



# CHANGE BEGINS WITH CHOICE

*Supporting the autonomy of  
nursing home residents with  
dementia through partnership*

Linda J.M. Hoek



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partnership

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# CHAPTER **1**

General Introduction

## GENERAL INTRODUCTION

Individuality and having control over one's life is increasingly important within modern day society, regardless of age, physical, or cognitive capacity. As the worldwide population of older persons with dementia increases,<sup>1</sup> the focus on providing care that supports autonomy and individual preferences becomes even more important.<sup>2-4</sup> Nonetheless, doing so is often complex and can be challenging when caring for people living in nursing homes, especially people with dementia. More involvement and support of the older person's social network is needed to fulfill people's needs and individual wishes to live at home for as long as possible, which is also supported and promoted by governmental policies.<sup>5</sup> When a person with dementia moves into a nursing home, the involvement of their social network remains important for residents' ability to live the life they want to live.<sup>3,6,7</sup> Ideally, nursing home staff and family members will form a partnership to provide care that addresses residents' needs and wishes, in which family and staff contribute on an equal basis. This is important for residents' well-being, as the family's personal knowledge of the resident and the staff's professional expertise can, optimally, be complementary.

This dissertation focuses on the support of autonomy of nursing home residents with dementia and establishing a partnership between family and nursing home staff. In this chapter, background information on dementia and nursing home care is given. In addition, an introduction to autonomy support in nursing home care is provided, and current knowledge regarding family-staff partnerships is described. Finally, the aims of the study are presented, and an outline of the dissertation is provided.

### *Dementia in nursing homes*

Dementia is the overarching term for a set of conditions that may affect thinking skills, memory, and problem solving.<sup>8,9</sup> It can severely change a person's independency, daily life and relationships.<sup>8,9</sup> Dementia is often diagnosed in the elderly population, and, up to now, no cure has been found. Worldwide, approximately 50 million people currently live with dementia, and these numbers are expected to increase in the future.<sup>10</sup> Most people with dementia preferably live at home for as long as possible, and the majority receive care at home.<sup>11</sup> Nonetheless, when the symptoms become more severe due to the progression of dementia, people increasingly need the support of their social network. As care at home becomes more complex and the care demands for informal caregivers, such as family and friends, become too high, moving to a nursing home where people receive specialist care might become inevitable.<sup>5,12</sup> In Western European countries, between 30–45% of people with dementia live in nursing homes or other residential care facilities.<sup>11,13,14</sup> In the Netherlands, this percentage is 30%. People with dementia in nursing homes in the Netherlands receive daily care provided by a multidisciplinary team that, among others, includes nursing staff, an elderly care physician, and psychologists. Most caregivers (88%) are certified nurses with at least two years of education.<sup>15</sup> Different nursing home care settings exist in the Netherlands. People with dementia may reside in either traditional nursing homes, small-scale homes, or green care farms for elderly persons. Traditional nursing homes are often characterized by large groups of residents, sometimes up to 30 per ward, and daily life is mostly determined by organizational rules and routines. The development of small-scale wards and green care farms are the result of a cultural change that has been going on for the past years. These provide a more familiar, homelike environment

where residents live within a joint household, often six to eight people per ward, in which activities are integrated into daily life.<sup>16</sup> Green care farms combine agricultural activities with care services.<sup>17</sup> Within this culture change, nursing homes focus on deinstitutionalization and diversity of living environments by creating a more home-like environment in which family has a more significant role.<sup>18,19</sup> It has developed in the past decades from providing care based on the biomedical model,<sup>20</sup> towards a more person- and relationship-centered approach that aims to address the needs and wishes of residents and their social network.

### ***Supporting resident autonomy***

Autonomy is a complex construct that refers to experiencing control, independence and freedom of choice.<sup>21</sup> Several views and definitions of autonomy can be identified, as these differ across different working fields.<sup>22</sup> Nursing home residents with dementia often face challenges voicing their needs and wishes. Therefore, they need to receive support within their relationship to others, in order to express their autonomy. This dissertation uses the construct of “relational autonomy,” which is often used in long-term care. It assumes that people can still exercise autonomy, regardless of being dependent on others for assistance in care or decision-making.<sup>21,23,24</sup> Compared to other views of autonomy, this concept of relational autonomy takes account of residents’ dependency on others and the experiences of residing in long-term care. Relational autonomy values residents’ individuality within the social context and relationships, emphasizing interconnectedness between residents and their social network, communication, and collaboration.<sup>25</sup>

Supporting autonomy is an important aspect of person-centered care, which emphasizes providing holistic care that is responsive to a person’s needs and preferences.<sup>26,27</sup> Understanding the resident, and empowering them in decision-making, are important concepts within person-centered care.<sup>26</sup> Nonetheless, despite the introduction of person-centered care, challenges remain in providing care that focuses on addressing residents’ needs, especially residents with dementia.<sup>22,28,29</sup> Person-centered care is reflected within relationship-centered care, which focuses not only on the person with dementia, but also on the relationship between dementia care triads, i.e., resident, family, and staff.<sup>30</sup> Relationship-centered care recognizes the importance of all interactions between these triads, with positive relationships and partnerships as a prerequisite to optimal care.<sup>31,32</sup> Partnerships between all three parties involved are needed to provide the best care that support residents in living the life they want to live.

Within the relationship between nursing home residents and their social environment, nursing home staff play a major role in the support of resident autonomy. They can, for example, support or impede residents’ autonomy by using (in)adequate verbal and non-verbal language, providing (limited) choice, or (insufficiently) exploring residents’ preferences.<sup>33,34</sup> Stimulating or increasing the feeling of autonomy of nursing home residents, however, can be challenging. Therefore, it is important for nursing home staff to build a trusting relationship with residents, and to be sensitive to residents’ needs by providing genuine attention. Previous research shows that, even with the best of intentions, staff might neglect resident autonomy by relying too much on preferences described in the care plan or previous experiences,<sup>28</sup> without considering residents’ needs and preferences on a daily basis. Therefore, there is a need for further research into support for resident autonomy within social relationships in nursing homes for people with dementia.

### ***Partnership within nursing homes***

After a person with dementia moves into a nursing home, nursing home staff often takes over most of their daily care. Nonetheless, involvement of family remains important and has increased over the years. The first existing nursing homes were institution-like environments where doctors or nurses made decisions on the resident's behalf, and family was only allowed to visit during set hours. As the culture change within the past decades focused more on providing person- and family-centered care in a home-like environment, the importance of involving family has gained more attention. It is recognized that maintaining a relationship with family and friends benefits residents' well-being.<sup>35</sup> Nowadays, family is more involved in residents' daily life in the nursing home.<sup>36</sup> Previous research has established that family caregivers take on roles such as advocating, are involved in decision-making regarding medical care and daily life, provide instrumental and emotional support,<sup>37</sup> and share information with staff regarding personal knowledge of the resident, including the resident's preferences and activities considered meaningful for the resident.<sup>38</sup>

Previous research has shown that even though family involvement is considered an important part of daily life in nursing homes,<sup>35</sup> collaboration between family and staff remains challenging. Numerous difficulties from both the family's and the staff's perspective can occur, such as differing expectations regarding resident care, roles, communication and responsibilities. Furthermore, the family might experience a high impact of supporting and caring for their loved one with dementia in the nursing home.<sup>39</sup> Moreover, they most likely do not have any experience with living in a nursing home and nursing home care, and might encounter difficulty in finding their role.<sup>37</sup> In addition, staffing issues, staff's time pressure, and holding on to a task-centered care approach, are factors that might hinder collaboration between staff and family.<sup>40,41</sup> Nonetheless, it is very important that family and staff develop an equal partnership to support resident autonomy and their well-being in the best way possible. Up until now, no effective interventions are available that facilitate long-term staff-family partnerships within the psychogeriatric nursing home. Therefore, more research is needed to gain additional insight in how the autonomy of nursing home residents is supported in order to be able to develop, implement, and evaluate interventions that stimulate staff-family partnerships.

### ***Aims of the study and dissertation outline***

Even though providing care that addresses resident autonomy is perceived as important, up until now, it is unknown how and to what extent the autonomy of nursing home residents with dementia is supported in current nursing home care. Furthermore, equal collaboration between staff and family might increase staff-family partnership. However, as there is no program available to structurally increase collaboration and develop these partnerships, more research on new approaches is needed. Therefore, this study aims to address the following leading research questions:

- 1) How and to what extent is the autonomy of nursing home residents with dementia supported?
- 2) How can we create partnerships between nursing home staff and family caregivers of nursing home residents with dementia, to increase resident autonomy?

Different perspectives and methods on the subject of resident autonomy have been researched and form the chapters of this dissertation.

**Chapter 2** presents the results of an observational study that aims to explore the extent to which autonomy of residents with dementia is supported by nursing home staff. Staff-resident interactions were observed during eleven morning care activities, collecting both quantitative and qualitative data. Data were collected using structured observation methods to assess if and how residents' preferences were taken into account.

**Chapter 3** reports the results of a qualitative study, which aims to gain insight into factors that support or impede autonomy for nursing home residents with dementia, according to family caregivers. Qualitative data were collected from the perspective of family caregivers, using semi-structured interviews.

**Chapter 4** provides insight into the experiences of family caregivers with collaboration with staff. Qualitative methods, i.e. semi-structured interviews, were used to gain insight into how family caregivers describe and view their current collaboration and partnership with staff.

**Chapter 5** gives an overview of the content of interventions that could foster family-staff partnership in nursing homes for people with dementia. It reports on the results of a systematic literature review, using the PRISMA-ScR checklist, and includes studies that report on interventions, programs and approaches developed to increase family involvement.

**Chapter 6** describes a process evaluation of a newly developed program aiming at facilitating and supporting family-staff partnership within nursing home wards, to increase residents' autonomy and well-being. This study reports on the feasibility of the program, in which family and staff jointly address problems or challenges in current care and find solutions on a regular basis. Participant attendance, performance of the program according to plan, participation in, and opinions on the program are assessed.

**Chapter 7** presents the main findings, provides a general discussion and an overview of the strengths and limitations, and considers important steps for future research.

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# CHAPTER 2

## **Autonomy Support of Nursing Home Residents with Dementia in Staff-Resident Interactions: Observations of Care**

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## ABSTRACT

**Objectives:** People with dementia living in nursing homes benefit from a social environment that fully supports their autonomy. Yet, it is unknown to what extent this is supported in daily practice. This study aimed to explore to which extent autonomy is supported within staff–resident interactions.

**Design:** An exploratory, cross-sectional study.

**Setting and Participants:** In total, interactions between 57 nursing home residents with dementia and staff from nine different psychogeriatric wards in the Netherlands were observed.

**Methods:** Structured observations were carried out to assess the support of resident autonomy within staff–resident interactions. Observations were performed during morning care and consisted of four main categories: getting up, physical care, physical appearance, and breakfast. For each morning care activity, the observers consecutively scored who initiated the care activity, how staff facilitated autonomy, how residents responded to staff, and how staff reacted to residents' responses. Each resident was observed during three different mornings. Additionally, qualitative field notes were taken to include environment and ambience.

**Results:** In total, 1770 care interactions were observed. Results show that autonomy seemed to be supported by staff in 60% of the interactions. However, missed opportunities to engage residents in choice were frequently observed. These mainly seem to occur during interactions in which staff members took over tasks, and seemed insensitive to residents' needs and wishes. Differences between staff approach, working procedures, and physical environment were observed across nursing home locations.

**Conclusions and Implications:** The findings of this study indicate that staff members support resident autonomy in more than half of the cases during care interactions. Nonetheless, improvements are needed to support resident autonomy. Staff should be encouraged to share and increase knowledge in dementia care in order to better address residents' individual needs. Especially for residents with severe dementia, it seems important that staff develops skills to support their autonomy.

## INTRODUCTION

In the past two decades, efforts have been made to provide person-centered care which is more responsive to nursing home residents' needs and wishes.<sup>1-3</sup> Person-centered care focuses on addressing individual needs and maintaining selfhood within interpersonal relationship.<sup>3</sup> It underlines respecting, valuing and understanding persons with dementia and their caregivers, through positive interactions and social events<sup>4</sup>. Universal human needs of autonomy, relatedness, and competence are important aspects of well-being for people with dementia in nursing homes.<sup>4,5</sup> Autonomy can be defined as one's ability to live the life one wants to live. Experiencing control and having freedom of choice are seen as expressions of autonomy.<sup>7</sup> People with dementia often face difficulties voicing their needs and wishes, and they may need support from their social environment to express their autonomy. However, being dependent on others and receiving support does not decrease residents' need for autonomy.<sup>8,9</sup> Therefore, concepts of relational autonomy and human interdependency should be considered in caregiving.<sup>10</sup> Within social relationships, autonomy can either be facilitated or impeded, and residents can still exercise autonomy regardless of their level of dependence on others due to cognitive or physical impairments. Nonetheless, stimulating autonomy within care remains a challenge.<sup>11</sup>

Although the concept of person-centered care has received considerable attention during past decades,<sup>12</sup> little is known about the extent to which resident autonomy is being supported by staff in practice during daily care in nursing homes. Staff sensitivity to residents' needs for social interaction, providing genuine attention, and building a trusting relationship are important to increase the feeling of resident autonomy.<sup>13</sup> In addition, staff need to engage residents in choice as much as possible.<sup>14,15</sup> For example, staff can support choice by showing food choices to residents, or by asking closed-ended (yes/no) questions regarding wishes for daily activities. Nonetheless, research suggests that nursing home residents with dementia may not be adequately engaged in choice by their social environment.<sup>14,16</sup> To support resident autonomy, it is essential to use adequate (non-)verbal communication that is adapted to residents' understanding, e.g., being alert to cues, recognizing individuality and personality, informing and discussing, understanding "beyond the spoken word," avoiding elder speak, and controlling language.<sup>17-20</sup>

Previous studies suggest that exercising autonomy is often influenced by factors regarding how nursing home residents are approached by staff and by institutional factors.<sup>21-23</sup> While knowing the person is considered important in providing person-centered care, staff can limit resident autonomy by making decisions based on previous experiences or interpretation of resident preferences.<sup>22-23</sup> Consequently, they neglect assessing preferences and exclude residents from decision-making.<sup>24</sup> Additionally, as staff may stereotype residents as "old" and lacking physical and cognitive capacity to exercise autonomy, residents are not being perceived as persons with individual preferences and are not taken seriously in decision-making.<sup>12,21,25</sup> Therefore, care should focus beyond physical and cognitive impairments and seek possibilities to enable residents to live life as fully as possible.<sup>26</sup> Nonetheless, the shift toward providing person-centered care remains challenging, as traditional working routines and processes focus on medical care within current nursing home practice. Most staff-resident interactions focus on finishing care tasks, regardless of resident's needs and wishes.<sup>13,27</sup> In addition, institutional factors such as routines, restricted door access, or having to live with strangers can also be barriers to resident autonomy.<sup>28-30</sup>

Knowledge of how autonomy is supported within staff–resident interactions is needed to increase knowledge of how to support resident autonomy in current practice. Important information on indicators of autonomy for nursing home residents has been provided.<sup>28–30</sup> Nonetheless, research on the subject has mostly been restricted to autonomy as a subdomain within person-centered care, and primarily incorporates staff perception of whether or not they perceive that residents are empowered in decision-making, involved in care planning, or have control over care.<sup>31–34</sup> Moreover, autonomy is often linked to practical matters, e.g., whether or not residents can bring their own belongings, listen to music of their choice, spend time with animals, or eat when and where they want. More research is needed to incorporate the relational perspective on autonomy, to cover more aspects of autonomy within daily nursing home care. Therefore, the aim of this study is to explore to which extent autonomy is supported within nursing homes for residents with dementia during staff–resident interactions. This is one of the first studies that explores how resident autonomy is supported within current practice by staff, and aims to describe patterns of how autonomy is supported within staff–resident interactions. In addition, a preliminary exploration of how the support of autonomy differs for residents with different cognitive and physical functioning within this sample was conducted.

## METHODS

### *Study design*

We conducted an exploratory, cross-sectional, observational study, in which qualitative and quantitative approaches are combined, between March 2017 and September 2018.

### *Setting and participants*

The sample consisted of people with dementia living in nine different psychogeriatric wards of six nursing homes in the southern part of the Netherlands. Eligibility criteria required residents to have an official diagnosis of dementia, or a Standardized Mini-Mental State Examination (SMMSE) score lower than 24.<sup>35</sup> A total of 120 residents met the inclusion criteria. In order to include a variety of perspectives from different nursing home environments, five large-scale wards and four small-scale wards from five different locations were included. In the Netherlands, two main types of nursing home facilities exist.<sup>36</sup> Within the large-scale wards, care is provided for around 20 residents or more, and has a more traditional way of providing care. Within small-scale wards, the aim is to provide care within a homelike, personal environment for a small number of residents (around six to eight), where household activities are integrated into daily life. Staff members within the selected wards were included in the study if they provided morning care for the participating residents. In the Netherlands, the majority of nursing staff (88%) consist of certified nursing assistants. Nurses who work in a nursing home in The Netherlands are required to have received education for at least 2 years. On average, staff had 15 years of nursing experience (with years ranging from 1 to 41) and 90% were certified nurses, 1,5% were baccalaureate nurses, and 8,5% support staff.

### *Measures*

*Resident characteristics.* A nurse provided information on residents' age, gender, and official dementia diagnosis. We measured cognitive status with the SMMSE with a score ranging from 0–30, with low scores indicating severe cognitive impairment.<sup>37</sup> We assessed functioning on Activities of Daily Living (ADL) with the Barthel-index, with scores ranging from 0–20 and lower scores indicating a higher dependency in ADL functioning.<sup>38</sup> We administered all characteristics within three weeks from the start of the observation period.

*The support of autonomy.* In this study, we observed the support of resident autonomy within staff–resident interactions during morning care, as staff–resident interactions occur frequently during this period. We clustered eleven morning care activities into four main categories: getting up, physical care, physical appearance, and breakfast (see Table 1). Accordingly, as instruments to measure resident autonomy within staff–resident interactions are lacking, we developed a standardized observation list in several steps. First, we performed participant observations on weekdays to explore how we can observe the support of resident autonomy within practice. Next, we discussed these pilot observations and the developed observation list within the research team. Accordingly, a first version of the observation list was set, containing all morning care activities that could be observed, and a categorization of the steps occurring within staff–resident- interactions, such as “who took the initiative” or “how did the resident/staff member respond.” We performed several test observations with the observation list to distinguish and define the definitions. We could have observed the care activities of toileting and medication, however, these were omitted from the observation list due to privacy issues and due to individual differences in medication use. This resulted in eleven morning care activities. Subsequently, we discussed the observation list within the research team to agree on step definitions and scoring. Finally, an observation guideline was developed and completed to standardize the observation method. Four trained observers (three researchers and one research assistant) conducted the observations. All observers were trained by the first author. The first step was reading and discussing the protocol and guideline. Second, duo observations were conducted by the first author and one observer. These test observation consisted of about three mornings, observing all morning care activities for six residents per morning together. Scoring was evaluated afterwards with the first researcher. After performing the first observations, we performed an evaluation to ensure alignment between the researchers. Two observers (LH & EV), who were involved in the majority of the observations, tested the observation reliability. They performed duo observations for six residents, and scored the complete observation list at the same time, for the same residents, to establish an absolute interobserver agreement. This was 93%, based on calculating agreement scores for each scoring option of the observation list.

**Table 1.** Description of care activities

Care activity	Description
<i>Getting up</i>	
Waking up	The way in which a resident starts his/her day. It entails the way a resident wakes up, gets out of bed, and how his/her autonomy is supported during both moments.
Getting out of bed	
<i>Physical care</i>	
Washing/bathing	The way in which a resident receives or performs personal care. It entails how a resident is being approached and how personal preferences are being met regarding washing and dental care.
Dental care	
<i>Physical appearance</i>	
Clothing	The way in which a resident wants to express or present him or herself regarding physical appearance. It entails how a resident is being approached and how personal preferences are being met regarding getting dressed, clothing, hairdressing, or shaving.
Getting dressed	
Hairdressing/grooming	
<i>Breakfast</i>	
Time to eat	The way in which breakfast is provided. It entails how a resident is able to and wants to have breakfast and how personal preferences are being met regarding time and type of breakfast.
What to eat	
What to drink	
Amount of breakfast	

For each morning care activity, the observers consecutively selected an option within the following four categories (creating an “observation path”): A) Initiative for care activity; B) Facilitating autonomy; C) Resident response to staff; and D) Staff reaction to resident’s approach, which is explained below. For detailed information, see Appendix 1.

**First step:** *Initiative for care activity*, i.e., who initiated the care activity? “Resident” or “Staff member.”

**Second step:** *Facilitating autonomy*, i.e., how did the nursing staff member approach the resident during the care activity? “Care activity without a verbal or non-verbal cue,” “Care activity with verbal or non-verbal cues,” or “Care activity with active support of choice.”

**Third step:** *Resident response to staff approach*, i.e., how did the resident respond to the staff member’s approach? “No reaction,” “Positive reaction,” or “Negative reaction.”

**Fourth step:** *Staff reaction to resident’s response*, i.e., how did the staff member react to the resident’s response? “Staff member complies with the resident’s request or reaction,” “Staff member proposes an alternative, and resident agrees,” “Staff member verbally responds to resident, but perseveres with own plan,” or “Staff member ignores resident’s reaction.”

Field notes were taken during the observation period in order to describe the situation during all interactions and to document aspects that stood out regarding environment and ambience.



### *Procedure*

The researcher observed each resident during all care activities on three randomly selected mornings (7–11.30 am on weekdays). We conducted continuous observations, which means that all care activities were observed from beginning to end. For practical reasons, the researcher sometimes changed the observation order of care activities for one resident or rescheduled a part to the next day. Within each ward, a registered nurse assessed the background information for all participating residents by using residents' records, combined with their own knowledge about the residents. We scored observations on a small, printed, structured observation list. During the observation, the researcher took notes and completed the observation list.

### *Ethical considerations*

The Ethics Committee of Zuyderland-Zuyd approved this study (No. 16-N-233). Participants' family caregivers gave written informed consent after receiving information about the purpose and procedure of the study. During the observations, we assured informed assent from the residents, i.e., the nurse asked each resident for their permission before the researcher entered the room. If residents gave permission, the researcher quietly sat down in the room. If the resident rejected the observer's presence, showed verbal or non-verbal negative mood signals, or when the resident was visibly distressed by the observer's presence, the observer would leave the room.<sup>39</sup>

### *Data analysis*

We digitalized and analyzed the observation lists, using the statistical software package SPSS 25. Descriptive statistics were used to obtain an overview of the distribution of who took the initiative for a care activity (Step A), and how autonomy was facilitated by the staff member (Step B). Next, in order to analyze complete observation paths (single interactions), Steps A, B, C, and D were concatenated within the SPSS data file. We used frequency tables to obtain the proportion of each observation path within the sample. In addition, for the purpose of exploring how background characteristics, i.e., SMMSE score and Barthel score, related to different steps within the interactions and the observation paths, scores were categorized as follows. The SMMSE score was categorized into severe (0–10), moderate (11–20), mild (21–26), and normal (27–30).<sup>36</sup> The Barthel score was categorized into low ADL dependency (15–20), ADL dependent/independent (10–14), and high ADL dependency (0–9).<sup>37</sup> Next, the content of the field notes regarding environment and ambience within each location was used to describe the context across locations and nurses.

## **RESULTS**

Both quantitative and qualitative results are presented below. Sample proportions are followed by qualitative descriptions.

### Sample characteristics

Of the 120 family caregivers of nursing home residents that we had approached for this study, 57 family caregivers gave informed consent (48% of eligible residents within the selected nursing home wards). Table 2 presents their characteristics. On average, residents experienced moderate to severe loss of cognitive functioning and needed extensive assistance with regards to physical functioning. During the observation period, we observed 75 different staff members during interactions with the selected residents.

**Table 2.** Resident Characteristics (n = 57)

Total	
Mean age (SD; range)	86.72 (5.97; 61–97)
Female (%)	46 (81)
Mean SMMSE score* (SD; range)	9.40 (7.58; <u>0</u> –27)
<i>SMMSE Categorization (frequency; percentage)</i>	
Severe (0-10)	24 (51.10)
Moderate (11-20)	21 (44.70)
Mild (21-26)	1 (2.10)
Normal (27-30)	1 (2.10)
Mean Barthel Score** (SD; range)	9.51 (5.67; <u>0</u> –20)
<i>Barthel Score categorization (frequency; percentage)</i>	
Low dependency (15-20)	12 (21.80)
Dependent/independent (10-14)	20 (36.40)
High dependency (0-9)	23 (41.80)

\*The SMMSE was assessed for 47 residents; 10 residents refused to participate, did not speak the language or were absent/sleeping multiple times during data collection

\*\* The Barthel was assessed for 55 residents; we received no information on Barthel scores from 2 residents

\*\*\* Underlined score indicates worse performance on scale

### Care observations

In total, we observed 1770 care interactions (see Table 3). Due to residents passing away before or during the study period (n = 5), residents verbally refusing observation during an observation day (n = 2), or residents who stayed in bed during the observation day or period, 94% of the intended observations (n = 1881) were completed.

### Initiative for care activity

On average, staff initiated 72% of the care activities; whereas residents initiated an average of 20% of the activities (see Table 3). Residents especially took initiative in “waking up” (69%) and to a lesser degree in “getting out of bed” (35%). Furthermore, dental care was frequently not performed during morning care observations (53%).

**Table 3.** Overview of care initiation

Care activity (and subcategories)		n (observed)	Initiative		
			Staff	Resident	Activity not performed during observation period
<i>Getting up</i>	<i>Waking up</i>	165	31%	69%	0%
	<i>Getting out of bed</i>	166	64%	35%	1%
<i>Physical care</i>	<i>Washing/bathing</i>	157	90%	7%	3%
	<i>Dental care</i>	156	42%	5%	53%
<i>Physical appearance</i>	<i>Clothing</i>	167	81%	16%	3%
	<i>Getting dressed</i>	167	84%	13%	3%
	<i>Hairdressing/grooming</i>	164	76%	16%	8%
<i>Breakfast</i>	<i>Time to eat</i>	164	88%	12%	0%
	<i>What to eat</i>	156	84%	13%	3%
	<i>What to drink</i>	158	86%	10%	4%
	<i>Amount of breakfast</i>	150	71%	22%	7%
	<i>Total (mean)</i>	1770	72%	20%	8%

Further exploration of the data indicates that residents with higher cognitive functioning (SMMSE) and higher independent ADL functioning (Barthel) appeared to initiate care activities more often themselves. Residents with higher cognitive functioning initiated care activities in more than 82% of cases, whereas residents with low cognitive functioning initiated care activities in less than 19% of cases. Residents with higher independent ADL functioning initiated care activities in more than 40% of cases, whereas residents with lower independent ADL functioning initiated care activities in less than 8% of cases.

#### *Facilitating autonomy*

In 30% of cases, staff performed the care activity without a verbal or non-verbal cue. An example of an observation is given below:

*In a rush to get Mrs. Peeters (all names are pseudonyms) ready for breakfast, nurse Ally gets a comb from the bathroom, walks up to Mrs. Peeters and starts brushing Mrs. Peeter's hair really quick without saying anything – Observation Hairdressing/grooming*

In 39% of cases, staff performed the care activity with a verbal or non-verbal cue. An example is given below:

*Nurse Mary picks up Mrs. Jansen's dentures from the bathroom and shows them to Mrs. Jansen, looks at her and jokingly says 'Let's get you some teeth'; Mrs. Jansen laughs and opens her mouth – Observation Dental care*

In 31% of cases, staff actively supported resident autonomy by engaging them in choice. An example is given below:

*The nurse softly knocks on the resident's door, enters the room and says, 'Good morning Mr. Peeters,' as Mr. Peeters had already put away the blanket; 'Do you want to get up already?' and Mr. Peeters slowly nods – Observation Getting up*

Further descriptive analyses showed that residents with very low cognitive functioning (SMMSE score 0–10) seemed to more often be approached by the nurse without a cue during the care activities, in 32% of cases, than people with higher scores of cognitive functioning. Nurses seem to perform care activities without a verbal or non-verbal cue mostly for residents with low independent ADL functioning (59% of cases). If the nurse performed the care activity without a cue, often residents showed no reaction (74% of cases). If the nurse performed the care activity with a cue, or when the resident was engaged in choice, the resident showed a (positive) reaction (60% and 82% of cases, respectively).

