nursing and Allied Health Literature) were searched. Studies were included if they described interventions designed to improve the transition from home to a nursing home.

Results: seventeen studies were identified, describing thirteen interventions. The majority of these interventions focused on nursing home adjustment with one study including the entire transition pathway. The study identified eight multicomponent and five single-component interventions. From the multicomponent interventions, seven main components were identified: education, relationships/communication, improving emotional well-being, personalized care, continuity of care, support provision, and ad hoc counseling. The study outcomes were heterogeneous, making them difficult to compare. The study outcomes varied, with studies often reporting nonsignificant changes for the main outcome measures.

Discussion and Implications: There is a mismatch between the theory on optimal transitional care and current transitional care interventions, as they often lack a comprehensive approach. This research is the first step toward a uniform definition of optimal transitional care and a tool to improve/develop (future) transitional care initiatives on the pathway from home to a nursing home.

Introduction

A transition can be defined as ‘the move between different healthcare settings or between different levels of care within the same setting’ (1). A common transition experienced by older people and informal caregivers is the transition from home to a nursing home. Generally, this transition pathway can be defined as having three transition phases: the pre-, mid-, and post-transition phases. Despite the differences in delineation in the existing definitions of each transition phase, a suitable definition is provided for all phases. The pre-transition phase begins when a nursing home admission is first discussed and it ends when a nursing home is chosen (2–5). In the mid-transition phase, the older person prepares for the move while on a nursing home waiting list. It ends when the physical move has taken place (3, 4, 6). Finally, the post-transition phase commences the day after placement and focuses on the adjustment to, and acceptance of, the new living situation (3–6). The transition from home to a nursing home can be experienced as a stressful and emotionally challenging event for both older people and informal caregivers (7–9).

For older people, this care transition often entails a sudden change in identity associated with changes in autonomy, daily routine, social status, and contacts (10–12). Informal caregivers can be confronted with feelings of grief and loneliness when relinquishing care to the nursing home (13, 14). These negative experiences can be intensified when transitional care is poorly coordinated and therefore fragmented (15, 16). Poor transitional care can lead to adverse outcomes for both the older person (e.g., mortality, medication-associated events, delirium, and falling incidents) and their informal caregivers (e.g., feelings of guilt, sadness, and failure) (1, 13, 17–20). Furthermore, it leads to an increased cost for the healthcare setting due to the duplication of services, which is associated with work overload and burnout in professional caregivers (21–25).

To avoid these negative outcomes, transitional care can be improved by developing comprehensive, multicomponent transitional care interventions (26). These interventions can focus on the different challenges throughout all transition phases. More specifically, in the pre-transition phase, challenges include, but are not limited to, a first-time transitional care discussion or choosing an appropriate nursing home. In the mid-transition, this can entail the transfer of medical information to the nursing home and organizing a warm welcome. Post-transition interventions can focus on making the resident and informal caregiver feel at home. Moreover, these interventions ideally provide a continuous pathway throughout the three phases of transitional care (1, 27). Preferably, the interventions are tailored to the needs of older people, informal caregivers, and professional caregivers, also referred to as the ’triad of care’ (5, 18, 26). A recent literature review by Groenvynck et al. (2020) led to the development of the TRANSCIT model. The model identified the need for communication, information, support, time, and a partnership with professional caregivers throughout the whole transition process. This extensive list of identified needs highlights the importance of integrating multiple intervention components throughout the transition from home to a nursing home. A multicomponent intervention is, moreover, encouraged by the WHO when aiming to improve transitional care (26).

Given this knowledge, the literature on the care pathway from home to a nursing home is relatively scarce as most transitional care research focuses on the transition from and to a hospital (28). As far as we are aware, only one systematic review has focused on interventions in the transition from home to a nursing home. However, this review focused on comparing the effectiveness of existing transitional care interventions. Moreover, the systematic review only included interventions offering support (29). Currently, a comprehensive overview of existing interventions and their intervention components is missing. Additionally, it is unclear how these interventions can contribute to the defragmentation of care while taking the care triad of older people, informal caregivers, and professional caregivers into account. Therefore, this scoping review aims to summarize the existing interventions designed to improve the transition from home to a nursing home by identifying their key components and intervention effectiveness.

Method

A scoping review was conducted following the steps of Arksey and O'Malley (2005) and adhering to the Preferred Reporting Items for Systematic Reviews and Meta-Analyses extension for Scoping Reviews (PRISMA-ScR) (30, 31). This review type was chosen to identify the intervention components, the scope, and gaps in the literature regarding care transitions (32). The PRISMA checklist for scoping reviews was used (Appendix 5A) (31). The five steps described by Arksey and O'Malley (2005) were followed. These steps were followed as they provide a framework for systematically conducting this scoping review to enhance reliability and replicability (30).

Data sources and search strategy

Stage 1: Identifying the research question

Based on the identified gap in the literature, a research question was formulated: 'Which interventions, aiming at the improvement of transitions from home to a nursing home, are described in the peer-reviewed literature?' This research question was used to build the search string for which four key terms were identified: 'older people,' 'transitional care,' 'home care,' and 'nursing home.' For each of the key terms, synonyms and related terms were searched. A librarian reviewed and finalized the search string for every electronic database employed. The search string for PubMed can be found in Appendix 5B.

Stage 2: Identifying relevant studies

Five electronic databases were searched for potential studies: PubMed, Medline, PsycINFO, CINAHL (Cumulated Index to Nursing and Allied Health Literature), and EMBASE (Excerpta Medica Database). The final search was performed on May 11, 2020. Additionally, relevant studies were identified using the reference lists of the included studies and the reference lists of reviews relevant to the research question.

Study selection

Stage 3: Study selection

The studies were included if they were published in Dutch or English and published between January 2000 and May 11, 2020. There were no restrictions regarding the study design. Studies were included if (a) they described an intervention aiming to improve transitional care; (b) the target populations, meaning the person(s) for whom the intervention was developed, were older people (65 and older), informal caregivers, and/or healthcare professionals (in)directly involved in the transition process; and, (c) the study focused on the transition from home to permanently residing in a nursing home. In this article, the term nursing home is used to define a long-term care facility where room and board and 24–hour assistance are provided to older people who have complex care needs due to physical and cognitive impairment (33). Studies were also included when the older person had a short hospital stay before a first-time nursing home admission. Moreover, studies focusing on a first-time nursing home admission, with the origin of the move not specifically stated, were also included. Studies were excluded if they did not describe an intervention or if the transition pathway or future care facility was not clearly defined.

The search results were uploaded to EndNote from which the screening process commenced. The first author screened the titles and subsequently the abstracts of the identified studies. A fellow researcher independently screened 10% of the studies. For both screenings, the first author made an easy-to-follow chart containing the inclusion and exclusion criteria of each screening phase. If the researchers did not reach a consensus of 90%, the second researcher screened an additional 10% of the records. Both authors screened the full-text articles. Disagreements were resolved by re-evaluating the inclusion and exclusion criteria with the second screener and via discussions with the entire research team.

Data extraction and analysis

Stage 4: Charting the data

A data-charting form was made, using the MS Office program Excel, to extract data from the included studies. The data-charting form included the aim of the intervention, the target population, and a description of the intervention characteristics. The interventions were described per component and linked to one of the transition phases (pre-, mid-, or post-transition) (27). Furthermore, study characteristics such as the goal, study design, participants' characteristics, and data collection methods were also charted.

Stage 5: Collating, summarizing, and reporting the results

Data analysis was performed for the study characteristics, intervention components, and effectiveness of the intervention. First, the study characteristics were analyzed descriptively. Second, a thematic analysis was performed, identifying the different intervention components used to improve the transition from home to a nursing home. Third, the included interventions were compared to the earlier described TRANSCIT model. More specifically, all interventions were categorized according to the three transition phases (the pre-transition, mid-transition, and post-transition phases) and compared to the overall key components: partnership, communication, information, support, and time (27). Finally, a summary was conceived, describing the process and outcome evaluations of the included studies.

Results

The database search identified 9,757 studies after duplicates had been removed (see flowchart, Figure 1). Following the screening of titles and abstracts, 106 studies qualified for full-text screening. A total of twelve out of these 106 were included in the scoping review. The snowball method led to the inclusion of an additional five studies. Finally, a total of seventeen studies were considered relevant to the research question. The seventeen studies described thirteen distinct interventions.

Study characteristics

An overview of the study characteristics is given in Table 1. The studies were conducted in the United States (*n* = 11), Australia (*n* = 2), the Netherlands (*n* = 2), and the United Kingdom (*n* = 2). The study designs used by the researchers were randomized control trials (*n* = 6) (34–39), quasi-experimental study designs (*n* = 2) (14, 40), mixed-method studies (*n* = 3) (41–43), observational studies (*n* = 3) (44–46), two study protocols (*n* = 2) (47, 48), and a qualitative explorative study (*n* = 1) (49).

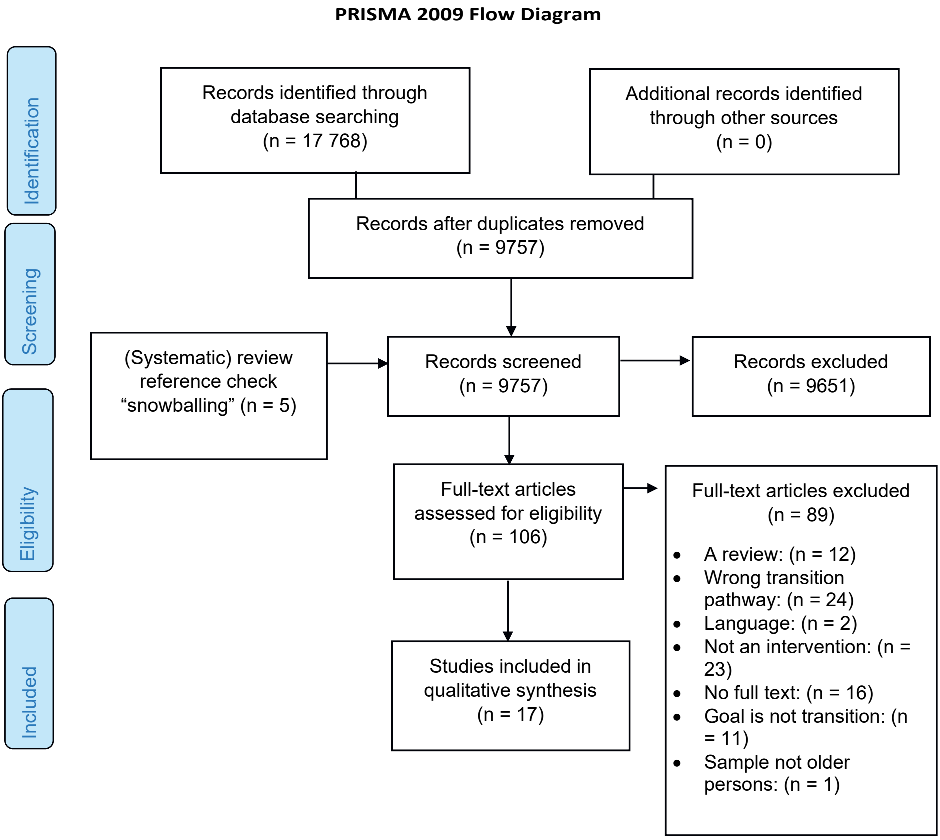

Figure 1: PRISMA flowchart: data selection process. PRISMA = Preferred Reporting Items for Systematic Reviews and Meta-Analyses.

The interventions

Table 1 presents the characteristics of the thirteen interventions. None of the described interventions directly targeted or focused their intervention on the entire triad of care, meaning the older person, informal caregiver, and professional caregivers. Only the study of Van Mierlo et al. (2015) directly targeted professional caregivers/informal caregivers and indirectly targeted the older person. Six interventions solely targeted informal caregivers. Five interventions mainly targeted older people, and of those, two interventions included older people with dementia (42, 43, 47). Finally, the study of Meiland et al. (2002) targeted the healthcare system by developing a better waiting list system. The most common interventionists were clinicians trained to conduct the intervention (14, 34–41, 47–49). Three interventions were delivered by professional caregivers responsible for the daily care of an older person (e.g., nursing staff and hospital physicians) (42, 43, 45, 46). Finally, Lichtenberg et al. (2007) trained peer, informal caregivers at the nursing home to deliver the intervention.

Table 1: Characteristics of the studies

Study; country	**Goal of study**	**Design**	**Sample and age[a]**	**Measures**	**Outcomes**
Crotty et al., 2004; Australia	To investigate whether the quality of first-time transfer of older people from a hospital to an NH would be improved by having a pharmacist coordinate the transition.	Randomized controlled trial	Older person (*n* = 110); age: 82 mean (6.4 SD)	Older people's medication charts; case note	**Intervention outcomes:** (a) the quality of prescribing; (b) hospital usage, falls, worsening mobility, increased confusion, worsening behaviours, and pain; and, (c) adverse drug events and some medication-related problems at admission
Davis et al., 2011; United States of America	**FITT-NH—intervention:** To report on the preliminary findings of the intervention for informal caregivers who had recently placed a family member with dementia into an NH for long-term care.	Randomized control trial	Informal caregivers (*n* = 53); age: 57.25 mean (10.67 SD)	Face-to-face assessments, self-report measures; audiotaped intervention sessions; assessment telephone calls	**Intervention outcomes:** (a) informal caregiver guilt, depression, burden; (b) hassles with staff; (c) satisfaction with the NH; and, (d) return to daily activities **Intervention outcomes:** (a) satisfaction with the program, and (b) adherence to the intervention
Davison et al., 2020; Australia	**PEARL—intervention:** To address the high rates of depression in NH by using an individually tailored care approach addressing the psychological needs of newly admitted older people.	Study protocol	Not applicable	Audiotaped sessions;	**Intervention outcomes:** depressive disorder/ symptoms **Secondary outcomes:** (a) treatment fidelity; (b) stress; (c) anxiety; (d) quality of life; (e) adjustment to an NH; (f) functional dependency; (g) meaningful activity in residential care; and, (h) resident perception of NH allocation
Gaugler et al., 2008; United States of America	**NYUCI—intervention:** To determine whether the availability of long-term counselling and support reduces the burden and depressive symptoms throughout the transition.	Randomized controlled trial	Informal caregiver (*n* = 385); age: 71.55 mean (8.71 SD) for the intervention group	Interviews, intervention records, and ad hoc telephone contact records	**Intervention outcomes:** (a) informal caregiver burden, and (b) informal caregivers' mood and psychological well-being

Gaugler et al., 2011; United States of America	**NYUCI—intervention:** To estimate the effects of comprehensive psychosocial support intervention and NH admission for a person with Alzheimer's disease on husband and wife caregivers' well-being.	Randomized controlled trial	Informal caregivers (*n* = 406); age: 71.6 mean (8.7 SD) for the intervention group; 71.0 mean (9.5 SD) for the control group	Interviews, intervention records, and ad hoc telephone contact records	**Intervention outcomes:** (a) informal caregiver burden, and (b) informal caregivers' mood and psychological well-being
Gaugler et al., 2015; United States of America	**RCTM—intervention:** Whether and how a psychosocial family intervention reduced negative experiences associated with the admittance of cognitively impaired older people in an NH.	Mixed-method study	Informal caregivers (*n* = 36); age: 62.9 mean (10.9 SD) for the intervention group; 62.5 mean (14.4 SD) for the control group	Interviews, checklist and counsellor notes, and focus groups	**Intervention outcomes:** (a) the transition placement and how the intervention helped informal caregivers and enhanced engagement with older people or NH staff; (b) dementia severity; (c) stress; (d) depressive symptoms; and, (e) informal caregiver adaptation to placement
Gaugler et al., 2020; United States of America	**RCTM—intervention:** To describe the protocol the intervention will employ to determine whether and how the intervention can help families better navigate NH transitions of cognitively impaired older people.	Study protocol	Not applicable	Surveys, contact log, counsellor notes, intervention review checklist, semi-structured interviews	**Intervention outcomes:** (a) the older people's ADL and IADL; (b) socio-emotional support and informal caregiver self-efficacy/competence; (c) primary subjective stress during NH placement; (d) NH stress; and, (e) informal caregivers' depressive symptoms
Hayward et al., 2018; United Kingdom	To develop and validate the feasibility and intervention focused on promoting healthy adjustment in the initial stage of residency, for older people with dementia following placement into an NH.	Mixed-method study	Older people (*n* = 13); age: 87.9 mean (7.2 SD)	Copies of the workbook, recorded field reports, semi-structured interviews	**Process outcomes:** (a) delivery of the intervention; (b) feasibility and barriers of implementation when implementation took place; (c) feasibility and barriers when implementation did not take place; (d) staff benefits yet resident outcome reports were contradictory; (e) improvements to SettleIN; and, (f) validation of qualitative results

Table 1 continues on next oage.

Table 1: *Continued*

Study; country	Goal of study	Design	Sample and age[a]	Measures	Outcomes
Lichtenberg, 2007; United States of America	**Mentoring model:** To test an intervention that aims to assist family caregivers who were beginning the transition to having their loved one in an NH.	Longitudinal observational study	Informal caregivers (*n* = 20); age: 60.1 mean (13.4 SD)	Assessment tools, mentor logs	**Process outcomes:** satisfaction with the mentor
Meiland et al., 2002; The Netherlands	**Urgency coding intervention:** To study an intervention's fair selection of older people waiting for admission to a psychogeriatric NH.	Longitudinal observational study	Dyad (*n* = 93); age: 83.2 mean (range 51–96) for older persons with dementia; 57.3 mean (range 24–89) for informal caregivers	Structured questionnaire in the face-to-face interview, self-reported questionnaires, interview, older people's files	**Intervention outcomes:** (a) the dynamics in the urgency code; (b) reasons for a higher urgency coding; (c) urgency codes related to the waiting time; (d) urgency codes concerning the preference for a particular NH; and, (e) transfer to the preferred NH
Mukamel et al., 2016; United States of America	To test whether the use of a personalized report card embedded in a reengineered discharge process can lead to better outcomes in the transition from hospital to an NH.	Randomized controlled trial	Older people (*n* = 225); age: 75.6 mean (10.5 SD) for the control group; 74.9 mean (9.9 SD) for the intervention group	Log information of data entered in the iPad, survey, and medical records	**Process outcomes:** perceived waiting time Intervention outcomes: (a) iPad use; (b) confidence and satisfaction with the decision; (c) hospital ranking and distance; and, (d) length of hospital stay
Paun & Farran, 2011; United States of America	**CGMI—intervention:** To present a study description focusing on the development and implementation of the intervention.	Quasi-experimental design	Informal caregivers (*n* = 34); age: 60.7 mean (10.65 SD)	A questionnaire	**Process outcomes:** (a) feasibility of the intervention; (b) experience with the intervention; and, (c) satisfaction with the intervention
Paun et al., 2015; United States of America	**CGMI—intervention:** To determine the feasibility and the preliminary effects of the intervention on informal caregivers' outcomes.	Quasi-experimental design	Informal caregivers (*n* = 83); age: 60.7 mean (10.65 SD)	Population survey, three direct questions	**Intervention outcomes:** (a) informal caregivers' conflict management skills; (b) exacerbators of grief in an NH environment; and, (c) informal caregiver knowledge, chronic grief, depression **Process outcomes:** (a) feasibility and (b) satisfaction with the program

Saint-Bryant et al., 2020; United Kingdom	To examine the feasibility and effectiveness of the enhanced version of the SettleIN intervention.	Mixed-method study	Older people (*n* = 19); age: 87.9 mean (7.20 SD)	Residents' care plan at the NH, semi-structured interviews	**Intervention outcomes:** (a) current adjustment support; (b) residents' psychological well-being; (c) residents' quality of life; and, (d) residents' overall adjustment **Implementation outcomes:** (a) recruitment and retention; (b) implementation; (c) program factors acting as barriers; (d) individual resident factors; (e) acceptability of SettleIN; and, (f) overcoming challenges
Schulz et al., 2014; United States of America	To test the efficacy of an informal caregiver intervention for family members who recently placed their relative in an NH.	Randomized control trial	Dyad (*n* = 217); age: 61.8 mean (10.78 SD) for informal caregiver; 82.8 mean (9.23 SD) for older people	Assessment tools	**Intervention outcomes:** (a) depression; (b) anxiety; (c) caregiver burden; (d) complicated grief; (e) perceived quality of care in the NH; (f) satisfaction with the care provided; (g) problems with the NH; (h) functional status; (i) perceived quality of life of the older person; and, (j) advanced care planning
Van Mierlo et al., 2015; The Netherlands	To conduct a process evaluation and evaluate a mental health care transfer intervention after an older person with dementia moves to an NH.	Qualitative explorative study design	Older people (*n* = 24) and informal caregivers (*n* = 20); age: 82 mean (7.5 SD) for older people; 57.7 mean (16.5 SD) for informal caregivers	File research, structured interviews, semi- structured questionnaire, clinical assessment	**Intervention outcomes:** (a) outcomes of barriers and facilitators of the implementation; (b) face-to-face evaluation by caregivers; and, (c) evaluation of the face-to-face follow-up by an NH staff/conductor of the intervention
Ward et al., 2008; United States of America	To develop an intervention that expedites the delivery of medication orders during the transfer of older people from the hospital to an NH.	Observational study	Older people (*n* = 20); age: 83.0 mean (9.22 SD)	NH medical records, medication administration records	**Intervention outcomes:** (a) implementation of the intervention protocol; (b) arrival time at the NH; (c) discrepancies in medication orders; (d) delay or omission of medication doses; and, (e) severity of omitted medication

Note: NH = nursing home; FITT-NH = Family Intervention: Telephone Tracking-Nursing Home; NYUCI = New York University Caregiver Intervention; PEARL = Program to Enhance Adjustment to Residential Living; RCTM = The Residential Care Transition Module; CGMI = Chronic Grief Management Intervention; ADL = activities of daily living; IADL = instrumental activities of daily living.

[a] Age in years.

The thirteen interventions are divided into two groups. The first group includes multi-component interventions. These are interventions conducted over multiple weeks/months, implementing multiple intervention elements. The second group describes single-component interventions. These interventions were shorter, denser, and focused on one specific element of the transition.

Multicomponent interventions

Eight of the thirteen interventions described a multicomponent intervention (Appendix 5C). The interventions were composed of multiple sessions, defined as meetings organized to exchange knowledge, educate, and/or offer support. The number of sessions varied between six and 21. Most sessions were one-on-one. However, they were often extended by inviting family and staff to participate (35–37, 39, 41–44, 47, 48). Paun et al. (2011, 2015) provided the only group-based program. Seven intervention components were identified from these eight interventions: education, relationships/communication, improving emotional well-being, personalized care, continuity of care, support provision, and ad hoc counselling.

Education

Education entailed the provision of information and the acquisition of skills to facilitate transitional care for both older people and informal caregivers. The education component could focus on all different challenges of transitional care, regardless of the transition phase. For instance, the education component of one intervention focused on multiple elements of the transition process (36, 37), whereas the education of another intervention focused on the adaptation of the informal caregiver to the new living situation (14, 35, 39–41, 44, 48). Hence, there was a diversity in transitional care challenges for which education was provided.

Seven of the eight interventions provided older people and informal caregivers with the necessary education aiming to aid adjustment to the nursing home. The informative education was usually provided to informal caregivers, mainly addressing four topics: (a) dementia; (b) problem solving; (c) nursing home policy and practice; and, (d) caregiving (14, 35–37, 39–44, 47, 48). Six of the eight interventions included educating informal caregivers on dementia (14, 35-37, 39–41, 44, 48). Four interventions provided education to older people and informal caregivers on the organizational structure and procedures of a nursing home (14, 39, 40, 44, 47). Finally, three interventions provided education to informal caregivers themselves on the importance of self-care. Knowledge concerning the psychological and physical effects of caregiving and the importance of 'care for the caregiver' was taught (35, 44). Additionally, information on advanced care planning (e.g., living will and power of attorney), residents' rights, and problem reporting at the nursing home was imparted to informal caregivers (39).

Furthermore, five of those interventions mentioned teaching problem-solving techniques and conflict resolution for informal caregivers. The study of Davison et al. (2020) also mentioned teaching problem-solving techniques and conflict resolution to older people. More specifically, three interventions offered training to their participants on the skills required to resolve problems or address barriers to adjustment. Two interventions aided problem solving (14, 35, 40, 41, 44, 47, 48).

Relationships/communication

This intervention component focused on the importance of efficient collaboration and communication between the care triad of professional caregivers, informal caregivers, and older people. More specifically, six interventions aimed to improve communication, facilitate cooperation, and mend relationships between residents, staff, or other family members to help with nursing home adjustment (14, 35–37, 40, 41, 44, 47, 48). This was done by improving autonomy and by providing techniques and strategies to facilitate communication (14, 35–37, 39–41, 44, 47, 48).

Improving emotional well-being

Six interventions used different strategies to improve emotional well-being throughout the transition from home to a nursing home. The strategies used were improving the coping process, helping to adjust, facilitating role acceptance, and encouraging positivity and well-being (14, 35, 39– 41, 44, 47, 48).

Three out of six interventions specifically addressed strategies to improve coping. Davis et al. (2011) and Lichtenberg et al. (2007) taught informal caregivers different coping styles, and how to handle general problems throughout transitional care. Two interventions aimed to improve adjustment to the new living situation for informal caregivers. Davis et al. (2011) targeted emotional adjustment by addressing feelings of guilt and loss while Paun et al. (2011, 2015) let informal caregivers discuss hindering and facilitating elements of the adjustment/acceptance that the older people are no longer home. Moreover, the intervention supported the relinquishment of old attachments. The same interventions also offered support in adapting to changes in the caregiver role (14, 35, 40). Finally, five interventions used strategies to improve older people and informal caregivers well-being and offer positivity (14, 35, 39–41, 47, 48). Three interventions achieved this by reinforcing positive thoughts, successes, and achievements (14, 35, 40, 47). Two interventions used relaxation techniques and exercises (39, 41, 48).

Personalized care

Several interventions described personalized care as a patient-centered care approach in which the preferences and needs of the target population are an integral part of the care intervention. Six of the eight interventions tailored their intervention to the needs, preferences, and life stories of both older people and informal caregivers (35–37, 39, 41–43, 47, 48). Gaugler et al. (2008, 2011) used individualized sessions to address the unmet needs of informal caregivers. However, they failed to provide information on how they tailored their intervention. Four studies conducted some form of assessment to achieve tailored care (35, 39, 42, 43, 47). Schulz et al. (2014) assessed the knowledge/skill levels of the informal caregivers before every session, while Hayward et al. (2018), Saint-Bryant et al. (2020), Gaugler et al. (2015, 2020), and Davis et al. (2011) assessed their participants at the beginning of the intervention. Davison et al. (2020) used a structured tool to develop a personalized plan for creating meaningful activities and increasing autonomy for the older person. Hayward et al. (2018) and Saint-Bryant et al. (2020) were the only ones who offered a completely individualized intervention for older people based on a needs assessment at the start of the intervention.

Continuity of care

Continuity of care referred to the follow-up of a transitional care intervention. This included transferring the responsibility for a successful intervention implementation from the interventionists to care professionals in the field. This entailed informing care professionals how to continue the intervention as well as gathering the necessary information to plan future care (35, 38, 41–43, 47–50). After terminating the intervention, in five of the included studies, the researchers transferred the necessary knowledge and information to professional caregivers responsible for further care of the older person (35, 38, 41, 47–49). The studies of Davison et al. (2020), Hayward et al. (2018), and Saint- Bryant et al. (2020) specifically focused on further implementation of their interventions. Davison et al. (2020) taught key staff members how to use their intervention and they selected individual actions to implement in future care. Hayward et al. (2018) and Saint-Bryant et al. (2020) summarized the older person’s perspective and used it to plan future care. Furthermore, four interventions kept written records of the intervention outcomes and goals to further optimize care (35, 41–43, 47, 48).

Support provision

Four interventions offered emotional and social support to improve transitional care for informal caregivers (35–37, 39, 41, 48). Emotional support was offered by Schulz et al. (2014) and Davis et al. (2011), who used psychological strategies (e.g., validation or venting) and offered a listening ear. Social support was found in three interventions. Davis et al. (2011) and Gaugler et al. (2015, 2020) encouraged participants to build a social network, providing support beyond the intervention—either as part of the intervention or within a family network. Finally, Gaugler et al. (2008, 2011) let participants join an Alzheimer's support group as part of the intervention.

Ad hoc counselling

In the three interventions, care on demand was offered by providing ad hoc support/counselling as part of the intervention (36, 37, 41–43, 48). The two interventions of Gaugler et al. (2008, 2011, 2015, 2020) left informal caregivers free to contact the study counsellor whenever a problem or change occurred. In the interventions of Hayward et al. (2018) and Saint-Bryant et al. (2020), the lead researcher provided weekly support to professional caregivers conducting the intervention.

Single-component interventions

The second group included five single-component interventions (Appendix 5D) (34, 38, 45, 46, 49). Three of the interventions focused on a specific element of the pre- and/or mid-transition phase. More specifically, one intervention was an urgency coding system aiming for a more efficient nursing home waiting list system (45). As part of one intervention, professional caregivers at the nursing home were informed about challenging behaviours in newly admitted older people and they supported the informal caregiver in their coping process (49). In the third intervention, an app was developed to create a personalized nursing home list based on the preferences and needs of older people (38). The two remaining interventions were medication reconciliation interventions from the hospital to a nursing home, in individuals who initially lived at home (34, 46).

Results concerning the TRANSCIT model

It was notable that only the intervention of Gaugler et al. (2008, 2011) looked at transitional care as a continuum, including all three transition phases in the intervention. However, Gaugler et al. (2008, 2011) only focused their intervention on informal caregivers. The other interventions all focused on one or two transition phases. More specifically, Mukamel et al. (2016) focused on the pre-transition phase, while the interventions of Meiland et al. (2002) and Ward et al. (2008) focused on the mid-transition phase.

Eight interventions focused on the post-transition phase. To be precise, they developed interventions to aid the adjustment process after older people relocated to a nursing home (14, 35, 39–44, 47–49). The remaining study of Crotty et al. (2004) focused on both the mid- and post-transition phases.

As the majority of studies only focused on one specific transition phase, the continued partnership between older people, informal caregivers, and professional caregivers could not be offered. The intervention of Gaugler et al. (2008, 2011), which included all the transition phases, inadvertently addressed this partnership by offering ad hoc care whenever the informal caregiver needed it. The key component information, as identified by the TRANSCIT model, was found in all but one intervention of Meiland et al. (2002) and it was delivered in different forms (e.g., psychoeducation and skill development). Moreover, the majority of interventions used communication to transfer care to other professional caregivers (14, 34–37, 40–44, 46–48). Nine interventions offered support. However, it was noticeable that support was mostly offered in interventions targeting informal caregivers (14, 35–37, 39–44, 47–49). Finally, only three interventions focused on guaranteeing sufficient time (38, 45, 46). To conclude, it was noticeable that although different key components of the TRANSCIT model were identified throughout each of the interventions, none of the interventions took into account all key components combined (communication, information, support, and time).

Process and outcome evaluation

The majority of studies (*n* = 15) reported on the process and/or effectiveness of the studied interventions. In general, the study outcomes were heterogeneous, making them difficult to compare. This was exacerbated by the broad intervention aims described in some studies. More specifically, the aims of the single-component interventions (e.g., medication reconciliation) were more strongly related to the outcomes measured (e.g., medication omittance). This can be explained by the specific focus of single-component interventions, allowing for concrete outcome measures. This focus was not present in the studies describing the multicomponent interventions, as they often had a broader aim (e.g., facilitating nursing home adjustment or skills and knowledge acquisition). More specifically, this meant that the aim of these multicomponent interventions (e.g., facilitating adjustment) could not directly be related to the outcome measured (e.g., burden). Therefore, it was difficult to compare the studies, focusing on the same goals, as they measured different outcomes.

Process outcomes such as satisfaction and feasibility were reported in twelve studies (14, 35–38, 40, 42–46, 49). Studies reporting on satisfaction were positive overall. Despite the occasional suggestion for improvement, the participants were satisfied with the interventions developed (35, 38, 40, 43–45, 49). The studies of Van Mierlo et al. (2015) and Ward et al. (2008) looked at the fidelity of their intervention. Ward et al. (2008) had good fidelity with the intervention being followed as intended, except for the timely handover of medication orders. This is in contrast to Van Mierlo et al. (2015), whose intervention was not able to advise professional caregivers on behavioural problems in admitted residents, as prescribed in the intervention protocol. The two interventions measuring feasibility indicated positive results (40, 42, 43).

The intervention effectiveness was measured by thirteen studies, six interventions in the multicomponent group, and four interventions in the single-component group (14, 34–43, 45, 46). In the multicomponent group, most studies indicated the importance of the evaluation of psychological well-being in informal caregivers after nursing home admission. These studies were generally unable to show significant effects. More specifically, five studies investigated depression and/ or depressive symptoms in the post-transition phase among informal caregivers. No significant changes were found (14, 35, 39–41). Notably, the two studies testing the effect of the intervention, which included the entire transition pathway from home to a nursing home (pre-, mid-, and post-transition), did find a positive effect on informal caregiver depression (36, 37). Other outcomes measured in the studies on the multicomponent interventions were caregiver guilt, caregiver burden, and caregiver stress. The effectiveness of these studies was mixed (35–37, 41). An example of these mixed results is the caregiver burden. The intervention performed by Davis et al. (2011) did not reduce caregiver burden, while the intervention of Gaugler et al. (2011) was able to reduce burden, but only in women. Moreover, interventions indicating these positive results were not able to indicate positive results at all the time points they measured (14, 36, 37, 39, 41).

All single-component interventions, except for Van Mierlo et al. (2015), reported on effectiveness. The intervention of Meiland et al. (2002) significantly reduced the waiting time for people with a higher or the highest urgency code, when compared with the ’normal’ urgency group.

The study of Mukamel et al. (2016) reported that older people choose significantly better-quality nursing homes. The quality of those nursing homes was determined based on the quality report cards. Finally, Crotty et al. (2004) and Ward et al. (2008) studied a medication reconciliation intervention. Crotty et al. (2004) showed a significant reduction in the medication appropriateness index. This is in contrast to Ward et al. (2008), whose intervention did not reduce the delay or omittance of medication doses.

Discussion

This scoping review examined the existing interventions designed to improve the transition from home to a nursing home by identifying their key components and intervention effectiveness. A comprehensive intervention, including the care triad of the older person, informal caregivers, and professional caregivers, taking into account all phases in the transition process, is missing. All thirteen included interventions focused on either a specific phase or target population throughout the transition process. None of the interventions included the care triad (older people, family caregivers, and professional caregivers), and only one intervention focused on all phases of the transition process. Eight interventions were multicomponent interventions, in which seven intervention components were identified: education, relationships/communication, improving emotional well-being, personalized care, continuity of care, support provision, and ad hoc counselling. These intervention components mostly addressed informal caregivers, thus dealing with the consequences of, and adjustments to a new life situation after the older person moved into a nursing home. The five remaining interventions were single-component interventions on a variety of topics. These were shorter, denser, and focused on one specific element of the transition. Overall, studies reported high levels of satisfaction with the interventions, although insight into the effectiveness was mixed, mainly due to the high heterogeneity of the outcome measures used.

The results of the scoping review indicated that almost all interventions from home to a nursing home focused on one phase of the transitional care process, with the majority focusing on the post-transition phase (14, 35, 39–44, 47, 48). This is in contrast to recommendations in the literature expressing the importance of including the entire transition process (27, 51, 52). Moreover, evidence suggests that the experience of the pre-transition phase can significantly affect the outcomes of the post-transition phase, which indicates the importance of starting a transitional care intervention before admission (7, 13, 53). However, the seven intervention components were derived from interventions that mostly focused on nursing home adjustment (the post-transition phase). This makes generalizing the identified intervention components as standard throughout the whole transition process difficult. Only one intervention by Gaugler et al. (2008, 2011) did comprise the entire transition process from pre-transition to post-transition. The intervention showed promising outcomes on effectiveness (e.g. depressive symptoms) (36).

The results of this scoping review showed that a comprehensive intervention that includes the care triad of the older person, informal caregivers, and professional caregivers is lacking. All interventions targeted a specific target population. Most studies focused their intervention on either the older person or the informal caregiver, with only two studies focusing on the role of the professional caregiver or the healthcare system. This might be explained by the fact that older studies, aiming to improve care for informal caregivers and older people with dementia, did not target the latter due to their cognitive status (35–38). Literature, however, emphasizes the importance of recognizing the older person (regardless of a dementia diagnosis), the informal caregiver, and the professional caregiver as an inseparable care triad throughout the transition process. More specifically, the professional caregiver should have the necessary skills to coordinate the care process in collaboration with the older person and the informal caregiver by integrating the perspectives of all involved (24, 26, 52, 54, 55). The importance of this care triad was also demonstrated in a recent review of needs during the transition period, as expressed by older people and informal caregivers. Here, older people and informal caregivers expressed the need to form a partnership with professional caregivers throughout the transition process from home to a nursing home (27).

Limitations

A few limitations need to be addressed. First, the search string built for this review might not have identified all transitional care interventions available from the literature due to the heterogeneity of terminology for transitional care and related interventions. The researchers consulted a librarian who specialized in building search strings. However, the researchers acknowledge that some degree of uncertainty remains about retrieving all relevant studies. Furthermore, some interventions might only be found in grey literature, which was not considered in this study. Additionally, language restrictions were imposed, including only Dutch and English language papers.