#### *Variations in the support of autonomy*

In total, 21 variations of how autonomy was supported – the observation paths – were observed during the observation period. An example of a path is described below:

**A) Initiative:** nurse.

*Nurse Anny picks up clothes from Mr. Maas' closet.*

**B) Facilitating autonomy:** Engaged in choice.

*Nurse Anny walks up to Mr. Maas and shows the pair of clothes and says, 'do you want to wear these today?'*

**C) Resident response:** Positive reaction.

*Mr. Maas looks at the clothes and briefly nods to nurse Anny.*

**D) Staff reaction:** Not needed to be scored.

*Nurse Anny puts down the clothes and helps Mr. Maas to take off his pajamas.*

After finishing all observations, the research team held several meetings to discuss and interpret the type of observation paths. Insight into the rich variety of possibilities and different approaches helped to support the interpretation process. We used the qualitative data, i.e. the field notes, to interpret the quantitative research findings as collected during the observations. This led to a categorization into either "autonomy supporting," "autonomy undermining," "autonomy impeding," or "undefined," see Figure 1 for all possible 21 observation paths and Table 4 for a description of the interpretation. A detailed overview of the categorization of the observation paths can be found in Appendix 2.

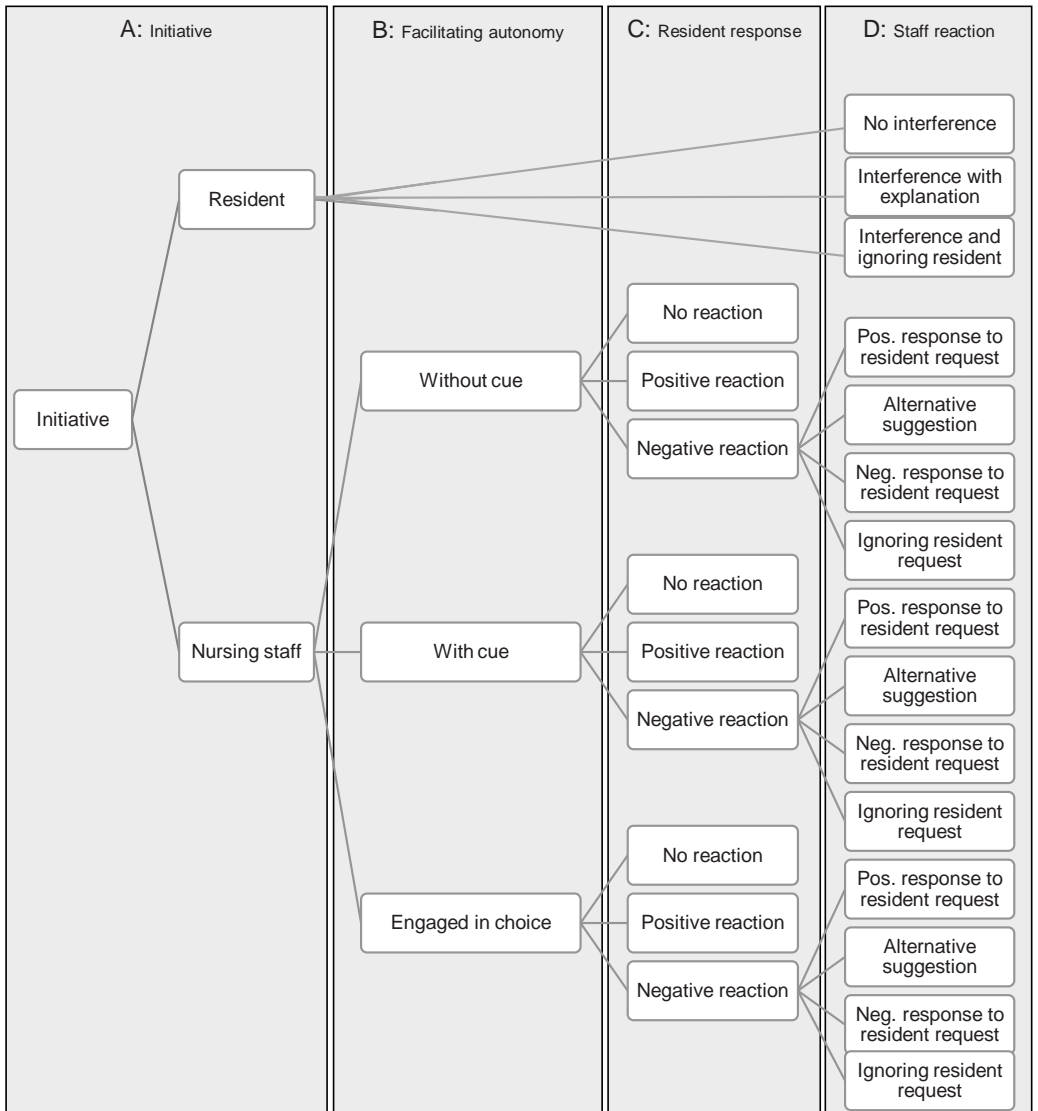


Figure 1. Representation of observation paths

**Table 4.** Definitions of the interpretation of autonomy manifestations and their occurrence

Interpretation	Definition	n(%)
<i>Autonomy supporting</i>	Resident autonomy was fully supported by the staff member; residents' expressed needs and wishes were met	755 (60%)
<i>Autonomy impeding</i>	Resident autonomy was impeded by the staff member; residents' needs and wishes were not taken into account by staff	320 (25%)
<i>Autonomy undermining</i>	Resident autonomy was undermined by the staff member; the expressed needs and wishes of the resident were ignored	11 (1%)
<i>Undefined</i>	The extent to which resident's autonomy was supported cannot directly be defined as facilitating, undermining, or impeding; variations existed regarding if and how resident autonomy was supported, as several perspectives on the care activity and its interpretation could be identified	182(14%)

*Autonomy supporting.* Autonomy supporting observation paths occurred 60% of the time. This category can be described as staff–resident interactions that fully support resident autonomy. All observation paths within this category ended positively. In these paths, the resident agreed (either verbal or non-verbal) to the nurse's request, and/or the nurse did not impede the resident's autonomy. The nurse listened to the resident and engaged the resident in choice by being sensitive to the resident's needs and wishes. Examples of situations of supporting of autonomy are:

*After Mrs. Meyer was washed and had put on clothes, she walks to the bathroom and picks up the comb and started brushing her hair; while nurse Patricia was making up the bed, she watched Mrs. Meyer brush her hair, and let her finish the task.*

*Being ready to have breakfast, Mrs. Pieters was brought to the breakfast table in her wheelchair; 'Good morning Annie,' nurse Katy says with a smile. Nurse Katy picks up the bread cart and says: 'here you go,' and nurse Katy shows Mrs. Pieters pieces of brown and white bread, and Mrs. Pieters nods toward the brown bread; nurse Katy picks up a plate and gives Mrs. Pieters a slice of brown bread.*

*Autonomy impeding.* In 25% of the observations, the interaction between staff and resident impeded resident autonomy. The nurse was not sensitive to resident autonomy, did not try to hear or figure out the resident's needs during the care activity, and refrained from personal contact. The nurse did not identify resident's needs and wishes, and seemed mainly concerned with performing care tasks. In

general, we did not observe a personal approach. Residents did not actively respond and appeared to follow whatever the nurse was doing. Examples of manifestations of autonomy impeding are:

*After being brought to the breakfast table, Mrs. Maas sat down and got a 'good morning.' Nurse Anny pours coffee into a cup and puts it on the table while she looks at the other six residents that sit at the table; she gives Mrs. Maas a plate and sits down beside another resident to help him.*

*Nurse Mary picks up clothes from the chair, and gently throws them on the bed and rapidly rolls up the shirt to help Mr. Dijk with getting dressed. As Mr. Dijk is not able to speak, nurse Mary refrains from verbal interaction and puts no effort into making contact; Mr. Dijk underwent the care activity.*

*Autonomy undermining.* In 1% of the observations, the interaction between staff and resident undermined resident autonomy. The nurses neglected and/or ignored residents' expressed need(s) and wish(es). Examples of situations in which autonomy was undermined are:

*After a rushed shower where Mrs. Visser got agitated, nurse Monica is in a hurry to do all consecutive care activities. Nurse Monica puts a t-shirt over Mrs. Visser's head while answering a colleague's question, who just enters the room. Mrs. Visser looks toward the floor, and nurse Monica kept talking with her colleague while finishing the task. Mrs. Visser moans and refuses to cooperate; nurse Monica ignores Mrs. Visser's reaction and roughly continues the care activity.*

*After being moved out of bed by a medical lift, Mrs. Peters was put on the toilet. Nurse Emmy turns on the shower and says to the observer 'it's just easier showering her as she already sits on the toilet than moving her to the medical shower chair,' and meanwhile starts washing Mrs. Peters without any cues, nor did she check for a right temperature. Mrs. Peters moans and freezes when the water touches her skin, while nurse Emmy says to the observer: 'Mrs. Peters doesn't like showering, but today is showering day,' and continues to shower.*

*Undefined.* In 14% of instances, we could not interpret the observation paths. We could not directly define observation paths within this category as facilitating, impeding, or undermining. The support of resident autonomy varied, as we could identify several perspectives on the situation. Examples of situations within this category are:

*In an effort to verbally engage Mr. Prins in the choice of clothes, nurse John asks, 'Shall we put these trousers on today?' and looks at Mr. Prins, but receives no response. Without further effort to get Mr. Prins to understand what he was asking, nurse John quickly puts on the trousers. After asking Mr. Prins for a type of t-shirt, he again receives no reaction. Nurse John finishes every consecutive care activity.*

*During breakfast, where residents sit at two large tables and there is a lot of background noise, nurse Clara gives Mrs. Smit a slice of bread with cheese, looks at her and says, 'There you go, a nice slice of bread' and friendly laughs at her. Mrs. Smit would not eat, until – after a while – nurse Clara asks, 'You don't like this?'*

*and Mrs. Smit moves her plate. Nurse Clara: 'I'll get you some raisin bread, here you go' and Mrs. Smit starts to eat.*

Within this category, many missed opportunities are identified, which are not truly facilitating, undermining, or impeding, however, the nurse's approach regarding the care activity could have been more autonomy supporting. The nurse did put an effort into making personal contact, however, most of the cues were verbally orientated and the nurses did not always take enough time to make sure that residents understood what was asked or suggested (either with verbal or non-verbal cues).

Further descriptive analyses showed that autonomy undermining and impeding observation paths were more often seen for residents with low cognitive functioning, i.e., in around 70% of cases. Autonomy supporting observation paths were more commonly seen during the care for residents with higher levels of cognitive functioning, i.e., in more than 60% of cases.

#### *Context across locations and nurses*

As observations took place in nine different nursing home wards, we observed differences regarding working procedures and physical environment to support or impede resident autonomy. Regarding working procedures, it seemed that each nurse used a similar approach for all residents. As we observed residents during three randomly chosen mornings, we observed the same resident in interactions with different staff members. For example:

*Mr. Willems was helped by nurse Tony, during two observation mornings. Tony did not give any cues nor did he engage Mr. Willems in choice, and seemed mostly concerned with finishing the care tasks on time. During these two mornings, Mr. Willems showed almost no verbal or non-verbal reaction to the care activities. During the third observation, a different nurse, Laura, helps Mr. Willems and approaches Mr. Willems with much more patience by taking time, tries to make eye contact with every new action, and frequently tries to involve Mr. Willems in choice. Then, Mr. Willems frequently laughs when nurse Laura makes eye contact and even tries to speak.*

Regarding breakfast, we observed differences across locations. For instance, in some small-scale wards, nurses only served breakfast when all six residents had received physical care and were ready to have breakfast together at the table, promoting the "eating with family, just like old times" vision. At other locations, staff members were present at 8 a.m. and served or helped residents when they got into the communal dining room. These staff members were not educated as nurses; however, the manager accepted them based on their strong affinity with caring for residents with dementia. At some locations, breakfast was already set up at the table in order for residents to choose from different types of bread or drinks, whereas others made sandwiches or drinks at the kitchen or cart that was not in the resident's sight.

Some locations had set up surveillance technology, which was most likely installed as a viable alternative to physical restraints. Although using this technology could interfere with resident autonomy, we observed that some nurses used it as a way to increase resident autonomy. For example, sensors that are linked to the nurse's beeper were placed beside the bed. When a resident got up, the nurse would go



and check if the resident needed help. Additionally, in-bedroom cameras were linked to computer displays to get information on whether or not residents were awake and in need of help.

Furthermore, we observed differences in ambience, often related to the amount of nurses present and their talking behavior. For example, when residents were helped by two nurses, personal attention was either increased due to doubled social interactors, or was decreased by nurses chatting together while finishing care activities.

## DISCUSSION

The current study described the extent to which staff supported or impeded the autonomy of nursing home residents with dementia during staff–resident interactions. The results indicate that staff supported resident autonomy during staff–resident interactions in more than half of the cases. In addition, data suggest that staff’s approach can increase resident autonomy, as resident consent and engagement in care activities appeared greater when staff actively supported resident autonomy. Nonetheless, there were still many cases in which staff seemed to ignore resident’s needs and wishes. In addition, differences within staff’s approach, working procedures, and physical environment exist, which may support or impede resident autonomy.

This study illustrates that staff use various ways to support resident autonomy, even though residents face difficulties in expressing their autonomy. Previous research confirms that staff support in decision-making for residents in residential care can lead to a greater sense of autonomy.<sup>19,25</sup> Residents can achieve autonomy in the relationship with their social environment, regardless of being reliant on others in addressing their needs and wishes.<sup>13</sup> The current study indicates that during staff–resident interactions, staff supported resident autonomy in more than half of the cases. This was particularly evident when staff offered choice or when staff explained the care activity, and waited for resident’s consent to pursue the care activity. This accords with previous work that showed different styles that staff use to either encourage or discourage participation in decision-making for residents with dementia.<sup>40</sup> These previous results suggest that positive communication and enabling characteristics within communication can enhance resident autonomy. Additionally, engaging residents in choice is considered a sign of respect, and enhances the feeling of being seen as a person with needs and wishes.<sup>1,41</sup>

This study indicates that residents were often not actively or fully engaged in the care activity. Staff play a major role in either supporting or impeding autonomy during morning care, as they initiate care in the majority of care activities. However, this study found that staff did not engage the resident one third of the time in care activities, and consequently, the resident did not actively consent to the care activity. Both residents and staff are at risk of becoming institutionalized, as staff mainly focus on residents’ cognitive impairment and lack of decision-making capacity.<sup>20,42</sup> Staff often base their caregiving approach on care plan documents and perceive this time-saving strategy as autonomy supporting.<sup>19</sup> This might explain why staff in the current study did not always seek residents’ preferences during interactions. This strategy, however, is perceived as contradictory to getting to know the person and exceeds ways to understand the resident with dementia as a person.<sup>1</sup> This study shows how staff approach residents in supporting autonomy, using a variety of verbal and non-verbal communication. Hence, staff need to recognize and be aware of the importance and capability of residents with dementia to be engaged in

meaningful social interaction.<sup>43</sup> Staff need to be given adequate time to receive educational support that could improve skills to better support autonomy. Consequently, residents might have more positive care experiences and resident distress might reduce.<sup>44,45</sup>

Another finding is that challenges seem to exist in supporting autonomy for residents with severely high cognitive impairment. Results indicate that the chances of being engaged in care were lower for residents with a poor level of cognitive functioning. We observed that staff especially encountered challenges when caring for residents that faced difficulty conveying or knowing what they need or want. Staff may find it difficult to perceive and recognize residents with dementia as relational human beings, due to their incapability to express needs and wishes.<sup>41</sup> Previous research indicates that staff acknowledge the importance of offering choice to residents who face challenges to make decisions.<sup>15,45</sup> Nonetheless, staff often experience difficulties in supporting autonomy for residents with extremely severe dementia. Staff might not keep up with the increasing complexity of care, do not have sufficient competences to care for residents with severe dementia, or some may not see them as equal human beings with the same needs.<sup>41,46</sup> Staff need to be given time to prioritize psychosocial needs, such as resident autonomy, as opposed to solely prioritizing physiological and biomedical needs.<sup>47,48</sup> Therefore, staff might benefit from receiving practical dementia care education, and sufficient resources and time to improve care that supports resident autonomy.<sup>49,50</sup>

The results of this study are subject to certain limitations. For instance, we only observed the support of resident autonomy during morning care, and analyzed using descriptive statistics. Therefore, this study cannot provide information on whether or not this is representative for all daily activities and may not be generalizable to other groups. In addition, although we asked residents and staff to maintain their usual routine, potential participant bias might have affected the outcome, as participants might have behaved differently knowing that they were being observed. This could have led to more autonomy supporting observations in which residents were better engaged in choice. Unfortunately, due to the methods used, this study did not assess whether or not residents themselves experienced more or less support of their autonomy, and how they felt about it. This study does, however, indicate that engaging residents in choice is more autonomy supportive, as more positive reactions were observed when staff asked questions or gave different options. While this study had its methodological limitations, observations were performed by multiple observers using a standardized observation manual to confirm that each observer conducted and scored the same steps.

## CONCLUSIONS AND IMPLICATIONS

The findings of this exploratory study show that the autonomy of nursing home residents with dementia is supported in more than half of interactions with staff. Nonetheless, there remains a large part in where autonomy is impeded, indicating that there is a need for further improvement. Therefore, it is important to develop interventions to support staff with education and practical skills, to optimally support the autonomy of nursing home residents with dementia. Further studies on interventions to educate staff need to be carried out in order to better support autonomy for residents with dementia living in a nursing home. Our results suggest that cognitive and physical functioning might be related to the level of support. Additional research is needed to confirm this finding and to optimize care that supports resident

autonomy for residents with very low levels of cognitive functioning, and residents with challenges to expressing themselves verbally. As this study suggests that there are differences in resident approach between individual staff members, peer learning and peer support within nurse teams might improve knowledge and skills by means of experimenting, sharing feedback, and challenging each other's viewpoint and approach.<sup>49,50</sup> Furthermore, research needs to be carried out to explore if staff' background, e.g. experience and education, might relate to how they support or interact with residents.

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**APPENDIX 1.** Detailed description of how observation path were scored

- A) Initiative for care activity.** Who initiated the care activity? This consisted of three options: resident, staff member, and other (volunteer, family caregiver, other). If a staff member or other person initiated the care activity, the next step, Step B, was scored. If the resident initiated the care activity, Step D was immediately scored and Steps B and C did not need to be scored.
- B) Facilitating autonomy.** How did the nursing staff member approach the resident during the care activity? Does this approach lead to the support of resident autonomy? The step consisted of three options: care activity without a verbal or non-verbal cue; care activity with verbal or non-verbal cues; and care activity with active support of choice. When a care activity was performed without a verbal or non-verbal cue, the resident was not actively engaged in choice in the care activity, and the nurse did not pay attention to resident autonomy. When the care activity with a verbal or non-verbal cue was performed, the nurse prepared the resident for the care activity by providing visual or auditory stimulation that related to the care activity, and paid attention to the resident's understanding of the cue. A care activity with active support of choice was scored if the resident was actively engaged in choice. When this step (Step B) is scored, then Step C is also scored.
- C) Resident response to staff approach.** How did the resident respond to the staff member's approach? This step consists of three options: no reaction, positive reaction, and negative reaction. No reaction was scored when the resident did not show any response or just complied with the task given by the staff member, without giving clear permission. A positive reaction was scored in case of a clear sign of permission or positive response of the resident, for example when answering positively, nodding, or blinking the eyes. A negative reaction was scored in the case of resistance of the resident to the staff member's task or approach, either verbally or non-verbally. If the latter option was scored, then Step D was also scored. If not, the observation path ends here.
- D) Staff reaction to resident response.** How did the staff member react to the resident's response? This step consists of four options: staff member complies with the resident's request or reaction; staff member proposes an alternative, and resident agrees; staff member verbally responds to the resident, but decides to do what he/she (staff member) wants; and staff member ignores the resident's reaction.



**APPENDIX 2.** Detailed overview of the categorization of the observation paths

Category		Observation paths (n = 21)			
		A	B	C	D
<i>Autonomy supporting</i>	1	Resident	-	-	No interference
	2	Nursing staff	With cue	Positive reaction	-
	3	Nursing staff	With cue	Negative reaction	Pos. response to resident request
	4	Nursing staff	Engaged in choice	Positive reaction	-
	5	Nursing staff	Engaged in choice	Negative reaction	Pos. response to resident request
<i>Autonomy impeding</i>	6	Nursing staff	Without cue	No reaction	
	7	Nursing staff	Without cue	Positive reaction	
	8	Nursing staff	Without cue	Negative reaction	Pos. response to resident request
	9	Nursing staff	Without cue	Negative reaction	Alternative suggestion
	10	Nursing staff	Without cue	Negative reaction	Neg. response to resident request
<i>Autonomy undermining</i>	11	Resident	-	-	Interference and ignoring resident
	12	Nursing staff	Without a cue	Negative reaction	Ignoring resident request
	13	Nursing staff	With cue	Negative reaction	Ignoring resident request
	14	Nursing staff	Engaged in choice	Negative reaction	Ignoring resident request
<i>Undefined</i>	15	Resident	-	-	Interference
	16	Nursing staff	With cue	No reaction	-
	17	Nursing staff	With cue	Negative reaction	Alternative suggestion
	18	Nursing staff	With cue	Negative reaction	Neg. response to resident request
	19	Nursing staff	Engaged in choice	No reaction	-
	20	Nursing staff	Engaged in choice	Negative reaction	Alternative suggestion
	21	Nursing staff	Engaged in choice	Negative reaction	Neg. response to resident request



# CHAPTER 3

## **Factors influencing autonomy of nursing home residents with dementia: the perception of family caregivers**

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## ABSTRACT

**Background:** Being able to live the life you want to live within a nursing home might be challenging for residents with dementia, as they become dependent on others in achieving autonomy. However, little is known about which factors support or impede resident autonomy within nursing homes.

**Objectives:** The purpose of this study was to gain insight into factors that support or impede autonomy for nursing home residents with dementia, from the perspective of their family caregivers.

**Design:** A qualitative study was conducted.

**Setting:** Five psychogeriatric nursing home wards within three care organizations in the Netherlands.

**Participants:** 30 family caregivers.

**Measurements:** Semi-structured interviews were held and a qualitative thematic approach was used.

**Findings:** This study identified several factors that seemed to influence resident autonomy within six themes: activities; personal approach; visits from family and friends; being part of a group; physical environment; and organization of care. Within these themes, factors were mentioned that could either support or impede resident autonomy. For example, being socially engaged with family and fellow residents and participation in meaningful activities were supporting factors. The inability to go outside when wished or having inadequate private space were impeding factors. Overall, daily life was mostly organized from a communal and task-centered perspective instead of adaptation to individual preferences.

**Conclusions:** The current study suggests that in order to improve the support of resident autonomy, nursing homes should focus on flexibility in providing care, finding ways to offer meaningful activities, and stimulating resident's social environment to continue social traditions.

## INTRODUCTION

There has been an ongoing culture change within nursing homes towards providing person-centered care that supports resident autonomy. This care philosophy emphasizes care provision that is tailored to residents' needs and wishes<sup>1</sup>. Understanding the person, empowerment in decision-making and relationships in care are important concepts within person centered-care.<sup>2</sup> Nonetheless, providing person-centered care might be challenging, especially when providing care to nursing home residents with dementia, as these residents often encounter difficulties expressing their needs and wishes and, therefore, are dependent on others.<sup>3</sup> The nursing home sector recognizes the importance of making a shift towards person-centered care that supports autonomy as much as possible, yet, there seems to be a gap between recognizing the value of providing person-centered care, and clinical practice.<sup>4,5</sup>

Nursing home residents with dementia are often highly dependent on their environment in achieving as much autonomy as possible. Nursing staff has an important role in supporting residents' choices over daily life.<sup>6</sup> For instance, residents need other people to support them to make decisions regarding daily routines and care preferences. A general belief is that people's autonomy is restricted if they become dependent on others.<sup>7</sup> This view, however, does not consider the fact that all humans are interdependent, and devalues people with disabilities who rely on the help of others. In light of a person-centered point of view, relational autonomy is presently considered as a more appropriate approach of conceptualizing autonomy for residents within long-term care settings.<sup>7</sup> This approach draws on the ideas of person-centered care, in which people's identities are developed and maintained within social relations, and a person can still be a free, autonomous individual within personal relations and mutual dependencies.<sup>8</sup> Therefore, it is important that the environment addresses the need for autonomy for residents, regardless of living in a nursing home and needing help from others.

Together with staff, family caregivers can support resident autonomy. Feeling at home and being able to live the life you want might be challenging to individuals after moving into a nursing home.<sup>9</sup> Limitations in privacy, the balance between feeling independent while being dependent on others due to the consequences of having dementia, and sharing a living space with other residents, challenge the sense of autonomy in daily life and feeling at home.<sup>10</sup> Therefore, family involvement is of major importance, as family can contribute to care by sharing biographical knowledge of the resident with staff as well as residents' preferences in everyday life.<sup>11</sup> Moreover, they can provide instrumental and emotional support, advocate for their relatives and indicate what might be valuable things in (daily) life and meaningful activities for the resident.<sup>12</sup> Therefore, the family caregiver's role, requires to be better integrated in the current life of nursing home residents in order to be able to help them to live the life they want to live within the nursing home.

In many nursing homes, however, it is difficult for family caregivers to support resident autonomy and stay actively involved. Although there is growing attention for providing person-centered care, nursing homes often still have an institutional character and focus on the provision of task-centered care, in which residents' daily lives are often highly determined by organizational rules and routines.<sup>13</sup> Moreover, supporting resident autonomy has not always been prioritized within long-term care.<sup>6</sup> Efforts to provide better person-centered care were made when developing small-scale living facilities that focus on normalization of daily life and meaningful activities within a joint small household. Previous research regarding these small-scale living facilities, indicates that individual needs and wishes were better met

when nurses actively sought residents' strengths and capacities.<sup>14</sup> In addition, residents' interest was stimulated when engaged in daily household activities, which increases the sense of home and the ability to live the life you want within a nursing home.<sup>15</sup>

Little is known about which factors support or impede autonomy of nursing home residents. Therefore, this study explores factors that influence resident autonomy, which is operationalized as the ability to live the life you want to live, as experienced by family caregivers.

## **METHODS**

For this study, a qualitative research design was chosen.<sup>16</sup> Semi-structured interviews were held to assess family caregivers' opinions on the extent to which they perceive that their loved ones can live the life they want within the nursing home, and which factors support or impede this.

### *Setting and Participants*

Participants were recruited from three different care organizations in the Netherlands, including three small-scale and two large-scale psychogeriatric nursing home wards. In the Netherlands, traditional, large-scale nursing home wards are characterized by providing care for a large group of residents per ward, where daily life is mostly determined by organizational rules and routines. In small-scale wards, residents live within a joint household with, generally, six to eight residents. Here, care aims to be provided within a fixed team and a homelike environment, and activities are integrated in daily life. The selected wards provided care for residents with moderate to severe cognitive impairment. Family caregivers were eligible for this study if they were involved in the care for a resident with dementia living at the included wards. Family caregivers who functioned as the main contact person, and were responsible for making decisions on behalf of the resident, were invited to participate in the study (N=58).

### *Procedure*

All participants were informed about the study in writing and received a consent form. Family caregivers who were willing to participate returned the consent form directly to the researchers and were called and asked when the interview could take place. Participants were interviewed individually; however, if the participant preferred that a second family caregiver was present, this person was allowed to join. Interviews were held at a location of the participant's choice. Participants were interviewed by a member of the research team between February and October 2017. Before starting the interview, participants were verbally debriefed about the study, informed about how the data would be processed, and reassured that any data would be treated confidentially.

### *Data collection*

Data were collected by semi-structured interviews.<sup>16</sup> In addition, the following background characteristics of participants were collected: age; gender; relationship to the resident (spouse, child, other); and how frequent they visited the nursing home. An interview guide, including a topic list, was developed to standardize the interview procedure. Participants were asked about the extent to which their relative is

able to live his or her life within the nursing home. Table 1 presents an overview of the topic list and examples of questions. When needed, the interviewer prompted participants to elaborate on factors that support having choice in valuable moments in the resident's daily life and things the resident appreciates and enjoys while living in a nursing home. Three researchers collected data (LH, EdV & RB). Interviews were audio-recorded and transcribed verbatim.

**Table 1.** Topics and example questions of the interview

Topic (themes)	Question (example)
Autonomy within the nursing home	To what extent do you feel that your relative can live his/her life in the way he/she wants in the ward? What things were important to your relative at home, and are still important now? To what extent are they still possible and why (not)?
Contributing factors to autonomy	What factors contribute to your relative living the life he/she wants?
Impeding factors to autonomy	What factors impede your relative living the life he/she wants?

#### *Data analysis*

A qualitative thematic approach was used to analyze the data.<sup>16</sup> Analyst triangulation was used in order to increase reliability of the data analyses.<sup>17</sup> First, to acquire an overall sense of the data and become familiar with the text, researcher LH read all transcripts. Initially, three transcripts were coded (LH) and the coding was discussed in detail with a second researcher (LH & HV). Relevant text fragments were identified, which were meaningful parts of the text, containing words and phrases. Fragments were compared among each other to find similarities and differences, assigned to a similar category and given a code that corresponds to and contains the meaning of the fragment. After that, all remaining transcripts were analyzed independently by two researchers (LH & EdV), using qualitative data analysis software MAXQDA<sup>18</sup>, and interpretations were compared as a form of cross-checking. In the case of disagreement, the most suitable interpretation was chosen, e.g. the interpretation which best signifies the meaning of what was expressed. A code scheme was developed, in which connections between categories were made, and codes were integrated and refined. Relationships and connections between codes were made in order to develop central themes that derived from the qualitative data. All codes were grouped and collectively categorized and main themes were identified. Weekly meetings were held between the researchers (LH, EdV & HV) during the analysis to discuss coding of the transcripts and interpretation of the data. After coding all transcripts, codes and themes were discussed within the whole research team for general interpretation of the data.

#### *Ethical procedure*

This study had been approved by the Ethics Committee of Zuyderland-Zuyd (No. 16-N-233). Participants submitted informed consent after receiving information about the purpose and procedure of the study. Participants could withdraw their voluntary participation at any moment during the study. Confidentiality of the interviews was guaranteed.

## FINDINGS

In total, 30 out of 58 family caregivers agreed to be interviewed. Seventeen caregivers did not return the consent form and 11 refused to participate. Participant characteristics are described in Table 2. Of the participants, the majority were daughters who visited their relatives at least once a week.

**Table 2.** Participant characteristics

Participants	Total (N=30)
Mean age in years (range)	57 (47–76)
Gender (n female)	26
Relationship with relative (n)	
Daughter	24
Son	3
Spouse	1
Niece	1
Legal representative	1
Visits relative more than once a week (n)	27

Most participants found it difficult to reflect on to what extent their relative is able to live the life he or she wants to live. They expressed difficulties determining whether their relative with dementia had the potential to carry out autonomy: most relatives were not able to express actively and verbally their wishes and needs. Participants stated that the cognitive decline caused loss of previous interests and the cognitive and/or verbal inability to express interests. Consequently, participants were asked to elaborate on specific situations that used to be important and meaningful for their relative at home, and whether these are still important and possible while living at the nursing home. Based on this, information on resident autonomy was deduced and reflected within six themes (Table 3) which are described in more detail below.

**Table 3.** Main themes

Theme	Definition/meaning
Activities	Residents' engagement in meaningful activities and stimulating their interest in activities
Personal approach	Personal attention for residents by staff and staff knowing residents' preferences and life history
Visits from family and friends	Continuation of family traditions and meaningful social encounters for residents
Being part of a group	Adjustment to living with fellow residents
Physical environment	Residents' personal belongings and freedom of movement
Organization of care	Nursing staff's working routines, staff teams and work flexibility



### *Activities*

The theme 'activities' concerns resident engagement in meaningful activities and stimulating their interest in activities. Participants indicated that autonomy was supported when residents were engaged in (meaningful) activities that suited their interest and when care professionals stimulated the interest of residents in participating in certain activities. The majority of participants indicated that care professionals could better address needs and adjust activities to residents' cognitive abilities when they organized activities at an individual level, or in a small group of residents with similar interests. In addition, most participants mentioned that activities were not tailored to residents' individual preferences. Activities were mainly organized by staff from a logistic point of view, instead of these being adapted to residents' personal preferences. Furthermore, for those residents whose interests matched the organized group activities, family caregivers felt that autonomy was supported, whereas activities adjusted to residents' personal preferences were rarely centrally organized.

*"Nothing happens at the ward. There are no activities for my father. He will not join activities such as arranging flowers, and he doesn't need his nails done. There is nothing to do for the gentlemen, I don't see it" [Daughter,56]*

Moreover, some participants mentioned that participation in activities in a familiar environment, such as the ward's living room, better supported autonomy, compared to organized activities in a communal room outside of the ward.

### *Personal approach*

The theme "personal approach" pertains to staff providing care that suited residents' preferences and giving personal attention to the residents throughout the day. Correspondingly, a personal approach was the ability to choose a specific ward before admission, maintaining residents' daily routines, being offered preferred food and taking care of the physical appearance as residents would have wished. Participants indicated that an important factor in achieving resident autonomy was the nursing staff making an effort to get to know the resident, by asking both resident and their family caregiver about preferences regarding activities and life history. These aspects were mainly discussed during the intake at admission but rarely at another point in time. Some participants were asked about how they felt about an update conversation during the year and responded positively. According to them, this would contribute to support resident autonomy. One participant responded:

*"At a certain point in time she started singing and they asked me 'do you think it's ok if she joined the singing group?' That's something I've noticed, they try things like 'wouldn't this or that be nice for your mother to do?'" [daughter,63]*

Only a few participants spontaneously indicated that their relative had a close relationship with (a member of) the nursing staff. These participants were more satisfied with the support of the autonomy of their relative whenever their relative received care from these nursing staff members.

### *Visits from family and friends*

Continuation of family traditions and meaningful social encounters were considered important by the family caregivers in supporting autonomy. All participants reported that residents were able to continue social activities they used to do when living at home, when they were able to welcome family and friends at any time. One contributing factor that was mentioned was nursing staff making participants feel welcome whenever they visited, as well as the presence of nursing staff on the ward during visits.

*“You really feel at ease, you feel like you’re being invited. As if you could come over whenever you want” [Daughter,56]*

Nonetheless, most of the participants were not able to visit their relative as much as they wished, due to work or travel distance. Keeping in contact by phone was mentioned as helpful for the resident to stay in touch with relatives. Residents, however, did not receive sufficient help with using the phone or with having a private area where they could make a call, according to some participants.

*“For me, I call a lot less now, otherwise I would have called on a daily basis, I called her every day. [...] And when I call now, it is more complicated because they have to transfer your call and then something goes wrong. Also, she sits in the living room, where the TV is turned on and people are chatting” [Daughter,58]*

### *Being part of a group*

Participants’ opinions differed as to whether living in a nursing home, and being a part of a group of residents or joint household, either supported or impeded the autonomy. Some participants felt that living in a group could positively support their relative’s interest in socially connecting to others, e.g., other residents and their family members.

*“Your mother is always cheery and peppy, she talks to everybody’, staff say. We had a family with five children and other people also came over a lot, a ‘Leave it to Beaver’ household. So, she’s always used to having people around. The only concern would be that my mother could get lonely, but I don’t feel like that’s the case. She sits and talks with everybody” [Daughter,57]*

On the other hand, a small number of participants viewed that living in a group was sometimes too busy for their relatives and that they preferred spending more time on their own during the day. Therefore, it was considered important for these residents to have a place where they could seclude themselves from the group when they wished.

*“It is hard for people to adjust to five other people you don’t even know. And they all have a completely different background, they didn’t choose them themselves. They are not friends or acquaintances or whatever” [Daughter,59]*

Tailoring daily routines to residents’ preferences played a major role in achieving autonomy; for example, getting up when they wanted to or having meals at a preferred time. Some participants mentioned that

autonomy was currently restricted, as residents' daily life was oriented toward what fits the group instead of the individual.

*"My mother doesn't like the music that's mostly played on the ward. She likes music we played at home back in the day. Now, she sings along with the music on the ward, only because she knows all the songs now by repeating and repeating" [Daughter,56]*

#### *Physical environment*

Being able to adjust the environment into a place that feels like home and experience the freedom to move within and outside the ward as much as residents wish, contributed to resident autonomy. In all cases, participants mentioned that being able to bring personal belongings and valuable belongings, such as furniture, carpets, photographs, clothes and toiletries, contributed to living in a familiar and homely environment.

*"We asked her before: 'by the time you would have to live in a smaller place, what would you bring?' [...]. Her bedclothes, she even took her own mattress and bedclothes, all those kinds of things. The most important thing, she took my father with her, the urn in her room, she brought things that were extremely important to her" [Daughter,53]*

It was suggested by participants that the ability to walk around the ward freely, without restrictions, addressed the need for physical movement and freedom within the ward. This contributed to autonomy as residents can freely choose to go wherever they want and residents do not feel restricted within their living environment. This was also the case when nursing staff accompanied residents for a walk within or outside the nursing home. In particular, for those residents who are wheelchair-dependent, some participants viewed that regular walks would help them be exposed to a different environment during the day. In addition, for the majority of participants, help from nursing staff and family caregivers, and a freely, easily and safely accessible garden or outside space contributed to the feeling of having autonomy.

Some participants indicated that sufficient access to private areas, belonging to the resident, improved resident autonomy. For example, if residents had access to their wardrobe they would experience more freedom, according to participants, even though this might cause inconvenience for nursing staff. The ability to have a private space to be alone outside of the bedroom, as well as a private space for residents to welcome family, are also factors that contributed to autonomy, indicated by the participants:

*"He needs his own space, right. And of course he has his own room but he is not capable of finding his own room and turning the key to open the door. So that is not an option" [Son,58]*

A small number of participants mentioned that their relative considered the nursing home as their home. They pointed out that their relative felt satisfied and at ease, and visibly enjoyed daily life at the nursing home. For a few other residents, for example, the ward was a familiar and safe environment and felt like their own home.

### *Organization of care*

Within the organization of nursing home care, several factors concerning nursing staff and working routines promoted resident autonomy according to the participants. Participants were unanimous in the view that deploying a fixed team on a ward enabled nurses and residents to know each other better. This would allow staff to develop a personal relationship with residents, and therefore enable them to approach residents in a more personal way, better addressing individual needs and preferences.

*“Well, what I think is really important and keep on seeing, is of course linked to staff changes. My mom, she wouldn’t accept the way she’s being taken care of. She can’t express it anymore, but it’s not the way she would want it. She would get angry, so to speak. Right from the beginning, I took a picture of her and I put that photograph over there, just to give an example of ‘this is my mom, this is how she felt human’. And some of the staff pay attention to this and others completely don’t [...]. And if I see her and how her hair is done, it’s greasy and she’s not wearing any make-up. My mom wouldn’t open the door to anyone like this back home” [Daughter,53]*

*“Well, a fixed team. Yes, it would be nice for mom if she had a steady, identifiable person instead of all these new faces. [...] Yes, someone who knows what she likes and prefers” [Daughter,53]*

Moreover, participants indicated that when staff had more freedom to work without a predetermined list of care tasks, resident autonomy could be better supported. For example, they would be able to effectively address residents’ daily needs, such as timely toilet use, preferred physical appearance and meaningful activities. Furthermore, if nurses had more time for tasks other than physical care, residents could better live the life they want – for example, going outside with residents when residents wanted to, being able to support residents with keeping their pet and participate in daily activities.

*“Someone takes care of the medicine, the other one starts with porridge [...]. It’s such a routine, right? Someone does this, the other one does that [...]. It’s ‘go, go, go, feeding, and done’ and then they clean up, it’s all that routine, it’s like ‘I have to be ready in time because my shift ends at 7 o’clock’. I think that’s what it is” [Daughter,59]*

Furthermore, in order to increase resident autonomy, some participants indicated that changing staff working hours could contribute to addressing residents’ needs regarding daily routines and habits. For example, residents should be able to go to bed when they want and stay up late when visiting their children’s home without being dependent on staff working hours during the evening.

*“For example, sometime last week, a staff member was in one of the living rooms and took all the residents to the other living room. Like she (staff member) said, she’d previously already done something with games: ‘for me to do that again, I feel like I’m not doing anything usefull’. She was really thinking about helping her colleagues with all those residents who had to be put to bed. That’s a typical example of nurses who might think ‘oh, I have to put ten people to bed’ or ‘I have to reach my quota for today” [Daughter,60]*

## DISCUSSION

The current study identified six themes that influenced autonomy of nursing home residents with dementia: 1) activities; 2) personal approach; 3) visits from family and friends; 4) being part of a group; 5) physical environment; and 6) organization of care. Within these themes, factors were mentioned that could either support or impede resident autonomy. The most important factors that were considered by family caregivers to influence resident autonomy were: 1) residents being involved in individual activities that suited their interest, while activities that were organized from a communal and logistic perspective impeded autonomy; 2) providing a personal approach by getting to know the resident positively influenced resident autonomy; 3) autonomy was supported when family and friends were able to visit, though private spaces for family to continue family traditions were absent; 4) being able to socially engage with fellow residents had a positive influence, whereas, on the other hand, daily life with fellow residents was mostly determined by what fits the group instead of the individual; 5) creating a homely environment supported resident autonomy, while limited freedom of movement was considered impeding; 6) having a fixed team supported autonomy while, nursing staff having fixed routines regarding moments of care, impeded resident autonomy.

Some methodological limitations need to be considered. All first-contact persons of the residents from the selected wards were approached, which led to an inclusion of a high number of daughters. Consequently, experiences from spouses have been underrepresented in this study. This could have led to somewhat other findings as spouses may have a different, closer relationship with a resident.<sup>19</sup> Adult children might grow into a different relationship, as they distance themselves from the parent when taking on a caring role.<sup>20</sup> Accordingly, they may take over the decision process as the hierarchy within the child-adult relationship changes.<sup>21</sup> Nonetheless, the sample is likely to be representative regarding gender, as women often take on the role of family caregiver.<sup>22</sup> We used a descriptive generic research design, and our sampling procedure did not primarily focus on attaining data saturation when recruiting participants. Instead, we mainly focused on recruiting participants to capture a variety of experiences with resident autonomy from different wards, as previous studies suggested that the nursing home environment influenced family caregivers' perception on the care process,<sup>23</sup> and autonomy in daily life in these homes may differ. Furthermore, participants had difficulties in determining whether their relative was able to live the life he or she wants. Other research methods, for example photo elicitation,<sup>24</sup> which is an interview method that uses visual images to elicit comments, may have been able to stimulate more response.

Our findings suggest that when residents are being cared for according to the nursing staff's fixed routines regarding moments of care, and staff's working shifts, this impedes resident autonomy. This is an impeding factor to resident autonomy as this task-centered focus gives staff little opportunity to recognize and respond to the daily needs and wishes of the resident. These findings are in accordance with recent studies indicating that nursing staff are often too much involved in taking over caring tasks, and therefore residents are poorly stimulated to make their own choices.<sup>25</sup> In order to provide care that incorporates residents' needs and wishes, care flexibility is essential.<sup>26</sup> More research is needed to explore the relationship between the identified factors and cognitive status, duration of stay, and other background characteristics. Participants acknowledge that autonomy could be better supported when staff have more freedom to work without a predetermined list of care tasks. Therefore, it is important for

staff to view the nursing home as a place to live in rather than a place to be cared for, in order to address residents' needs and wishes.<sup>27</sup>

Another finding was that family caregivers perceived that resident autonomy was impeded when activities were mainly organized from a logistic and communal principle. Therefore, it was perceived as important that the staff are able to spontaneously organize meaningful activities, in an individual or small setting. This would support resident autonomy as staff would be able to directly address residents' needs and wishes and activities, and could therefore be more meaningful to the resident. Our findings suggest that going outside is, amongst others, a meaningful activity for many residents. When staff are able to spontaneously arrange this activity, this would contribute to activities that are more meaningful and therefore, residents are better supported in living the life they want. This also accords with earlier observations, which showed that being able to go outside was mentioned as a meaningful activity and, therefore, is related to a higher quality of life for nursing home residents with dementia.<sup>28</sup> In addition, our findings indicate that in order to enhance the feeling of having the choice to go wherever you want, the physical environment should be developed to facilitate the possibility for residents to independently go outside into a safe environment.

As is well known, it is exceedingly important for nursing home residents with dementia to keep a social connection to their family and friends. The current study found that while all participants were able to visit their loved one anytime during the day, there was a need to have a private space or suitable area to continue social traditions, such as celebrating birthdays together with family, or just being together amongst family, away from the communal group. In addition, besides being socially involved in the residents' life, it is also important for family to be involved in the care of their relative to support resident autonomy.<sup>29</sup> In order to do so, they have to feel at home and welcome, and be able to take part in decision-making about the resident's care equally, instead of solely being a visitor.<sup>30</sup> Nonetheless, communication between family and staff appears to remain challenging, causing shortcomings in discussing roles.<sup>31</sup> This can hinder the support of resident autonomy. Moreover, as participants repeatedly mentioned frequent changes in care staff, family caregivers, nursing staff and residents might face difficulties in developing a strong relationship, which is needed to support resident autonomy. Therefore, this study indicates that low staff turnover is important for residents and family caregivers to allow them to adjust to the nursing home and develop a personal connection with nursing staff. In that way, knowledge of residents' life preferences can mutually be transferred, as a basis to create a solid partnership in supporting resident autonomy.<sup>28,32</sup>

Findings of this study indicate that several factors might improve the support of resident autonomy. Improvements should focus on good implementation of person-centered care by creating possibilities to better tailor care to residents' preferences regarding daily routines, social and meaningful activities. Realizing improvements regarding supporting resident autonomy might be a challenge, as providing an opportunity to make own choices and, consequently, being able to live the life residents want, has not been a priority in current nursing home care.<sup>6</sup> Nonetheless, the most important improvements that can be made concern the care professionals. They need to be given the opportunity to know and understand the residents in order to provide care and activities that suit the residents' interests. Care professionals should be able to provide care that is based on residents' personal preferences and support the life residents want to live. In addition, creating a familiar, homely environment and enabling residents to go outside whenever they want should be facilitated to better

support autonomy. Lastly, the physical environment should encourage residents and family caregivers to continue social activities in private.

In conclusion, the current study suggests that there are still numerous possibilities to improve the support of resident autonomy. Enabling flexibility in providing care, finding ways to offer activities that are meaningful to residents, and stimulating resident's social environment to continue social traditions are of major importance in supporting resident autonomy. Based on the findings of this study, efforts should be made to improve the support of resident autonomy within nursing home care.

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# CHAPTER 4

## **Interventions to Foster Family Inclusion in Nursing Homes for People with Dementia: A Systematic Review**

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## **ABSTRACT**

### **Background**

Family inclusion in nursing homes is central to the provision of individualized care for people with dementia. Although positive effects can be recognized, barriers have been identified that hamper family inclusion in nursing homes. Specifically for people with dementia, insight into the content of interventions to foster family inclusion is lacking.

### **Methods**

A systematic review was performed by systematically searching the databases PubMed, Cinahl, PsycInfo and Embase. Studies were eligible if they examined (1) nursing home settings, (2) interventions to foster the inclusion of family members from people with dementia, (3) were original research articles in which effects/experiences of/with these interventions were evaluated, and (4) were written in English, Dutch or German. Findings were summarized systematically.

### **Results**

Twenty-nine studies were included. Two interventions were targeted at creating family-staff partnerships from a two-way perspective. Other interventions focused on single components, such as including family members in formal decisions (n=9), enabling them to make better informed decisions and/or participate more actively (n=7), or providing psychoeducation for family members (n=3). Within the interventions, family and staff members are often treated differently. Effects on actual increase in family inclusion remain unclear.

### **Conclusions**

Very few interventions exist that try to enhance equal family-staff partnerships in nursing homes. Future interventions should pay specific attention to mutual exchange and reciprocity between family and staff. As little is known about promising (components of) interventions to foster family inclusion in nursing homes for people with dementia, more effectiveness research is needed.

**Keywords:** family involvement, long-term care, psychogeriatrics

## BACKGROUND

Person-centered care approaches are increasingly being implemented in various healthcare settings and are widely recognized as an essential component of quality care.<sup>1,2</sup> While, ideally, these approaches should involve the person (i.e., the patient/resident), their families (not only the primary caregiver, but all family members (e.g., partners, (grand)children, siblings), and the care providers, a recent review of systematic reviews has demonstrated that only a minority of person-centered care interventions pay attention to the role of family members.<sup>1</sup> In nursing homes, family inclusion is a central element for the provision of individualized care for people with dementia.<sup>3</sup> As the relationship between people with dementia and their family members has developed over a life course, it is likely that families' roles continue once a person with dementia enters a nursing home.<sup>4-6</sup> Early research indicated that it is a myth to believe that family members abandon their relatives that live in a nursing home.<sup>7,8</sup> In contrast, although their role might change in the sense that they are less involved in the physical care and decision-making,<sup>9</sup> they stay involved after the person with dementia moves into a nursing home. Family members' sharing of information on the person's biography, meaningful activities and daily life preferences with staff might lead to positive effects for nursing home residents.<sup>10</sup> In addition to people with dementia, family members themselves may also benefit from the inclusion of family in nursing home settings. Family inclusion refers to creating democratic engagement of families within nursing homes, by providing family members with opportunities and resources that empower them to actively participate in their relatives' life as well as in the nursing home as a community.<sup>6</sup> For family members, being involved in the nursing home may lead to enhanced satisfaction with the care provided to residents and an enriched own wellbeing.<sup>11,12</sup> At the same time, family inclusion has a potential for conflicts, as different family members (e.g., a son and a daughter of the resident) may differ in their opinion on 'what is best' for the resident. As family members provide help to people with dementia in various ways, e.g., through providing hand-on or socio-emotional care or monitoring,<sup>13</sup> staff members may also benefit from their involvement. In addition, nursing home organizations as a whole may benefit from the inclusion of family members. From a business perspective, family members in nursing homes are indirect customers who do not purchase services themselves, but only accompany the direct customer.<sup>14</sup> Nevertheless, research has indicated that nursing home organizations may benefit from getting their indirect customers more engaged with the organization.<sup>15</sup> Organizations in different sectors increasingly recognize the importance of (indirect) customer engagement behaviors.<sup>15,16</sup> These behaviors can be defined as customers' voluntary, helpful behaviors towards an organization after and beyond purchasing goods or services.<sup>14</sup> Indirect customer engagement behaviors of family members in nursing homes can occur in interacting with staff members, providing feedback or complying with organizational rules and procedures, but also in the interaction with other (potential, indirect) customers, by helping them or by spreading a positive word of mouth or writing online reviews about the nursing home.<sup>14</sup>

Although positive effects of family inclusion for residents, family members, staff and the organization as a whole can be recognized, a wide variety of barriers have been identified that hamper family inclusion in nursing homes. In a sociopolitical environment of staff shortages and scarce resources in nursing homes, family members are easily seen as a commodity<sup>6,17</sup> or as a resource for augmenting staff.<sup>18</sup> While family members in many countries are considered as being able to form an unpaid workforce in nursing homes,

adequate support of family members in nursing homes is often lacking.<sup>6</sup> For example, family members are often left alone to deal with complex emotions related to the decision that a loved one has to enter a nursing home.<sup>6,19</sup> Staff members often find it difficult to collaborate with family members and may consider them as being 'difficult' or demanding.<sup>20,21</sup> While family members need to understand that there are limits to what a nursing home can offer, it is important that nursing home organizations take into account family members' capacities and personal situation too. Professional caregivers could see family members as a valuable resource in providing person-centred care for their residents, instead of fearing that family may become additional clients themselves and increase their workload. Contextual factors like the geographic proximity, the employment status or family members' own health status may have an impact on the role family members want to or can play in nursing homes.<sup>6</sup> In addition, Cohen et al.<sup>11</sup> demonstrated that family involvement for residents with dementia is different compared to residents without dementia. They found that while family members of people with dementia spent more time on activities to support resident care (e.g., related to nutrition, mobility or discussing care with staff), family members of residents without dementia spent more time on their social and community engagement (e.g., taking residents on trips, shopping), often outside the nursing home. This demonstrates that, particularly for family members of people with dementia, the tasks often go beyond solely visiting the relative. Instead, family members conduct caregiving tasks that could be considered a staff responsibility, which might be particularly burdensome for family members.<sup>11</sup>

In a recent critical examination of how resident care is negotiated among staff and family members in nursing homes, Puurveen et al.<sup>22</sup> conclude that in formal care conferences (also known as case conferences or inter-/multidisciplinary team meetings), family members occupy a 'marginal position relative to staff.' Instead of being a dialogic space promoting family inclusion, they found that care conferences are spaces in which staff members perform 'expert one-way communication'.<sup>22</sup> Considering the citizen participation ladder of Edelenbos & Klijn,<sup>23</sup> five levels of participation can be distinguished, i.e., 'informing,' 'consulting,' 'advising,' 'co-producing' and 'co-deciding.' Translated to family inclusion in nursing homes, 'informing' means that the nursing home organization determines the agenda for decision-making and informs family about decisions only, while 'co-deciding' stands for equal shared decision-making between family and staff members. Thus, the degree and type of family inclusion in the care conferences assessed by Puurveen et al.<sup>22</sup> can be classified as 'informing' only. To meaningfully contribute to person-centered care, especially for people with dementia, formal care conferences and other interventions aimed at increasing person-centeredness through family involvement should promote mutual exchange and reciprocity between staff and family members and should empower family members to participate as equals.<sup>22,24</sup>

In earlier systematic reviews, Haesler et al.<sup>25-28</sup> assessed factors that are important in the development of constructive family-staff relationships in the care of older institutionalized adults, including both hospitals and institutional long-term care settings. Based on their most recent review conducted in 2010,<sup>27</sup> they conclude that interventions to promote constructive family-staff relationships were those that include collaboration in care planning and decision-making, promote effective communication skills, define a clear process and involve multidisciplinary healthcare teams. However, as the engagement of family members of people with dementia differs from that of family members of residents without dementia, the

opportunities and resources that empower them to actively participate in their relatives' life as well as in the nursing home as a community might also differ. Specifically for people with dementia in nursing homes, an overview of interventions to foster the inclusion of family members of people with dementia is lacking. A qualitative meta-synthesis conducted by Petriwskyj et al.<sup>29</sup> provides insight into the experiences of family involvement in decision-making for people with dementia in residential care, without considering specific interventions. In 2015, Nguyen et al.<sup>30</sup> published a protocol for a systematic review on interventions to improve communication and cooperation in order to promote effective family–staff relationships for family members of people with dementia living in residential aged care facilities.

The aim of this systematic review is to obtain insight into the content of interventions to foster the inclusion of family members (e.g., partners, (grand)children, siblings) of people with dementia living in nursing homes within the nursing home setting. We take a broad view and do not only focus on interventions that contribute to family inclusion in family–staff interactions, but also take into account interventions to facilitate family–resident or family–family engagement in the nursing home setting. This means that, besides focusing on family–staff relationships, we also pay attention to how to enable family members to better engage with their relatives or with family members of other residents, and therefore consider interventions that contribute to family involvement and give a voice to family within the whole nursing home community. We are predominantly interested in the content of existing interventions, with the aim of contributing to the development of future interventions to involve family members of people with dementia within the nursing home setting.

## METHODS

### *Search strategy*

A systematic review was performed by systematically searching the databases PubMed, Cinahl, PsycInfo and Embase. The search strategy included terms related to family, dementia, nursing homes, involvement, and interventions (see Table 1). Search terms with respect to family (e.g., family OR caregiver\* OR spous\* OR relativ\* OR informal care\*) were combined with the Boolean operator AND with search terms related to dementia (dementia OR demented OR Alzheimer\* OR cognitive declin\*), search terms related to the nursing home setting (long-term care OR care hom\* OR housing for the elderly OR special care unit\* OR homes for the aged OR institutional\*), search terms related to involvement (participat\* OR relationship\* OR collaborat\* OR involve\* OR interact\* OR role\* OR engag\*), and search terms related to interventions (program\* OR intervention\* OR strateg\*). Articles published between January 1st, 2000 and February 7<sup>th</sup>, 2019 were included. Bibliographies of included articles were searched for additional references.