Second, data extraction and analysis were challenging for reasons of incomplete or vague intervention descriptions in some studies. Vague descriptions of interventions complicated the thematic analysis of the intervention components as it was often unclear just how the interventions were conducted. Moreover, these incomplete descriptions made us unable to identify the exact transition pathway of the study. This may have led to the exclusion of relevant studies. Finally, a quality appraisal of the included studies was not performed, as this review primarily aimed to provide an overview of existing interventions focusing on improving the transition from home to a nursing home. However, for the additional aim of considering the effects of such interventions, omitting such a quality assessment is a limitation.

Practice and/or policy implications

Transitional care is defined as a set of actions designed to guarantee continuity of care (1). This scoping review identified a clear mismatch between optimal transitional care as defined in the literature and transitional care initiatives evaluated in scientific studies. More specifically, this review has shown that a comprehensive intervention, starting when transitional care is first considered (pre- transition) and ending when the older person/informal caregiver adjusted to the new living situation (post-transition), and in which the older person, informal caregiver, and professional caregivers are considered an inseparable care triad, is missing in the literature. Perhaps it might not be feasible for an intervention, concerning budget and time constriction, to include all transitional care phases. However, interventionists should appraise the previous and proceeding phases following a certain transition event (e.g. choosing a nursing home). Yet, this kind of appraisal was not found in current intervention studies. It probably indicates that transitional care is still insufficient, and often too narrowly focused, possibly leading to fragmented care (25). Moreover, it suggests that healthcare organizations are often considered as individual entities, rather than links in a continuous chain.

Interventions aiming to create continuity and ensure coordination between care settings are highly warranted. Researchers, policymakers, (in)formal caregivers, and older people should work together to define optimal transitional care and uniform outcome measures (1, 26). This standardization can aid in the comparison of alternative transitional care interventions, thus enabling the identification of the most effective transitional care interventions and their components. Moreover, a partnership between these policymakers, (in)formal caregivers, and older people should be established, starting in the pre-transition phase and continuing into the post-transition phase (16, 18, 27). This scoping review offers the first step toward the identification of common elements in designing an intervention facilitating the transition from home toward a nursing home. The seven potentially relevant intervention components could be used to develop a transitional care plan based on the needs of older people and their families (1, 26). Combining components in a multifaceted intervention is supported by the WHO, indicating the importance of combining different intervention components to optimize the transition process (26). As most of these intervention components were created from interventions designed for the post-transition phase, future research should focus on determining the effectiveness of these components throughout the transition process and identify any missing intervention components. Moreover, these intervention components, once evaluated, can be used as a first step in composing a tool or guideline aiming at the improvement of current transitional care initiatives and the development of overarching transitional care initiatives.

Conclusions

This review identified a mismatch between optimal transitional care and the focus/content of existing, transitional care interventions designed to improve the transition from home to a nursing home. The majority of interventions either focused on a specific transition phase rather than the overall transition continuum or focused on specific stakeholders rather than all stakeholders involved. This limits a continuous partnership in which the needs of the older person and informal caregiver are paramount. However, common intervention components have been identified: education, relationships/communication, improving emotional well-being, personalized care, continuity of care, support provision, and ad hoc counselling. These components can be considered in building a comprehensive transitional care intervention that optimizes and defragmentizes the transitional care pathway from home to a nursing home.

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Appendices

Appendix 5A. The PRISMA checklist for a scoping review

SECTION	ITEM	PRISMA-ScR CHECKLIST ITEM	REPORTED
TITLE			
Title	1	Identify the report as a scoping review.	✓
ABSTRACT			
Structured summary	2	Provide a structured summary that includes (as applicable): background, objectives, eligibility criteria, sources of evidence, charting methods, results, and conclusions that relate to the review questions and objectives.	✓
INTRODUCTION			
Rationale	3	Describe the rationale for the review in the context of what is already known. Explain why the review questions/objectives lend themselves to a scoping review approach.	✓
Objectives	4	Provide an explicit statement of the questions and objectives being addressed with reference to their key elements (e.g., population or participants, concepts, and context) or other relevant key elements used to conceptualize the review questions and/or objectives.	✓
METHODS			
Protocol and registration	5	Indicate whether a review protocol exists; state if and where it can be accessed (e.g., a Web address); and if available, provide registration information, including the registration number.	N/A
Eligibility criteria	6	Specify characteristics of the sources of evidence used as eligibility criteria (e.g., years considered, language, and publication status), and provide a rationale.	✓
Information sources*	7	Describe all information sources in the search (e.g., databases with dates of coverage and contact with authors to identify additional sources), as well as the date the most recent search was executed.	✓
Search	8	Present the full electronic search strategy for at least 1 database, including any limits used, such that it could be repeated.	Appendix 5B
Selection of sources of evidence†	9	State the process for selecting sources of evidence (i.e., screening and eligibility) included in the scoping review.	✓
Data charting process‡	10	Describe the methods of charting data from the included sources of evidence (e.g., calibrated forms or forms that have been tested by the team before their use, and whether data charting was done independently or in duplicate) and any processes for obtaining and confirming data from investigators.	✓
Data items	11	List and define all variables for which data were sought and any assumptions and simplifications made.	✓
Critical appraisal of individual	12	If done, provide a rationale for conducting a critical appraisal of included sources of evidence; describe the	N/A

Appendix 5A continues on next oage.

Appendix 5A. *Continued*

SECTION	ITEM	PRISMA-ScR CHECKLIST ITEM	REPORTED
Sources of evidence		Methods used and how this information was used in any data synthesis (if appropriate).	
Synthesis of results	13	Describe the methods of handling and summarizing the data that were charted.	✓
RESULTS			
Selection of sources of evidence	14	Give numbers of sources of evidence screened, assessed for eligibility, and included in the review, with reasons for exclusions at each stage, ideally using a flow diagram.	✓
Characteristics of sources of evidence	15	For each source of evidence, present characteristics for which data were charted and provide the citations.	✓
Critical appraisal within sources of evidence	16	If done, present data on critical appraisal of included sources of evidence (see item 12).	N/A
Results of individual sources of evidence	17	For each included source of evidence, present the relevant data that were charted that relate to the review questions and objectives.	Appendix 5C-5D
Synthesis of results	18	Summarize and/or present the charting results as they relate to the review questions and objectives.	✓
DISCUSSION			
Summary of evidence	19	Summarize the main results (including an overview of concepts, themes, and types of evidence available), link to the review questions and objectives, and consider the relevance to key groups.	✓
Limitations	20	Discuss the limitations of the scoping review process.	✓
Conclusions	21	Provide a general interpretation of the results with respect to the review questions and objectives, as well as potential implications and/or next steps.	✓
FUNDING			
Funding	22	Describe sources of funding for the included sources of evidence, as well as sources of funding for the scoping review. Describe the role of the funders of the scoping review.	/

Appendix 5B. Search string pubMed

Keyword	Search string
Older people	"Aged"[MeSH] OR Aged[tiab] OR elder*[tiab] OR patient[tiab] OR patients[tiab] OR "Patients"[Mesh:NoExp] OR old[tiab] OR older[tiab] OR resident[tiab] OR residents[tiab] OR gerontol*[tiab] OR geriatr*[tiab] OR psychogeriatr*[tiab] OR "Geriatrics"[Mesh] OR senior*[tiab] OR dementia[tiab] OR "Dementia"[MeSH] OR Alzheimer*[tiab]
Transition	"Health Facility Moving"[Mesh] OR place[Tiab] OR Placement[Tiab] OR admit*[Tiab] OR "Patient Admission"[Mesh] OR admission*[Tiab] OR "Continuity of Patient Care"[Mesh:NoExp] OR continuity[Tiab] OR entry[Tiab] OR "Patient Handoff"[Mesh] OR Handoff[Tiab] OR "hand off"[tiab] OR handover[tiab] OR "hand-over"[Tiab] OR "Patient Transfer"[Mesh] OR Transfer[Tiab] OR Transition*[Tiab] OR "Transitional Care"[Mesh] OR relocat*[Tiab] OR "Institutionalization"[Mesh:NoExp] OR institutionali*[Tiab] OR "Patient Discharge"[Mesh] OR Discharg* [Tiab]
Nursing home	"Long term care"[tiab] OR "Long-term Care"[MeSH] OR long-term-service*[tiab] OR nursing-home*[tiab] OR care-hom*[tiab] OR "Residential Facilities"[Mesh:NoExp] OR "Homes for the Aged"[Mesh] OR "Nursing Homes"[Mesh] OR Residential-Facilit*[tiab] OR Skilled-Nursing-Facilit*[tiab]
Home (care)	"community"[tiab] OR "in home"[tiab] OR "home based"[tiab] OR "at home"[tiab] OR "home care"[tiab] OR "Adult Day Care Centers"[Mesh] OR "day-care"[tiab] OR daycare[tiab] OR Home-service*[tiab] OR residential[tiab]
NOT	"Hospice and Palliative Care Nursing"[Mesh] OR "Terminal Care"[Mesh] OR "Palliative Care"[Mesh] OR "Palliative Medicine"[Mesh] OR "Hospice Care"[Mesh] OR "Hospices"[Mesh] OR (("Infant"[Mesh] OR "Child" [Mesh] OR "Adolescent"[Mesh]) NOT "Aged"[Mesh]) OR pediatr*[tiab] OR "Pediatrics"[MeSH] OR "Intellectual Disability"[Mesh] OR "Substance-Related Disorders"[Mesh] OR "Substance Abuse Treatment Centers"[Mesh] OR "Substance Abuse Detection"[Mesh]

Appendix 5C. Multicomponent interventions

Study; (Intervention)	The goal of the intervention	The intervention	Target population	Length of intervention	How delivered	Effectiveness
Davis et al., 2011 (FITT-NH)	To reduce informal caregivers' stress, improve mood and quality of interactions with the NH staff to facilitate adjustment to NH admission.	Three components: **(1) History gathering and structured assessment of informal caregiver areas.** **(2) Follow-up:** Consisting of psychoeducation. **(3) Termination calls:** Reviewing caregiver progress and reinforcing success, coping strategies, and positive change.	**Informal caregivers of people with dementia:** **(1)** It is the first NH placement from home or an acute hospital stay. **(2)** The older person has a formal diagnosis of dementia made by a physician.	10 contacts over 3 months.	Telephone calls.	**(1) Caregiver guilt:** There was a significantly greater reduction in feelings of guilt related to placement. **(2) Hassles with staff:** Fewer problems and concerns with NH care were reported. **(3) Satisfaction with the program:** They were highly satisfied with the intervention.
Davison et al., 2020 (PEARL)	To reduce older people's depression and improve anxiety, quality of life, and perceived adjustment to the NH.	Three sessions and two boosters: **(1)** Validation, orientation, and social relations. **(2)** Increasing meaningful activity and enhancing competence. **(3)** Enhancing autonomy. **(4) Booster 1:** Review and problem solving. **(5) Booster 2:** Review, problem-solving, and future planning.	**Older people:** **(1)** 60 years or older. **(2)** Normal cognition or mild–moderate dementia. **(3)** Admitted within the previous 4 weeks. **(4)** Older people with or without depression.	7 weeks, 3x a week (45–60 minutes). 2, 4 weeks after the last sessions, 2 additional sessions.	Face-to-face follow-up and by telephone.	Effectiveness is not measured in this intervention.

Appendix 5C continues on next oage.

Appendix 5C. *Continued*

Study; (Intervention)	The goal of the intervention	The intervention	Target population	Length of intervention	How delivered	Effectiveness
Gaugler et al., 2008, 2011 (NYUCI)	To reduce the burden and depressive symptoms of caregivers of people with AD before and after NH admission.	Three components: **(1) Individual and family counselling:** Six individual and family sessions based on their needs. **(2) Support group participation:** From the Alzheimer's Association. **(3) Ad hoc counselling:** Participants contact the study counsellors to address any concerns, crises, or changes.	**Informal caregivers:** **(1)** Spouse of people with Alzheimer's disease. **(2)** They had to live at home with an older person.	6 sessions in the first 4 months; after 4 months, weekly support group meetings.	In-person and by phone.	Gaugler, 2008: **(1) The burden in informal caregivers:** Significantly lower at each point after NHA. **(2) Depressive symptoms:** A significant reduction after NHA and an accelerated decrease in symptoms after NHA. **(3) Depression scores:** Significantly lower at all points before NHA except for baseline. Gaugler, 2011: No significant results were found.
Gaugler et al., 2015, 2020 (RCTM)	To focus on the identification of potential stressors associated with NH placement in informal caregivers and assisting them to develop more effective individual coping strategies and enhance self- efficacy following the transition.	Six consultation sessions: **(1) Psychoeducation** **(2) Promotion of communication** **(3) Skills in problem-solving** **(4) Older people's behavior management strategies** **(5) Concrete planning:** To optimize personal and socio-emotional care assistance for older people in NHs. **(6) Making families aware:** Caregivers learn about treatments, care provision, and offering support in different care settings. **(7) Emotional health and stress management** **(8) Ad hoc sessions:** Provide ongoing, informal counseling	**Family caregivers of people with dementia:** **(1)** The older person was admitted in the past 12 months. **(2)** The family member cared for the older person.	6 sessions: sessions 1–3 are scheduled approximately 1 week apart and sessions 4–6 are scheduled 1 month apart.	Gaugler, 2015: Not explicitly mentioned. Gaugler, 2020: By telephone, web conference, e-mail, and text.	Gaugler, 2015: **(1) Caregiver stress**: It was significantly lower at the 4-month time point and experienced overload was significantly lower. **(2) Depressive symptoms:** More sessions are associated with a significant decrease over 4 months. More ad hoc sessions have more chances of reporting a decrease in depressive symptoms. **(3) Focus groups: a)** Feeling of gratitude when the transition was managed. **b)** Beneficial external support: the intervention. **c)** A need for further education for families, friends, healthcare providers, facilities, and communities. Gaugler, 2020: Outcomes are to be measured.

Hayward et al., 2018; Saint-Bryant et al., 2020 (SettleIN)	To promote healthy adjustment in older people by improving their mood and increasing their quality of life.	Three components: **(1) A needs assessment:** To facilitate participation. **(2) Healthy adjustment:** Entailing orientation, lifestyle, family & friends, and identity. **(3) Future planning:** Capturing the perspective of the older person on the NH and guiding staff to consider how the adjustment progress is maintained.	**Older people:** **(1)** 65 years or older. **(2)** Permanent NH placement in the last 4 weeks. **(3)** A diagnosis of dementia as defined by DSM-5. **(4)** FAST; a score of mild to moderately severe.	A 4-week program delivered over six weeks.	In-person	Hayward, 2018: Staff reported positive older person outcomes: **(1)** Older people became familiar with other residents and the NH. **(2)** Improvements were found in mood, trust, and creating connections with others. Moreover, there was a reduction in unwanted behavior and an increase in engagement. Saint-Bryant, 2020: No Intervention outcomes.
Lichtenberg, 2007 (Mentoring Model)	To assist family caregivers who started the admission of an older person to an NH.	Three sessions and additional: **Session 1:** Didactic teaching about caregiving and re-examining informal caregivers' transition experiences. **Session 2:** Understanding the NH organizational system. **Session 3:** Integrating one's own caregiving experience and strengths with an awareness of how to mentor others. Further monthly training.	**Informal caregivers**: Deciding on placing an older person in a NH.	Contacts weekly for 12 weeks.	In-person, phone, and e- mail contact.	**Satisfaction:** All participants reported being very satisfied or satisfied. It was comforting to have the support of a more experienced caregiver.

Appendix 5C continues on next oage.

Appendix 5C. *Continued*

Study; (Intervention)	The goal of the intervention	The intervention	Target population	Length of intervention	How delivered	Effectiveness
Paun & Farran, 2011; Paun et al., 2015 (CGMI)	To improve knowledge and skills to assist informal caregivers of older people with dementia who placed their family members in an NH.	Three components: **(1) Knowledge** (Alzheimer's disease, NH, and community resources) **(2) Skill development:** In communication, conflict resolution and hands-on care **(3) Chronic grief management:** (e.g. Recognizing losses)	**Alzheimer's disease informal caregivers:** **(1)** An older person has a dementia diagnosis. **(2)** Identified as the primary caregiver of the care recipient. **(3)** The older person is within the first year of placement.	12 meetings over 12 consecutive weeks, length of time (60– 90 minutes).	A conference room at the NH.	Paun & Farran 2011: **(1) Feasibility:** 10/12 attendance sessions. **(2) Experience:** The group members bonded early on and were comfortable enough to share feelings/emotions. **(3) Satisfaction:** The intervention was helpful and timely. Suggestions to improve the manual were occasionally made. **(4) The program evaluations:** Intervention was helpful and they indicated that they would like to continue the sessions. Paun, 2015: **(1) Heartfelt sadness and longing:** There was a significant improvement in the 3 months. **(2) Caregivers' guilt:** There was a significant difference.

Schulz et al., 2014	To address the needs of family caregivers: **(1)** psychiatric problems **(2)** knowledge about the LTC procedures and resident trajectories **(3)** End-of-life care planning for the older person.	Three components: **(1) Systematic Screening:** Determining psychiatric status and making a treatment protocol. **(2) Education:** The organization and operating procedures of NH and a plan for caregiver participation in the care of the older person. **(3) Education:** Older people's trajectories in NH and assistance with end-of-life planning.	**Informal caregivers:** A family member/ partner	11 sessions (90-minutes) distributed over a 4- to 6-month period.	Face-to- face delivery and telephone calls.	**(1) The older people's quality of life:** It increased over time. Moreover, they were more likely to engage in advanced care planning over time. At the 12-month time point, the perceived quality of life was significantly higher in the intervention group. **(2) Complicated grief:** The complicated grief experienced was significantly lower at the 18- month time point.

Notes. NH=Nursing home; NHA = Nursing home admission; AD = Alzheimer disease; LTC= Long-term care.