**Table 1:** Steps and detailed search terms used in the PubMed search\*

Step	Search terms
1	<i>Subject area 1: Family members</i> (((((((family[MeSH Terms]) OR caregivers[MeSH Terms]) OR spouses[MeSH Terms]) OR family[Title/Abstract]) OR relativ*[Title/Abstract]) OR spous*[Title/Abstract]) OR caregiver*[Title/Abstract]) OR (informal care*[Title/Abstract])
2	<i>Subject area 2: Dementia</i> (((dementia[MeSH Terms]) OR dementia[Title/Abstract]) OR demented[Title/Abstract]) OR alzheimer*[Title/Abstract]) OR (cognitive declin*[Title/Abstract])
3	<i>Subject area 3: Nursing homes</i> ((((((((((long-term care[MeSH Terms]) OR residential facilities[MeSH Terms]) OR (nursing hom*[Title/Abstract])) OR (residential care[Title/Abstract])) OR (assisted living[Title/Abstract])) OR (long-term care[Title/Abstract])) OR (care hom*[Title/Abstract])) OR (housing for the elderly[Title/Abstract])) OR (special care unit*[Title/Abstract])) OR (homes for the aged[Title/Abstract])) OR institutional*[Title/Abstract]
4	<i>Subject area 4: Involvement</i> (((((((participat*[Title/Abstract]) OR relationship*[Title/Abstract]) OR collaborat*[Title/Abstract]) OR involve*[Title/Abstract]) OR interact*[Title/Abstract]) OR role*[Title/Abstract]) OR engag*[Title/Abstract]
5	<i>Subject area 5: Interventions</i> ((program*[Title/Abstract]) OR intervention*[Title/Abstract]) OR strateg*[Title/Abstract]

\* Detailed search strategies used in the other databases (Cinahl, PsycInfo and Embase) are available upon request.

#### *Eligibility criteria*

Studies were eligible if they (1) examined specifically the nursing home setting, (2) examined interventions to foster the inclusion of family members from people with dementia, (3) were original research articles in which the effects/experiences of/with these interventions were evaluated, and (4) were written in English, Dutch or German.

#### *Study screening and data extraction*

Retrieved articles were managed in an Endnote library (version X8). Two researchers (RB, LJM) independently screened the titles of all articles for relevance. After reaching consensus on the result of independently screening the titles, both researchers screened the abstracts of potentially relevant articles. After reaching consensus on the result of independently screening the abstracts, full-text articles were obtained for all potentially relevant studies. Both researchers independently screened the full-text articles and scored them as 'include,' 'possibly include' or 'exclude.' By discussing disagreement between the two researchers, consensus about the final list of included studies was reached. The principal researcher developed a standardized data extraction form (specifically developed for the current study) and extracted data from included articles. All extracted data were double-checked by a second researcher (EdV). For each article, data on the following aspects were extracted: author; publication year; country; sample characteristics; research methods; aim of the study; components and duration of interventions; treatment of control group; relevant outcome measures/themes analyzed; and study findings. All extracted data were discussed within the research team.



*Data synthesis and analysis*

Because of the heterogeneity in studies regarding their design and content, and as we were predominantly interested in the components of interventions, no meta-analysis or quality assessments were conducted. Instead, the findings of included studies were summarized systematically, based on the aim and type of the intervention and its individual components, by two members of the research team (RH, EdV) and discussed within the research team. First, we distinguished between interventions that facilitated family inclusion in family–staff interactions and those that facilitated family–resident or family–family engagement. Second, based on the content of the included studies, the interventions facilitating family inclusion in family–staff interactions were further classified into interventions aimed at (1) creating family–staff partnerships, (2) including family members in formal decisions, (3) enabling them to make better informed decisions and/or participate more actively in future interactions with staff, or (4) providing psychoeducation for family members to, inter alia (i.e., meaning ‘among other things’), improving future interactions with staff. For each intervention, a summary of its effects was written by two members of the research team and discussed within the research team.

**RESULTS**

Figure 1 presents the PRISMA flow diagram of the inclusion process. In total, 29 studies were included (Table 2).

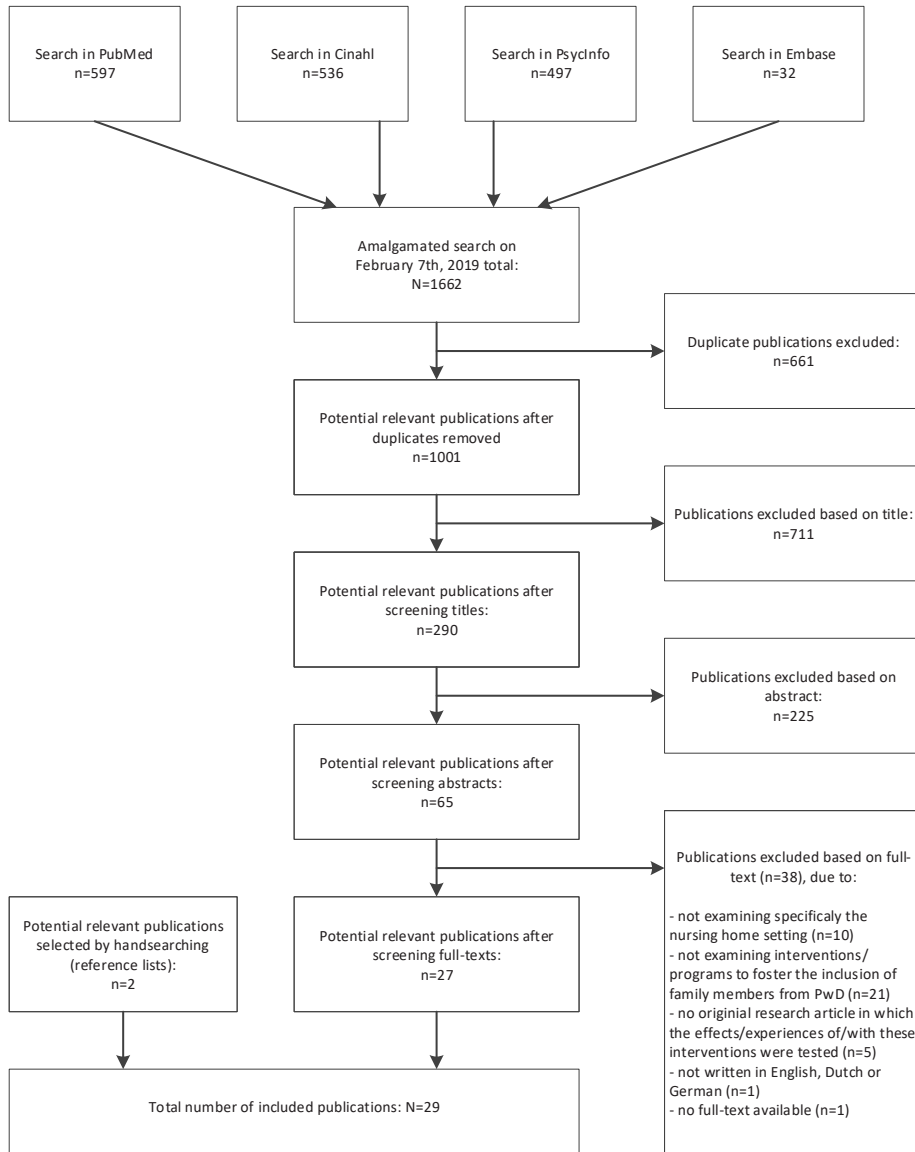


Figure 1: PRISMA flow diagram of the search process

*General characteristics of included studies*

Most of the studies (n=25) aimed to contribute to family inclusion in family–staff interactions, while only a few (n=6) considered interventions contributing to family–resident or family–family engagement. Two of the studies<sup>31,32</sup> aimed to cover both family–staff interactions and family–resident engagement. The 29 included studies were published from 2003 onwards, with more than half of them published within the last five years. Eleven of the included studies were published in 2017 or 2018. Studies were conducted in Australia (n=5), Belgium (n=1), Canada (n=4), Israel (n=1), Italy (n=2), the Netherlands (n=3), the UK (n=4), and the US (n=12). In total, 24 different interventions were tested in the included studies. In two studies,<sup>33,34</sup> the same data set and findings were presented.

**Table 2:** General characteristics of included studies (n=29)

<b>Author</b>	<b>Country</b>	<b>Type of intervention</b>	<b>Effects/Results</b>
Agar et al. (2017)	Australia	Facilitated family case conferencing	No significant group effect for family members' satisfaction with care during the last 90 days of residents' life.
Ampe et al. (2017)	Belgium	'We DECide' – Discussing End-of-Life Choices	Advance care planning policy was significantly more compliant with 'best practice' after the intervention, while policy in the control group was not. Advance care planning discussions did not take place more often, nor were residents and family more involved in the discussions.
Arcand et al. (2009)	Canada	Pilot educational program for nursing staff and physicians on comfort care and advanced dementia; booklet	No significant effects of the intervention were found, although the post-intervention group expressed greater satisfaction in the area of communication with the healthcare team (8.0 vs. 6.6) and greater satisfaction with end-of-life care (8.3 vs. 7.3).
Beer et al. (2011)	Australia	Educational intervention for GPs and care staff	Nearly two third of general practitioners reported that the participants' learning needs were met 'entirely'. 95% of the staff members reported that the session met participants' learning needs. In addition, qualitative feedback was very positive.
Bramble et al. (2011)	Australia	Family involvement in care (FIC) intervention	Participation in FIC led to an improvement of caregiver knowledge. Knowledge about dementia increased significantly. Family satisfaction was negatively related to staff consideration of relatives and management effectiveness. Staff well-being and job satisfaction were negatively related to their perceived inappropriate behavior of residents.
Brazil et al. (2018)	UK	Family focused advance care planning (ACP) intervention	Reduction in total Decisional Conflict Scale score in the intervention group compared with the usual care group.

Chisholm et al. (2018)	US	Goals of Care video decision aid for families of residents with advanced dementia	Staff perceived the intervention as positive and it was perceived as 'more compatible with current practices' by male staff, nurses, more experienced staff.
Dassa (2018)	Israel	Individualized database using personal music and photos that present life episodes	All three participants encountered difficulties when visiting the nursing home, mostly related to communication barriers. All three reported that using the individualized database led, for example, to better communication with their residents and less feelings of disconnection.
Davis et al. (2011)	US	Family Intervention: Telephone Tracking-Nursing Home (FITT-NH) for improving dementia caregivers' adjustment following nursing home placement	Caregivers receiving FITT-NH showed a greater reduction in feelings of guilt relate to placement compared to standard care. And also reported fewer problems and concerns with nursing home care (hassles) compared to standard care. FITT-NH caregivers also showed a trend toward a resumption of pre-caregiver activities (% of previous activities) compared to standard care.
Ducharme et al. (2005)	Canada	'Taking Care of Myself', psychoeducational group program for daughters	Daughters' competence in dealing with staff and their perceived challenge of the caregiver role increased.
Jablonski et al. (2005)	US	Family involvement in care (FIC) intervention	The experimental group showed less global deterioration during the study. Increased family involvement showed less global deterioration in residents.
Kellett et al. (2010)	Australia	Family Biography Workshop (FBW)	Participating family members were enabled to 'stand outside' and see the residents as a whole person. For staff, it was helpful to see the resident in a 'family context'. Residents benefited, as staff's know how on engaging with them increased.
Kuhn & Forrest. (2012)	US	Pilot palliative care education, training, consultations, and administrative coaching	Limited improvements for residents, staff and family members were demonstrate at the first nursing home (site 1), and significant improvements at the other nursing home (site 2).
Maas et al. (2004)	US	Family Involvement in Care (FIC) partnership intervention	An intervention effect was found for family disregard with staff, and the effect varied by generation. For conflicts with staff, no significant effect was found. An intervention effect was found for families' perceptions of physical care and activities: evaluation of physical care significantly increased for the intervention

Mariani et al. (2018)	Italy Netherlands	Staff training program on the use of shared-decision making (SDM) with residents and family caregivers in the care planning process	group and the intervention effect for activities was conditioned by interaction with generation (again, the trend for the older comparison group was significantly negative. No intervention effect on families' perception of management effectiveness was found. Many care plans developed during the intervention showed a high level of agreement with the care planning recommendations. In Italian and Dutch problem statements, the problem statements became clearer. In Italy, documentation of objectives and residents' and families' involvement increased, too.
McNiel & Westphal (2018)	US	Namaste Care program	Results suggest that Namaste Care™ may be useful for residents who can no longer participate in 'regular' nursing home activities.
Moore et al. (2017)	UK	'Compassion Intervention' to enhance end-of-life care in advanced dementia	Due to the recruitment of only four family members, the researchers were unable to assess the effects on family members.
Paun et al. (2015)	US	Chronic Grief Management Intervention (CGMI)	Overall, no significant effects. At baseline, family members in the intervention group scored higher and therefore differed significantly from the control group with regard to loss of relationship with their family member placed in long-term care and heartfelt sadness and longing). Family members in the intervention group were highly satisfied with the program.
Reinhardt et al. (2014)	US	Discussing and providing information about end-of-life care options with family members and psychosocial support for family members	No significant effects for depressive symptoms or life satisfaction of family members.

Robison et al. (2007)	US	Partners in Caregiving in the Special Care Unit Environment (PIC-SCU)	In the intervention group, staff behavior (providing news, encouragement or suggestion to family) increased over 6 months, but did not change significantly for the control group. In the intervention group, families' ease of talking to staff increased and remained elevated at 6 months, whereas scores for the control group were static. When examining intergenerational differences between spousal and other same generation family members and children or younger generation family members, same-generation family members in the intervention group increases their involvement in the short term, whereas control family involvement declined (no significant differences for younger generation family members). All other outcomes were not statistically significant.
Rosemond et al. (2017)	US	Goals of Care intervention: video decision-aid about goals of care viewed by family members of residents with dementia, followed by their participation in a care plan discussion with staff	Deciding on goals of care in the presence of trust vs absence of trust: (When decision makers expressed trust in the NH, positive relationships with staff were evident): 1. End-of-life experience was positive vs negative 2. Goals of care discussions were dynamic vs perceived to be ignored 3. Formal goals of care discussions were not always necessary vs created confusion.
Rosen et al. (2003)	US	Web-based educational program (prototype)	Comparing answers before and after the program, family members gained knowledge about dementia. Most respondents indicated that the program was 'very much' providing information he/she needed, 2 indicated that 'somewhat'. A indicated that the program would be 'very much' helpful to family members who recently placed a loved one in a nursing home.
Saini et al. (2016)	UK	'Compassion Intervention' to enhance end-of-life care in advanced dementia	Four major themes described strategies for improving practice: family and staff education about dementia progression and end-of-life care; appreciating in-depth end-of-life discussions compared with simple documentation of care preferences; provision of time and space for sensitive discussions; and having an independent healthcare professional or team for the end-of-life discussions.
Snyder et al. (2013)	US	Decision aid to improve decision making about feeding options in dementia care	Comparing answers before and after exposure to the decision aid, family members had/were after exposure: more correct answers to knowledge items on tube feeding, decreased expectations of benefits from tube feeding, decreased levels of overall decisional conflict, unchanged treatment preferences (nearly all chose

<p>assistance with oral feeding over tube feeding and preferences did not change, more certain about their choice of oral feeding.</p>		
<p>Reaching out to each other: 1. Families re-connected with their relatives 2. Families recognized the compassion of care staff and appreciated the difficulties caring for people with advanced dementia; Enhanced well-being: 1. For one wife the guilt she felt for placing her husband in the care home and leaving him each day after visiting was lifted 2. A daughter summarized that Namaste made visits easier, helped her re-connect with her mother and recover a meaningful role in her mother's life</p>	<p>UK Namaste Care program</p>	
<p>The tool facilitated a more open dialogue between the palliation resource nurse (a role specifically developed) and family members. These nurses as well as family members gained confidence in discussing the death of their relative with dementia. In some cases, specific decisions around future care were discussed. Family members and nurses were satisfied with these discussions.</p>	<p>Australia Tool to aid talking about dementia and dying</p>	<p>Stirling et al. (2014)</p>
<p>The booklet was found highly acceptable and useful by Canadian and Dutch families, but less so by Italian families.</p>	<p>Canada Family booklet on comfort care in dementia</p>	<p>Van der Steen et al. (2012)</p>
<p>There was a great need for written explanation about palliative care in dementia: The booklet is seen as suitable and useful. All respondents saw a role for caregivers in giving out the booklet. Half of the respondents felt that the booklet should also be available without having contact with caregivers; sometimes even before admission. An adapted version might support caregivers and family in practice.</p>	<p>Netherlands Family booklet on comfort care in dementia</p>	<p>Van der Steen et al. (2011)</p>
<p>In the intervention group, compared to usual care: more families received an information booklet; more families had contact with the physician in last month of life; more families had face-to-face contact with the physician in last month of life; no difference in number of families that had a discussion of advanced directives last month of life; more frequent use of volunteers to give family a respite.</p>	<p>Canada Multicomponent intervention to improve quality of care and quality of dying in advanced dementia</p>	<p>Verreault et al. (2018)</p>



*Components of interventions to foster family–staff interactions*

We identified 25 studies in which 21 different interventions for fostering family inclusion in family–staff interactions were tested (Table 3). These 21 interventions were aimed at creating family–staff partnerships (n=2), including family members in formal decisions (n=9), enabling them to make better informed decisions and/or participate more actively in future interactions with staff (n=7), and providing psychoeducation for family members to, i.a., improving future interactions with staff (n=3).

**Table 3:** Overview of interventions fostering family inclusion in family-staff interactions

Aim of the intervention: Study: Component(s) of interventions described in included studies:*	Creating family-staff partnerships		Family inclusion in formal decisions										Enabling family to make better informed decisions/participate more actively in future interactions with staff					Psychoeducation for family				
	1	2	3	4	5	6	7	8	9	10	11	12	13	14	15	16	17	18	19	20	21	
DIRECT FAMILY-STAFF INTERACTION																						
Formal family-staff discussion	+	+	+	+	+	+	+		+	+												
INDIRECT FAMILY-STAFF INTERACTION																						
Family consultation/discussion by/with third party			+	+	+			+														
Staff informed about family decision				+	+			+														
Staff discussion with third party			+					+														
PREPARATION/FACILITATION DISCUSSION																						
Person who evaluates necessity of and facilitates the family-staff discussion														+								
Agenda setting for the discussion		+	+	+																		
Discussion tool for family							+															
Discussion tool for staff							+		+													
FORMALIZATION OF ACTIONS/PLANS DISCUSSED			+	+																		
EMOTIONAL SUPPORT FAMILY EDUCATION FAMILY-STAFF INTERACTIONS								+										+		+		+
Family educational sessions		+													+							+



### *Creating family-staff partnerships*

Two different interventions aimed at creating family-staff partnerships were found. In three of the included studies, the 'Family involvement in care (FIC)' program<sup>35-37</sup> and in one the 'Partners in Caregiving in the Special Care Unit Environment (PIC-SCU)'<sup>38</sup> program were tested. Both interventions consisted of formal family-staff discussions and educational sessions for staff. In the FIC program, family and staff discussed a partnership agreement and held monthly catch-up meetings, while in the PIC-SCU a joint meeting between family, staff and the nursing home administrator was held to set goals regarding procedures and policies that affect families. To prepare the formal discussions, staff in the FIC program participated in educational sessions on dementia, the role of family in nursing homes, as well as on role negotiation and conflict resolution with family members. Family members received an information booklet on dementia and the role of family in nursing homes. In addition, a primary nurse was assigned to family members.<sup>35-37</sup> In the PIC-SCU program, separate educational sessions were provided for staff and family members to prepare the formal discussion. Both parties received education on dementia, family-staff communication, cultural and ethnic differences, understanding differences in values between family and staff, and on role negotiation and conflict resolution with family/staff. Prior to the actual discussion, family and staff separately set the agenda.<sup>38</sup>

### *Including family members in formal decisions*

In eight of the included studies,<sup>39-46</sup> the inclusion of family members in formal decisions within the nursing homes was fostered through interventions aimed at giving family members the opportunity to decide about the residents' end-of-life care in the nursing home. In the study by Mariani et al.,<sup>47</sup> people with dementia and their family members were involved in care planning and the development of personalized care plans. In another study,<sup>32</sup> the 'Family Biography Workshop,' in which family and staff members collaboratively develop biographies for people with dementia, was tested. Family members in included studies participated in formal discussions with direct care staff (n=6),<sup>32,39,41, 44, 46, 47</sup> discussions with a palliative care team (n=1),<sup>43</sup> and/or in discussions with an intervention coordinator/facilitator, without talking directly with direct care staff (n=4).<sup>40, 42, 43, 45</sup> In one study,<sup>45</sup> family members could attend an educational session prior to the discussion. In three studies,<sup>42,45,47</sup> educational sessions for staff members were provided, focusing on how to shape family-staff interactions (n=2) or dementia and care-related aspects (n=2). In one study, the formal family-staff discussion was facilitated by providing a discussion tool to staff (tool to aid talking about dementia and dying)<sup>46</sup> and in two studies to family and staff (Goals of Care video decision aid)<sup>41,44</sup> In two other studies, family members<sup>40</sup> or family members and staff<sup>42</sup> received an information booklet. In one study,<sup>43</sup> a palliative care social worker provided emotional support to family members via phone.

### *Enabling family members to make better informed decisions or participate more actively*

The interventions in eight of the included studies were aimed at enabling family members to make better informed decisions and/or participate more actively in future discussions with staff.<sup>33, 34, 48-53</sup> In five studies,<sup>48-51,53</sup> educational sessions for staff members were organized, providing knowledge about how to shape family-staff interactions (n=5) or about dementia or care-related aspects (e.g., end-of-life care). In one study, family members could also attend educational sessions.<sup>51</sup> In four studies,<sup>33, 34, 49, 53</sup> an information booklet was provided to family members, and in one to staff members as well.<sup>49</sup>

*Psychoeducation for family members*

In three studies,<sup>31, 54, 55</sup> psychoeducational interventions for family members were provided, consisting of emotional support (n=3)<sup>31, 54, 55</sup> and educational sessions for family members (n=2).<sup>31, 54</sup> Davis et al.<sup>54</sup> provided the 'Family Intervention: Telephone Tracking – Nursing Home' (FITT-NH) aimed at improving family members' adjustment following residents' nursing home admission. FITT-NH consisted of emotional support for individual family members, directing them to appropriate resources within the facility, and teaching them strategies to cope with ongoing problems related to nursing home placement [54]. Another intervention, tested by Ducharme et al.,<sup>31</sup> was the 'Taking Care of Myself' program, a group program aimed at empowering daughters of residents to, i.a., express their point of view to staff. In the third study,<sup>55</sup> the Chronic Grief Management Intervention (CGMI) was tested. The CGMI is a group program for family members, aimed at providing education on dementia and on teaching skills in communication and conflict resolution with staff, and chronic grief management.

*Components of interventions to foster family–resident or family–family engagement*

We identified six studies in which five different interventions contributing to family–resident or family–family engagement were tested.<sup>31, 32, 56-59</sup> The 'Taking Care of Myself Program' tested in the study by Ducharme et al.,<sup>31</sup> was – besides empowering daughters to express their view to staff members – also aimed at empowering them to feel at ease with their resident, improving their visits. In the 'Family Biography Workshop' described by Kellett et al.,<sup>32</sup> family members were also invited to share the biographical materials with their relatives, thus getting involved with the person with dementia. Dassa<sup>56</sup> tested a program in which family members created an individualized database with personal music and photos representing life episodes of their relative with dementia. The idea was that family members could use these personal music and photos to communicate more easily with their relative, leading to an alleviation of family caregiver burden during nursing home visits. In the study by Rosen et al.,<sup>58</sup> a prototype of a web-based educational program for family members was tested. Family members received online education on dementia and residents' behavioral disturbances related to dementia, and on how to communicate with a resident with dementia.<sup>58</sup> In the studies by McNiel & Westphal<sup>57</sup> and Stacpoole et al.,<sup>59</sup> the Namaste Care program was tested, a program with sensory, psychosocial and spiritual components intended to enhance quality of life and quality of care for people with advanced dementia. In the two studies, one of the key elements of the Namaste Care program was a meeting with residents' family members and friends, exploring residents' sources of comfort and pleasure to create an individual sensory biography of the resident. Besides contributing to the wellbeing of the resident, the Namaste Care room provides opportunities for family–resident or family–family engagement.<sup>57</sup>

*Evaluation of interventions*

Overall, few studies assessed whether or not the described intervention led to an increase in family inclusion within the nursing home. For example, in the studies aimed at including family members in formal decisions, it was not always assessed whether, due to the intervention, family members had been more often involved in decision-making. In addition, two different approaches were used for the evaluation of interventions, i.e., assessing the effectiveness of interventions or qualitatively evaluating the experiences of participants, both considering a variety of outcome measures at the family, staff or

resident level. Even when different studies assessed the same intervention, the outcome measures differed. For example, in the studies describing interventions aimed at increasing family–staff partnerships, a variety of effects on family, staff members or people with dementia as well as experiences from family and staff members were considered. Overall, the four studies did not find promising effects for family–staff partnerships. In two studies testing FIC,<sup>35,37</sup> even negative effects for staff (e.g., an increase in role stress and role strain) and family members (e.g., decreased satisfaction with care) were found. Although for the PIC-SCU program<sup>38</sup> small improvements for some outcomes were found, the improvements were not sustained long-term, while participating family and staff members were very positive about the program and would recommend it to others. In some studies, it was difficult to test the effectiveness due to small sample sizes. For one study, the authors themselves indicated that the study was underpowered.<sup>39</sup> In another study,<sup>42</sup> the intervention was pilot-tested in two wards, with promising effects for one ward only. In general, it can be concluded that little can be said about the effectiveness of interventions in increasing family inclusion in nursing homes for people with dementia, while the experiences of participating family and staff members were positive. Even in the absence of statistically significant effects, most family members were satisfied with the interventions. In some studies, the effects on or experiences of spouses and children of people with dementia differed.

### DISCUSSION AND IMPLICATIONS

From the broad palette of interventions (n=24) to foster the inclusion of family members of people with dementia within the nursing home setting identified in this literature study, most were aimed at fostering family inclusion in family–staff interactions (n=21), while little attention was paid to family–resident or family–family engagement within the nursing home community (n=6). Only two of the 21 interventions (FIC, PIC-SCU)<sup>35-38</sup> were targeted at creating partnerships between family and staff members. The other 19 family–staff interaction interventions focused on including family members in formal decisions (n=9), enabling them to make better informed decisions and/or participate more actively in future interactions with staff (n=7), or providing psychoeducation for family members to, i.a., improve future interactions with staff (n=3). Nevertheless, based on the number of studies included in this review (n=29), it can be concluded that the number of studies of interventions to foster family involvement in nursing homes for people with dementia is increasing. At the same time, the interventions often seem to focus predominantly on staff members. In general, it is difficult to conclude whether or not the included interventions led to an actual increase in family inclusion within the nursing home.

With the aim to contribute to the development of future interventions to involve family members of people with dementia within the nursing home setting, we had a closer look at the content of included interventions. The citizen participation ladder of Edelenbos & Klijn<sup>23</sup> enables us to broadly map the degree and type of family inclusion within the included interventions. In most included interventions, family members' role can be classified as 'informing' or 'consulting.' Interventions in which family members received an information booklet only,<sup>33, 34, 49, 53</sup> are examples of 'informing' family members. The PIC-SCU<sup>38</sup> program is the only intervention aimed at 'co-deciding' between family and staff members. The FIC-program<sup>35-37</sup> does not convincingly draw towards building a partnership between family and staff

members, as it focuses more on family members and how to maximize their contribution within the nursing home. Within the family–staff interaction interventions, family and staff members are often not treated equally, hampering mutual exchange and reciprocity between staff and family members. Especially with regard to education, educational sessions are often solely organized for staff members,<sup>35-37, 42, 47, 49, 50, 53</sup> while family members receive an information booklet only. In the three psychoeducational interventions for family members, a role for staff members is lacking completely.<sup>31, 54, 55</sup> Although an educational component is part of many of the included interventions, the content of education differs across interventions. While a number of interventions pay attention to education regarding family–staff interactions (e.g., how to shape the relationship), other interventions focus more on education about dementia or care-related aspects (e.g., medical decisions at the end of life).

#### *Implications for practice and future interventions*

As equal involvement of family members in nursing homes seems complex, nursing home organizations might benefit from investing more time and money to foster family inclusion within the nursing home. Based on the findings of this literature study, the following recommendations can be made:

#### *Pay more attention to mutual exchange and reciprocity between family and staff members*

The PIC-SCU program was the only program aimed at ‘co-deciding’ between family and staff members.<sup>38</sup> In this program, family and staff members were treated as equal, while in other studies, often more attention was paid to staff members. To foster mutual exchange and reciprocity, for example, more attention could be paid to two-way communication between family and staff members. In addition, if educational sessions for staff are organized, the participation of family members should be considered as well. When considering the citizen participation ladder of Edelenbos & Klijn,<sup>23</sup> current interventions focus too much on one-way ‘informing’ or ‘consulting.’

#### *Consider a broader role for family members of people with dementia in nursing homes*

The included interventions aimed at fostering the inclusion of family members in formal decisions focus nearly solely on decisions about the residents’ end-of-life care in the nursing home, with only two interventions involving family members and people with dementia in the broader care planning and development of personalized care plans or the development of a resident biography.<sup>32,47</sup> Family inclusion refers to creating democratic engagement of families by providing them with opportunities and resources that empower them to actively participate in their relatives’ life as well as in the nursing home as a community.<sup>6</sup> Therefore, focusing on family members’ decision-making on residents’ end-of-life care is too limited. In addition, more attention should be paid to interventions that contribute to family–resident or family–family engagement, as prior research has indicated that family members find it difficult to interact with their relative with dementia.<sup>60</sup> Moreover, to our knowledge, stimulating collaboration between family members from different relatives receives little attention.

#### *Provide more (formal) opportunities for family–staff discussions*

In only seven of the 21 family–staff interaction interventions do actual discussions between family and staff members take place (see Table 3). Prior research indicated that a lack of formalized opportunities

for families to talk to staff members and participate in decision-making can ultimately result in miscommunication between both parties.<sup>6, 9, 61</sup> Also, in times of high workloads, communicating with family members, especially those perceived as 'difficult' or 'demanding,' might not be a priority of staff members.<sup>27, 62</sup> In addition, prior research indicated that family members often find it difficult to talk to staff members too.<sup>63</sup> Without formal opportunities to talk to staff members, it might be the case that only the more dominant family members take their opportunity to talk to staff.

*Consider the role of an independent discussion leader/facilitator*

In four of the included interventions, an independent facilitator led the discussions with family members, so that family members did not talk directly with direct care staff members.<sup>40, 42, 43, 45</sup> Installing a third party to collaborate with family members might be a good starting point to gain family members' trust and to make it more easy for them to raise their voices, as family members may experience fear of speaking up for their relatives.<sup>6</sup> An independent discussion leader or facilitator might be installed to make sure that an actual dialogue between family and staff members takes place and could translate and explain the medical jargon often used by staff members. This could be a staff member who is not involved in the care of the residents, or a person who is not involved in the care organization (such as a counselor).

*Provide more education opportunities for family and staff members*

As equal involvement of family members in nursing homes is complex and seems to be absent in most nursing homes, it might be wise to educate family and staff members more about the possible roles of the other and on how to shape equal relationships with each other. Qualitative studies on building relationships between family members of people with dementia and staff in nursing homes<sup>31, 64-66</sup> may give an indication of what might be important elements of future educational interventions in family-staff relationships. For example, it seems that good communication about differences in family and nurse expectations of 'good care' can be considered a necessity to prevent conflicts [66], highlighting the need for communication skills training. Other staff behaviors and characteristics that were associated with smoother family-staff relationships were: providing family with information by initiating a dialogue; answering families' questions or sharing private information (e.g., staff sharing information about their family);<sup>64, 65</sup> having strong interpersonal skills (e.g., being emphatic, communicating in a non-offending way, showing interest toward the resident);<sup>65, 67</sup> valuing family perceptions and expertise;<sup>66</sup> being responsive to family concerns;<sup>67</sup> allowing family to be involved in care and to collaborate with staff;<sup>65, 67</sup> being transparent in the event of incidents or accidents;<sup>67</sup> and being in the same age range as the family members.<sup>66</sup> Identified strategies that family members might use to improve family-staff relationships were being open to staff (e.g., sharing demographic or care-related information),<sup>64</sup> offering help to or showing willingness to collaborate with staff members,<sup>64, 67</sup> making emotional adjustments (e.g., looking at the situation from each other's perspectives),<sup>64</sup> and using a 'diplomatic' communication style.<sup>67</sup>

At the same time, in the case of people with dementia, the dementia disease has an influence on the type of relationship that is developed between family and staff members. First, because the role of family members of people with dementia in nursing homes differs from the role of family members of people without dementia.<sup>11</sup> Second, because family members of people with dementia often struggle with understanding dementia and its consequences for their relative, which might lead to misunderstandings



with staff.<sup>66</sup> Therefore, family members might benefit from receiving education about the dementia disease and its consequences for their relative.<sup>68</sup> Prior research has indicated that staff members might also benefit from gaining more knowledge about dementia, how to care for people with dementia,<sup>69</sup> and how to involve their family members.

*Pay ongoing attention to the specific characteristics, abilities, wishes and needs of family members of people with dementia*

As in some of the included studies the effects on or experiences of spouses and children of people with dementia differed, it might be wise to target the interventions more specifically to the needs and different characteristics of family members. Contextual factors like geographic proximity, the employment status or family members' own health status may have an impact on the role family members want to or can play in nursing homes.<sup>6</sup> As it is known that family members' roles continue once a person with dementia enters a nursing home,<sup>4-6</sup> it is notable that only one of the included interventions<sup>54</sup> is targeted at family members whose relative recently entered the nursing home, delivering emotional support for family members, directing them towards appropriate resources in the facility, and teaching them to cope with ongoing problems related to the nursing home placement. Investing in the wellbeing of family members whose relatives have recently entered the nursing home might contribute to a smoother development of family-staff relationships from the beginning, as family members might feel more understood instead of left alone with complex emotions.<sup>6,19</sup> In addition, as nursing home settings are characterized by dying and the death of residents, it is important to continue paying attention to the emotions of family members the whole time their relative with dementia is living in the nursing home, as these emotions can shape the role a family wants to play within the nursing home.<sup>6, 70, 71</sup>

*Implications for future research on the effectiveness of and experiences with interventions*

Future studies in which interventions are tested should pay more attention to the assessment of whether or not the intervention led to an actual increase in family inclusion within the nursing home. In addition, they should carefully think about whether the components of the intervention are targeted at reaching the aim of the intervention. For example, if the intervention is aimed at reaching an equal partnership between family and staff members, it should consist of components that foster mutual exchange and reciprocity among both groups. Prior intervention research conducted in the nursing home setting (e.g. interventions to reduce the use of physical restraints), indicates that multicomponent interventions consisting of education, coaching and policy components might be more effective than single-component interventions that solely focus on education.<sup>72-74</sup> The fact that, based on the included studies, no firm conclusions can be drawn on the interventions' effectiveness, may be an indication of how difficult the evaluation is. Before implementing a new intervention, researchers should define adequate sample sizes and carefully select research designs and outcome measures.

Ideally, not only family members but also the people with dementia themselves and staff members should benefit from the intervention.<sup>1</sup> Therefore, resident and staff outcome measures should be considered as well. While it is difficult to include the voice of people with dementia, a better evaluation of care from their perspective is necessary to deliver care that meets their needs more effectively.<sup>75</sup> Besides assessing the effectiveness of interventions, the experiences of participating family, staff members, and, if possible,

people with dementia should also be considered. The recently developed INDividually Experienced QUALity of Long-term care (INDEXQUAL) framework<sup>76</sup> could serve as a framework for developing new methods to assess experienced quality of care within the relationships of care recipient (person with dementia), professional caregiver (staff member) and informal caregiver (family member). The INDEXQUAL could also be used to assess whether or not and how the recipient, professional caregivers and informal caregivers have the feeling that family inclusion has been improved. As in some of the included studies the experiences of spouses and children of people with dementia differed, it might be wise to distinguish between different subgroups when analyzing the effectiveness or interpreting the experiences for family members.

As the involvement of family members of people with dementia in nursing homes is shaped by changes in their relationships (e.g., with the person with dementia or staff members) and roles over time, a participatory action research design with a continuing cyclical process of phases of ‘observing,’ ‘reflecting,’ ‘planning,’ and ‘acting’ might be applied for the evaluation of interventions.<sup>77</sup> Since, up until now, little is known on promising components of interventions to foster family inclusion in nursing homes for people with dementia, applying a participatory action research design can enable researchers to first test the effects of or experiences with individual components (e.g., ‘educational sessions,’ ‘formal family–staff discussion’) of interventions separately. Promising individual components might later be combined in a multicomponent intervention.

### *Strengths and limitations of the review*

This review is the first to provide an extensive overview of interventions to foster the inclusion of family members of people with dementia living in nursing homes. Two members of the research team carefully screened all potential relevant publications based on prior defined inclusion criteria. As we considered only articles that were written in English, Dutch or German, potentially relevant articles written in another language may have been missed. Furthermore, studies might have been missed that used other terms to express family inclusion in nursing homes, as a large variety of terminology exists. In addition, our search was limited to interventions reported in scientific articles. Potential interventions published in grey literature only might have been missed. Due to the heterogeneity in study designs, it was not feasible to conduct a meta-analysis. As we were predominantly interested in the components of interventions, no quality assessments of included studies were conducted. This is especially relevant for the interpretation of results. Nevertheless, the findings of included studies were summarized systematically. This was done independently by two members of the research team and discussed within the whole research team. At the same time, a general weakness of literature reviews on existing interventions is that, often, the interventions are not described in detail. A consultation of the first authors of included studies may have enabled us to describe the components of interventions in more detail. While, in this review, we focus on formal interventions, there are many informal ways in which family members can be involved in the nursing nursing home, e.g., in informal conversations with staff. Ideally, staff members should be ‘open’ for these informal quotes and expressions.

## **CONCLUSIONS**

Very few interventions exist that try to enhance an equal partnership between family and staff in nursing homes. Future interventions should pay specific attention to mutual exchange and reciprocity between family and staff members, to enable individual and tailored support for residents that are highly dependent on their social network. As little is known about promising (components of) interventions to foster family inclusion in nursing homes for people with dementia, more effectiveness research is needed.

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# CHAPTER 5

## **Partnerships in Nursing Homes: How Do Family Caregivers of Residents with Dementia Perceive Collaboration with Staff?**

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## ABSTRACT

**Background:** Partnerships between family and nursing staff in nursing homes are essential to address residents' needs and wishes. Collaboration is needed to create partnerships; nonetheless, challenges exist.

**Aim:** This study aims to gain insights into the experiences of families collaborating with staff. Method: Semi-structured interviews were held with 30 family caregivers of nursing home residents with dementia.

**Findings:** Data reflected three themes, which shaped collaboration with staff from families' perspective: "communication", "trust and dependency", and "involvement".

**Discussion:** Good communication appeared to be a requisite condition for having trust in staff and quality of involvement in residents' life. Good communication was described as having informal contact with staff, which enabled family and staff to build a personal connection. Consequently, this seemed to increase trust and satisfaction regarding involvement.

**Conclusion:** Findings suggest that increasing informal contact and building a personal connection should be a priority for staff in order to improve collaboration and to create partnerships with families.

## INTRODUCTION

When dementia progresses, people become increasingly reliant on their social environment to meet their needs and wishes.<sup>1</sup> When care at home becomes too complex, people with dementia may move to a nursing home, where they receive more intensive, specialized care among other residents with dementia.<sup>2</sup> Nonetheless, family involvement and continuation of family roles remains essential for residents to be able to live the life they want, as families and their relatives have developed a relationship over time.<sup>3,4</sup> However, families often experience uncertainties regarding their role after the person with dementia moved in to a nursing home, as it often contains more than solely visiting.<sup>5</sup> After moving into a nursing home, families take on other roles and are less involved in physical care and decision-making.<sup>5</sup> As advocates, family caregivers can work together with nursing home staff by sharing information on the resident's biography, meaningful activities, and preferences in care and daily life.<sup>6</sup> In addition, they can also be involved in making decisions regarding care plans, and provide emotional and instrumental support.<sup>7</sup>

It is challenging in nursing homes to build a partnership between family and nursing staff, in which both collaborate as partners in care.<sup>7-9</sup> Nursing home staff often find it difficult to collaborate with family caregivers and have been known to consider the family to be "difficult" and demanding.<sup>10,11</sup> In addition, nursing staff often perceive the nursing home as their working arena.<sup>8</sup> Therefore, collaboration and communication with family caregivers might be perceived by nursing home staff as having to justify work tasks. Another aspect that interferes with collaboration is that, in general, nursing home staff feel that family caregivers may not take into account that they provide care to a group of residents living together, instead of solely caring for individuals.<sup>12</sup> On the other hand, challenges exist from the perspective of family caregivers, because it might be difficult to collaborate with staff as equal partners. For example, family caregivers are commonly seen only as visitors by the nursing home staff and are not always involved in resident care plan changes.<sup>8,13</sup> In addition, because nursing staff regularly work according to care and administrative tasks and routines, it might be difficult for family caregivers to initiate contact with nursing home staff because this may require interrupting staff routines.<sup>14,15</sup> Furthermore, nursing staff usually take over physical care tasks after residents' admission to a nursing home.<sup>1,16</sup> Hence, family caregivers might expect that staff will provide all the care, and that this care is of high quality.<sup>17</sup> Nonetheless, to be able to address residents' needs and wishes, and for residents to maintain and engage in social relationships, it is important to provide care from a relationship centered perspective with positive relationships between residents, family caregivers and staff.<sup>18</sup>

There is a need to facilitate a partnership between family and staff to fulfill residents' needs and wishes within current practice. These partnerships need to underline the importance of reciprocity between family and staff, by creating mutual respect and acknowledging each other's important contribution, as equals in care. Nonetheless, challenges exist and evidence on intervention programs that encourage or create partnership between family caregivers and nursing home staff is scarce. Recent studies on improving family involvement within nursing home care mainly target interventions that address specific goals, such as decision-making at the end of life stage and advanced care planning.<sup>1,19</sup> Only three broader intervention programs aimed to improve collaboration and partnership between family members and nursing staff in nursing homes.<sup>20-22</sup> Two intervention programs targeted family involvement within dementia specific facilities. These were designed to involve families within nursing

home care by aiming at negotiating partnership,<sup>20</sup> and to improve collaboration and communication between family and staff.<sup>21</sup> One intervention aimed at helping family caregivers to identify activities in which they could participate, and to help them to create a role for themselves.<sup>22</sup> These three intervention programs addressed the importance of finding ways to involve family within nursing homes. Nonetheless, these did not emphasize creating partnerships between family and staff to jointly support residents in living the life they want, which needs to be a central starting point within providing relationship-centered nursing home care. As nursing staff members frequently report difficulties in collaborating with family caregivers,<sup>10</sup> more knowledge is needed on how family experiences partnerships in order to improve interventions that aim at building a partnership between family and staff that recognizes both equal important contributions to resident's life. Up to now, far too little attention has been paid to family caregiver's perspective. Exploring their perspective on current partnership needs to be established before interventions that aim to build a partnership between family and staff can be improved.

In recent years, radical alterations have been made to create a homelike environment, including family members within the part of the caregiving process, in order to better address residents' needs and wishes,<sup>23-25</sup> These initiatives have characteristics that may improve family members' involvement with nursing staff, such as a small-scale homelike environment, more opportunities to interact with staff because of smaller caseload levels, and more resident autonomy. For example, previous research showed that family members had more personal contact with staff and were more intensively involved in everyday household activities in small-scale nursing homes,<sup>26</sup> Furthermore, nursing staff working in small-scale, homelike care environments showed better listening skills toward residents compared with those in more institutional, large-scale nursing home wards.<sup>27</sup>

Since alterations have been made within nursing home care, as part of the culture change movement, more knowledge on how family caregivers currently experience collaboration and partnership within the care for their relative with staff is needed. This study aims to provide new insights into experiences of family caregivers of nursing home residents with dementia with collaboration between them and the nursing staff, and how their experiences and preferred roles are being involved. This knowledge could support care organizations worldwide with improving collaboration, and with developing solid partnerships between family caregivers and nursing staff in the nursing home. This study will contribute to a deeper understanding of factors that are important when developing new interventions aimed at involving family caregivers of nursing home residents with dementia and developing partnerships between family and staff.

## **METHOD**

### *Design*

For the purpose of this study, a qualitative descriptive research design was chosen. Data were collected through semi-structured interviews with family caregivers of nursing home residents with dementia. The COREQ guideline was used in reporting information on this study.<sup>28</sup>

*Participants*

Family caregivers of nursing home residents were recruited to participate in the study. Eligibility criteria for family caregivers were: providing care for their relative with dementia who lived in a nursing home. In the Netherlands, a standardized assessment procedure is carried out by a governmental agency, and in accordance with the residents' family or legal guardian, before a person is admitted to a nursing home. . The sampling procedure focused on including a variety of perspectives from different nursing home environments. Therefore, family caregivers were recruited from five different nursing home wards, within three different psychogeriatric care organizations, in the south of the Netherlands, based on convenience sampling. We aimed a sample of about five family caregivers per ward, i.e. 25 interviews in total. Two large-scale wards and three small-scale wards were included in this study. Within these large-scale wards, care was provided for 18 to 21 residents, and daily life was mostly determined by routines in reference to the institution and what fit the group of residents and/or staff; small-scale wards aimed to provide care within a homelike, personal environment for six residents, where activities were integrated into daily life. In four study sites, regular changes in staff members were existent. All 58 main contact persons, e.g. family caregivers that function as contact between resident's family and the ward, for residents with dementia within the chosen wards were invited to participate in the study. These main contact persons were chosen, as of all family caregivers, they are often the most present at the ward and have the first, and most contact with staff. They were given the opportunity to either participate themselves or to invite another family caregiver (along) to participate.

Of the 58 family caregivers invited to participate in the study, 30 agreed to be interviewed, 11 refused to participate, and 17 family caregivers did not return the consent form. Table 1 provides an overview of family caregiver characteristics. Nineteen family caregivers from two large-scale wards participated in the study and 11 family caregivers from three small-scale wards participated. Although data saturation was not the guiding principle in the sampling process, after about 20 interviews, redundancy in the data was identified.

**Table 1.** Family caregiver (N=30) characteristics

Characteristics	Family caregivers <i>M (SD)</i>
Age	57.12 (5.41)
	n (%)
Gender	
Female	27 (90)
Male	3 (10)
Relationship with relative	
Daughter	24 (80)
Son	3 (10)
Spouse	1 (0.03)
Niece	1 (0.03)
Legal representative	1 (0.03)
Visits relative more than once a week	27 (90)
Nursing home facility	
Large-scale ward	19 (63)
Small-scale ward	11 (37)

### *Procedure*

Prior to data collection, the researcher informed family caregivers about the goal and content of the study during an information meeting which was facilitated by the ward manager. Written information on the study and an informed consent form was handed out subsequently. Family caregivers who were not able to attend the information meeting received written information on the study and an informed consent form by mail, which was sent by the ward manager. On obtaining written informed consent from the family caregivers, the researchers called them to plan an interview. Interviews were held between February and October 2017. The interviews lasted 20 to 50 minutes, with one exception of an interview that lasted about 120 minutes. In an attempt to make each interviewee feel as comfortable as possible, a second relative of the resident was allowed to participate in the interview, as three interviewees preferred this. Also, the interview took place at a location that was convenient for the family caregiver: for example, at their home, the nursing home, or at Maastricht University. Before interviewing the family caregivers, the purpose of the research was clearly explained and family caregivers were assured that the data would be treated confidentially.

### *Data Collection*

Semi-structured interviews were conducted to collect data on the experiences of family caregivers of nursing home residents with dementia with regard to their collaboration with nursing home staff. Background information of the family caregivers was collected—specifically, gender, age, relationship to the resident (spouse, child, other), frequency of visitations, and the amount of months the resident had been at the nursing home. Three researchers performed the interviews (LH, EdV, & RB) using a standardized interview guide. The interview started with a comprehensive question with regard to feeling



at home, to gather a first sense of the family caregiver’s opinions about the ward in general. Consequently, more specific questions on their experiences with collaboration—including the things that hinder or facilitate it—were asked. Interview questions are presented in Table 1. Probing questions, such as “Can you elaborate more on (...)?” or “Why do think so?” were asked to obtain more in-depth information. The interview data were recorded on a digital audio recorder and transcribed verbatim.

**Table 2.** Interview questions

Topic (themes)	Question (example)
Comprehensive/introductory questions	Would you say you feel at home or welcome at the ward? (Do you feel at ease?)
	What makes you feel at home or welcome? What contributes to or hinders this?
Specific questions regarding collaboration with nursing home staff	How would you describe the collaboration between you and nursing home staff at the facility where your loved one lives?
	Which things do you work together on?
	Are you able to do everything you would like to do for your relative?
	Are you being invited by the nursing home staff to participate in care or other activities?
	What aspects regarding collaboration with nursing home staff are going well?
	What aspects regarding collaboration with nursing home staff could be improved upon, according to you?

### *Data Analysis*

The analysis contained a qualitative thematic approach.<sup>29</sup> Two researchers (LH & EdV) and two research assistants compiled the audio data by transcribing the interviews; this process achieved closeness and familiarity with the data. Subsequently, transcripts were coded so as to convert raw data into meaningful groups of text. This included identifying ideas, concepts, and themes that were connected to one another and giving them a definition or code. A codebook was developed, containing all codes that related to the purpose of the study. The qualitative data analysis software MAXQDA was used in assisting the researchers to structure the process and to visually organize the coding process. After all information from the transcripts was broken down into codes, the researchers sought to find (sub)themes across all codes. All themes were then critically checked for content and quality in order to ensure consistent relationships. Thereafter, interpretations were made across themes, and patterns within the data were identified. Finally, conclusions were drawn with regard to answering the research question.

*Rigor*

This study established rigor by including a variety of nursing home wards in order to obtain different views on the topic. To increase the reliability of the analysis, the whole team was involved during the data analysis process as a form of analyst triangulation,<sup>30</sup> meaning that perspectives from the six different researchers were compared. For example, interviews were conducted by three researchers (LH, EdV & RB). Next, audiotaped data were transcribed verbatim by two researchers (LH & EdV) and two research assistants. Four transcripts were read and coded by LH and discussed in detail with HV. Subsequently, all transcripts were coded according to an initial codebook by either LH or EdV, and checked by the other in order to find (dis)agreements on interpretations in text fragments. Disagreements were discussed and an interpretation that best matched the meaning of what was expressed was agreed upon. Moreover, researchers LH, EdV and HV discussed all interpretations on a weekly basis. General interpretations of the data were discussed within the whole team. The research team consisted of six researchers who all had experience in research in the field of dementia and long-term care. However, they had different fields of expertise; three in (clinical) psychology, one in nursing, one in health policy, and one in quality improvement. This promoted a deep understanding of the context and interpretation of the phenomenon in current nursing home practice.

*Ethical Considerations*

Ethical approval for this study was obtained from the Ethics Committee of Zuyderland-Zuyd (No. 16-N-233). Family caregivers voluntarily signed informed consent after they were fully informed about the purpose and procedures of the study. They were reassured that data would be kept confidential and that they could discontinue their participation at any time during the study.

**FINDINGS**

The data reflects three themes that shaped collaboration with nursing home staff from the perspective of family caregivers (Table 3). The theme, “communication”, appeared to be a requisite condition for creating trust and quality of involvement, which were part of the themes “trust and dependency” and “involvement”.

**Table 3.** Collaboration: themes, content, and description

Theme	Content	Description
Communication	Informal contact; need for contact; informing & inviting	A way of having contact or interaction with staff, either formal or informal.
Trust & Dependency	Monitoring; personal connection	Feeling highly responsible for a relative while being dependent on staff care provision, and deciding whether to trust staff by monitoring and creating a personal connection.
Involvement	Advocacy; visiting; caring activities	Being involved in relative’s daily life by means of looking after the relative and keeping control over relative’s daily life by visiting and caring for the relative.

Most family caregivers expressed that they did not identify themselves as being part of a collaboration with nursing home staff. They described that they themselves performed individual tasks regarding care, which were separate from those performed by the nursing home staff. Almost all family caregivers assigned physical care tasks to nursing home staff, whereas social tasks, such as visiting and undertaking individual activities, they assigned to themselves. The themes are described in more detail below.

### *Communication*

Communication was of major importance for family caregivers when describing how they experienced collaboration. Communication was seen as a way of having contact or interaction with staff, which was considered a requisite condition for collaboration. Family caregivers described contact as being both formal and informal. Formal contact consisted of types of information and invitations, whereas informal contact was expressed in terms of having personal conversations.

*Informal contact.* A factor that the family caregivers considered as facilitating communication was having informal and personal dialog with staff—for example, being greeted when entering the room or staff asking, “How are you?” These conversations, although small, were important to family caregivers. It made them feel welcome when visiting and made it easier for them to talk to staff. Family caregivers who felt welcome and at home described more positive experiences regarding communication with staff.

*Because I know the staff and they know me. They also immediately see when something is wrong, because I might look different. They ask ‘Is something wrong?’ It’s becoming a little family, you know. (Daughter (1), large-scale facility 1)*

*Need for contact.* More than half of the family caregivers expressed a need for having more contact with nursing home staff than they currently had. However, some experienced barriers to communication with staff that prevented them from having the desired contact. Reasons for this varied. Some were afraid of being seen as “moaners” and, therefore, kept their concerns to themselves because they said that they would not like to negatively comment on the care provided. In addition, some felt afraid of the consequences for their relative if they expressed criticism.

*These are organization guidelines. It’s not up to me to interfere with them. I would not do that. It is in the best interest of my mother, so I have to watch what I’m saying and how I express things. I would not want them to think “Oh, it’s her again.” That could be at the expense of their approach toward my Mom. I have to protect her a little. (Daughter (1), large-scale facility 2)*

Moreover, some argued that they would not seek interaction with staff because they would not want to be a burden on staff by interrupting their routines. In addition to these barriers regarding beliefs, low visible staff presence and having unfamiliar staff taking care of their relatives hindered communication, according to family caregivers. At some wards, family caregivers mentioned a high staff turnover, which made it difficult for family to find ways to engage in communication with new staff. This was mostly evident in one ward where staff would retreat into a private office with a closed door.

*The staff are busy doing their own things and they have loads of work to do. They don't have time to talk with people who enter the ward. The reception is completely deserted; only occasionally does someone sit there. There is no sense of making contact with people who come in. (Daughter (2), large-scale facility 2)*

In addition, some family caregivers described that it was not always possible to contact staff, because they faced difficulties contacting staff outside of secretary office hours.

*Informing and inviting.* Family caregivers mentioned two forms of communication between family caregivers and nursing home staff: i.e., informing and inviting. Most family caregivers described examples of how they informed nursing home staff and vice versa, either at the staff's request or spontaneously. For example, family caregivers informed nursing home staff about how their relatives like to be cared for, their relatives' health concerns, having clothing items in need of laundering, or when they wanted to show appreciation toward staff.

*I complimented it. I came over last week and said "May I ask who provided care for her this morning?" I said, "Look how nice Mom looks right now. It's so nice to see her looking so well." (Daughter (2), large-scale facility 1)*

Correspondingly, all family caregivers described that staff often informed them either about medical issues, such as treatment updates, visitations from the elderly care physician, and falls, or about practical issues, such as running out of soap or torn leggings. Family caregivers mentioned that staff provided this information often via telephone or e-mail, depending on the seriousness. A few family caregivers expressed that staff would occasionally inform them about how their relative spent his or her day, or whether or not their relative enjoyed the day or showed signs of agitation.

In addition to communicating through information, most family caregivers also described communication through invitation. They expressed how staff invited them to participate in organized communal activities, such as going to the zoo, musical evenings, or Christmas dinner. Family caregivers expressed that staff mostly displayed invitations on the ward's noticeboard, through a public letter, or generic e-mail. Family caregivers from one ward said that the manager would also personally invite family caregivers, which they appreciated. By contrast, family caregivers from another ward mentioned that they were not invited to participate in any activities.