Appendix 5D. Single-component interventions

Study; (Intervention)	The goal of the intervention	The intervention	Target population	Length of intervention	How delivered	Effectiveness
Crotty et al., 2004	To transfer medication information to professional caregivers in NHs.	Facilitate medication transfer: **(1)** The transfer of information to a NH: The pharmacist made a transfer summary. **(2)** Coordinated medication review. **(3)** Case conference: The transition pharmacist provided info concerning medication use and transfer appropriateness.	**Older people:** **(1)** Making the first-time transition from a hospital to a NH. **(2)** If they or their caregiver gave consent. **(3)** They had a life expectancy of more than 1 month.	From hospitalization until 28 days after NH admission.	On paper: A medication transfer summary. And case conference = unclear.	**(1) Medication appropriateness index (MAI):** The mean MAI was significantly lower in the intervention group at the 8-week follow-up (p = 0.007). **(2) The MAI components:** Improvement was seen in 8/10. This compared to the control group where 7/10 components got worse.
Meiland et al., 2002 (urgency coding)	To manage the waiting list for admission to a psychogeriatric NH by using an urgency coding system in daily practice.	Urgency coding system: It is a new urgency coding system, to manage the waiting list for a NH. A geriatrician and a social psychiatry nurse determine it.	**Dyads:** **Older person: (1)** The older person has to indicate a psychogeriatric NH between March 1997 and August 1998. **(2)** Nonacute NH admission. **(3)** There has to be an informal primary caregiver who can be interviewed.	The urgency code was determined when the older person was placed on the list.	Not applicable.	**(1) Time on the waiting list:** A significant difference in mean waiting time between 'normal,' high, and highest urgency group. **(2) Effectiveness: a)** People with high/highest urgency were admitted sooner to NH. **b)** A 'normal' urgency often received a higher urgency to hasten admission. **c)** People who maintained 'normal' urgency codes were also admitted to an NH, but with long waiting times. **(3) Satisfaction with the waiting time:** 23.8% of caregivers categorized as higher than 'normal' urgency group found the waiting time too long. Long waiting times did not influence satisfaction with the waiting period. Some caregivers perceived the waiting period as too short.

Study; (Intervention)	The goal of the intervention	The intervention	Target population	Length of intervention	How delivered	Effectiveness
Mukamel et al., 2016 (NHCplus app)	Testing the use of a personalized report card, embedded in a re-engineered discharge process, can lead to better outcomes in the discharge process from the hospital to an NH.	NHCPlus app: **(1)** Personalization of NH preferences. **(2)** The final list of chosen NHs is sent to the discharge planner to begin placement.	**Older people:** **(1)** Admitted to the hospital. **(2)** They were admitted from the community and discharged to the NH.	From the moment a decision to transition was made until a patient made their final NH list.	An app was used for the intervention.	**(1) Hospital ranking & distance:** Significantly higher amounts of the highest-ranking NH by NHC five-star-system were chosen based on the overall measure, the health inspection measure, and the QM measure. **(2) Distance:** There was a significantly greater distance from the previous residence to the NH. **(3) Confidence and satisfaction:** Older people had significantly higher confidence in and satisfaction with the NH placement decision.
Van Mierlo et al., 2015	To improve well-being and quality of care in both people with dementia and their caregivers.	Three consultation components: **(1)** A follow-up visit to a registered nurse to transfer behavioral disturbances information. **(2)** A visit to the family caregiver to support their coping. **(3)** A visit to a person with dementia: Made a short clinical assessment of the well-being and behaviour of that person.	**Dyad:** **A person with dementia: (1)** Known by the outpatient clinic of GGZ Ingeest. **(2)** They were expected to be admitted into a NH soon OR they were advised to move to a NH. **Informal caregivers:/**	Three follow-up visits, six weeks after admission to the NH.	Face-to-face delivery or by telephone calls.	**(1) Satisfaction:** **a)** Visit was positive and very pleasant. **b)** It enabled caregivers to close a chapter in their lives with the community psychiatric nurse (CPN). **c)** They valued the time and attention the CPNs gave regarding their experience and processing of the NH placement. **d)** Some informal caregivers reported that the visit reassured them and made them realize that the older person is comfortable in the NH. **e)** The follow-up visit time was sufficient.

Appendix 5D continues on next oage.

Appendix 5D. *Continued*

Study; (Intervention)	The goal of the intervention	The intervention	Target population	Length of intervention	How delivered	Effectiveness
Ward et al., 2008	To prevent the pharmacy from receiving treatment and medication orders of admitted patients too late.	Facilitate medication transfer: **(1)** A NH-specific form. **(2)** The form is faxed to NH before older people leave the hospital. **(3)** The medication order was faxed to the pharmacy before the patient arrived at the NH.	**Older people:** **(1)** Aged 65 years or older. **(2)** They were being discharged from either of 2 university-affiliated hospitals.	From hospitalization until the day of NH admission.	On paper: NH-specific forms and faxing of information.	**Missed medication:** The intervention group had a significantly higher proportion of missed medication than the control group (100% vs. 70%, respectively).

Note. NH=Nursing home.

6

Chapter 6

The experiences of the care triad during the transition from home to a nursing home: A longitudinal multiple case study

Submitted:
Groenvynck, L., de Boer, B., Beaulen, A., de Vries, E., Hamers, J. P. H., van Achterberg, T., van Rossum, E., Verbeek, H. The experiences of the care triad during the transition from home to a nursing home: a longitudinal multiple case study.

7

Chapter 7

General discussion

The transition from home to a nursing home is a common care transition that is often described as being a fragmented and uncoordinated care process. This discontinued care process can significantly influence the outcomes of older people with dementia, informal caregivers, and professional caregivers. Understanding the underlying mechanisms and experiences of this care process could enable the development and implementation of comprehensive transitional care initiatives. Therefore, this thesis aimed to understand the experiences and needs of older people with dementia, informal caregivers, and professional caregivers throughout the transition from home to a nursing home. The study aimed to contribute to the theoretical understanding of transitional care processes and give directions for improving these processes. The research question that guided this dissertation was:

> *What are the needs and experiences of older people with dementia, informal caregivers, and professional caregivers during the transition from home to a nursing home?*

This final chapter aims to summarize the main findings of this dissertation. Additionally, it addresses methodological and theoretical considerations. The chapter ends with recommendations for practice, policy, and research.

Main findings

A review of the literature identified that throughout the transition from home to a nursing home, older people, and informal caregivers needed support, communication, information, time, and a partnership with professional caregivers to optimize the transition process. These key needs are interrelated, and interdependent, and are summarized in the TRANSCIT model **(Chapter 2)**. Following the literature review, additional studies were undertaken to understand the experiences of older people with dementia, informal caregivers, and professional caregivers throughout the transition from home to a nursing home. These studies showed that the care triads experienced an overall feeling of lack of control and unpredictability throughout the transition process. The overall lack of control could be related to the feelings of dependability within the care triad, a discontinued transition process, and a reactive rather than a proactive transition decision **(Chapter 6)**. The rationale for this reactive transition decision could be explained partially by a study capturing the experiences of informal caregivers during the transition from home to a nursing home. More specifically, informal caregivers experienced the transitional care process as paradoxical. They experienced contradictory emotions and struggled to find a balance between the need for distance and the need to remain involved after the older person resided in a nursing home. Moreover, they wanted a timely transitional care plan retrospectively while prospectively they aimed to postpone the transition process **(Chapter 4)**. Due to the experienced lack of control and unpredictability, the care triad felt that there was no such thing as an ’optimal’ transition. Older people with dementia expressed a wish to remain individuals who are autonomous and have social contacts should they ever move to a nursing home **(Chapter 3)**. Despite the care triads’ negative and emotional experiences throughout the care process, only thirteen interventions aiming to improve the transition process from home to a nursing home were retrieved from databases. When analysing these interventions, they did not match the needs of the older people and informal caregivers as identified by the TRANSCIT model. All thirteen included interventions focused on either a specific phase or target population. None of the interventions included the entire care triad (older people, informal caregivers, and professional caregivers), and only one intervention focused on all phases of the transition process. Nevertheless, studies reported high levels of satisfaction with the interventions, although insight into the effectiveness was mixed **(Chapter 5)**. There is a clear mismatch between the needs identified by the care triad and the currently existing research interventions.

Methodological considerations

This methodological section will address four key considerations. Initially, it will delineate the recruitment strategies employed in various studies in relation to their corresponding outcomes. Subsequently, an analysis of the implications of the Covid-19 pandemic on research will be undertaken. The third segment will focus on challenges associated with the inclusion of older people with dementia in research endeavors. Lastly, the researchers will undertake a comparative evaluation of the merits and drawbacks of retrospective and prospective research approaches.

Selection bias

This paragraph discusses how the recruitment of participants may have impacted study outcomes. Firstly, this paragraph delves into self-selection bias and its impact on participant characteristics. Secondly, it explores the two-step recruitment method employed, potentially resulting in the under-representation of more vulnerable individuals.

The transition from home to a nursing home was an emotionally challenging process and stressful event for everyone involved (1–3). Consequently, the researchers included participants who were open and willing to share their stories. This may have introduced self-selection bias (4). The people who consented to participate may differ from those who declined participation (4, 5). The participants are likely to be more open, cognitively strong and with a good socio-economic status. They often are genuinely interested in the topic (5–7). In this dissertation, the participants included in the different studies were open and verbally strong and some had a healthcare background. The participants were able to give an in-depth description of the transitional care experiences as they were able to describe complex and emotionally challenging feelings, perspectives, and experiences. Therefore, they are more likely to successfully navigate a very complex healthcare system (8). This could have positively influenced the transitional care process and related experiences (9). The transitional care process may have been even more uncontrollable, paradoxical, and frightening than reported in these studies.

Moreover, this dissertation used a two-step recruitment method to include participants. The participants were recruited with the assistance of professional caregivers, who played a crucial role in facilitating the connection between the research team and potential participants. These professional caregivers indirectly decided which of their clients best fit the in-and exclusion criteria of the studies. This method of participant recruitment can lead to bias, as these professionals become gatekeepers who decide which participants are allowed to be approached by the researcher (10). There is a risk that the professional caregivers may selectively choose participants based on specific characteristics, such as opting for individuals who are already cared for by skilful and informed informal caregivers. Moreover, the researchers often approached dementia case managers. These professional caregivers provide additional support in navigating the healthcare system and the transitional care process. However, only 41% of older people with dementia are assigned a dementia case manager in the Netherlands (11). This could further influence the results of the study as these participants might have experienced more support and information provision. While intended to protect vulnerable patients, this two-step recruitment approach may under-represent the most vulnerable, such as older people with dementia lacking formal or informal support (12, 13). As with the self-selection bias, this could have led to a more positive representation of transitional care experiences.

Research during the COVID-19 pandemic

The COVID-19 pandemic complicated data collection for this study and may have had an impact on the outcomes reported in this dissertation. The COVID-19 pandemic triggered global lockdowns and social isolation (14, 15). Both family homes and nursing homes implemented restrictive visiting measures to mitigate infection risks (16). This complicated the data collection of the final study, which was conducted immediately after the Covid-19 pandemic. The research team often adopted online or telephone interviews as a method of data collection, following the preferences of the participants. This approach was deemed necessary due to the participants being classified as a high-risk population.

During the pandemic, the use of video technology for academic purposes was accelerated while older people and their families became familiar with online video chat (17–19). However, these online or telephone conversations could have affected the results of the final study. More specifically, when using video interviews, the researcher has more difficulty recognizing facial expressions and body language (20, 21). This is important when conducting emotionally sensitive research. Therefore, the results of the study may not have been as thorough and comprehensive when utilizing video conversations as when conducting live interviews. Phone conversations further eliminated this aspect of non-verbal communication (22). This could have further impacted the results of this study. More especially, when the researcher was able to visit the participant's home, she had a better idea of the context and the interactions between different participants. Especially when interviewing different people at the same time (e.g. professional caregiver and older person), the dynamics and non-verbal looks towards each other were often supportive for or in contradiction to what they told verbally. This could have impacted the follow-up questions of the researcher. Nonetheless, the researchers believe that these issues had a small impact on the results of the study as the researcher conducted the first interviews at the participants' homes. Moreover, research by Krowel et al. (2016) found that the quality and quantity of data are only marginally better for face-to-face interviews in comparison to video interviews (23). In addition, despite the pandemic, the researchers felt that they were still able to comprehensively capture the perspectives and experiences of the care triad throughout the transition from home to a nursing home.

Including people with dementia in research

The researchers focused on including older people with dementia throughout the transition process. However, during this dissertation, it became clear that including older people with dementia in academic research remains challenging. The researchers aimed to include all the participants with dementia who were involved in the patient journey study. Nevertheless, only two people shared their transitional care journey from home to a nursing home. Where possible, the researchers aimed to include the older person with dementia in the conversations. Even when the informal caregivers tended to take over the conversation, the researcher explicitly asked for the experience of the older person. The inability of older people to participate throughout the entire transition process was related to two things: 1) not all older people were informed about the transition decision; and, 2) by the time older individuals moved into a nursing home their dementia had often advanced significantly.

This dissertation highlights how older people with dementia become non-participants in their transitional care journey and they are often unaware of the lingering transition decision (24). It is difficult to interview a person about a subject they are not informed about. Nonetheless, the researcher focused on including people with dementia where possible. Additionally, the researchers focused an entire study on capturing the perspectives of older people with dementia regarding a potential future move to a nursing home. Despite numerous constraints regarding the inclusion of older people with dementia, this dissertation was able to capture their experiences successfully.

Furthermore, when older people have advanced dementia, it becomes harder to include them in the studies as the most used data-collection method was interviews (25). New data-collection methods focusing on the inclusion of people with dementia are emerging (26). Examples are visual methodologies such as photography (27–29), participatory methods, such as keeping a diary (30), and ethnographic techniques such as observations and immersion (31, 32). However, the appropriateness of these novice methods for emotional topics, such as transitional care, remains uncertain. Moreover, none of these studies that focused on innovative data-collection methods included people with ‘severe’ or ‘late–stage dementia’ (33). Further exploration of these evolving methods is warranted to enhance inclusivity in future research on transitional care. Nevertheless, this dissertation did show that interviewing older people with dementia is possible. Asking older people about their current and past life experiences provides insights into their future care needs and wishes.

Retrospective versus prospective research

This paragraph delineates the distinctions between retrospective and prospective research and their relevance to the outcomes of this dissertation. Specifically, the paragraph discusses the different forms of memory biases associated with retrospective research and reflects on the advantages and disadvantages of prospective, longitudinal research.

This research has identified significant disparities between prospective and retrospective experiences within the context of transitional care. For instance, from a prospective view, informal caregivers of people with dementia aim to enable older individuals to reside at home for as long as possible. However, upon retrospective reflection, they expressed a preference for a timely transitional care process. Additionally, retrospectively, the transition decision is seen as a singular event. Prospectively, it is identified that the transition decision is a longitudinal process characterized by doubt. Several factors contribute to these notable differences in perspectives and experiences. Both prospective and retrospective research have their advantages and disadvantages.

Retrospective qualitative studies are most often found in the literature. This is a cost and time-effective research method that allows the participant to look back on the past. Recalling past events is often associated with different forms of recall and memory bias

(34, 35). The inability of a participant to correctly remember a past event could have influenced the outcomes of this dissertation (34). The clearest example was found in the judgement of informal caregivers regarding the timing of the move and its relation to nursing home satisfaction. If the nursing home was perceived as satisfactory, participants regarded the transition as timely. However, inadequate care led to the contemplation of returning home, despite recognizing the unsustainability of that option. This retrospective analysis could be related to the misinformation effect (36). Older people and informal caregivers could remember the home situation and its sustainability differently depending on the present experiences at the nursing home.

Another form of bias related to retrospective research is 'hindsight bias', wherein outcomes appear more predictable in hindsight (37). This bias may explain why participants retrospectively desired a transitional care plan, as in hindsight, they could have predicted that dementia would progress and a transition would become inevitable. However, during the actual transition process, older people and informal caregivers may have held the belief that a nursing home was unnecessary and that the dementia would not advance.

Prospective longitudinal research on transitional care has been sparsely conducted (38), given its time-consuming and costly nature (39). The recruitment of older people with dementia, informal, and professional caregivers – to capture the transition process in prospective longitudinal research – poses greater challenges compared to retrospective research. Firstly, the follow-up time can be as long as one needs to wait for an event to occur (40). More specifically, in the patient journey study, the researcher and professional caregivers could not predict who would make the transition. People had to be recruited at different phases of the transition process to be able to capture the actual move and the entire transition process. Secondly, in longitudinal research, there is a risk for attrition bias (40), as participants often drop out before the end of the study. This was evident in the longitudinal, patient journey study. Three care triads opted to stop the study immediately before and after the actual transition, describing it as a family moment. However, the participants reconnected with the researcher a few weeks after the move, underscoring the impact of the researcher–participant relationship.

While the bond between the researcher and participants may inadvertently introduce biases, establishing trust and building rapport is crucial for effective data collection (41, 42). This is especially true when conducting research regarding a sensitive topic and/or with vulnerable people (43, 44). In prospective, longitudinal research, the bond between the researcher and the participant can lead to a rich description of the context. For example, when older people and informal caregivers provide information about family dynamics, it gives the researcher insight into the transition decision choices. This researcher–participant bond improved the depth and quality of the research outcomes

(45). However, this bond or relationship could have influenced the results of the study (42, 46). The participants being able to share their stories, emotions, and their ability to vent, may have had some therapeutic benefits that in turn could have positively influenced the care experiences (47). Moreover, transitional care is characterized by chaos and fragmentation, by having a constantly available presence (the researcher); the participants may have experienced the transitional care process differently.

Theoretical considerations

During the transition from home to a nursing home, the ‘transition decision’ was a central part of the care process and affected the transitional care outcomes. This dissertation found that a transition decision is contingent upon various complicating factors. Therefore, the theoretical consideration within the discussion addresses: 1) the lingering question pertaining to the feasibility of optimizing this complex and emotionally charged transitional care process; 2) the subjective nature of ‘optimal transitional care timing;’ and, 3) the absence of a shared decision-making process.

1. Defining optimal transitional care

This paragraph starts by summarizing the two definitions of transitional care. These definitions are compared to the currently organized transition process from home to a nursing home in the Dutch context. This discussion reveals a theoretical mismatch between theory and practice. This mismatch is related to the emotional implications of the care process, the perceived satisfaction with the transition process and its relation to nursing home care, and the identified organizational/financial barriers of the Dutch healthcare system.

Various definitions are employed to characterize the concept of transition. In the beginning, the transition of care was narrowly defined as the ‘clinical handover’, referring to the transfer of care from one professional caregiver to the next (48). However, this concept proves insufficient, particularly in the context of the transition from home to a nursing home. Transitional care encompasses three distinct phases: the pre-transition, mid-transition, and post-transition. Throughout these three phases, older people, informal, and professional caregivers should collaborate to establish a new ‘home’ at the nursing home.

Cole et al. (2003) expanded the definition, characterizing transitional care as a set of actions designed to facilitate coordination and continuity across different levels and settings. This comprehensive approach necessitates the development of a transitional care plan, where a professional caregiver, well-acquainted with the wishes, needs, and preferences of the patients, plays a pivotal role (49). However, a critical examination of the organized care pathway from home to a nursing home reveals a conspicuous absence of a comprehensive transitional care process, as defined by Cole et al. (2003). This dissertation has unveiled the inherent discontinuity in the transition process, accompanied by a conspicuous lack of care coordination. Even with the designated role of the dementia case manager in guiding and supporting older people and informal caregivers, the perceived time constraints and regulatory limitations hinder their capacity to furnish the requisite support and information. Additionally, the existence of a transitional care plan does not guarantee adherence, as organizational intricacies within the healthcare system often hinder its implementation. Currently, care organizations tend to overly prioritize compliance with guidelines and procedures established by individual care settings, rather than emphasizing the creation of a new home-like environment that fosters a sense of home for older people and informal caregivers. The paradoxical nature of the transition from home to a nursing home is evident, characterized by an experienced lack of control. The wishes, preferences, and needs of older people and informal caregivers for information, support, time, communication, and partnership, as identified by the TRANSCIT model, cannot be guaranteed. The pivotal question persists: is an optimal transitional care process feasible? The ongoing struggle between the desire to age in place and the imperative for a timely, well-prepared move raises complex considerations.