*They were interns, I guess, who I didn't know. If they had asked family caregivers, someone would have signed up to participate. If they had asked me, I would have joined and I think others would have too. (Daughter (3), large-scale facility 1)*

A few family caregivers expressed that they recalled being invited to talk about their relative's wishes and needs during the intake at admission, but rarely afterwards. Few family caregivers mentioned having occasional informal contact, such as personal contact that does not regard care and entails contact at a personal level. These few family caregivers and others who often communicated with staff expressed positive beliefs regarding care, and were more satisfied with the ward in general, as opposed to other family caregivers.

### *Trust and Dependency*

Having trust was one of the important aspects to good collaboration. Family caregivers reflected on issues that were related to having trust in nursing home staff and how this was experienced while being dependent on staff with regard to care provision for their relative. Family caregivers perceived that they were dependent on staff, as staff mostly determined the resident's daily life. Family caregivers felt highly responsible for their relative and, therefore, having trust in staff and how they take care of their relative was essential for them to establish a partnership.

*Monitoring.* A recurrent theme in the interviews was a sense amongst family caregivers that they had to monitor the resident care provided by staff. Family caregivers expressed a lack of trust regarding how care was provided, staff's failure to honor agreements, and staff's lack of communication with family regarding agreements and the status of these agreements.

*For example, she went to the dentist today to have her teeth cleaned. They (the staff) have to make efforts to clean them better, which we talked about earlier, after the last time she went to the dentist. You have to keep an eye on those things. (Daughter (1), small-scale facility 2)*

Family caregivers who expressed that staff honored commitments had more trust in staff. Subsequently, they were more satisfied with collaboration and had less concerns when thinking about their relative living in a nursing home.

*Personal connection.* Moreover, the majority of the family caregivers stated that it was important to them to have a personal connection with nursing home staff members. For example, most family caregivers explained situations in which they would wait to ask certain things because the principal staff contact person was not present at the ward during their visit. Family caregivers reported that they would not ask other staff because they either did not know them, they knew other staff did not have the personal information, or they did not establish a relationship of trust with other staff and were not sure whether or not they could make agreements with them.

*I notice that when I pass something on, it isn't written down or it will be forgotten. Then, I'd prefer to go straight to our principal contact person, because she writes it down and then everybody can read it. (Daughter (1), small-scale facility 1)*

In addition, some family caregivers described feeling surprised when staff were receptive to receiving feedback because they did not expect this. Family caregivers described that when staff were open to receiving feedback, this was helpful for them to address issues and have small conversations in the future. This would make communicating easier because they experienced fewer barriers to addressing issues.

Furthermore, most family caregivers elaborated on how they passed on information to other family caregivers of their relative. Some also pre-discussed strategies with other family caregivers on how to negotiate issues with staff.

### *Involvement*

In describing collaboration with nursing home staff, family reflected upon own involvement in resident's daily life by means of advocacy, visiting their relative, and caring for their relative. Overall, the family caregivers demonstrated that, in general, they were satisfied with the quantity of their current involvement (e.g., frequency of visits and participation in resident's daily life). However, the quality of their involvement (e.g., satisfaction with how they were involved by staff in resident's daily life) could be improved upon.

*Advocacy.* Family caregivers described various ways in which they looked after residents' interests as advocates. All family caregivers stated that everything they did was in the best interests of their relatives, and expressed this, for example, by saying, "My mother would have loved this or my mother would not have wanted this." Family caregivers did not literally mention that they would like to manage the resident's life; however, they described their experiences with monitoring the resident's life within the nursing home. For example, they explained how they felt about certain situations and how they intervened, often out of dissatisfaction, or contributed when needed.

*For example, at a certain point, she broke her leg and took painkillers four times a day. At some point, I said, "Wouldn't you decrease the amount of painkillers?" They took my advice and discussed it with the doctor. It slowly decreased. I don't know everything, but I thought, "Do you guys think about that?" (Daughter (2), small-scale facility 1)*

Most family caregivers mentioned how they contributed to residents' life by performing practical tasks, such as buying clothes, washing clothes, and decorating the resident's room. Moreover, most family caregivers expressed the need to have more knowledge about the resident's daily life. Nonetheless, they experienced little involvement with staff regarding care planning or discussing care plans, and were not fully able to carry out their role as advocates in the care of their relative.

*If we had a shared folder, we could leave comments on it and the communication could be shaped in that way, even if the principal contact person is around. I don't care who I talk to; I just want to know that things are being done and that I can follow the decision process and what will be happening. (Daughter (4), large-scale facility 1)*

*Visiting.* Almost all family caregivers perceived no restrictions about visiting. For example, they could visit when wanted, they could walk or undertake trips outside of the ward with their relative when they wished, and grandchildren were welcome anytime. A small number of those interviewed suggested that they were not able to do whatever they wanted because of unfamiliarity with some staff members, due to staff changes. This made it difficult to know what they were allowed to do during visitation—for example, did they have a right to spontaneously get coffee or fruit at the ward. In addition, a few interviewees, from both small-scale and large-scale wards, argued that they sometimes had the feeling that they were interfering with staff routines and ward rules when asking for something.

*Sometimes my sister will take a look. I won't call about difficult questions because there's little chance that the person who picks up the phone has any idea what I'm talking about and she could have used that time to brush someone's teeth or something. (Daughter (5), large-scale facility 1)*

*Caring activities.* Family caregivers revealed small examples of collaboration regarding resident care. Most family caregivers would argue that caring tasks are the staff's responsibility.

*Often, when I go to my Mom, she is still in bed and I help her get up. Then, a member of staff walks in and says "You're on a roll!" I respond, "You can take over now!" I will focus on other things but, to me, that is the staff's responsibility, but there you go. (Daughter (3), large-scale facility 2)*

In addition, they mentioned that tasks such as showering, helping residents to go to the bathroom, and cutting nails were staff tasks. Only a minority of family caregivers mentioned that they performed care tasks when visiting. For example, they described how they would help residents who were unable to eat independently with eating and drinking, help their relative to go to the bathroom, or escort them to the hairdresser. Additionally, there were some family caregivers involved in tasks such as cooking or playing the piano at the ward, and some described that they were able to have dinner together with their relative. Except for one family caregiver, none of the family caregivers mentioned that they would organize activities for residents on their own initiative. Furthermore, one family caregiver expressed that the manager introduced compulsory tasks for family caregivers, such as cooking or participating in activities. This, however, caused family caregivers to resist participation and become upset.

Even though family caregivers wanted to be involved in residents' lives, only a few family caregivers stated that they experienced shared decision-making regarding preferences in daily routines, meaningful activities, and medical decisions. Family caregivers who communicated often with staff were more satisfied about the decision-making process. They expressed that staff called them to inform them about medical or behavioral changes. In addition, some expressed that they were involved in care by being asked by staff to discuss how a certain situation regarding behavior or care could best be resolved.

*They called me and said, "We called the doctor. Can you come over? Maybe you can talk some sense into her because it's getting dangerous." So, I went and talked to my Mom, and participated in her delusion by justifying her thoughts and actions. Then, my Mom calmed down and went with me, and the staff member gave me a thumbs up and complimented me on how I handled the situation. (Daughter (2), small-scale facility 2)*

## DISCUSSION

This study has identified that family caregivers perceive collaboration by means of "communication", "trust and dependency" and "involvement". Data suggest that communication is a requisite condition for having trust and affects the perceived quality of family caregivers' involvement in the daily lives of their relatives. Family caregivers considered having informal contact with staff as good communication, which enabled family caregivers and nursing home staff to build a personal connection. Accordingly, this seemed to increase trust and satisfaction regarding quality of family caregivers' involvement in the daily life of the resident.

Within all aspects of communications, the present study especially highlights the importance of having informal communication and creating a personal connection, in order for family caregivers to feel

involved within the nursing home. Findings of our study indicate that these are requisite conditions for establishing trust and good quality of family caregivers' involvement. In addition, the findings provide a deeper understanding of building a positive collaboration in nursing homes, by enhancing good communication and increasing personal contact and trust between family and staff. Our findings are in line with a more general definition of collaboration, which can be defined as a dynamic, voluntary form of interaction or activity between two or more people.<sup>31</sup> It implies having interaction regarding goal setting and decision-making, within an environment of mutual trust, harmony, and respect.<sup>32</sup> Also, it was reported that sharing, partnership, interdependency, and power are related concepts for collaboration in general.<sup>31,32</sup> In addition, open and honest communication, being attentive to each other, and valuing each other's perspective and contributions appear to be important elements regarding developing partnerships between people.<sup>32,33</sup> Especially in nursing homes, collaboration and partnership between family and staff is needed in order to address residents' needs and wishes. Hence, because family caregivers within this study expressed a need for contact, there is a need to develop an intervention that is targeted at combining both family caregivers and nursing staff. In that way, family and staff can optimally share personal and professional knowledge to improve residents' daily lives.

Our study provides deeper insights into the importance of having a fixed nursing home staff team, e.g. having low staff turnover, which is essential for family caregivers to collaborate with staff and build a partnership. Family caregivers within the current study experienced difficulties building a collaborative environment with new staff members. As family caregivers felt responsible for their relative and were dependent on nursing staff regarding care for their relative, the sometimes complicated process of building trust restarted with the introduction of new staff. These findings add to previous research which underlines the complexity of having to trust others with care<sup>34</sup> and building a partnership, because it is suggested that staff might perceive family caregivers as difficult and describe interactions as complicated and time-consuming.<sup>8,10,35</sup> This might further complicate building partnerships. Subsequently, collaborating by means of "us" and "them" is problematic when developing partnerships,<sup>8</sup> and might result in low levels of communication, while family caregivers within this study expressed a need for having more contact. What is more, building a partnership is most likely a continuous, challenging and ongoing process, starting from the phase of the resident moving into the nursing home, to facing challenges in collaboration as dementia progresses. Especially then, good communication is imperative.

Furthermore, our study's findings show that family caregivers perceive their role within the nursing home as much more than being 'merely a visitor'. However, they do not regard themselves as true partners in care. This is in line with previous research from Baumbusch and Phinney,<sup>5</sup> who also found that family perceives that their role within the care for their loved one is much broader than only visiting. Moreover, the findings of this study have extended our knowledge of how family involvement is perceived, by exploring the perspectives of family caregivers. This was important because existing interventions regarding improving family involvement were mainly developed based on knowledge from staff' perspective. In order for family caregivers to be partners in care instead of visitors, findings from this study suggest that family caregivers need to be involved as equals in decision-making to establish a partnership. Within all aspects of resident's daily life, family's important role and involvement should be acknowledged as equally important as staff' role, as staff' role currently holds more power. Especially since earlier research on staff' perception of family involvement in nursing homes shows that, even though staff consider the importance of incorporating the role of family within daily care,<sup>36</sup> they often



perceive family caregivers as non-experts with regard to medical care and decision-making.<sup>8</sup> Besides, due to high staff workloads and time pressure,<sup>37,38</sup> communicating with family caregivers, and especially with those who are perceived as 'difficult' and 'demanding,' is most likely not regarded as a priority by nursing home staff. Additionally, family caregivers within our study expressed that they still perceive the nursing home as the staff's territory and described being dependent on staff in various ways with regard to care for their relative. However, family caregivers did not express that they were aware of staff's perspective on the importance of family involvement, while the staff is dependent on family in various ways in order to provide the best care.

#### *Limitations*

Some limitations regarding this study should be considered. While a variety of nursing home wards was included in the study in order to enhance result's contextuality and increase transferability, we included a considerable number of daughters. It is unfortunate that this study did not include more views of spouses of residents, who might collaborate with staff in different ways because they have a different relationship with the resident.<sup>39</sup> Notwithstanding the relatively limited number of included spouses or sons, this work offers valuable insights into current practice, because women are predominantly represented within care as family caregivers.<sup>8,9</sup> Furthermore, as including views from a variety of nursing home wards was aimed for, data saturation was not a guiding principle in the sampling process. For the purpose of this study, therefore, we might have interviewed less participants as data saturation was decided upon after about 20 interviews. Finally, this study did not incorporate the views of nursing staff; including the views of staff could have contributed to providing recommendations for collaboration in practice, based on the comparison of both views.

#### *Implications for further research*

The findings of this study have implications for further research. First, further research is needed to develop and evaluate intervention programs that create a partnership between family and staff, regarding the nursing home care for residents with dementia. It needs to be identified which staff competencies are needed and how nursing home staff can collaborate with people holding other interests, in order to establish communication, trust and both frequency and quality of family involvement. Interventions need to focus on building a partnership around residents' needs and wishes, by improving informal and formal communication and developing a personal connection between family caregivers and nursing staff. In addition, these need to emphasize reciprocity, by targeting both family caregivers and staff, and acknowledging each other's important contribution and being equal partners in care. Furthermore, as nursing staff' positive attitude towards developing partnerships is crucial, further research needs to focus on whether the nursing home environment is able to provide a trusting and collaborative atmosphere.

### *Implications for practice*

Our findings indicate that, in particular, having informal communication is important as this is a way to build a personal connection and trust between family caregivers and nursing home staff. Based on this study, it is suggested that nursing staff should be aware of the positive effects of welcoming family, approaching them personally, being friendly and look for ways to intensify the quantity and quality of informal contact, in order to build a personal connection. Additionally, good communication requires going beyond sharing information on medical status and daily care. Instead, combining improving formal and informal ways to communicate must be considered. Digital platforms such as social media might enhance contact and improve relationships between family and staff,<sup>40</sup> for example by sharing experiences with residents' daily life within the nursing home. Consequently, family caregivers need to be given the opportunity to be engaged within resident daily life by nursing home staff. In addition, they need to be supported within decision-making regarding medical decisions and discussions<sup>41</sup> to become a full and equal member of the team. Therefore, it is of major importance for staff and family caregivers to engage in dialogue and find new ways to communicate and collaborate to improve residents' daily lives.

### *Conclusion*

Findings of our study suggest that in the opinion of family caregivers, staff mostly determine residents' daily life. Staff might not always be aware of the importance of family involvement. Furthermore, family caregivers might not consider their role as equal partners in care. Therefore, increasing informal contact and building a personal connection should be a priority for staff in order to improve collaboration and to create partnerships with families.

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# CHAPTER 6

## **“Because we both care”: Process evaluation of a program to create family-staff partnership in the care for nursing home residents with dementia**

This chapter was submitted as: Hoek LJM, Van Haastregt JCM, Backhaus R, Hamers JPH, Verbeek H.  
“Because we both care”: Process evaluation of a program to create family-staff partnership in the care  
for nursing home residents with dementia.

**ABSTRACT**

**Background:** Staff-family partnerships are important for addressing the needs of nursing home residents with dementia. Nonetheless, challenges exist in developing these partnerships. This study aims to gain insight into the feasibility of a partnership program focusing on supporting equal family-staff partnerships within nursing homes.

**Methods:** A prospective multi-method study was used to assess the feasibility of the program in a nursing home ward for people with dementia. The program aimed to facilitate and support an equal family-staff partnership to increase residents' autonomy. During monthly 90-minute meetings, a joint group of 10 staff and family representatives focused on finding solutions for challenges in residents' daily lives.

**Results:** Evaluation after nine months revealed that both staff and family were satisfied with the program and experienced benefits. In addition, the program encouraged family and staff to propose actions to increase residents' well-being.

**Conclusion:** This program could support relationship-centered care based on addressing needs within dementia care triads.

## BACKGROUND

People with dementia need their social environment to address their needs and wishes.<sup>1,2</sup> Continuation of family relationships and social events, such as visits from family and friends, remains essential for the well-being of persons with dementia, after moving into a nursing home.<sup>3,4</sup> However, even though family caregivers remain involved in roles and tasks such as advocating, monitoring care, providing emotional and instrumental support,<sup>5,6</sup> the role of resident's family caregivers often changes. Family caregivers, for example, often become less involved in physical care and decision-making, and might face uncertainties regarding their role and the role of nursing home staff.<sup>7</sup> As family involvement is regarded an important aspect within the lives of nursing home residents<sup>8</sup>, creating family-staff partnerships based on shared responsibilities and equality needs to be aimed for to optimally support resident's autonomy, and to increase their well-being.

Realizing partnerships between family caregivers and nursing home staff remains a challenge within current nursing home practice.<sup>6,9,10</sup> Family involvement is often viewed by nursing home staff in terms of assisting with specific aspects of daily life within the nursing home, such as helping with activities. Nonetheless, staff hardly perceive partnership in all aspects of the care for the residents.<sup>9</sup> In addition, nursing staff members might regard family caregivers as demanding and difficult to work with.<sup>11,12</sup> Family caregivers, on the other hand, often feel like visitors and are frequently perceived as such by the nursing home staff.<sup>9</sup> Consequently, both staff and family caregivers are likely to have certain expectations and reservations regarding creating a partnership in the care for the residents with dementia.

New approaches to create partnerships between family caregivers and nursing home staff are needed to better address resident's needs and wishes. Several approaches over the past two decades showed positive short-term effects for outcome measures such as perception on collaboration and role satisfaction.<sup>13-15</sup> However, these approaches, did not primarily aim at creating partnerships that emphasize jointly addressing resident's needs and wishes, to increase autonomy and the well-being of residents. Especially in the care for people with dementia, the emphasis should be on relationship-centered nursing home care, i.e., care that focuses on creating an enriched social environment that supports relationships between residents, family and staff.<sup>16</sup> As family and staff currently have limited tools to establish good partnerships, we need to develop feasible and effective programs that aim to establish family-staff partnership and recognize the importance of the contribution of both family and staff to residents' life and well-being.

Programs aimed at facilitating and supporting family-staff partnerships need to emphasize the significance of reciprocity between staff and family. Equality, acknowledging each other's important contribution, sharing responsibility and mutual respect between family caregivers and staff is needed.<sup>17,18</sup> Additionally, it is important that staff and family caregivers develop a personal relationship. Therefore, they need to receive opportunities to improve communication that go beyond briefly sharing practicalities. Next, nursing home organizations need to structurally embed the voice of both family and staff in order to increase family involvement. Previous studies have shown how the reflective and cyclical process of "looking, thinking, and acting" can empower groups of people to jointly develop and share a vision.<sup>19-22</sup> It can stimulate identifying fields of importance, and develop ideas that can improve current nursing home situation.<sup>23,24</sup> A partnership emphasizing the common goal of jointly addressing residents' needs and wishes could be developed using these principles.

When developing a new program, the first step is to assess whether the program is feasible in current nursing home practice. Therefore, the aim of this study was to gain insight into the feasibility of a partnership program in daily nursing home practice. This process evaluation is structured according to the framework proposed by Saunders, Evans and Joshi,<sup>25</sup> addressing participants' attendance to the program (reach), performance of the program according to plan (fidelity and dose delivered), participation in the program (dose received exposure), and the opinion of the participants on the intervention (dose received satisfaction and context).

## RESEARCH DESIGN AND METHODS

A prospective multi-method study was carried out to evaluate the feasibility of the partnership program. The study was conducted between September 2017 and May 2018 in a psychogeriatric nursing home ward in the Netherlands.

### *Partnership program*

The aim of the Partnership program is to facilitate and support an equal family-staff partnership within nursing home wards in order to increase residents' autonomy, by addressing problems or challenges in current care and finding solutions supported by both family caregivers and nursing staff. The program consists of monthly 90-minute meetings with family and staff from a nursing home ward, moderated by two process facilitators. The program consists of three phases, which are represented in Figure 1 and described below. The program was developed in co-creation with resident councils, representatives of nursing homes and experts in the nursing home field, and was based on the current literature on family-staff partnerships. A draft version of the program was pilot tested within three psychogeriatric nursing home wards from two different nursing homes during a period of six and twelve months. This development process is described in Appendix A.

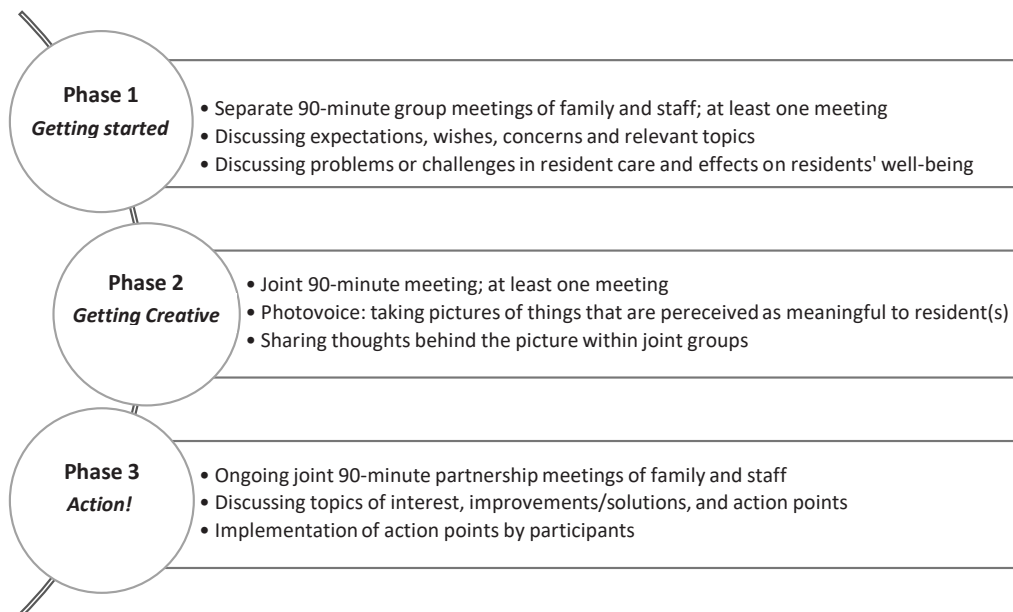
In the first phase, separate group meetings (at least one) of family and staff take place. The intended number of participants in each group is five to ten persons. This first phase aims to create a safe and open environment within the groups. The goal of the program is explained and expectations, wishes, and concerns are discussed. In addition, participants start by discussing problems or challenges in the care for the residents and how this might affect the well-being of the residents. These separate group meetings continue until all participants of both groups agree on moving on to the next phase in which the two groups are combined.

In the second phase, an equal staff-family ratio and an optimal group size of ten participants is aimed for.<sup>26</sup> This means that in case the separate groups are larger than five persons, the participants are advised to alternate (based on availability). The second phase consists of at least one joint meeting in which the photovoice method<sup>27</sup> is used to provide more insight into situations that are meaningful for the resident and that might contribute to their well-being. This photovoice method is introduced during the last separate meeting of Phase 1. Photovoice is a way of letting people take photographs that capture their experience regarding a certain subject.<sup>27-30</sup> People often regard photovoice as a creative and fun way to get into conversation and it allows a deeper understanding of how the photographer sees the world.<sup>28</sup> Additionally, participants may feel more recognized and appreciated in their expertise and experiences,

and it can assist in setting goals.<sup>28</sup> In preparation of the first joint meeting, family and staff take pictures of things that they perceive as meaningful to the resident(s). Next, during the joint meeting, all participants show the pictures and share their thoughts behind taking the picture with the whole group. Participants decide on if they want to continue discussing the photographs during the next meeting or if they want to go on to the third phase.

In the third phase, ongoing joint meetings with an equal staff-family ratio and a maximum of approximately ten people take place, where participants think of improvements they expect to contribute to the autonomy and well-being of the residents. These improvements can be inspired by the stories behind the pictures from Phase 2, and are based on problems and challenges in the care for the residents that participants encountered in the preceding period. During each meeting, the participants first decide which topics (problems, challenges, and improvements) they want to discuss. Next, they discuss solutions and related actions, and finally, they formulate action points and indicate the people who are responsible for the action points. Process facilitators take notes during the meetings, and share the action points with the ward manager to discuss possibilities of implementing them. Consecutive meetings start with a short summary of the notes from the previous meeting, the progress on the action points, the manager's comments or feedback on the action points, and the results of the realized actions. At the end of each meeting, new action points and the agenda for the next meeting are set.

During the meetings, the role of the two trained process facilitators is to provide structure, create a safe environment, stimulate participants to voice their thoughts, and enhance solutions.<sup>26,31</sup> The first facilitator moderates the meetings and the second facilitator supports the first facilitator in her/his role and functions as a substitute for the first facilitator in case he/she is unable to attend. Facilitators should be professionals experienced with group processes, and should not be directly related to the ward, so that they can function as an independent moderator without any conflict of interest.



**Figure 1.** Overview of the program phases

### **Setting and Participants**

This study was performed in a psychogeriatric nursing home ward in the south of the Netherlands. The ward was selected based on support of the manager for the program and willingness of the manager to facilitate the meetings within the ward, and a stable organizational situation during the time of implementation (no major organizational, procedural or staffing changes or conflicting implementation process were anticipated during the implementation period). These characteristics appeared essential for success, as resulted from the pilot study (see appendix 1).

The researchers invited all (nursing and nursing support) staff who worked on this ward (n=30) and all family caregivers (n=21) who functioned as the main contact person of the 21 residents on this ward to join the program. The researchers organized a meeting where they explained the goal of the program and participation in the study. It was explained that participation was based on voicing the needs of all residents living at the ward, not only the voice of specific individuals. Absent family caregivers and staff were send a letter with information on the program and study. Participants could indicate their interest in joining the meetings by contacting one of the two process facilitators. The two process facilitators were selected based on their experience with working in groups, and based on the fact that they were independent from the staff members and family caregivers of this ward. They received the two-hour training and a manual for facilitators beforehand.

**Data collection**

During the one-year period in which the program was implemented, data was collected from the family caregivers, staff and process facilitators. Table 1 represents an overview of the measurements used in this study.

*Registration forms and meeting minutes.* The process facilitators registered participants' attendance during every meeting, and kept record of the content and action points of the partnership meetings by making notes after each meeting.

*Evaluation questionnaire.* All participants who participated in the meetings at least twice received an evaluation questionnaire after nine months. It consisted of 23 questions and statements regarding participation, attendance, opinion on the meetings, and context, based on Saunders' framework.<sup>25</sup> The forms were handed out and filled out, or sent by (e)mail.

*Group interview.* After nine months, all participating family caregivers and nursing home staff received an invitation from one of the researchers (JvH), to evaluate the partnership meetings by means of a group interview. The researcher conducting the group interviews (JvH) was not involved in the partnership meeting process. Family members, staff members and process facilitators were invited to participate in a separate group interview. During the group interviews participation, attendance, opinion on the meetings, satisfaction and context were addressed.

**Table 1.** Overview of process evaluation measurements

	Registration forms and minutes	Evaluation forms and group interviews		
		Family caregivers	Nursing staff members	Process facilitators
<i>Attendance</i>				
Attendance information meeting	X			
Attendance partnership meeting	X	X	X	X
<i>Performance according to plan</i>				
Number, frequency and duration of the meetings	X			
Completion of the three phases	X			
<i>Active participation in the program</i>				
Active participation during the meetings		X	X	X
Participants' input	X	X	X	X
Action plans	X	X	X	X
<i>Opinion on the program and environmental factors</i>				
Perceived benefits		X	X	
Facilitators and barriers		X	X	X
Suggestions for improvement		X	X	X

### ***Data analysis***

Quantitative data from evaluation forms, registration forms and minutes were analyzed with descriptive statistics. IBM SPSS statistics was used to analyze the evaluation forms. Qualitative data from the group interviews were summarized, based on detailed notes taken during the interviews. Next, qualitative data from the meeting minutes and minutes from the photovoice method meetings were screened for relevant information regarding the process outcomes.

### ***Ethical considerations***

This study had been approved by the Ethics Committee of Zuyderland-Zuyd (No. 16-N-233). Participants were informed about the purpose and procedure of the study and provided written informed consent. Participants could withdraw their voluntary participation at any moment during the study. Confidentiality of the interviews was guaranteed.

## **RESULTS**

### ***Participant characteristics, response and attendance***

*Family caregivers.* Of the 21 family caregivers who were invited to the information meeting about the study and partnership program, 12 actually attended the meeting. Of these 12 family caregivers, six persons signed up for participation in the study and were invited to participate in the program. All six participating family caregivers were daughters, and their ages ranged from 50 to 64. On average, five family members were present during each meeting (ranging from three to six persons). Reasons for family absence during the meetings were having long travel distance between home and the nursing home, having time-consuming jobs, being sick, and/or having other occupations. Four family members filled out the questionnaire and participated in the group interview. The other two family members did not participate in the evaluation as their loved ones had recently passed away.