First, the emotional impact of the transitional care process is not taken into consideration. Naylor et al. (2018) identify nine components of transitional care, with only one focusing on the emotions associated with care transitions (50). However, this model mainly focuses on the transition from hospital to home, a transition pathway associated with recovery and health, whereas the emotion associated with the transition from home to a nursing home has a more significant impact. More specifically, a nursing home is frequently regarded as a last resort, prompting older people and informal caregivers to await a perceived ‘tipping point’ before contemplating the transition decision (24). The unpredictability of dementia progression renders the identification of this tipping point impossible to predict (51). Exploratory alternatives, such as living with a family member (52) or additional home assistance (24), are often pursued before entertaining the notion of transitional care. Even when placed on a waiting list, the transition decision remains deferred. Caldwell et al. (2014) conceptualize this as an initial step towards the transition, marked by lingering doubts and emotional complexities. Both this dissertation and extant literature underscore the prerequisite for older people and informal caregivers to experience a form of ‘readiness’ before being able to start the transition process (51). This readiness is particularly elusive for older people lacking insight into their disease. They can have more difficulties experiencing a feeling of readiness (24, 53). This aversion to moving to a nursing home is compounded by negative perceptions surrounding these care facilities, viewed as sites of compromised care quality, restricted autonomy, and a perceived loss of rights (52). These negative perceptions have been aggravated by the COVID-19 pandemic. Negative media coverage and public scrutiny concerning nursing homes (54) likely contributed to participants' heightened reluctance and delay in making care transition decisions. Research suggests that societal taboos and stigmatization towards nursing homes can deter individuals from seeking such care (55). Additionally, this dissertation showed that people were sensitive regarding the opinions and feedback of others. Often nursing homes were chosen based on the feedback and recommendations of others (56). The negative impact of COVID-19 restrictions may have altered these recommendations, affecting participants' transitional care decisions post-pandemic. Moreover, nursing homes are often viewed as a place where you die (57, 58). The amalgamation of negative perceptions and emotional factors complicates the timely initiation of a transitional care process, given the subjectivity and indefinability of readiness. This intricate interplay poses a substantial challenge for professional caregivers seeking to initiate the transitional care process and facilitate a timely transition decision.

Furthermore, older people and informal caregivers' satisfaction with the timing and actual transition decision was related to the perceived satisfaction with the care at the nursing home. Initially, this could suggest that the transitional care experiences are not related to the care outcomes such as 'feeling at home' (59) for older individuals and 'reduced care burden' (60) for informal caregivers. More specifically, satisfaction or dissatisfaction with nursing home care is the only relevant factor in the transition process. However, the ability to make a shared, timely, and informed transition decision is directly related to the satisfaction with the nursing home. A well-executed transitional care plan enables informed decision-making by allowing older people and informal caregivers to familiarize themselves with various nursing home settings, potentially visiting different facilities at different times. The ultimate goal of the care plan should centre on creating an environment that focuses on making older people and informal caregivers feel at home. This entails meticulous consideration and alignment of their distinct needs and preferences concerning future care.

Finally, the realization of a timely, shared decision is unattainable due to strict organizational and financial barriers between home and nursing home care (61). Each health organization is still considered an individual entity rather than linked in a continuous chain. Changes could be made to bridge that gap.

2. A timely transition decision

The upcoming paragraphs discuss the uncertainty and arbitrariness surrounding the idea of 'optimal transitional care timing'. The timing of a transition decision is influenced by 1) negative perceptions regarding nursing homes; 2) the promotion of sustainable living at home; and, 3) the financial and organizational barriers. There are some instruments and recommendations to aid the transition decision. Nevertheless, it remains a longitudinal concept characterized by doubt.

Timeliness was an important concept concerning transitional care in this dissertation. The majority of definitions delineating transitional care overlook the significance of a timely transition decision (49, 62). Only Naylor et al. (2006/2011) specifically emphasized the importance of a timely transition process when defining transitional care (63, 64). However, the literature lacks practical indicators or parameters to gauge the timeliness of a transition decision. Notably, the study by Cole et al. (2018), aimed at determining the existence of an optimal transition time, failed to distinctly define this 'optimal transitional care timing' (51). Consequently, the 'right time' for a transition decision remains indefinable and it remains a subjective term in the literature (65). Different factors explain why the timeliness of transitional care remains arbitrary.

Specifically, there are negative perceptions and stigmatization concerning a nursing home move. The care triad feels the need to justify the transition decision for themselves and others. Informal caregivers, in particular, tend to wait until there is an imminent threat to the health of the older person or themselves before making a transition decision. The decision is often led by the emergence of a 'tipping point' (e.g. the older person wanders outside while the informal caregiver is grocery shopping) (66). However, this dissertation and corroborating research posit that for an effective transition, such a 'tipping point' must coincide with the availability of immediate access to a nursing home (66). In the Netherlands as well as other countries, this synchronicity is rare as the availability of nursing home beds is scarce (67). Older people and informal caregivers face prolonged waits, allowing doubts to arise and possibly leading to the retraction of the transition decision when the home situation temporarily stabilizes. This doubt has the potential to precipitate a crisis, resulting in a hastened and uncoordinated care process, thereby impacting the outcomes for everyone involved. This dissertation and the study by Cole et al. (2018) show that the transition decision is not a singular event but a lengthy process characterized by doubt.

Moreover, older people and informal caregivers exhibit a preference for the familiarity and comfort of their homes. Research indicates that older individuals spend approximately 72% of their time at home (68). Particularly for people living with dementia, home symbolizes physical health (69), independence, and autonomy (70). It is seen as a haven where older people have privacy, where they are in control, and can maintain daily routines and hobbies (71, 72). It is the place associated with feeling safe and secure. Moreover, the environment and services surrounding the home have important implications for the quality of life (71, 73). However, when older individuals are diagnosed with dementia, living at home becomes challenging and risky and the advantages associated with living at home may gradually be lost (74, 75). In that stage, nursing homes may improve older people's quality of life, by ensuring their safety, enabling social contacts, and guaranteeing constant care provision (76).

Nonetheless, the majority of older people indicate the importance of ageing at home rather than relocating to a nursing home (77, 78). Consequently, the promotion of sustainable living at home for older people has become a global governmental priority (79). This is also true in the Netherlands, where recently the Ministry of Health, Welfare and Sports developed a governmental programme aiming to facilitate independent living at home for as long as possible (WOZO) (80). Despite this being supported by older individuals themselves, this emphasis on remaining at home may impose an increasing burden on informal caregivers, particularly considering the anticipated decline in the number of informal caregivers over time (77, 80). Furthermore, this focus on 'as long as possible' can contribute to the stigmatization of already scrutinized long-term care facilities (54), potentially complicating the already intricate and emotionally charged transition decision for older people and informal caregivers (81). This is especially the case for informal caregivers who are often conflicted between attending to the care needs of older individuals while balancing their own needs and abilities (81). This governmental emphasis may induce heightened feelings of pressure and guilt from society. This can intensify the stress surrounding the transition decision (82) and can potentially lead to postponing the nursing home transition, thereby risking a crisis that could adversely affect the adjustment and acceptance of nursing home living (83).

Finally, this dissertation highlights that organizing a timely and well-coordinated care process is fraught with challenges due to financial and organizational barriers. Various factors influenced the timing of the transition decision, with the regulations of the Dutch healthcare system exerting a particularly significant influence. More specifically, the government funds long-term care facilities, which allow older people and informal caregivers to choose a nursing home that best fits their needs. It facilitates the transition decision that is independent of financial resources. However, governmental support also means that older people must fulfil specific conditions before gaining access to long-term care support (84). The foremost condition necessitates a requirement for 24-hour care and supervision (85). However, this level of care has a significant impact on the lives of informal caregivers, who may face heightened care burden when caring for older individuals with advanced dementia. The time to make an informed and shared decision might become tighter. This circumstance may impede the ability to make a timely and mutually shared decision, potentially increasing the likelihood of a crisis.

Some studies have developed instruments to aid the transition decision. However, these instruments are not validated or do solely focus on one participant of the care triad. For example, Roy et al. (2018) conducted a systematic review to identify a set of factors to determine the need for a nursing home move for older people. They identified 88 potential factors that could influence the transition decision (86). However, it is impractical to bring all these different factors into practice.

This dissertation was not able to establish a clear set of criteria for timely transitional care. The studies suggest that older people aspire to be individuals who maintain autonomy and have social connections. Consequently, the absence of these essential needs in the home environment could serve as an indication for moving into a nursing home. Additionally, a timely care transition could be facilitated by regular communication with a trusted professional caregiver who provides information and support for both older people and informal caregivers. This is often referred to as shared decision-making (87).

3. A shared transition decision

Currently, there is a mismatch between anticipated shared decision-making and actual decision-making processes in practice. When making transitional care decisions, both informal caregivers and professional caregivers face challenges.

Contrary to the timeliness of the transition decision, consensus exists regarding the imperative need for shared decision-making in transitional care.

> ‘*Shared decision-making is an approach where clinicians and patients make decisions together using the best available evidence. Patients are encouraged to think about the available screening, treatment, or management options and the likely benefits and harms of each so that they can communicate their preferences and help select the best course of action for them. Shared decision-making respects patient autonomy and promotes patient engagement (87).*’

When comparing the definition of shared decision-making with the decision-making process as experienced by the care triad, shared decision-making was non-existent.

First, the definition of shared decision-making focuses on an equal partnership between professional caregivers and clients during the decision-making process (87). Contrarily, during the transitional care process, transition decisions are mostly made by the informal caregivers and their families. (66, 82). Informal caregivers and professional caregivers often want to protect older people. They assume that the older person's cognitive decline might mean that they do not fully understand the implications of a transition decision. Informal caregivers and professional caregivers fear that the older person's lack of understanding could confuse them, which could negatively impact their well-being and elicit negative emotions such as anger and sadness. Therefore, the majority of older individuals were eventually excluded from the transition decision. However, not involving older people can lead to feelings of detachment from their previous life and experienced difficulties in feeling at home (83, 88). This discontinuity in the care process can impact the adjustment and acceptance of the new living situation (89). It may even have health implications, as evidenced by Laughlin et al.'s study (2007), which associated forced admission with increased mortality one year after the move (90).

Secondly, a clear partnership during the transition decision, an intricate part of shared decision-making, was absent (87). This dissertation underscores the importance of an equal partnership with a professional caregiver to arrive at a well-informed decision. Professional caregivers exert significant influence over the participation of older people and informal caregivers in transition decisions (91) and may also impact the timing of such transitions. However, the care style and levels of involvement among professionals vary. The question persists: what type of care style best facilitates the transition process? Existing literature indicates that some older people and informal caregivers seek confirmation from professional caregivers regarding the necessity of a transition (92). Nonetheless, studies by Kraun et al. (2022) and Dyrstad et al. (2015) suggest that an assertive care style may jeopardize the shared nature of the decision (91, 93). This balance between confirmation of the necessity of a transition and actually making the decision is difficult. Finally, the definition of shared decision-making emphasizes the availability of the necessary information for optimal care decisions (87). Currently, the care triads lack essential information regarding the transitional care process (e.g. information about the date of the move).

The comparison between the definition of shared decision-making and decision-making during transitional care highlights a clear mismatch. The relative absence of shared decision-making during transitional care may impede the transitional care process. Therefore, other academics and the researchers in this dissertation advocate for advanced care conversations at the earliest opportunity (94), taking into account that older people are still capable of making informed decisions (95). According to the research team behind this work for this dissertation, a shared transition decision is possible when initiating timely conversations regarding future care. This approach enables the active participation of older people with dementia at a stage where the disease is less advanced. Consequently, they can articulate their needs, preferences, and desires concerning future care. It should be emphasized that care needs change over time and are influenced by the surrounding context. Therefore, a single advanced care conversation might not always accurately capture older people's future care wishes, and repeated conversations will often be needed. Furthermore, the researchers posit that professional caregivers can assume a more integral role in this decision-making process by communicating their perspective on when a care transition is deemed necessary. This is also confirmed by Kraun et al. (2023) who found that professional caregivers have a pivotal role in empowering older people and informal caregivers during transition decisions (96). This not only alleviates the burden on informal caregivers but also ensures that the decision to transition is a shared endeavour. Moreover, the early initiation of discussions allows for the gathering of comprehensive information and facilitates a thorough exploration of various care possibilities. This proactive approach contributes to a more informed and collaborative decision-making process in the realm of transitional care. Hopefully, this aids older people and informal caregivers to feel at home in the nursing home.

Implications

1. Practice and policy

This dissertation addresses crucial considerations for professional caregivers and policy-makers engaged in the intricate transition process from home to a nursing home.

Firstly, older people with dementia should be asked about their past and present life and care experiences. This enables professional caregivers to create a deeper understanding of older people's perspectives of potential, future nursing home care. The active involvement of individuals with dementia in their transitional care process is paramount (97). This can be achieved by the timely starting of the transition discussion together with the older person when they are still able to participate in the conversation. This enables older individuals to share their future care wishes and perspectives. Additionally, by the timely familiarization of the older person with their potential future residence, they might be more open to converse about the sensitive topic as the transition decision becomes imminent. If these conversations are done in time, it might alleviate the caregiving burden as informal caregivers are informed concerning the older people's future care wishes.

Secondly, it is essential to ensure that informal caregivers receive ample support, fostering shared decision-making to alleviate some of the caregiving burden. A trusted professional caregiver, family, and peers who have experienced the challenges associated with transitional care should ideally offer this support. Furthermore, a designated professional caregiver should guide and lead the transition process. Ideally, this trusted professional caregiver should be involved in the lives of the older individuals and informal caregivers before the start of the transition process. In the Netherlands, the dementia case manager can provide that support and trust. Policymakers should consider extending the role of dementia case managers to the post-transition, facilitating collaboration among professionals during this period. Currently, dementia case managers are allowed to remain involved until 6 weeks after the move. However, in practice, this rarely happens due to time constraints. Therefore, efforts should be made to alleviate the workload and better embed the role of the dementia case manager in the post-transition phase. Routine care for these professionals should encompass continuous support and guidance during the post-transitional phase.

Thirdly, professional caregivers must be educated on the longitudinal nature of transition decisions, emphasizing the need for time, information, communication, and support to facilitate a shared transition decision. Defining the ideal time to consider a transitional care move is difficult. However, if older people are no longer able to live an autonomous, individual, and social life, a transition decision might be warranted. Therefore, professional caregivers should evaluate these exigencies as part of daily care. Rather than simply focusing on caregiver burnout and the physical health of older people.

Fourthly, nursing home staff should introduce themselves before the move. Enhancing the transition process involves a gradual introduction between the care triad at home and the staff at the nursing homes. More specifically, before the actual move, older people and informal caregivers should be introduced to the staff of the nursing home who will provide care in the post-transition phase. This introduction ideally takes place through a series of meetings, providing ample opportunity for mutual understanding and enabling nursing home staff to familiarize themselves with the habits, routines, and preferences of older individuals. Moreover, instead of relying solely on written handovers, professional caregivers should sit together regularly and collaboratively prepare for impending care transitions.

Finally, policymakers and care organizations should focus on defragmenting the transitional care process to create a continuous transition process from home to a nursing home. It also requires organizational changes, such as shared access to health and care information, to ensure continuity of care. Additionally, policymakers should contribute to the development of living initiatives that challenge the currently fragmented healthcare system. One example of this is the concept of vital communities. Vital communities strive to establish mutually beneficial partnerships with professional caregivers, allowing older people to age in place while receiving the necessary care to ensure safety and alleviate burden (98, 99). Another pragmatic approach, adopted by a Dutch care organization, enables professional caregivers in the home care setting to continue providing care once the older person resides in a nursing home. This not only guarantees a more continued care process but it provides more support to older individuals and informal caregivers as they have a trusted and familiar professional caregiver in their new living environment. Innovative nursing homes should prioritize the establishment of an environment that enables older people and informal caregivers to experience a sense of home and familiarity, despite the facility not being their residence. Achieving this requires a patient-centred reorganization of the financial system. Incentives can be foreseen to aid professional caregivers in coordinating the transition. Such incentives are important as Wieczorek et al. (2022) et al. found that financial incentives could improve the care process. Nevertheless, incentives are not enough as they may only have short-term improvements and the long-term care outcomes remain uncertain (100, 101). However, these financial and organizational barriers cannot be resolved immediately. The improvement of the transitional care process is possible within the current healthcare system. It does require care organizations and professional caregivers to think resourcefully, and it requires an innovative mindset. Currently, healthcare regulations are still identified as an inevitable barrier to transitional care.

2. Research

The results and discussion presented in this dissertation have unveiled several unresolved queries that warrant further investigation to enhance the transition from home to a nursing home.

Firstly, research should focus on the involvement of older people with dementia. Currently, older individuals are often excluded from research as their consent to participate in research studies hinges on the ability of a person to comprehend the information and implications presented (102). Moreover, classic data collection methods such as interviewing are not always feasible for older people experiencing more advanced dementia. Future research should therefore explore emerging innovative consent forms and data collection methods for obtaining informed consent among cognitively impaired individuals (26, 103). Consequently, future research should aim to comprehensively explore the experiences and perspectives of older people with dementia throughout all three phases of the transition from home to a nursing home, irrespective of their dementia severity. This could be achieved by conducting prospective research as it allows for more precise information on the needs of older people with dementia during transitional care.

Secondly, a comprehensive transitional care intervention, that encompasses the three transitional care phases and integrates the care needs, wishes, and experiences of older people and informal caregivers does not currently exist. Therefore, future research should focus on the development of such an intervention that includes the three phases of the transition process as well as the perspectives of the entire care triad. Moreover, the intervention should focus on the key needs identified in the TRANSCIT model. More specifically, the intervention should focus on the partnership of the care triad by providing information, efficient communication, practical/emotional support, and sufficient time. These key needs can be facilitated by the implementation of important intervention components, such as education, relationship/communication, and improving emotional well-being. Future research should concentrate on determining the feasibility of implementing such a comprehensive transitional care initiative.

Thirdly, a notable absence of a standardized quality-monitoring system for transitional care during the transition from home to a nursing home exists. Therefore, monitoring potential improvements in the transitional care pathway is difficult (104). Researchers should emphasize defining optimal transitional care and establishing uniform outcome measures to facilitate the evaluation of transitional care processes (48, 49).

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8

Chapter 8

Summary

Samenvatting

Summary

The transition from home to a nursing home is a common care process, especially for older people with dementia. It is an emotionally challenging process that is often fragmentized. This fragmentation is related to negative outcomes for older people, informal caregivers, and professional caregivers. Enhancing the care process necessitates a thorough exploration of the experiences of older people with dementia, informal caregivers, and professional caregivers across the three phases of transitional care. This approach enables a deeper comprehension of the underlying mechanisms that contribute to currently experienced adverse outcomes.

This dissertation aims to contribute to the theoretical understanding of the transitional care process and give directions for enhancing this process by capturing the transitional care experiences and needs of older people with dementia, informal caregivers, and professional caregivers throughout the transition from home to a nursing home. This chapter provides the summaries of the studies conducted in this dissertation.

Chapter 1 presents an introduction to this dissertation. It provides background and numerical information regarding paramount key concepts. Information is provided about dementia prevalence and pathophysiology, the concept of transitional care, the transition pathway from home to a nursing home within the Dutch healthcare system, and the implications of that transition on the care triad. The introduction ends by providing an overview of the upcoming chapters and their respective research inquiries.

Chapter 2 presents the results of a comprehensive overview of the needs of older people and informal caregivers during the transition from home to a nursing home. A literature review was conducted using the electronic databases CINAHL and PubMed to capture these needs. The included studies had to enquire about older people and/or informal caregivers' experiences, needs, identified barriers, or facilitators during the transition process. The extracted data were mapped to the three phases of the transition, leading to the TRANSCIT model. The TRANSCIT model was preliminarily validated by a group of experts in research and practice. The model identifies four key needs including information, communication, support, and time to improve the transition process. These key needs can be realized by a partnership between the care triad. The model could become a guideline to reduce fragmentation and optimize the transition from home to a nursing home.

The TRANSCIT model guided the research questions of **Chapters 3 and 4**. **Chapter 3** captures the perspectives of older people with dementia regarding a potential move to a nursing home and their wishes for future care. This study followed a qualitative

phenomenological design. The perspectives of eighteen community-dwelling older people living with dementia were explored. Data analysis consisted of a stepwise interpretive phenomenological analysis. The results indicated that the majority of older people living at home feared the idea of potentially having to move to a nursing home. Nevertheless, the participants stated that they wished to remain autonomous individuals who are in contact with others should they ever move to a nursing home. These wishes were identified by asking older people about their current and past experiences with care provision. This indicates that professional caregivers should listen to older people's life stories to understand their care needs and wishes. Moreover, these results provide insight into a potential 'suitable time' to suggest a move to a nursing home.

Chapter 4 examines the experiences of informal caregivers during the transition from home to a nursing home. This chapter uses an interpretative phenomenological design to capture the experiences of 24 informal caregivers caring for a person with dementia. The data analysis method was interpretative phenomenological analysis. The informal caregivers experienced the transitional care process as being paradoxical. Firstly, they experienced both positive and negative emotions. Secondly, they indicated the need for a timely transitional care process. Conversely, they all postponed the nursing home transition for as long as possible. Finally, they experienced an internal struggle between the need to be involved and the need to distance themselves in the care process. These paradoxes were all influenced by the healthcare system.

The adverse and paradoxical experiences documented in prior studies have prompted an inquiry into existing transitional care interventions designed to improve the quality of transitional care. Consequently, **Chapter 5** provides a summary of existing interventions aiming at improving the transition from home to a nursing home. Moreover, the effectiveness and key components of the identified interventions are presented. The scoping review was performed utilizing the databases PubMed, EMBASE, PsycINFO, Medline, and CINAHL. This scoping review identified seventeen studies describing thirteen distinct interventions. The majority of the studies were conducted in the United States and employed a randomized control trial design. Eight of the identified interventions were multicomponent. These are interventions conducted over multiple weeks/ months and comprised of different intervention elements. The remaining five were single-component interventions. These interventions were smaller and focused on a specific part of the transition pathway. From the multicomponent interventions, seven intervention components were identified: education, relationships/communication, improving emotional well-being, personalized care, continuity of care, support provision, and ad hoc counselling. The outcomes of the interventions were difficult to compare, as they were heterogeneous. The majority of these interventions focused on nursing home adjustment, with only one study including the entire transition pathway. These results suggest a mismatch between theoretically defined 'optimal transitional care' and currently existing care initiatives. Further information is needed on the experiences of the care triad to enable the improvement/development of transitional care interventions.

The disparity between theory and practice prompted the initiation of a final study. **Chapter 6** presents a prospective, multiple-case study using the patient journey mapping methodology. The study followed the journey of five care triads of older people with dementia, informal caregivers, and professional caregivers throughout the transition from home to a nursing home. The goal was to capture the experiences of the care triads and facilitate more insight into the care process. The study was conducted over 18 months using semi-structured interviews, follow-up moments, and logbooks to capture the experiences. All this data was analysed using individual and cross-case analysis. The prospective view identified a lack of control experienced by the care triads throughout the entire transition process. This lack of control and unpredictability was related to three factors. First, there was a dependency among the members of the care triad. Each participant felt dependent on other participants leading to a perceived lack of control. Secondly, there was a reactive rather than proactive transition decision. More specifically, participants had difficulties in identifying the right transition time. They doubted the transition decision due to uncertainties regarding the timing of the move, societal taboos, and government policy. Thirdly, there was a discontinued transition process. Different professional caregivers were responsible for a small part of the transition. This led to miscommunication of information and inconsistency during the handover of care. More research is needed to empower the care triad enabling an optimal transitional care process.

Chapter 7 summarizes the main findings of the dissertation. It reflects on the methodological and theoretical considerations of the different studies. Moreover, practice and policy implications give some guidance to improving the transition pathway. Finally, suggestions for future research are given.

Samenvatting

De verhuizing van thuis naar een verpleeghuis is een veelvoorkomend zorgproces, voornamelijk voor oudere mensen met dementie. Het is een emotionele uitdaging die regelmatig gefragmenteerd verloopt. Deze fragmentatie resulteert in complicaties voor ouderen, mantelzorgers en professionele zorgverleners. Het verbeteren van het zorgproces vereist een grondige verdieping in de ervaringen van ouderen met dementie, mantelzorgers en professionele zorgverleners in de drie fasen van de transitie. Deze onderzoeksmethode kan leiden tot een beter begrip van de onderliggende mechanismen die ten grondslag liggen aan deze complicaties.

Dit proefschrift heeft tot doel bij te dragen aan het theoretisch begrip van het transitieproces en om richtlijnen te geven voor het verbeteren van dit proces door de ervaringen en behoeften vast te leggen van ouderen met dementie, mantelzorgers en professionele zorgverleners tijdens de transitie van thuis naar een verpleeghuis. Dit hoofdstuk omvat een samenvatting van de studies die in dit proefschrift zijn uitgevoerd.

Hoofdstuk 1 biedt een inleiding op dit proefschrift. Het omvat achtergrondinformatie en numerieke gegevens over de belangrijkste concepten binnen het onderzoeksveld. Het hoofdstuk verstrekt daarnaast informatie inzake de prevalentie en pathofysiologie van dementie, het concept van transitie, het verhuistraject van thuis naar een verpleeghuis binnen het Nederlandse gezondheidszorgsysteem en de implicaties van die transitie voor de zorgdriehoek. De inleiding eindigt met een overzicht van de komende hoofdstukken en hun respectievelijke onderzoeksvragen.

Hoofdstuk 2 presenteert het overzicht van de behoeften van ouderen en mantelzorgers tijdens de transitie van thuis naar een verpleeghuis. Om deze behoeften te identificeren werd een literatuuronderzoek uitgevoerd met behulp van de elektronische databases CINAHL en PubMed. Een vereiste voor de opgenomen studies is een onderzoeksveld dat gecentreerd is rond de ervaringen, behoeften, geïdentificeerde barrières of facilitators van ouderen en/of mantelzorgers tijdens het transitieproces. De verzamelde gegevens werden in kaart gebracht binnen de drie fasen van de transitie, wat resulteerde in het TRANSCIT-model. Het TRANSCIT-model werd preliminair gevalideerd door een groep experts op het gebied van onderzoek en praktijk. Het model identificeert vier belangrijke behoeften, namelijk informatie, communicatie, ondersteuning en tijd. Deze noden zijn noodzakelijke factoren om het transitieproces te verbeteren. Deze behoeften kunnen vervuld worden door een partnerschap te realiseren met de zorgdriehoek. Het TRANSCIT-model kan een algemene richtlijn worden om de kans op fragmentatie te verminderen en de transitie van thuis naar een verpleeghuis te optimaliseren.

Het TRANSCIT-model leidde tot de onderzoeksvragen die in hoofdstukken 3 en 4 aan bod komen. **Hoofdstuk 3** legt de perspectieven vast van ouderen met dementie met betrekking tot een mogelijke verhuizing naar een verpleeghuis en hun wensen voor toekomstige zorg. Deze studie volgde een kwalitatief fenomenologisch design, waar de perspectieven van achttien thuiswonende ouderen met dementie werden onderzocht. Daarnaast volgde de gegevensanalyse een stapsgewijze interpretatieve fenomenologische methode. De resultaten toonden aan dat de meerderheid van de ouderen die thuis woonden angstig waren ten aanzien van het idee dat ze mogelijk naar een verpleeghuis zouden verhuizen. Ondanks de ervaren angst, verklaarden de deelnemers dat ze autonome individuen die in contact staan met anderen wilden blijven als ze ooit naar een verpleeghuis zouden verhuizen. Deze wens werd geïdentificeerd door ouderen te vragen naar hun huidige en eerdere ervaringen met het ontvangen van zorg. Dit geeft aan dat professionele zorgverleners naar de levensverhalen van ouderen moeten luisteren om hun zorgbehoeften en -wensen te begrijpen. Bovendien bieden deze resultaten inzicht in een potentieel ’geschikt moment’ om een verhuizing naar een verpleeghuis voor te stellen.

Hoofdstuk 4 onderzoekt de ervaringen van mantelzorgers tijdens de transitie van thuis naar een verpleeghuis. Dit hoofdstuk maakt gebruik van een interpretatief fenomenologisch design om de ervaringen vast te leggen van 24 mantelzorgers die voor een persoon met dementie zorgen. De gegevens werden geanalyseerd volgens een interpretatieve fenomenologische methode. Hieruit volgde dat de mantelzorgers het transitieproces als paradoxicaal ervaarden. Ten eerste beleefden ze zowel positieve als negatieve emoties tijdens het proces. Daarnaast gaven ze aan behoefte te hebben aan een tijdig transitieplan. Desalniettemin stelden alle participanten de transitie naar het verpleeghuis zo lang mogelijk uit. Ten slotte voerden de mantelzorgers een interne strijd tussen de behoefte om betrokken te zijn en de behoefte om afstand te nemen in het zorgproces. Al deze paradoxen werden beïnvloed door de manier waarop het gezondheidszorgsysteem in Nederland is georganiseerd.

De negatieve en paradoxale ervaringen die in eerdere studies werden gedocumenteerd hebben geleid tot een eigen onderzoek naar bestaande transitie-interventies met als doel de kwaliteit van het huidige transitieproces te verbeteren. Als gevolg hiervan geeft **hoofdstuk 5** een samenvatting van de bestaande interventies gericht op het verbeteren van de transitie van thuis naar een verpleeghuis. Daarnaast worden de effectiviteit en de belangrijkste componenten van de geïdentificeerde interventies gepresenteerd. De scoping review werd uitgevoerd met behulp van de databases PubMed, EMBASE, PsycINFO, Medline en CINAHL. Deze review identificeerde zeventien studies die dertien verschillende interventies beschreven. De meerderheid van deze studies werd uitgevoerd in de Verenigde Staten en maakte gebruik van een gerandomiseerd gecontroleerd onderzoeksdesign. Acht van de geïdentificeerde interventies waren multi-componenten interventies. Dit zijn interventies die over meerdere weken/maanden worden uitgevoerd en bestaan uit verschillende interventie-elementen. De overige vijf interventies waren enkelvoudig. Deze interventies waren kleiner en gericht op een specifiek onderdeel van het transitieproces. Uit de multi-componenten interventies werden zeven interventiecomponenten geïdentificeerd: educatie; relaties/communicatie; verbetering van emotioneel welzijn; gepersonaliseerde zorg; continuïteit van zorg; ondersteuningsverlening; en ad hoc counseling. Een vergelijking van de resultaten van de interventies bleek moeilijk, gezien deze heterogeen waren. De meerderheid van de interventies richtte zich namelijk op het aanpassen aan wonen in een verpleeghuis, waarvan slechts één studie het hele transitieproces omvatte. Deze resultaten suggereren een mismatch tussen theoretisch gedefinieerde 'optimale transitiezorg' en momenteel bestaande zorginitiatieven. Er is nood aan meer informatie ten aanzien van de ervaringen binnen de zorgdriehoek om verbeteringen of verdere ontwikkelingen van transitie-interventies mogelijk te maken of door te voeren.

De bestaande onbalans tussen theorie en praktijk heeft geleid tot een laatste studie. **Hoofdstuk 6** beschrijft deze prospectieve, meervoudige casestudy uitgevoerd volgens de methodologie van de 'patiëntenreis'. De studie volgde het verhaal van vijf zorgdriehoeken, bestaande uit ouderen met dementie, mantelzorgers en professionele zorgverleners tijdens de transitie van thuis naar een verpleeghuis. Het onderzoek doelde op het vastleggen van de ervaringen van de zorgdriehoeken en op meer inzicht verwerven in het zorgproces. Het onderzoek liep achttien maanden en maakte gebruik van semi-gestructureerde interviews, follow-up momenten en logboeken om de ervaringen van de participanten vast te leggen. Alle gegevens werden geanalyseerd door middel van individuele en crosscase-analyse. De resultaten brachten een gebrek aan controle aan het licht die werd ervaren door de zorgdriehoeken gedurende het hele transitieproces. Dit gebrek aan controle en voorspelbaarheid kon toegewezen worden aan drie factoren. Ten eerste bestond een onderlinge afhankelijkheid binnen de zorgdriehoek. Iedere deelnemer voelde zich namelijk afhankelijk van de andere deelnemers. Daarnaast was de transitiebeslissing reactief in plaats van proactief. Meer specifiek hadden deelnemers moeite om het goede transitiemoment te identificeren. Ze twijfelden aan de transitiebeslissing vanwege onzekerheden over het tijdstip van de verhuizing, maatschappelijke taboes en het bestaande overheidsbeleid. Ten derde was er sprake van een gefragmenteerd transitieproces. Verschillende professionele zorgverleners waren verantwoordelijk voor een klein onderdeel van de transitie. Dit leidde tot miscommunicatie en onregelmatigheid van zorg tijdens deze transitie. Meer onderzoek is nodig om de zorgdriehoek te versterken en een optimaal transitieproces mogelijk te maken.

Hoofdstuk 7 vat de belangrijkste bevindingen van het proefschrift samen. Het reflecteert op de methodologische en theoretische overwegingen van de verschillende studies. Daarnaast geven praktijk- en beleidsimplicaties enige richting voor het verbeteren van het transitieproces. Ten slotte worden suggesties gegeven voor toekomstig onderzoek.

9

Chapter 9

Impact

Impact

This chapter provides insight into the impact of the outcomes of this dissertation on practice and future research. First, this chapter delineates small changes that can positively influence the experiences of the care triad during the transition process. Secondly, the implications for future research are provided. Finally, the dissemination of the findings on a national and international scale is detailed.

Small changes can have a great impact

This research highlights the substantial impact that professional caregivers can have in facilitating the care process. While comprehensive financial and organizational changes are indispensable to defragment and optimize transitional care, small adjustments in daily practice can already yield significant benefits for future care triads embarking on the transition from home to a nursing home.

Change 1: guiding the way – the essential partnership within a care triad

Throughout the transition from home to a nursing home, establishing a partnership among professional caregivers, older people, and informal caregivers is crucial. This is regardless of the transition process ending with a move to a nursing home. Consequently, the appointment of a dedicated professional caregiver is recommended to provide essential guidance and initiate this collaborative effort. Within this partnership, equality should be maintained, ensuring that individuals, including older people with dementia, are fully informed and actively involved in the care process. This would not just alleviate the burden for the informal caregivers (1); it would also help older individuals' acceptance of the transitional care decision (2, 3).

In the Netherlands, the dementia case manager should actively guide the care triad throughout the transition process. They should be involved in the care process, preferably as soon as possible, enabling a bond of trust and mutual respect. This dissertation underscores the pivotal role of trust in facilitating discussions regarding transition. The primary responsibility of the dementia case manager lies in centralizing information and disseminating it to the relevant partners in the transition process. Moreover, as dementia case managers leverage extensive knowledge, they should guide the members of the care triad by informing them of the care possibilities and preferably suggesting the best care option tailored to each unique situation. This research has shown that support and guidance by dementia case managers are appreciated during the transition decision (4, 5).

Lastly, policymakers have to allow these dementia case managers to continue their caregiving role beyond the mid-transition. The trusted care professional plays a critical role in the provision of practical and emotional support at the start of the post-transition phase.

Change 2: it is never too early for a timely conversation

Throughout this dissertation, the researchers found that the majority of older people and informal caregivers moved to a nursing home after the occurrence of a crisis. This often results in a hurried and fragmented transitional care pathway. Therefore, professional caregivers should initiate discussions regarding the transitional care process proactively. When older people are no longer able to live an autonomous, individual, and social life, a transitional care process might become inevitable. Nursing homes can alleviate the care burden of informal caregivers and improve the quality of life of older individuals. Therefore, the ideal time for this discourse is as soon as a foundation of trust is established among the participants of the care triad. The majority of dementia case managers who participated in the studies were able to gain the trust of older people and informal caregivers. The study by Afram et al. (2015) recommends discussing transitional care at an early stage (6), but this early stage was not defined. However, research has shown that older people and informal caregivers should feel ready to discuss the transition (7). Dementia case managers can support older individuals and informal caregivers to establish this feeling of readiness. Nevertheless, these conversations have to be recurrent, occurring at various junctures within the care process.

During these discussions, professional caregivers should focus on providing information on the care options (e.g. the different nursing home types, moving in with family, or providing more support at home). They should also articulate the consequences associated with deferring specific care decisions, elucidating the potential outcomes of postponing a nursing home move, for instance. Timely conversations can have significant benefits as they allow for timely information, and the possibility to share the decision as the older person is more able to have cognitive dialogues. These conversations can lead to a timely move. Moreover, a timely transition discussion enables a gradual care process. For instance, older people and informal caregivers can take the time to visit multiple nursing homes, familiarizing themselves with the environment and staff.