*Nursing home staff.* Of 30 nursing home staff members who were invited to the information meeting, 15 actually attended. Of these 15 staff members, ten staff members signed up for participation in the group meetings and were invited to alternately join the partnership meetings in groups of six persons, depending on their working schedules. This was somewhat higher than the intended number of approximately 10 participants in the combined group. However, 12 persons was still considered acceptable as absence due to unforeseen circumstances was anticipated. Prior to each meeting, the staff members registered their attendance. All 10 participating staff members were female, of whom six were registered nurses, one was a baccalaureate-educated registered nurse in training, and three were support staff. On average, five staff members were present during the meetings (ranging from four to six persons). Reasons for staff member's absence were having an unforeseen work shift during the planned meeting, being sick, and/or experiencing heavy workload before and after the meeting. Six staff members who attended at least two meetings filled out the questionnaire and participated in the group interview. The remaining four staff members were not able to participate due to competing working shifts and unforeseen personal circumstances during the planned interview.



*Process facilitators.* Two process facilitators moderated the meetings. The first process facilitator was a policy maker of the participating care organization, and was involved in innovation projects regarding care of older persons and had experience with group processes. The first author (LJM), who is a researcher with experience regarding group processes, filled the role of the second facilitator. During two meetings, only the first and only the second facilitator was present. During the other meetings, both facilitators were present.

***Performance according to plan (fidelity and dose delivered)***

The partnership meetings started in September 2017. In total, eight meetings took place between September 2017 and May 2018. Although it was planned to have monthly meetings, the next meeting was sometimes extended to five or six weeks after the previous one due to vacation periods and other meetings or activities that were arranged in the nursing home. Every meeting lasted 90 minutes, as planned. There was a mean group size of 10 persons per meeting. Both ratio and group size slightly fluctuated every meeting (range 8-12).

All three phases were completed. Phase 1 consisted of three meetings, Phase 2 consisted of one meeting, and four meetings were held within Phase 3. During Phase 1, process facilitators encouraged participants to express their expectations, wishes and concerns, according to plan. In addition, problems and challenges in addressing residents' well-being were discussed. During Phase 2, the photovoice method was used, according to plan. During Phase 3, joint meetings were held and participants determined the meeting content and came up with action points, which were discussed with the manager afterwards and implemented, as planned. Most meetings followed the same structure, however, during two meetings there were no concrete action plans as the group felt the need to further elaborate on a certain topic during the next meeting before action plans could be made. In addition, sometimes the action plans were not implemented before the next meeting, and content of the discussion regarding the plan was continued during the next meeting.

***Participation in the program (dose received exposure)***

Both staff and family reported that during the partnership meetings, everyone actively participated, either with or without facilitators' encouragement to speak.

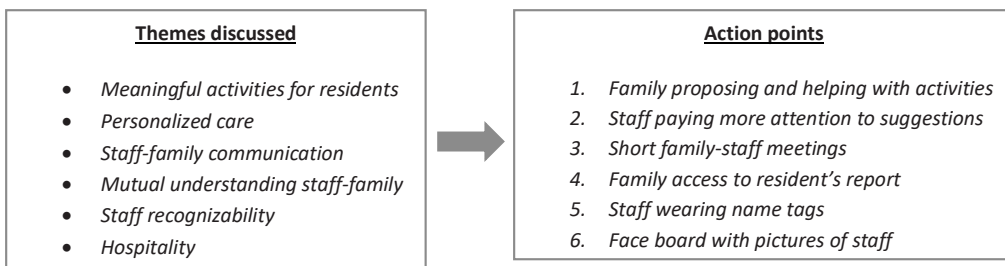
During Phase 1, participants discussed their concerns and wishes and both groups expressed their hope for sufficient willingness from both family and staff members to continue the meetings, and to change something at the ward to improve residents' well-being. However, some participants were a little hesitant to voice their thoughts. As the meetings progressed, all participants opened up more and felt free to express their opinion.

During Phase 2, all participants actively participated in the photovoice assignment. All took pictures of situations that are perceived meaningful to the resident(s). All participants showed and discussed pictures of social and leisure activities. For example, both family and staff showed photographs of residents listening to music or singing, getting a haircut, having a head massage, riding a horse, walking outside with family, receiving visits from grandchildren, folding laundry and cooking together. The themes that derived from both groups (staff and family) were about the same. Nevertheless, family members were more likely to take pictures of meaningful individual activities with their loved ones at home, and

staff would more often take pictures of group activities or special individual activities, such as painting nails or a special evening snack.

During Phase 3, participants discussed how they could increase meaningful activities for all residents. See Figure 2 for a short description of the themes addressed and action points. Topics discussed regarded improving personalized care, strengthening and increasing the frequency of staff-family communication, increasing staff recognizability, improving hospitality, and enhancing mutual understanding between family and staff. In particular, communication was an extensively explored theme. Both family and staff expressed their need for more profound conversations and reducing the barriers to asking questions. During the meetings, participants reflected upon given examples, and discussed their reasons for their behavior during those situations. The participants indicated that showing each other their views and reasons for their behavior or actions, made them more responsive to each other's experience.

Several actions derived from the partnership meetings (see Figure 2). For example, family caregivers proposed and helped with new activities, and joined current activities. Furthermore, short (10-minute) weekly family-staff meetings, in which family would set the agenda, were planned. In addition, joint access to resident personal care plans and reports was given, staff would wear nametags, and a face board was introduced with staff members' photographs with a daily update of which staff member was present at the ward.



**Figure 2.** Content of the meetings

***Opinion on the intervention (dose received satisfaction and context)***

*Experienced benefits.* One of the main goals if this program is to facilitate and support family-staff partnership within nursing home care to increase residents' autonomy. The majority of the participants experienced that relevant topics were discussed during the meetings, and they were satisfied with the possibility to determine the content and agenda of the meeting themselves. Participants' opinions on the program, assessed with an evaluation form, are presented in Table 2. The majority of both staff and family felt that, due to the program, they worked together more often and that they experienced a good atmosphere on the ward. Both groups regarded using photovoice as a starting point as a fun and creative way to reveal important themes, and it stimulated participants' enthusiasm. During the group interviews, participants said that they felt listened to, experienced improvements regarding communication, personal relationship, mutual trust and that contact between them felt equal. In addition, both became more

conscious of what is important for residents and that care better addressed resident’s needs and wishes. During the group interview with staff, they expressed their appreciation towards the increased role of family caregivers, for example during holidays and other activities and that the living environment felt more homely and welcoming. The group interview with family caregivers revealed that family felt that they could approach staff members more easily, felt better understood, and they experienced that they were given a voice within the ward. Likewise, family caregivers expressed that staff paid more attention to their suggestions for improvement.

**Table 2.** Participants’ opinion on the program (n=10)

Agreement on program evaluation statements	Participants’ agreement* with statement (n)
<i>Due to the meetings...</i>	
<i>Communication between family caregivers and staff has improved</i>	7
<i>Family caregivers have more influence on how things should be at the ward (care, activities, environment)</i>	7
<i>Staff have become more conscious of what is important for residents</i>	9
<i>Family caregivers have become more conscious of what is important for residents</i>	8
<i>Improvements have been made at the ward</i>	8
<i>Care better addresses resident’s needs and wishes</i>	8
<i>Family caregivers and staff work together more often</i>	10
<i>The ward ambience has improved</i>	9

\*5 Point Likert-Scale; number of participants that (totally) agreed with the statement

*Suggestions for improvement.* Both groups expressed their wish to continue the partnership meetings, however, although the frequency of one meeting each month was appreciated during the first meetings, the majority of family members would prefer a lower frequency of once every two months. They said that it sometimes was a lot to join every month if there were other activities or ward meetings they had to attend. In addition, all participants indicated that the meeting time, 90 minutes, was just right. Nonetheless, all family caregivers and staff recommended including more different family caregivers and staff alternating in the meetings. They indicated the importance of involvement of other family caregivers, to ensure a wider support of family’s voice within the ward. However, process facilitators indicated that continuity of attendants seems important for creating a safe and open environment. All participants recommended implementation of the program within other nursing home wards.

*Factors influencing the program.* All participants said that creating a safe environment in the separate groups at the start of the program allowed them to discuss all themes and struggles, in both separate and joint group meetings. In addition, the majority of the participants were satisfied with the

(role of the) process facilitators within the meetings. Some family caregivers, however, felt that facilitators could have provided more structure during the first meetings. Next, according to the process facilitators, an important facilitator for the successful implementation of the program was that the ward manager was open to all changes and was willing to collaborate and facilitate all that was necessary before and during the partnership meetings. In addition, family members' and staff willingness to participate in the meetings, and them being open to change current practice were identified as positive contributors. One barrier mentioned by a staff member was that staff members' working shifts did not always allow them to attend the meetings.

### DISCUSSION

The aim of the present study was to gain insight into the feasibility of a new program aiming at facilitating and supporting family-staff partnership, to increase resident' autonomy of nursing home residents with dementia, by addressing problems or challenges in current care and finding solutions. This process evaluation study showed that the program was largely performed according to plan and that the overall attendance rate was high. Furthermore, participants were actively involved in the program, experienced benefits from the program, and were satisfied with the program. Participants recommended continuation of the program on their own ward and implementation of the program within other nursing home wards.

The findings of the study indicate that the program supported family and staff in jointly proposing actions that could increase residents' well-being. The high attendance rate, which might be related to participant's enthusiasm about the program, their willingness to change the current situation, and their wish to increase partnership to improve resident' autonomy. The photovoice was perceived by the participants as a fun and approachable assignment, as a starting point of joint meetings. This was also regarded as such in previous studies that used this method to gain insight into perspectives on residents' well-being.<sup>30</sup> In addition, the method of discussing the current situation, ideas for improvement and implementation of action plans seemed to have encouraged participants' involvement in the program, which was also seen in previous research.<sup>19-22</sup> Furthermore, implementation of this program might have benefited from several factors as proposed in Rogers' diffusion of innovation theory,<sup>32</sup> for example, the visible and clear impact on collaboration, resident care and ambience in the ward, i.e. observability, might have increased participants' contribution to the program. In addition, as working methods within current nursing home wards in general do not sufficiently facilitate developing a staff-family partnership, the program seemed to have clear benefits for the participants (i.e. relative advantage).

Furthermore, the fact that the program was developed in close cooperation with representatives of the nursing homes, resident councils and experts in the nursing home domain, might have increased the match between program content and participants' positive opinion on it.<sup>32,33</sup> In addition, process facilitators regarded the support of the manager during implementation as a positive factor. Management influence has also been seen as an important factor for implementing innovations within other studies regarding implementation of change in other nursing home sites.<sup>34</sup> Last, this study showed that it is important that staff's working shifts are adapted to staff members who want to attend the meetings. Therefore, timely scheduling of the meetings and flexibility of working shifts is important in order for

nursing staff members to be actively involved. In addition, it was found that the regular meetings in which family and staff together owned the content and agenda helped them to feel empowered, bring them closer, and to understand each other better, which was also suggested in previous studies.<sup>24</sup>

This study has several limitations. First, a limitation of this study was the risk of response bias, as participants might tend to give socially desirable answers. In order to prevent this, a researcher (JvH) who was not involved in the meeting process administer the interviews in this study, and handing out questionnaires to be filled out anonymously. Second, this study was conducted in one nursing home ward, therefore it remains unclear whether our findings will be generalizable to other nursing home wards. Third, as participants were interviewed about events that occurred over the past nine months, recall bias could have occurred. Nonetheless, a large part of the data was collected prospectively.

### **Conclusions**

This study showed that the partnership program was feasible in daily nursing home practice. The program was largely performed according to protocol, showed active participation, and was positively evaluated by its participants. Nonetheless, several recommendations can be made to further improve the program. First, the frequency of the meetings could be lowered after the first meeting in Phase 3, depending on participants' preferences. Second, efforts should be made to include more different family caregivers. Third, it is recommended to only implement the program when it is supported by the management to ensure optimal implementation and sustainability of the program. Future research should focus on implementation of the program within other nursing home wards to further optimize the program and to assess its feasibility in other nursing home settings. Moreover, it is important to assess the effectiveness of the program on family-staff collaboration and resident well-being in a controlled study.

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## Chapter 6

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# CHAPTER 7

General Discussion

## General discussion

The aim of the studies in this dissertation was to provide insight into supporting the autonomy of nursing home residents with dementia through creating staff-family partnership within nursing homes. This dissertation focused on relational autonomy, which refers to valuing residents' individuality within the social context and relationships. An analysis of the current situation regarding resident autonomy was carried out. Interviews were held with family caregivers and observations of staff-resident interactions were performed. Furthermore, a program was developed through co-creation that aims to encourage staff-family partnership. The program was based on a review of the literature and assessed on its feasibility in nursing home practice. These studies add to the knowledge on staff-family partnership and may contribute to increasing the support of resident autonomy and well-being. In addition, they contribute to an increased understanding of supporting resident autonomy. Hence, this dissertation had two main research questions:

- 1) How and to what extent is the autonomy of nursing home residents with dementia supported?
- 2) How can we create partnerships between nursing home staff and family caregivers of nursing home residents with dementia, to increase resident autonomy?

The main findings of these studies are described and discussed in this chapter, as well as methodological and theoretical considerations and future directions for research and nursing home practice.

### MAIN FINDINGS

Findings of the studies described in this dissertation showed that resident autonomy can be supported in nursing home care through social relations and interactions in various ways. However, opportunities to fully support resident autonomy seem to be insufficiently used in current practice. Our study showed that resident autonomy was not sufficiently supported in almost half of the care activities during daily care. The extent to which residents were supported in their autonomy appeared to be dependent on how staff approached the resident. For instance, the communication strategies used, use of eye contact and exerting patience. In addition, family caregivers identified factors supporting autonomy. These factors were related to staff being more responsive to residents' needs during care activities, a safe and accessible outside environment, stimulation of social events, and increasing activities that are important or meaningful to the resident. However, these factors seemed not to be used optimally.

Furthermore, our studies showed that family perceived no real and equal partnership with staff in nursing homes. Family caregivers often found it hard to establish good communication, and family expressed a need for real and attentive contact. These communicational factors seemed to be prerequisites for good collaboration and developing partnership and require active involvement and support from the nursing home. Furthermore, there is a need for effective programs that improve collaboration between staff and family and increase resident autonomy and well-being. Existing programs often have a one-sided focus (i.e. only on family or staff), and lack reciprocity and a solid basis to facilitate staff-family partnership. In co-creation with practice, we have developed a program to create partnership between staff and family. It focused on equal partnership and commenced with separate family and staff

group meetings that developed into joint group meetings. Throughout the program, staff and family worked together on improving resident autonomy in daily life. The first results show that the program seems promising: participants expressed positive experiences, were satisfied, experienced benefits for themselves and for residents, and worked together to increase the support of resident autonomy. The program appears to be feasible in daily nursing home practice.

## **METHODOLOGICAL CONSIDERATIONS**

In the following paragraphs, considerations of the methodologies used and their strengths and limitations are outlined.

### *Study design*

The studies in this dissertation were exploratory and developmental in nature. The feasibility and the perceived benefits of a partnership program were assessed. However, our feasibility study does not provide a decisive answer to the question whether the program has favorable effects on (relational) autonomy and resident well-being, as this can only be assessed in an experimental design. However, as experiments can be costly, burdensome and time-consuming for participants, we considered it essential to first gain insight in the feasibility and perceived benefits of the program, before assessing its effects in an experimental study. Our study design followed principles of co-creation, with the MRC Framework for complex health interventions as a guideline.<sup>1-3</sup> We used a reflective and cyclical process that focuses on learning from those who know by “looking, thinking, and acting”.<sup>2</sup> The research process was operationalized by the researchers, initiating regular meetings and involving “those who know”: client councils, experts in the field of nursing home care, and policy makers working in nursing home care organizations. It is suggested that this process can maximize the fit between the needs and important issues in practice. Our design allowed us to attain knowledge of current practice, get feedback on our research and implementation ideas, and acquire advice on following steps on a regular basis.

However, our design could be improved. First, factors such as different backgrounds, lack of knowledge, and too much involvement by some parties or persons could have had a hindering effect. For example, the use of this qualitative approach was at risk of having single events or exceptional occurrences, which were important to participants, become overestimated during the process. Therefore, it is hard to determine the effects of these factors on the outcomes. Moreover, another limitation of our design was that it did not allow for testing program effectiveness. As a first step, we focused on the development and feasibility of a program. Therefore, we can only elaborate on effects as perceived by participants. The positive effects experienced, however, encourage further implementation of the program on a larger scale.

### *Study population*

The participating nursing home wards were selected based on support of the manager for the program and the willingness of the manager to facilitate the meetings within the ward. This was important, as a ward manager’s approval and collaboration are essential in starting up research in a nursing home ward. Wards were also checked for the absence of major organizational changes. Even though constant changes are everyday occurrences in nursing home practice, each ward was checked for possible interference due

to major organizational, procedural or staffing changes, or conflicting implementation process during the implementation period. Nonetheless, the ward manager's willingness to participate could possibly have been influenced by an already applied focus in current practice on increasing the support of resident autonomy and person-centered care. Consequently, a limitation of our study might be an overestimation of how autonomy is supported within current practice. The staff-resident interactions observed in this study might have been more autonomy-supportive than in other wards.

Moreover, the study population for the studies performed was selected from the same wards. This means that some individual family caregivers were represented multiple times in different studies. As we used multiple qualitative research methods, this could have led to an overrepresentation of certain experiences, opinions or views. For the purpose of our studies, however, we incorporated up to six nursing homes and nine wards that varied in organization, ward size, location, and staff, which has most probably lead to a diversity in the samples. As our population, sample sizes, and designs did not allow for generalization of the results to nursing home care in general, further research is needed.

Furthermore, due to the selection of a ward manager that was enthusiastic and willing to participate in the process evaluation, it is possible that the feasibility of the intervention is overestimated. The results of the process evaluation might portray an easier established staff-family partnership than is possible in most nursing home wards. Based on the current study, we only know to some extent which contextual elements or beneficial prerequisites were important for conducting the program. Our results from the program evaluation suggest that having a supportive management is very important in supporting resident autonomy through staff-resident partnership. This is in line with previous research on implementation strategies in health services, which confirm the prerequisite role of a facilitating management in innovation.<sup>4,5</sup>

#### *Assessment of resident autonomy within nursing homes*

Currently, there is no standardized instrument to measure relational autonomy for nursing home residents with dementia. Domains or items that link to autonomy are incorporated into some instruments available, such as questionnaires and observation lists.<sup>6-10</sup> Even though these measurements can provide some insight into autonomy, none of them provides insight into the relational component of autonomy. Besides, these instruments often only assess staff's appraisal of how they support resident autonomy and lack a rich spectrum of factors that relate to this in daily life. In order to assess relational autonomy, a self-developed observation list was used to perform observations. This method allowed the capture of social interactions within a natural care environment. In addition, experiences of family caregivers with the support of resident autonomy were collected to obtain a broad view of elements that might support autonomy of residents within the nursing home.

The most important limitation of how we assessed relational autonomy in our study is that residents' view of how their autonomy is supported was not directly assessed in the study. Residents' cognitive and verbal challenges made it difficult to assess their perspective on a complex construct such as autonomy. However, as an alternative, we used photo voice as a method to incorporate residents' view, through the eyes of their social network. This entailed that family and staff took pictures of what they felt was important and meaningful for residents, as an operationalization of autonomy, in order for them to further elaborate on how these important things were realized in practice. Although this is seen as a viable way to integrate residents' voice in research, we do realize that the residents' perspective

might differ from that of their proxies. Hence, our results might have been biased and may cause differences, as opposed to the residents' view. The use of proxies as important surrogate resources for people with dementia is often seen in dementia research. Nonetheless, proxies can experience feelings of doubt and uncertainty regarding their decisions made on behalf of the resident,<sup>11,12</sup> indicating that their view might be different from that of the resident. Incorporating residents' view has been a challenge in other research as well.<sup>13</sup> This may be caused by the inability to use standardized measurements, which require people to have capacities to verbally express themselves, independently fill out a questionnaire, or answer pre-structured questions. Future research should focus on developing methods to enhance residents' voice in research in order for people with severe dementia to participate, which was also underlined by previous studies.<sup>13,14</sup> Practical methods need to be introduced that incorporate all perspectives within the dementia care triad. For example, individual conversations with residents, family, and staff can be a starting point to reflect on their different perspectives and to enhance good dementia care.<sup>14</sup>

### **THEORETICAL CONSIDERATIONS**

In our study, it was observed that resident autonomy can be supported in various ways. From a relational perspective, our studies suggest that reactions and approaches of other people towards nursing home residents are defining for the support of their autonomy, especially for residents who are less verbally expressive. Facilitating autonomy can be difficult, which is recognized by other studies as well.<sup>15,16</sup> Results of our study show that certain factors might be essential to improve the support of resident autonomy, which will be discussed in the following paragraphs.

First, staff's attitudes towards dementia and awareness may impact how they support resident autonomy. Our results showed that staff used different approaches during their work routines, which either support or impede resident autonomy. Differences in staff approaches might be underpinned by differences in attitudes towards people with dementia.<sup>17-19</sup> For example, staff may believe that people with dementia lose their need for autonomy when they are incapable of knowing and/or expressing what they want.<sup>20-24</sup> A previous study on staff attitudes towards dementia showed that staff more often perceived residents negatively by being more focused on incapability than a person's capabilities.<sup>25</sup> This attitude does not contribute to the support of resident autonomy, such as finding ways to engage or support residents in choice. Adjusting staff's approach to residents' individual capacities may contribute to an enhanced support of resident autonomy.<sup>19,26</sup> It appears that nurses who are under 50 years old and have received special training in dementia care are more likely to have a positive attitude towards dementia and might provide care that focuses more on people's well-being and promoting health, compared to older nurses who did not receive special training.<sup>17</sup>

Second, family can provide a major contribution to providing care that enhances the support of resident autonomy, in collaboration with staff. Our studies show that family caregivers indicate unused opportunities to improve support for resident autonomy in current practice. However, it appears that staff and family do not collaborate optimally, which might leave these opportunities unaddressed. This suboptimal collaboration might be influenced by differences in role perception, which further impedes the support of resident autonomy. Previous research indicates that throughout the years, family caregivers take on more roles, from being visitors to taking part in decision making on behalf of the

resident.<sup>27,28</sup> Yet it appears that the perception of the family's role can be different among staff members,<sup>27</sup> which may enforce the suboptimal collaboration. For example, staff members may still perceive family as difficult, controlling, and as visitors who should not interfere with the staff's task of providing daily care.<sup>27,29-31</sup> One of our studies suggests that family already takes on many more roles than solely visiting and implies that family involvement goes beyond having an instrumental role, e.g. washing clothes and decorating the resident's room. It can be said that family wants to be involved in the nursing home on a more relational level.<sup>32-34</sup> Our results indicate that families want to maintain a social relationship with the resident and continue their life as before. Besides, they perceive a need for a personal connection between them and the staff, which is in line with earlier research that addresses the importance of enhancing connection through staff-family communication.<sup>29,33,35,36</sup> As part of providing relationship-centered care, the need and focus for interpersonal relationships requires more attention in current nursing home practice.<sup>37</sup> It is suggested that both staff and families should commence with distancing themselves from the "us-them" mentality,<sup>34</sup> and for nursing homes to facilitate more frequent informal conversations between staff and family.

Third, the aforementioned results indicate that it is essential to implement a program that can facilitate partnership, as staff and family perceive barriers in current practice. We developed a program that may facilitate staff-family partnership. This program embraced relationship-centered elements, in which all relationships within the dementia care triad are important and should receive equal attention.<sup>38,39</sup> It focused on reciprocity, working together by envisioning the same goal, improving communication, and sharing of responsibilities, which are suggested to be important elements in providing relationship-centered care.<sup>39,40</sup> This is essential because these can increase mutual respect and recognition of each other's roles, which is seen as a first step towards inclusion of family caregivers in the nursing home.<sup>34</sup> In addition, this appears necessary for family to take part in the dementia care triad, and in order for them to be seen as equals in making decisions that impact the daily life of their loved ones.<sup>27,31,34</sup> Although our program contained important elements, it is important to continue testing it for optimization. The program might be improved, for example, by discussing staff and family roles as a fixed component in the program. Furthermore, in order for staff and family to work together in practice, certain prerequisites need to be fulfilled. Primarily, there needs to be a willingness on the part of nursing home care organizations to be self-critical and be able (and willing) to let go of routines that might have a negative influence on the autonomy and resident well-being. Nonetheless, changing attitudes and cultures within nursing homes is challenging. It is necessary for innovation to engage all levels within the organization. Previous research regarding culture change in nursing homes suggests that everyone involved in resident care should be engaged in this change.<sup>41</sup> Our feasibility study suggests that positive change in staff-family relationships can be established when actively involving staff and family in a program.

### **FUTURE DIRECTIONS**

Based on the results of the studies in this dissertation, there are several implications for future nursing home practice and research in the field of dementia.



### *Practice*

First, nursing home care should focus on relationship-centeredness in order for residents to have autonomy in care. Attention is needed for staff and family to communicate constructively, share experiences, address equality, and emphasize the importance of incorporating voices of both staff and family. Even though we did not assess evaluation of our partnership program yet, nursing homes could use a further developed version of our program to encourage relationship-centeredness based on reciprocity between family and staff, working together, improving communication, and sharing responsibilities. In addition, new technologies might be used or developed. For example, introducing a digital platform to share resident care plans or digital communication tools could facilitate communication between staff and family.

Second, creating a learning environment for staff to improve their autonomy supporting skills is helpful. They can, for example, create knowledge and skills by observing each other, or having regular team meetings to share, discuss and challenge approaches for individual residents. Learning from each other might stimulate positive attitudes towards dementia. In addition, staff might benefit from education in dementia care that focuses on how to use visual and tactile cues and using different communication strategies that could identify needs and wishes of nursing home residents with dementia. As an illustration, staff members should make eye contact with the resident before providing choice and show patience during care. Staff need to use communication strategies that support resident understanding, e.g. taking time to listen, speaking slowly and simply, and making eye contact.

Third, family caregivers need to be involved in nursing homes as more than just residents' visitors. Among other things, establishing a personal connection or relationship between staff and family can be enabled by improving and strengthening personal and informal communication. For example, staff can ask family about how they are doing, make time for more frequent informal conversations, wear nametags or have a face board, and introduce themselves to family.

Fourth, the nursing home management needs to develop and advocate a clear and supportive view of family involvement. Based on the process evaluation of our partnership program, it might be suggested that supportive management has a positive influence on how nursing staff engages family in the nursing home. Therefore, nursing home ward managers should be aware that they hold a significant role in promoting family involvement and staff-family partnership and react based on that.

### *Research*

First, it is necessary to gain more insights into staff attitudes towards dementia. It is suggested that staff with more positive attitudes are more likely to provide care that supports resident autonomy. It is necessary to research how staff perceives people with dementia before, for instance, designing programs that can improve resident autonomy.

Next, it is important to research which knowledge and skills are needed for staff to optimally support resident autonomy. Our study showed that staff is capable of supporting resident autonomy of residents with severe dementia; however, there are major differences in individual staff members' approaches. Hence, the subject of which strategies are effective in supporting resident autonomy can be researched in more detail. Future research should focus on individual staff approaches or techniques to support resident autonomy, for example, (non-verbal) communication.

Finally, the effectiveness of the partnership program needs to be researched. The current program was positively evaluated by participants; however, it was only evaluated for process outcomes in one ward. In order to determine whether the program can facilitate staff-family partnership and improve autonomy and wellbeing of nursing home residents, an effect evaluation needs to be performed in a controlled study. Outcome measures should, among other things, regard experienced collaboration and partnership from the perspective of both family and staff, resident relational autonomy and resident wellbeing. Subsequently, research into which prerequisites need to be fulfilled and which implementation strategies need to be used for different wards is needed before it can be used as an effective stand-alone program to use in practice.

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# SUMMARY





The focus on providing care that supports autonomy and individual preferences becomes increasingly important. Nonetheless, doing so is often complex and can be challenging when caring for people living in nursing homes, especially people with dementia. This dissertation focuses on the support of autonomy of nursing home residents with dementia through establishing a partnership between family and nursing home staff. This dissertation has two aims. The first aim is to gain insight in how and to what extent the autonomy of residents with dementia living in nursing homes, is supported. The second aim is to gain insight in how a partnership between family and nursing staff to increase resident autonomy, can be created. In more detail, the studies in this dissertation focused on relational autonomy, which entails respecting residents' individuality within the social context and relationships. The current situation regarding resident autonomy was analyzed through performing interviews with family caregivers and observations of staff-resident interactions. Furthermore, a review of the literature was conducted to gain insight in interventions that could support family-staff partnership in nursing homes for people with dementia. Subsequently, based on the results of this review and in co-creation with representatives of residents, staff and experts in the nursing home field, a program was developed that aims to encourage staff-family partnership. Next, the feasibility of this program in nursing home practice was assessed. The current chapter gives a summary of the studies in this dissertation.