Even after a move into a nursing home, the timing of information provision remains paramount. Specifically, on the day of the relocation, the focus should shift towards introducing staff and acquainting oneself with the nursing home. Delicate subjects, such as advance care planning and other emotionally charged topics, are to be addressed at more suitable times, avoiding unnecessary stress on the day of the move.

Change 3: dismantling taboos surrounding dementia and nursing homes

From the results in this dissertation, it became apparent that stigmatization and taboos, although not always clearly visible, could significantly affect the transitional care experiences of the care triad. Specifically, older people with dementia are often excluded from discussions related to transitional care due to concerns for their well-being. This dissertation clearly showed that older people with dementia were able to express their experiences and preferences concerning future care. This exclusion may stem from the prevailing perception of people with dementia held by others. Notably, half of the general population believes that older individuals with dementia are incapable of engaging in meaningful conversations (8). Media play a crucial role in either perpetuating or mitigating stigmatization and stereotyping (9). Consequently, prioritizing the destigmatization of dementia in both research and practice is imperative, possibly through initiatives such as anti-stigma and educational campaigns (10).

Furthermore, media coverage during the COVID-19 pandemic exacerbated the negative portrayal of nursing homes (11). Even professional caregivers, who support older people and informal caregivers throughout the transition process, harbour negative perceptions of nursing homes. A potential strategy to destigmatize nursing homes involves shifting the current health system's focus from merely 'ageing in place for as long as possible' to fostering a comfortable and high-quality life at home. In this context, 'home' could ideally be a residential home or a nursing home where both older people and informal caregivers feel at home. Home is defined as a place of privacy and feeling safe and in control. It is associated with being able to maintain hobbies and routines (12, 13). Destigmatizing dementia and nursing homes will pave the way for more open and constructive conversations regarding the topic of transitional care.

The impact on research

This dissertation employed various research methods to derive its findings. Notably, it successfully captured the experiences of older individuals with dementia, delving into the often taboo subject of transitional care. This is unique considering the predominant focus on older individuals without cognitive decline in existing research (14). Throughout this dissertation, diverse methods were employed to include older people with dementia in the research. Recognizing the difficulty that many older individuals faced in discussing transitional care and the perceived threat of moving to a nursing home, the researchers facilitated conversations by presenting potential scenarios – for instance, exploring hypothetical situations, such as the possibility of a fall or the inability of a spouse to provide care, enabling participants to articulate their feelings and express their wishes for future care.

Furthermore, this dissertation advocates the inclusion of questions about past life experiences, recognizing them as predictors of future wishes and perspectives. This is especially true for participants experiencing cognitive decline. The researchers asked older people with dementia about their past and current life experiences, enabling them to understand their future wishes and perspectives. The research studies revealed that a simple act of asking questions about the progressive nature of dementia and the need for a potential nursing home move provided valuable insights into the wishes and perspectives of older individuals. This not only enriched the understanding of the participants' wishes for the future but also offered new insights for their families.

This dissertation provided a prospective view of transitional care, employing the patient journey mapping methodology borrowed from marketing research (15). The methodology was able to provide an in-depth understanding of the care triad experiences. The methodology offered a nuanced understanding of the care triad experiences, shedding light on the current transitional care process and the impact of healthcare regulations and legislation on outcomes. The prospective perspective facilitated the formulation of practical and organizational recommendations to enhance the healthcare system, specifically addressing the gap between home and nursing home care and its consequences for the care experiences. However, it is acknowledged that the employed research method is time-intensive and challenging.

The researchers offer suggestions for future studies utilizing similar methodologies. They underscore the importance of establishing a strong bond between researchers and participants. Specifically, participants need to feel comfortable and motivated to participate over the extended duration of a care journey, especially, when such a care journey takes months or even years. The bond between a researcher and participant allows for context information and more in-depth conversations (16). Moreover, researchers should possess a deep understanding of the research subject before data collection to facilitate comprehensive and relevant inquiries. Providing researchers with adequate time to perform the study ensures the flexibility to follow the natural flow of a care journey, fostering rapport-building and enhancing data collection.

The findings of this dissertation can serve as a foundation for the improvement of existing or the development of new transitional care interventions. One example could be the "Partner in Balans" application. This online program is designed to assist informal caregivers involved in the care for individuals with dementia. By aiding caregivers in adapting to the evolving challenges posed by the disease, the tool facilitates effective home care, allowing caregivers to continue their daily lives. The outcomes of this research may be integrated as an additional module within the web tool. Once incorporated, the insights drawn from the experiences and perspectives of the care triad, as expounded upon in this dissertation, can provide valuable data elucidating the barriers and facilitators intrinsic to the current transitional care process.

Furthermore, the experiences and perspectives of the care triad can serve an instructive guide for informal caregivers, aiding their future decision-making processes and providing a comprehensive overview of the transitional care pathway. These insights hold the potential to contribute to the optimization of transitional care process, thereby enhancing the overall transitional care experiences and outcomes for both older individuals and their informal caregivers (17).

Dissemination of the findings

The findings of this dissertation have been widely disseminated both nationally and internationally. Nationally, the researchers have delivered various presentations and lectures on transitional care. Specifically, presentations were conducted at Zuyd University of Applied Sciences and the Maastricht University within the Faculty of Health, Medicine and Life Sciences, highlighting the outcomes of different studies. Moreover, the researcher presented the results of her studies to dementia case managers in training and the professional Association for Professional Caregivers and Nurses (V&VN), educating them on transitional care. Furthermore, in collaboration with a participant in the patient journey, a presentation was delivered at the “Dialogen Rondom Dementie” event organized by the Alzheimer’s Centre Limburg. Additionally, the research from this dissertation has been shared within the Living Lab in Ageing and Long-term Care, Limburg (Academische Werkplaats Ouderenzorg Limburg), involving presentations at various partner organizations (e.g. Meander and Zuyderland).

Nearly all studies have undergone submission and publication in peer-reviewed, high-impact, open-access journals, including notable journals such as JAMDA and The Gerontologist. The findings were also presented at multiple international conferences, such as the International Scientific Nursing and Midwifery Congress (CARE4), the Gerontological Society of America Annual Scientific Meeting (GSA), and the European Geriatric Medicine Society (EuGMS). The researcher also presented the dissertation’s results over three years as a participant in the European Academy of Nursing Science summer school, an esteemed programme bringing together researchers who have made significant contributions to nursing science in Europe.

Beyond academic forums, the researcher was educated to become a health innovator and independent researcher as part of TRANS-SENIOR. The European-funded project enabled the researcher to gain knowledge, research expertise, and transferable research skills. The extensive international network of research experts associated with this project further disseminated the dissertation findings through their formal website and various social media channels such as YouTube and LinkedIn.

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Chapter 10

Addenda

Publications
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Living Lab in Ageing and Long-Term Care

Publications

International scientific journals:

Groenvynck L, de Boer B, Hamers JPH, van Achterberg T, van Rossum E, & Verbeek, H. (2021). Toward a partnership in the transition from home to a nursing home: The TRANSCIT Model. J Am Med Dir Assoc, 22(2), 351-356. doi:10.1016/j.jamda.2020.09.041

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Groenvynck L, Khemai C, de Boer B, Beaulen A, Hamers JPH, van Achterberg T, van Rossum E, Meijers JMM, Verbeek H. The perspectives of older people living with dementia regarding a possible move to a nursing home. Aging Ment Health. 2023 Nov-Dec;27(12):2377-2385. doi: 10.1080/13607863.2023.2203693. Epub 2023 Apr 26. PMID: 37099667.

Groenvynck L, de Boer B, Beaulen A, de Vries E, Hamers JPH, van Achterberg T, . . . Verbeek, H. (2022). The paradoxes experienced by informal caregivers of people with dementia during the transition from home to a nursing home. Age and Ageing, 51(2). doi:10.1093/ageing/afab241

Fakha A, **Groenvynck L**, de Boer B, van Achterberg T, Hamers J, Verbeek H. A myriad of factors influencing the implementation of transitional care innovations: a scoping review. Implement Sci. 2021; 16(1):21. https://doi.org/10.1186/s13012-021-01087-2

Conference abstracts:

Groenvynck L, de Boer B, van Achterberg T, Hamers J.P., Verbeek H. A mismatch between theory and practice in the transition from home to a nursing home: A scoping review. (Symposium - transitions to long-term residential care settings). The Gerontological Society of America (GSA) Annual Scientific Meeting, November 10-14, 2021; Phoenix, AZ, USA.

Groenvynck L, de Boer B, van Achterberg T, Hamers J.P., Verbeek H. Interventions to improve the transition from home to a nursing home. International Scientific Nursing and Midwifery Conference, 4th edition (CARE4 2022), February 8-10, 2022; Ghent, Belgium.

Groenvynck L, de Boer B, Hamers J.P., Verbeek H, van Achterberg T.. Interventions to improve the transition from home to a nursing home. European Geriatric Medicine Society (EuGMS), 18th International Congress, September 28-30, 2022; London, UK.

Groenvynck L, de Boer B, van Achterberg T, Hamers J.P., Verbeek H. The paradoxical experiences of informal caregivers during the transition from home to a nursing Home. The Gerontological Society of America (GSA) Annual Scientific Meeting, November 2-6, 2022; Indianapolis, IN, USA.

Groenvynck L, de Boer B, van Achterberg T, Hamers J.P., Verbeek H. The paradoxical experiences of informal caregivers during the transition from home to a nursing home. European Academy of Nursing Science (EANS) summer conference, July 7-8, 2022; Lithuania.

Dankwoord

Toegegeven, ik heb dit moment, het schrijven van het dankwoord zo lang mogelijk uitgesteld. En het zal me uiteindelijk enkele weken kosten om de juiste woorden op papier te krijgen. Ik vind het namelijk moeilijk om zoveel dankbaarheid, mooie momenten en herinneringen simpelweg even neer te pennen. Dat lijkt me te eenvoudig. Ik vraag me dan af, kunnen we dit alles herleiden tot enkele woorden op het einde van een boekje. Toch ga ik mijn best doen om deze momenten van dankbaarheid te vangen in woorden.

De deelnemers aan het onderzoek

Ik wil starten door mijn oprechte dankbaarheid te uiten aan alle deelnemers van de “patient journey”. Bij aanvang van deze studie heb ik u allen verteld dat, vanwege privacy redenen, u zou worden geïdentificeerd aan de hand van een nummer, en ik heb u ook altijd dat specifieke nummer gegeven. “Vanaf nu bent u casus nummer 5 voor mij”, zei ik. Dit bracht altijd een glimlach op uw gezichten. Maar hoewel u op papier een nummer bent, voor anderen, heb ik het voorrecht gehad om de mensen achter die nummers te leren kennen. Vaak zaten we samen, vergezeld van een heerlijke kop thee of cake, urenlang aan tafel te praten over de uitdagende overgang van thuis naar het verpleeghuis. Uw openhartigheid en bereidheid om uw ervaringen en verhalen te delen, hebben dit onderzoek mogelijk gemaakt.

Het was een voorrecht om te luisteren naar uw verhalen, die doordrenkt waren van emotie, liefde en moeilijke beslissingen. U hebt mij een diepgaand inzicht gegeven in de complexiteit van deze transitie. Uw woorden waren niet alleen hartverwarmend, maar ook inspirerend. Uw veerkracht en liefdevolle zorg voor uw dierbaren hebben diepe indruk op mij gemaakt en zullen ongetwijfeld anderen inspireren. Uw bijdrage zal een blijvende impact hebben op het verbeteren van de zorg voor mensen met dementie en hun families. Uw woorden fungeren als lichtbakens voor anderen die vergelijkbare uitdagingen doormaken.

Ik wil ook graag mijn oprechte dank betuigen aan alle organisaties en zorgverleners die hebben deelgenomen aan het onderzoek, specifiek Meandergroep Zuid-Limburg, de zorgverleners van Hulp bij dementie parkstad, midden-Limburg en Noord-Limburg. Inmiddels zijn we ons allemaal bewust van de immense druk waaronder de zorgsector staat. Naast de emotionele belasting hebben jullie te maken met een tekort aan collega’s. Ondanks deze uitdagingen hebben velen van jullie de tijd genomen om deel te nemen aan de studies en ons door te verwijzen naar de juiste personen. Verschillende zorgverleners hebben me begeleid en me de werking van het zorgsysteem en de obstakels die de zorgverlening bemoeilijken, bijgebracht. Jullie inzichten waren waardevoller dan duizend boeken samen. Ontzettend bedankt om jullie wijsheid met mij te delen.

Het team

Bedankt aan mijn fantastische promotieteam: Bram, Hilde, Theo, Erik en Jan. Het is een voorrecht geweest om met jullie samen te werken. Mijn herinneringen aan ons allereerste promotieoverleg op 14 februari 2019, rond Jan's imposante ronde tafel, zijn nog steeds levendig. Ik verwachtte dat jullie me zouden vertellen hoe het project eruit zou gaan zien en welke stappen ik moest volgen. Echter, bleef het muisstil en wachtte iedereen geduldig tot ik het woord nam.

Jullie gaven me de vrijheid om het project naar eigen inzicht vorm te geven. Hoewel we regelmatig discussies hadden over de details, slaagden we er telkens weer in om tot een consensus te komen. Het was een waar genoegen om op deze manier aan een project te werken. Elk overleg bracht nieuwe inzichten met zich mee. Jullie hadden allemaal jullie eigen visie en ideeën, waardoor ik continu nieuwe lessen kon leren en wijsheid kon vergaren uit jullie diverse perspectieven. Nogmaals, hartelijk dank voor jullie waardevolle bijdrage en de samenwerking.

Bram, ik wil je graag bedanken voor alles wat je voor me hebt gedaan. Eerlijk gezegd kan ik me niet veel herinneren van ons eerste sollicitatiegesprek, behalve dat je gedurende heel ons gesprek enthousiast was. Je vriendelijke knikjes en glimlach gaven me een geruststellend gevoel, en ik ben er nog steeds niet zeker van of dat kwam door mijn woorden of simpelweg door jouw natuurlijke vriendelijkheid. Hoe dan ook, dankzij jou kon ik met een goed gevoel de sollicitatie verlaten. Zonder jouw steun was dat niet gelukt.
Vanaf het begin gaf jij mij een gevoel van vertrouwen. Terwijl ik slechts mogelijke obstakels zag, zag jij kansen en moedigde je mij aan om door te gaan. Jouw mantra van "Gewoon doen, wat is het ergste dat kan gebeuren?" blijft me bij als een herinnering aan jouw vertrouwen in mijn capaciteiten. Het maakt me trots om jouw eerste promovenda te zijn. Iedereen die jou als dagelijks begeleider heeft, kan van geluk spreken.
Nogmaals, Bram, bedankt voor alles wat je voor me hebt gedaan. Jouw steun en vertrouwen hebben een blijvende impact op me gehad en ik zal jou altijd dankbaar zijn voor onze fijne samenwerking.

Hilde, ik wil je enorm bedanken voor de rol die je hebt gespeeld als mijn promotor in dit project. Jouw enthousiasme is werkelijk aanstekelijk en heeft me keer op keer gemotiveerd. Ik ben dankbaar voor de vrijheid die je me altijd hebt gegeven om mijn eigen beslissingen te nemen, en voor het vertrouwen dat je in me had wanneer ik knopen moest doorhakken. Bedankt voor alle kansen die je me hebt geboden, zoals de mogelijkheid om deel te nemen aan de EANS. Je hebt niet alleen gezorgd dat ik me op het werk op mijn plek voelde, maar je hebt ook altijd gewaakt over een goede balans tussen werk en privé. Ik zal nooit vergeten wat je me zei: "Vakantie is net zo belangrijk als werk, want het stimuleert de creativiteit." Daar kan ik alleen maar mee instemmen.

Je hebt me soms uit mijn comfortzone gehaald en ik ben zo blij dat je dat hebt gedaan. Het heeft me sterker gemaakt en meer zelfvertrouwen gegeven. Dus nogmaals, bedankt voor alles!

Theo, ik wil je oprecht bedanken, want zonder jou zou ik deze woorden nu niet neerpennen. Het was dankzij jouw uitnodiging aan twee medestudenten en mijzelf voor de vacature van TRANS-SENIOR dat ik hier ben beland. En ik ben ontzettend blij dat ik daarop ben ingegaan. Door jou heb ik mijn passie voor onderzoek ontdekt.
Elke keer als ik naar de KU Leuven kom, voelt het als thuiskomen. De sfeer is er altijd zo knus en gezellig, en iedereen is welkom, zelfs de huisdieren! Ik heb enorm genoten van de vele dartspelletjes in het kleine keukentje, ook al verloor ik keer op keer.
Met jou heb ik vaak gebrainstormd over hoe we het project vorm konden geven, maar we hebben ook persoonlijke verhalen gedeeld over ons dagelijks leven. Ik ben zelfs bij jou en Geert uitgenodigd voor een gezellig etentje. Ik ben vereerd dat ik jou "promotor" maar vooral collega kon noemen!

Jan, ik wil graag mijn dankbaarheid uitspreken voor jouw ondersteuning tijdens mijn promotietraject. Het feit dat je onze overleggen altijd begon en eindigde met een compliment gaf me telkens weer de motivatie en het vertrouwen om verder te gaan. Ik waardeer enorm hoe jij voortdurend kritische vragen stelde en mij uitdaagde om mijn ideeën te verdedigen. Dankzij jouw aanmoediging ben ik gegroeid, zowel professioneel als persoonlijk.
Bovendien heb ik dankzij jou ingezien dat koffie drinken niet alleen een pauze is, maar ook een vorm van werken. Jouw inzichten over het belang van netwerken hebben mijn perspectief verbreed. Jan, ik ben ontzettend dankbaar voor alles wat je voor me hebt gedaan. Bedankt!

Erik, bedankt dat je steeds met een brede glimlach deel hebt genomen aan de promotieoverleggen. Jouw adviezen waren altijd zeer gewaardeerd. Hoewel ik niet altijd alle inside jokes tussen jou en Jan volledig begreep, was het altijd leuk om naar te luisteren en de positieve sfeer te ervaren. Dankjewel voor het delen van die momenten en het bijdragen aan een prettige werkomgeving.
Ik waardeer het ook enorm dat je altijd zo vriendelijk en positief was en mijn ideeën steunde tijdens de groepsdiscussies. Bovendien heb ik veel gehad aan jouw advies over mijn toekomst in onderzoek, waarbij je me de drie takken van onderwijs, onderzoek en praktijk hebt uitgelegd.
Bedankt voor de goede sfeer en waardevol advies. Ik kijk met een positief en warm gevoel terug op jouw bijdrage aan dit fantastisch avontuur.

Judith Meijers, graag wil ik je hartelijk bedanken voor je onschatbare bijdrage aan mijn proefschrift. Jouw toewijding en inzet bij het verzamelen van de waardevolle DEDICATED interviews, samen met Sascha en Chandni, hebben een cruciale rol gespeeld in het tot stand komen van twee solide wetenschappelijke artikelen. Deze bijdragen hebben mijn proefschrift verrijkt en hebben een significante impact gehad op mijn onderzoek. DEDICATED is een prachtig project. Maar ik had ook de eer om jou mijn mentor te noemen. Bij jou kon ik altijd aankloppen met vragen en onzekerheden. Op momenten dat ik het even moeilijk had of echt niet meer wist, was jij er altijd. Je bood niet alleen advies, maar vooral een luisterend oor. En dat is vaak van onschatbare waarde. Jouw enthousiasme en vrolijkheid zijn werkelijk aanstekelijk geweest. Dank je wel voor je voortdurende steun en begeleiding. Jouw positieve invloed heeft een diepe indruk op me achtergelaten en heeft mijn groei binnen dit project enorm verrijkt. Bedankt voor alles.

Leden beoordelingscommissie
Prof. Dr. Marjolein de Vugt, Prof. Dr. Katrien Luijkx, Prof. Dr. Philip Moons, Prof. Dr. Joseph E. Gaugler, Prof. Dr. Jos M.G.A. Schols, en Dr. Math Gulpers; ik wil mijn dankbaarheid en waardering uitspreken voor de tijd en aandacht die jullie hebben besteed aan het lezen van mijn proefschrift. Ik kijk ernaar uit om jullie inzichten te ontvangen tijdens mijn verdediging en waardeer nu al de vragen die jullie zullen stellen. Ik hoop dat deze uitwisseling van gedachten en ideeën ons begrip verrijken en ons werk verder verbeteren.

TRANS-SENIOR Consortium, I am writing to express my deepest gratitude for the incredible opportunity to be a part of your project. The experience has been nothing short of transformative, and I am immensely thankful for everything I have gained from it.
The array of lectures and classes offered through the consortium has expanded my knowledge and enriched my understanding. Working alongside the best of the best has been both inspiring and enlightening, pushing me to grow professionally and personally.
Moreover, I am grateful for the opportunity to forge new and lasting friendships with my colleagues. Our shared experiences have created bonds that I treasure deeply.
One of the highlights of my time with the consortium has been the chance to visit beautiful cities and immerse myself in their cultures. The combination of important lectures and delicious local cuisine made each trip a memorable and enriching experience. I still vividly recall my first event in Leuven, looking around at everyone and realizing that I was truly a part of this amazing team. It was a moment of profound pride.
So thank you, for providing me with opportunities for growth, learning, and lasting friendships.

Klarissa, Het is met een hart vol dankbaarheid dat ik deze woorden schrijf om mijn diepe waardering voor jou als mijn paranimf uit te drukken. Hoewel onze paden nog niet zo

lang geleden kruisten, voelde ik vanaf het allereerste moment een sterke connectie en wist ik meteen dat ik jou wilde vragen om deze speciale rol te vervullen. Jouw empathie en oprechtheid waren meteen voelbaar, en vanaf dag één hadden we veel plezier samen. Het was voor mij een ware eer om te zien hoe jij, ondanks de uitdagende periode waarin je jezelf bevond door de ziekte van je vader, vol enthousiasme instapte en mij bijstond, zelfs te midden van de stress in jouw eigen leven. Je onvermoeibare steun en toewijding hebben niet alleen mijn uitstelgedrag doen verdwijnen, maar hebben er ook voor gezorgd dat alles tijdig klaar was, en dat met een glimlach op je gezicht.
Ik kijk nu al uit naar de viering op 3 juni, waar we samen zullen zijn om dit bijzondere moment te vieren. Dank je wel, Klarissa, niet alleen voor het zijn van mijn paranimf, maar ook voor het zijn van een fantastische collega en vriend.

Monique, ik hoop dat deze boodschap je met dezelfde oprechtheid en warmte bereikt als waarmee ik haar schrijf. Ik wil je namelijk uit de grond van mijn hart bedanken voor je onschatbare bijdrage aan dit bijzondere moment in mijn leven.
Het was door jouw samenwerking met Amal dat onze paden elkaar hebben gekruist, en daar ben ik dankbaar voor. Vanaf het allereerste moment dat ik je leerde kennen, werd ik getroffen door je ongekende passie en gedrevenheid voor onderzoek. Het was werkelijk inspirerend om te zien hoe je elke uitdaging met een positieve instelling en een aanstekelijke glimlach tegemoet trad. Voor jou leek niets onmogelijk, en geen enkele taak te zwaar. Toen Amal jou en mij vroeg om paranimf te worden, ging je er meteen vol enthousiasme en toewijding voor. Jouw gedrevenheid en de manier waarop je je taak opnam, waren voor mij vanaf het eerste moment bewonderenswaardig. Ik wist meteen: zo’n paranimf wil ik ook hebben. En het vervult me dan ook met grote eer dat jij ook mijn paranimf wilt zijn, naast Klarissa.
Duizendmaal dank dat je op 3 juni naast me wilt staan en dit moment met me wilt delen.

Amal, you made this journey truly special, and I am immensely grateful for all your support throughout the PhD and beyond.
You were the best office buddy! I’ll always remember those moments huddled around the heater in our freezing office, sipping on coffee and delving into discussions about science. Your command of the English language has always left me in awe.
One of my fondest memories with you is our trips to Zuyd, where we found ourselves lounging in those sunbathing chairs in the middle of winter, enjoying refreshing drinks and engaging in heartfelt discussions about life. Those moments of camaraderie and reflection were truly invaluable to me.
Your advice has been sublime, and I continue to draw upon the insights you’ve shared with me, applying them to both my personal and professional life. Amal, thank you for being the friend that I could always count on.

Roomies: Laura, Philippe en Quincy, Ik wil graag even de tijd nemen om jullie te bedanken voor het maken van onze werkplek tot dé plek waar iedereen wil zijn. Jullie hebben onze bureau omgetoverd tot een bruisende hub waar collega's graag langskomen voor een gezellig praatje of iets lekkers uit onze gigantische snoepkast!
Het is fantastisch om te zien hoe jullie een sfeer van warmte en verbondenheid hebben gecreëerd op de afdeling, waarin iedereen zich welkom voelt. Jullie hebben niet alleen onze werkruimte verlevendigd, maar ook onze werkdagen verrijkt met jullie aanstekelijke energie en positiviteit.
Ik heb enorm genoten van deelname aan de leuke uitstapjes die jullie hebben georganiseerd en van de gezellige momenten die we samen hebben beleefd. Het is een voorrecht om deel uit te maken van zo'n geweldig team van collega's.
Nogmaals hartelijk dank voor jullie vriendschap, steun en gezelligheid. Ik kijk uit naar nog veel meer mooie herinneringen en leuke momenten samen.

Bedankt aan alle **administratief medewerkers van dub,** voor jullie voortdurende ondersteuning en toewijding. Jullie zijn altijd beschikbaar geweest om mijn administratieve vragen te beantwoorden, en dat heeft mijn werk aanzienlijk vergemakkelijkt.
Brigitte, het is moeilijk te geloven dat het alweer vijf jaar geleden is sinds ik begon op Maastricht. In die beginperiode waren er tal van vragen en onzekerheden die door mijn hoofd spookten. Gelukkig leerde ik al snel de meest waardevolle woorden kennen: "Vraag het anders aan Brigitte, die weet alles." En het bleek nog waar te zijn ook.
Telkens wanneer ik met vragen zat, wist ik dat ik bij jou terecht kon. Ik kan me zelfs voorstellen dat het soms leek alsof de helft van jouw agenda was gevuld met vragen van mijn kant. Toch nam je altijd de tijd om alles rustig uit te leggen en te regelen. Ik ben ontzettend dankbaar dat ik altijd op jou heb kunnen rekenen voor hulp en advies.
Michelle, ik wil je enorm bedanken voor al je onschatbare hulp bij het overwinnen van de administratieve uitdagingen die gepaard gingen met het inleveren van mijn proefschrift. Zonder jouw begeleiding en toewijding zou ik nooit in staat zijn geweest om deze berg aan papierwerk te overwinnen. Bedankt!

Audrey en Erica, Ik wil mijn diepe waardering uitspreken voor jullie buitengewone toewijding en onmisbare bijdragen als onderzoekers. Gedurende onze tijd samen hebben jullie mij zoveel geleerd over kwalitatief onderzoek en analyses. Samen hebben we urenlang gebrainstormd, onze gedachten geordend en de juiste lijnen uitgezet. Hoewel mijn samenvattingen op het whiteboard vaak een onleesbare wirwar leken, namen jullie altijd de tijd om alles te begrijpen en samen met mij te kijken hoe we het beter konden maken.
Ik durf te zeggen dat onze gezamenlijke inspanningen hebben geleid tot de productie van mooie en scherpzinnige studies. Dit alles was alleen mogelijk dankzij jullie bijdragen en expertise.

Audrey en Erica, jullie zijn niet alleen geweldige onderzoekers, maar ook fantastische teamgenoten. Ik ben dankbaar voor de kans om met jullie samen te werken en te leren van jullie kennis en ervaring.

Beste collega's van Dub, Dank jullie allemaal! Vanaf het allereerste begin hebben jullie mij welkom doen voelen in deze gemeenschap, en dat heeft een enorm verschil gemaakt in mijn ervaring hier. Jullie openheid, vriendelijkheid en bereidheid om te helpen hebben ervoor gezorgd dat ik me altijd thuis voelde en dat ik altijd bij jullie terecht kon met vragen of problemen. Jullie hebben een werkomgeving gecreëerd die niet alleen professioneel is, maar ook warm en ondersteunend - een omgeving waarin ik me op mijn gemak voelde en waarin ik kon gedijen.
Zoals mijn proefschrift suggereert, is het gevoel van ergens thuis te zijn cruciaal voor ons algemeen welzijn. En ik kan met oprechtheid zeggen dat jullie bijdrage aan het creëren van zo'n omgeving hier bij Dub van onschatbare waarde is geweest.
Specifiek wil ik ook **Jolanda** bedanken, die mij heeft aangenomen als post-onderzoeker voor een super interessant en leerrijk project. Dit heeft mij de mogelijkheid geboden om nog een jaar langer in deze fantastische werkomgeving te blijven werken.
Ik ben super dankbaar voor de kans om deel uit te maken van dit team en kijk ernaar uit om nog veel meer waardevolle momenten met jullie te delen.

Ik wil graag mijn oprechte dankbaarheid uiten aan **de collega's van de KU Leuven** voor de kans om er te mogen werken. De gedetailleerde kennis die ik heb opgedaan over verschillende onderzoekstechnieken heeft me enorm geholpen en zal van onschatbare waarde blijven. Elke keer dat ik naar Leuven kom, voelt het als thuiskomen. Wat een warme en gezellige sfeer.

Familie & dierbaren

Liefste ouders, broer (Greg) en zus (Lana), bedankt voor jullie onvoorwaardelijke steun gedurende de afgelopen jaren. Bij jullie kan ik altijd terecht voor advies en een luisterend oor, en dat betekent ontzettend veel voor me.
Jullie zijn er altijd geweest, door dik en dun, om me te steunen en te begeleiden. Jullie warmte, begrip en liefde hebben me door moeilijke momenten heen geholpen en hebben mijn vreugdevolle momenten nog specialer gemaakt.
Het is geruststellend om te weten dat ik op jullie kan rekenen, ongeacht wat er gebeurt. Jullie zijn niet alleen mijn familie, maar ook mijn rotsen in de branding, en ik ben ontzettend dankbaar voor de band die we delen.

Lieve **Tinne, Tinne en Charlotte,** al meer dan de helft van mijn leven mag ik jullie mijn beste vriendinnen noemen, en ik kan me geen leven voorstellen zonder jullie aan mijn zijde.

Samen hebben we de meest onvergetelijke avonturen beleefd, van gezellige picknicks tot het redden van elkaars leven toen we onbezonnen het kanaal overzwommen.
Jullie hebben altijd voor me klaargestaan, ongeacht de situatie. We hebben samen gehuild, gelachen en elkaars successen gevierd. Ik wil jullie bedanken voor jullie onvoorwaardelijke steun en vriendschap. Jullie hebben mij gevormd tot de persoon die ik vandaag ben. Ik heb van jullie geleerd om hard te werken en nooit op te geven, en daar ben ik jullie eeuwig dankbaar voor.
Tinne, Tinne en Charlotte, jullie zijn echt fantastisch, en ik koester onze vriendschap meer dan woorden kunnen uitdrukken.

Yves, ik ken je al jaren dankzij je fantastische dochter Charlotte! De herinnering aan jouw schitterende zeilboot, waarop ik het voorrecht had om mee te varen, blijft me nog altijd bij. Maar ik wil je vooral bedanken voor al je hulp tijdens mijn stages en mijn hele studietraject. Jouw advies was altijd spot-on. Jij gaf me een mogelijkheid om mijn verpleegkundige vaardigheden te oefenen en mijn onzekerheden aan te kaarten. Je stond altijd klaar met advies en hebt me bij elke stap ondersteund. Je benadrukte het belang van het TRANS-SENIOR-project, en ik ben blij dat ik naar je geluisterd heb. Het heeft echt een grote impact gehad, zoals je voorspelde. Bedankt voor alles wat je hebt gedaan.

Prof. Dr. Marc Gewillig, bedankt voor alles wat je hebt gedaan. Je steun betekent veel voor me. Sinds mijn geboorte sta je altijd voor me klaar, zowel tijdens de goede als de moeilijke momenten.
Bij elk consult ging het niet alleen over mijn gezondheid, maar ook over hoe het ging met mijn school, vrienden, hobby's en interesses. Je had altijd een brede kijk op mijn welzijn, en dat waardeer ik enorm.
Tijdens mijn verpleegkundeopleiding was je er altijd om me te helpen, zelfs als het zwaar was. Het feit dat je op de hoogte was van mijn artikelen en de congressen die ik bijwoonde, laat zien hoe betrokken je bent.
Het compliment dat je me gaf tijdens onze laatste consultatie, waarbij je zei dat je trots op me was, betekende veel voor me. Het is een bevestiging van ons harde werk. Nogmaals, bedankt voor alles. Zonder jouw steun had ik hier niet gestaan.

Tenslotte wil ik specifiek **Tinne Hoskens** bedanken voor het creëren van de prachtige cover voor mijn proefschrift. Jouw enthousiasme en talent hebben echt het verschil gemaakt, en ik ben ontzettend dankbaar voor al je hulp. Het voelde alsof je dit project voor jezelf maakte, zo zorgvuldig en persoonlijk was je benadering. Geen enkele illustrator had iets zo moois en treffends kunnen creëren als jij hebt gedaan.
Ook wil ik mijn **nichtje Lori** enorm bedanken. Op de dag van de inlevering van mijn proefschrift heb je urenlang met mij gezeten, mijn onzekerheden over bepaalde woorden en

schrijfwijzen doorgenomen en gecorrigeerd. Je stond altijd paraat, zelfs als er snel iets vertaald moest worden. Je steun en hulp waren werkelijk onschatbaar.

Tinne, Lori, jullie hebben beide een onschatbare bijdrage geleverd aan dit project, en ik kan niet genoeg benadrukken hoe dankbaar ik ben voor jullie hulp en steun.

About the author

Lindsay Groenvynck, born on the 29th of July 1993, earned her bachelor's degree in nursing science in 2015. Following her graduation, she worked as a nurse at child and family services for a year. In 2018, Lindsay furthered her education by obtaining a master's degree in nursing and midwifery with a specialization in research from KU Leuven.

Her fervent interest in research led Lindsay to apply for TRANS-SENIOR, a program funded by the European Union's Horizon 2020 research and innovation initiative, operating under the Marie Skłodowska-Curie grant agreement. This collaborative venture, comprising a joint PhD, afforded Lindsay the opportunity to work across two renowned institutions. At Maastricht University, she worked as a researcher within the Living Lab of Ageing and Long-Term Care. Simultaneously, she worked at KU Leuven in Belgium.

Her research focused on understanding the transitional care experiences of older people with dementia, informal caregivers, and healthcare professionals as they move from home to a nursing home.

The TRANS-SENIOR program fostered international collaboration among its participants, requiring Lindsay to travel to partner universities for lectures on research methodologies, such as implementation science, and workshops on personal development skills like time management. Over the course of four years, Lindsay spent time at various institutions, including six months at KU Leuven and shorter stints at the White and Yellow Cross Flanders, a Flemish home care organization, and Meander, a Dutch long-term care organization.

In her inaugural year with TRANS-SENIOR, Lindsay was honored with selection for the European Academy of Nursing Science (EANS). Participation in the three-year EANS summer school equipped Lindsay with an extensive toolkit of research techniques and methodologies, rooted in the MRC framework of complex interventions.

Presently, Lindsay remains engaged in academia, employed at Maastricht University's Department of Health Services Research (HSR). Here, she actively contributes to a project aimed at developing guidelines for optimal geriatric rehabilitation following stroke or hip fracture incidents.

Living lab in ageing and long-term care

This thesis is part of the Living Lab in Ageing and Long-Term Care, a formal and structural multidisciplinary network consisting of Maastricht University, nine long-term care organizations (MeanderGroep Zuid-Limburg, Sevagram, Envida, Cicero Zorggroep, Zuyderland, Vivantes, De Zorggroep, Land van Horne & Proteion), Intermediate Vocational Training Institutes Gilde and VISTA college and Zuyd University of Applied Sciences, all located in the southern part of the Netherlands. In the Living Lab we aim to improve quality of care and life for older people and quality of work for staff employed in long-term care via a structural multidisciplinary collaboration between research, policy, education and practice. Practitioners (such as nurses, physicians, psychologists, physio- and occupational therapists), work together with managers, researchers, students, teachers and older people themselves to develop and test innovations in long-term care.

Academische werkplaats ouderenzorg Limburg

Dit proefschrift is onderdeel van de Academische Werkplaats Ouderenzorg Limburg, een structureel, multidisciplinair samenwerkingsverband tussen de Universiteit Maastricht, negen zorgorganisaties (MeanderGroep Zuid-Limburg, Sevagram, Envida, Cicero Zorggroep, Zuyderland, Vivantes, De Zorggroep, Land van Horne & Proteion), Gilde Zorgcollege, VISTA college en Zuyd Hogeschool. In de werkplaats draait het om het verbeteren van de kwaliteit van leven en zorg voor ouderen en de kwaliteit van werk voor iedereen die in de ouderenzorg werkt. Zorgverleners (zoals verpleegkundigen, verzorgenden, artsen, psychologen, fysio- en ergotherapeuten), beleidsmakers, onderzoekers, studenten en ouderen zelf wisselen kennis en ervaring uit. Daarnaast evalueren we vernieuwingen in de dagelijkse zorg. Praktijk, beleid, onderzoek en onderwijs gaan hierbij hand in hand.

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