**Chapter 1** provides a general introduction on the subject of dementia and nursing home care. Background information is provided on dementia and nursing home care, and an introduction to autonomy support in nursing home care is provided. In addition, current knowledge regarding family-staff partnerships is described. Finally, the aims of the study are presented, and an outline of the dissertation is provided.

**Chapter 2** reports on the results of an observational study that aimed to explore the extent to which autonomy of residents with dementia is supported by nursing home staff. An exploratory, cross-sectional study was carried out to assess staff-resident interactions during eleven morning care activities. Both quantitative and qualitative data were collected using structured observation methods to assess the support of autonomy. During morning care, 1770 care interactions were observed, using a self-developed observation list. Analysis of the data showed that autonomy seemed to be supported by staff in 60% of the interactions. Staff supported resident autonomy by being sensitive to resident's needs and wishes and taking on a person-centered care approach. However, missed opportunities to address residents needs and wishes were frequently observed. These mainly seem to occur during interactions in which staff members took over tasks, and seemed insensitive to residents' needs and wishes. Our results indicate that there are differences between staff members' approach towards residents, and their working procedures. In addition, differences across nursing home locations were observed regarding the physical environment, for example, outdoor accessibility or having a homely environment. Our study showed that resident autonomy is not or only partly supported in 40% of the interactions, and mainly seen during interactions with residents with severe dementia. Therefore, our results indicate that improvements are needed in nursing homes to better support resident autonomy. Increasing a learning environment to enhance nursing home care that better focuses on resident autonomy is recommended. Particularly in the care for people with severe dementia, staff needs to develop new skills to improve resident autonomy, which may be enforced by peer learning.

In **Chapter 3** a qualitative study is described which was performed to explore experiences of family caregivers with factors that, according to them, support or impede the autonomy for nursing home

residents with dementia. We held semi-structured interviews with 30 family caregivers of nursing home residents with dementia. This study revealed six factors that influenced resident autonomy according to family caregivers, and were either autonomy supporting or impeding: 1) “activities”: activities that were organized from a communal and logistic perspective impeded autonomy, while residents’ involvement in individual activities that suited their interests supported autonomy; 2) “personal approach”: providing a personal approach by getting to know the resident positively influenced resident autonomy; 3) “visits from family and friends”: the lack of private spaces for family to continue family traditions were autonomy impeding, whereas abilities for family and friends to visit were regarded as autonomy supporting; 4) “being part of a group”: the daily life with fellow residents was mostly determined by what fits the group instead of the individual impeded autonomy, while, on the other hand, being able to socially engage with fellow residents had a positive influence; 5) “physical environment”: limited freedom of movement within and outside the nursing home was autonomy impeding, while creating a homely environment could support autonomy; and 6) “organization of care”: a fixed nursing team was regarded as autonomy supporting, while nursing staff’ fixed routines regarding moments of care, impeded resident autonomy. In order to better support resident autonomy it is important to enable flexibility in providing care, find ways to offer activities that are meaningful to residents, and stimulate resident’s social environment to continue social traditions.

**Chapter 4** gives an overview of interventions that could support family-staff partnership in nursing homes for people with dementia. A systematic literature review, using the PRISMA-ScR checklist, was performed in order to report on studies that examined interventions, programs and approaches aimed to increase family involvement in nursing homes. Results of the 29 included studies revealed that only two interventions were targeted at creating family-staff partnerships from a two-way perspective, i.e., involving both family and staff together. The other 27 studies targeted either staff or family and often used single components (e.g. only education). These 27 studies entailed either increasing family involvement in formal decision making, enabling family caregivers to (participate more actively) in making better informed decisions, or accommodating family caregivers with psychoeducation. Results indicated that family caregivers and staff members were either targeted at family or staff, implying a lack of equality and reciprocity between the two, which makes it difficult to truly establish partnership. Effects of the interventions remain yet unclear. It is often unknown whether family inclusion increased after implementation of the interventions or programs. Furthermore, as different outcomes were measured, and not always in line with the aims of the intervention, it was difficult to appraise the effects. It is suggested that important components entail mutual exchange and reciprocity between family caregivers and nursing home staff.

**Chapter 5** describes a qualitative study in which the experiences of family caregivers with collaboration with staff were assessed. Semi-structured interviews were held with 30 family caregivers of nursing home residents with dementia to explore how family caregivers describe and view their current collaboration and partnership with staff. Findings reflected three themes, i.e., “communication”, “trust and dependency”, and “involvement”. The findings suggest that good communication between family and staff was a prerequisite condition for having trust in staff and quality of involvement in residents’ life. It appeared important for family caregivers to have frequent informal contact with staff in order for them to build a personal relationship. Findings revealed that this could increase family caregivers’ trust in staff and satisfaction regarding their involvement in the nursing home. The findings of this study implicate that

in order for family and staff to improve collaboration and build a partnership, informal contact and building a personal relationship should be prioritized in nursing homes.

**Chapter 6** describes the findings of a process evaluation of a newly developed program aiming at facilitating and supporting family-staff partnership within nursing home wards, to increase residents' autonomy and well-being. The program was developed based on the results of the systematic review and in co-creation with resident councils, representatives of nursing homes and experts in the nursing home field. We used a prospective multi-method study to test the feasibility of the program, including assessment of participant attendance, performance of the program according to plan, participation in, and opinions on the program. The program consisted of monthly 90-minute meetings, in which family and staff jointly address problems or challenges in current care, search for solutions for challenges in residents' daily lives and implement these solutions in daily practice. The evaluation of the program took place after nine months and revealed that the program was largely performed according to plan and that the overall attendance rate was high. Furthermore, participants were actively involved in the program, experienced benefits from the program, and were satisfied with the program. Participants recommended continuation of the program on their own ward and implementation of the program within other nursing home wards. Furthermore, the program was able to encourage family and staff to propose actions that regarded increasing residents' well-being. The program was regarded as promising in supporting staff-family partnership, and addressing needs within the dementia care triads, as part of relationship-centered care. Additionally, management support appeared important for optimal implementation and performance of the program. In order to test effectiveness of the program, further research is needed.

In **Chapter 7**, the main findings of the studies in this dissertation are presented. This research has shown that resident autonomy can be supported in several ways for residents with dementia living in nursing homes, and can be facilitated by a program aimed to help staff and family engage in care for residents at the nursing home ward. The partnership program that was developed is one of the first to help family and staff to create partnership. In addition, it describes a general discussion and an overview of the strengths and limitations of this dissertation are described. Furthermore, it reflects on recommendations for practice and future research.



# SAMENVATTING



In de huidige zorg wordt er steeds meer waarde gehecht aan ondersteuning van de eigen regie (autonomie) en individuele voorkeuren van mensen die zorg nodig hebben. Deze manier van zorg verlenen is, echter, vaak complex en uitdagend voor mensen die in een verpleeghuis wonen, met name voor mensen met dementie. Het onderzoek beschreven in dit proefschrift focust zich op de ondersteuning van de eigen regie van verpleeghuisbewoners met dementie, door het aangaan van partnerschap tussen naasten van bewoners en zorgverleners. Dit onderzoek heeft twee doelen. Het eerste doel is inzicht te verkrijgen in hoe en in welke mate de eigen regie van mensen met dementie die in een verpleeghuis wonen, wordt ondersteund. Het tweede doel richt zich op het verkrijgen van inzicht in hoe partnerschap tussen naasten van verpleeghuisbewoners en zorgverleners kan worden gecreëerd, om zo de eigen regie van bewoners te vergroten. Het onderzoek richt zich op relationele autonomie (eigen regie). Dit houdt in dat de individualiteit van iemand wordt gerespecteerd binnen de sociale context en relaties. De eigen regie van bewoners is onderzocht, met behulp van interviews met naasten van bewoners en observaties van interacties tussen zorgverleners en bewoners. Verder is er een literatuuronderzoek gedaan om meer inzicht te krijgen in interventies die partnerschap tussen naasten en zorgverleners kunnen ondersteunen. Op basis van de resultaten van dit literatuuronderzoek en in co-creatie met vertegenwoordigers van bewoners, zorgverleners en experts op het gebied van verpleeghuiszorg is er vervolgens een programma ontwikkeld. Dit programma heeft als doel het faciliteren van partnerschap tussen naasten en zorgverleners, om zo de eigen regie van verpleeghuisbewoners te bevorderen. De uitvoerbaarheid van dit programma is in een eerste pilot onderzoek getest. In dit hoofdstuk wordt een samenvatting gegeven van de vijf deelstudies waaruit het onderzoek, beschreven in dit proefschrift bestaat.

**Hoofdstuk 1** geeft een algemene introductie op de belangrijkste thema's die in dit proefschrift aan bod komen. Allereerst wordt ingegaan op dementie en verpleeghuiszorg en de ondersteuning van eigen regie van verpleeghuisbewoners. Daarnaast wordt een overzicht gegeven van de huidige kennis met betrekking tot partnerschap tussen naasten en zorgverleners. Als laatste worden in dit hoofdstuk de doelen per deelstudie gepresenteerd en wordt een overzicht gegeven van de opbouw van het proefschrift.

**Hoofdstuk 2** beschrijft de resultaten van een observatiestudie. Deze studie had als doel het exploreren van de mate waarin de eigen regie van verpleeghuisbewoners met dementie wordt ondersteund door zorgverleners. Het betreft een exploratieve, cross-sectionele studie waarin de interactie tussen bewoner en zorgverlener in kaart is gebracht tijdens elf ochtendzorgactiviteiten. Zowel kwantitatieve als kwalitatieve onderzoeksmethoden zijn gebruikt om de ondersteuning van de eigen regie te meten. Er zijn 1770 interacties tijdens ochtendzorgactiviteiten geobserveerd, bij in totaal 57 verpleeghuisbewoners met dementie. Hierbij is gebruik gemaakt van een speciaal voor dit onderzoek ontwikkelde observatielijst. Analyse van de data laat zien dat de eigen regie van bewoners in 60% van de interacties wordt ondersteund door de zorgverleners. Dat wil zeggen dat bij deze interacties de zorgverleners ontvankelijk waren voor de wensen en behoeften van bewoners en dat zij zorg verleenden op een persoonsgerichte wijze. Desondanks liet analyse van de data ook zien dat de zorgverleners regelmatig kansen misten om in te gaan op de wensen en behoeften van bewoners tijdens zorgactiviteiten, of dat deze wensen en behoeften werden belemmerd of genegeerd. Deze deelstudie toont aan dat de eigen regie van mensen met dementie die in het verpleeghuis wonen niet of deels wordt ondersteund in 40% van de interacties. Dit kwam vooral voor bij interacties met mensen met een ernstigere vorm van dementie en interacties waarbij zorgverleners taken overnamen en minder of niet gevoelig waren voor de wensen en behoeften van de bewoner. De resultaten van deze deelstudie laten

zien dat er verschillen zijn tussen zorgverleners, gelet op hoe zij de bewoners benaderen en hun manier van werken (bijvoorbeeld gericht op het afwerken van taken versus gericht op ingaan op de behoeften van de bewoner op dat moment). Daarnaast zijn er verschillen gevonden tussen verpleeghuisafdelingen wat betreft aspecten in de fysieke omgeving die van invloed lijken te zijn op de eigen regie van de bewoner, bijvoorbeeld het wel of niet hebben van de mogelijkheid om naar buiten te kunnen, of het wel of niet hebben van een huiselijke omgeving. De resultaten van deze deelstudie laten zien dat er mogelijkheden zijn om de huidige verpleeghuiszorg te verbeteren. Deze verbeteringen kunnen bijvoorbeeld liggen in het creëren van een leeromgeving waarin kennis en vaardigheden aangaande (goede) dementiezorg en het ondersteunen van eigen regie, wordt gestimuleerd. Met name in de zorg voor mensen met een ernstigere vorm van dementie zouden zorgverleners zich nieuwe kennis en vaardigheden eigen moeten maken om de eigen regie van de bewoner te verbeteren. Intercollegiaal leren zou dit proces kunnen ondersteunen.

**Hoofdstuk 3** beschrijft de resultaten van een kwalitatieve studie naar factoren die de eigen regie van bewoners ondersteunen of belemmeren, volgens naasten van verpleeghuisbewoners. Voor deze deelstudie zijn 30 semigestructureerde interviews gehouden met naasten van verpleeghuisbewoners met dementie. Analyse van resultaten laat zien dat er zes factoren zijn die invloed hebben op de eigen regie van bewoners, volgens naasten. Deze factoren kunnen zowel ondersteunend als belemmerend zijn: 1) “activiteiten”: activiteiten die vanuit een gemeenschappelijk en/of logistiek perspectief werden georganiseerd werden als belemmerend ervaren; betrokkenheid van bewoners bij individuele activiteiten die aansloten bij hun interesse werden als ondersteunend ervaren, 2) “persoonlijke benadering”: het leren kennen van de bewoner droeg volgens naasten positief bij aan de eigen regie van de bewoner, 3) “bezoek van familie en vrienden”: het ontbreken van een privéruimte voor familie om familietradities voort te zetten werd ervaren als belemmerend; mogelijkheden voor familie en vrienden om langs te komen werd ervaren als ondersteunend, 4) “onderdeel zijn van een groep”: het dagelijks leven werd voornamelijk bepaald door wat past bij de groep als geheel in plaats van te kijken naar het individu werd als belemmerend ervaren; de mogelijkheid om sociaal betrokken te zijn bij andere bewoners werd ervaren als een positief, 5) “fysieke omgeving”: beperkte bewegingsvrijheid binnen en buiten het verpleeghuis werd gezien als belemmerend voor de eigen regie, terwijl het creëren van een huiselijke omgeving eigen regie kon stimuleren volgens naasten, en 6) “organisatie van zorg”: een vast team van zorgverleners werd als ondersteunend ervaren; vaste routines tijdens zorg werd als belemmerend ervaren. Op basis van deze deelstudie kan geconcludeerd worden dat, om de eigen regie van mensen met dementie die in het verpleeghuis wonen beter te ondersteunen, het belangrijk is om te focussen op flexibiliteit in de zorgverlening, het aanbieden van activiteiten die betekenisvol zijn voor de bewoner en het stimuleren van voortzetting van sociale gewoontes of tradities.

**Hoofdstuk 4** geeft een overzicht van interventies die partnerschap tussen naasten van verpleeghuisbewoners en zorgverleners zouden kunnen ondersteunen. Er is een literatuuronderzoek uitgevoerd, gebruik makend van de PRISMA-ScR checklist, naar wetenschappelijk onderzochte interventies die als doel hadden om familiebetrokkenheid in het verpleeghuis te vergroten. Resultaten van de 29 geïnccludeerde studies laten zien dat slechts twee interventies gericht waren op het creëren van partnerschap vanuit een wederzijds perspectief, i.e. het gezamenlijk betrekken van zowel naasten als zorgverleners. De overige 27 onderzoeken richtten zich uitsluitend op óf zorgverleners óf naasten en bestonden vaak slechts uit één enkele component, bijvoorbeeld alleen educatie. In deze 27 onderzoeken



werd voornamelijk nagegaan of de onderzochte interventies bijdroegen aan het vergroten van familiebetrokkenheid tijdens formele besluitvorming, meer (actieve) participatie bij het maken van beter geïnformeerde beslissingen, of het geven van psycho-educatie aan familie. Deze deelstudie laat zien dat familie en zorgverleners vaak verschillend werden benaderd binnen de interventies, wat duidt op afwezigheid van gelijkwaardigheid en wederkerigheid tussen beide. Dit maakt het moeilijk om echt partnerschap aan te gaan. Daarnaast zijn de effecten van de programma's op familiebetrokkenheid en partnerschap vaak onbekend. Ook werden er verschillende uitkomsten gemeten die niet altijd in lijn liggen met de doelstelling van de beschreven interventies, waardoor beoordeling van effecten moeilijk is. Dit onderzoek suggereert dat maar weinig interventies gebruikt kunnen worden als basis voor het faciliteren van gelijkwaardig partnerschap tussen naasten en zorgverleners in het verpleeghuis. Er kan worden afgeleid dat gelijkwaardigheid en wederkerigheid tussen zowel naasten als zorgverleners belangrijke componenten zijn voor een dergelijk programma om partnerschap te faciliteren.

**Hoofdstuk 5** beschrijft een kwalitatieve studie naar de ervaringen van naasten van verpleeghuisbewoners met dementie met samenwerking met zorgverleners. Er zijn 30 semigestructureerde interviews gehouden met naasten van verpleeghuisbewoners met dementie om inzicht te krijgen in hoe zij de huidige samenwerking met zorgverleners ervaren. Analyse van de data laat drie hoofdthema's zien, i.e., "communicatie", "vertrouwen en afhankelijkheid" en "betrokkenheid". De bevindingen laten zien dat goede communicatie tussen naasten en zorgverleners een voorwaarde is voor het hebben van vertrouwen in zorgverleners en de kwaliteit van de betrokkenheid in het leven van de bewoner. Naasten blijken het belangrijk te vinden om frequent en informeel contact te hebben met zorgverleners om een persoonlijke relatie aan te kunnen gaan. Deze deelstudie laat zien dat die persoonlijke relatie het vertrouwen in zorgverleners en tevredenheid rondom hun betrokkenheid in het verpleeghuis kan vergroten. De bevindingen van deze deelstudie impliceren dat informeel contact en het opbouwen van een persoonlijke relatie essentieel zijn voor het verbeteren van samenwerking en het opbouwen van partnerschap tussen naasten en zorgverleners prioriteit zouden moeten hebben in het verpleeghuis.

**Hoofdstuk 6** beschrijft de bevindingen van een procesevaluatie van een nieuw ontwikkeld partnerschap programma, dat zich richt op het faciliteren en ondersteunen van partnerschap tussen naasten van verpleeghuisbewoners met dementie en zorgverleners, met als doel het verbeteren van de eigen regie en het welzijn van bewoners. Het programma is ontwikkeld op basis van de resultaten van de literatuuronderzoek, beschreven in hoofdstuk 4, en is ontwikkeld in co-creatie met cliëntenraden, beleidsmedewerkers van verpleeghuizen en experts op het gebied van verpleeghuiszorg. Het programma bestond uit maandelijkse bijeenkomsten van 90 minuten waarbij 10 naasten en zorgverleners gezamenlijk oplossingen zochten voor de uitdagingen rondom eigen regie in het dagelijks leven van verpleeghuisbewoners. Deze deelstudie maakte gebruik van meerdere methoden om de haalbaarheid en uitvoerbaarheid van het programma te evalueren. Hierbij is gekeken naar aanwezigheid en (actieve) deelname van participanten (naasten en zorgverleners), uitvoering van het programma volgens plan en meningen van participanten over het programma. Het programma bestond uit maandelijkse bijeenkomsten van 90 minuten, waarbij naasten van verpleeghuisbewoners met dementie en zorgverleners gezamenlijk bijeenkwamen om problemen en/of uitdagingen in de huidige zorg aan te pakken. Dit deden ze door oplossingen te bedenken voor problemen in het dagelijks leven van bewoners en deze in de dagelijkse praktijk uit te voeren. Het programma is na negen maanden geëvalueerd en liet

zien dat het grotendeels volgens plan is verlopen en dat de deelname van de participanten hoog was. Daarnaast waren participanten actief betrokken in het programma, ervoeren zij voordelen van het programma en waren tevreden met het programma. Participanten gaven aan dat ze het programma voort wilden zetten op de eigen verpleeghuisafdeling en zouden de implementatie van het programma op andere verpleeghuisafdelingen aanbevelen. Daarnaast bleek het programma naast en zorgverleners te stimuleren om actiepunten, met betrekking tot verbetering van de eigen regie en welzijn van bewoners, te bedenken en in te voeren. Het programma lijkt veelbelovend in het ondersteunen van partnerschap en het voorzien in de behoeften van zowel bewoner, naaste en zorgverlener. Ondersteuning van het management lijkt van belang te zijn bij de implementatie van het programma. Vervolgonderzoek is nodig om de effectiviteit van het programma te evalueren.

In **Hoofdstuk 7** worden de belangrijkste bevindingen van de deelstudies van dit proefschrift beschreven. Het onderzoek heeft aangetoond dat de eigen regie van verpleeghuisbewoners met dementie op verschillende manieren ondersteund kan worden door zorgverleners, familieleden en de omgeving. Samenwerking en partnerschap tussen naasten en zorgverleners ontstaat niet zomaar, daar is een actieve aanpak voor nodig. Voor dit proefschrift is een programma ontwikkeld dat veelbelovend lijkt te zijn in het structureel faciliteren van samenwerking en partnerschap tussen naasten en zorgverleners. Daarnaast wordt in dit hoofdstuk de algehele discussie beschreven en geeft het een overzicht van de sterke punten en beperkingen van dit proefschrift. Ook worden er aanbevelingen gedaan voor de praktijk en vervolgonderzoek.





# VALORIZATION



This chapter elaborates on the societal value of this dissertation's findings. It describes how this research may contribute to the improvement of quality of care in Dutch nursing homes. Furthermore, it describes the dissemination of findings.

This dissertation was embedded within nursing home practice through its development within the Living Lab in Aging and Long-Term Care. This is a formal multidisciplinary network consisting of Maastricht University, seven large long-term care organizations, Gilde Intermediate Vocational Training Institute and Zuyd University of Applied Sciences, VISTA College, all located in the southern part of the Netherlands. Through structural multidisciplinary collaboration between research, policy, education and practice, it aims to improve the quality of long-term care in nursing homes and embed scientific research in everyday practice. This dissertation's studies were initiated by, and in close collaboration with, different partners within the Living Lab. We held regular meetings with nursing homes' client councils, policy makers and experts in the field to maximize the fit between research and practice. All were closely involved in the research process, informing and advising the researchers, among others, of research ideas, the planned approach, implementation strategies and interpretation of the results.

Policy in Dutch nursing home care organizations, including those that are part of the Living Lab, is aimed at providing care according to residents' preferences in order for residents to continue the life they had before. Although this person-centered approach is promoted in nursing homes in Western countries, there are opportunities left unused to address residents' autonomy. Especially in dementia care, it is even more challenging to know what residents need and provide care that supports their autonomy. Residents with dementia may face difficulties voicing their needs and may rely on others for help. Therefore, there is a need for relationship-centered care in which interpersonal relationships between residents, family caregivers and staff are central to providing nursing home care.

Our results indicate that relationships within the dementia care triad can be improved to support resident autonomy. In order to improve a range of aspects of residents' daily life, the National Health Care Institute ("Zorginstituut Nederland") published a quality framework for nursing homes in the Netherlands ("Kwaliteitskader verpleeghuiszorg"). This framework presents norms for a range of themes that regard provision of current nursing home practice. The framework consists of eight themes, of which four focus on content (i.e. "Person-directed care and support," "Living and well-being," "Safety," and "Learning and improving quality of care") and four on process (i.e. "Leadership, governance and management," "Nursing care staffing," "Use of resources," and "Use of information"). It provides certain guidelines for each theme while giving nursing home care organizations freedom to decide how they implement strategies that correspond to these. The framework provides guidelines; however, it still might be a struggle for nursing home staff, family caregivers and residents to give a meaningful interpretation of the recommendations in current practice. Our studies mainly provide practical implications for the themes "Person-directed care and support" and "Living and well-being," and will be elaborated upon hereafter.

#### *Person-directed care and support*

Our results showed that if staff puts effort into engaging residents in choice, residents responded more often than when care activities were performed out of routine. Residents with severe dementia were capable of indicating choice as long as nursing staff gave them a chance to be involved in the care activity. As the quality framework prescribes, efforts should be made to make real contact, knowing how to personally appeal to the resident, let the resident know they are being seen. Our research findings are in

line with the framework stating that real contact, knowing the person and their preferences, acknowledging the other as a person, are essential for residents and their loved ones. Personal attention can be given to residents by focusing on communication strategies that acknowledge residents as persons: speaking calmly and clearly, having patience and giving the resident a chance to react, and making eye contact. In addition, in order to improve the staff-family relationship, there is a need for more frequent contact and informal conversations that can enhance personal relationships.

In addition, according to the quality framework, “person-directed care and support” regards the way in which residents are at the center of care provision, in order to contribute most optimally to residents’ quality of life. Following the norms within this theme, care providers’ approach should be focused on residents’ wishes and care plans should be made as soon as residents move into a nursing home. Even though using care plans can be an effective way to shape communication between staff, it runs the risk of being used mistakenly as a fixed guideline for residents’ wishes. Moreover, making care plans within a short period of time hampers getting to know the resident due to the short time period in which care plans should be made. This may erroneously enforce centralizing the care plan over residents’ daily needs and wishes. This might further result in institutionalization in which the resident becomes unfamiliar with having choices over daily things and staff performing care based on what once was documented as the resident’s preference.

#### *Living and well-being*

The quality framework refers to “Living and well-being” as the way in which nursing home care staff and nursing home care organizations focus on, improve and support residents’ optimal quality of life and well-being, and that of their loved ones, in the provision of care. Our studies suggest that many family caregivers do not always feel at home or welcome in the nursing home. Pursuing existing relationships, routines and habits with residents, feeling welcome in the nursing home, and being able to do whatever they want to do with/for their loved one are important. The current description in the quality framework does not carry out this message explicitly, nor does it provide sufficient tools to establish staff-family partnership. The framework’s subthemes “meaningful activities” and “family participation” need more attention for relationship-centered care. For example, it states that “caregivers provide space for family to participate.” This implies that it is a one-way process in which the nursing home holds a dominant role and may facilitate task-centeredness. For instance, it states that “the policy on family participation is written down and familiar for family and staff.” It implies an already established view, predominated by the nursing home and does not encourage opening up the conversation with family caregivers. Furthermore, statements such as “family’s tasks and responsibilities are clear,” are relatively task-centered, and implies no space for active discussion, nor does it seem to enhance family’s well-being. As families have been seen as visitors in the nursing home for a long time, these statements might still not encourage nursing home care organizations to develop new ways to establish equal staff-family partnership. Family participation can be used as a concept in which nursing homes expect that family



caregivers participate in more activities as a substitute for understaffing. Instead, it is needed to include family in order to increase residents' well-being.

In order to enhance relationship-centered care, active interventions are needed to establish family-staff partnerships. Our partnership program may be used, as it focuses on staff-family partnerships that aim to bring nursing home staff and family together. The program contains elements of reciprocity and working together in order to improve resident autonomy. Moreover, it focuses on improving communication and sharing of responsibilities. Nursing home ward managers could introduce our program to facilitate staff-family partnership, as it appeared promising. The process evaluation showed that the program was feasible within daily nursing home practice. Both staff and family caregivers were satisfied with the program content, experienced benefits for themselves and for residents, and worked together to increase support for resident autonomy.

#### *Originality of the research: innovative elements*

This dissertation has several innovative elements regarding research into the support of the autonomy of nursing home residents with dementia. First, Chapter 2 describes the first study on how and to what extent the autonomy of residents with dementia is supported within interactions with staff. Although explorative in nature, the newly developed observation list is the first to provide insight into staff approach and residents' reactions during care activities. Results of this study may encourage nursing home staff to look critically at their working routines in order to improve the support of resident autonomy. Future research can build on our observation study to improve support for resident autonomy and develop new instruments that capture how autonomy is supported within interpersonal relations.

Second, in order to provide good dementia care, it is important to incorporate all perspectives within the dementia care triad, i.e. those of residents, family caregivers and staff. Previous research has mostly focused on staff's view of different aspects of nursing home care for people with dementia. Chapters 3 and 5 of this dissertation present our studies into the experiences of family caregivers of nursing home residents with dementia on the support of autonomy, and on collaboration with staff. As nursing homes increasingly focus on relationship-centered care, the results of our studies contribute to the current knowledge by providing important information on elements that can enhance the relationship between family and staff.

Third, we developed an initial program that aims to facilitate staff-family partnership in order to increase resident autonomy and well-being, which is described in Chapter 6. Even though programs have been developed to stimulate staff-family collaboration, our innovative program contains elements that are in line with relationship-centered care, such as reciprocity, equality, and respect. Based on the feasibility test we performed, it can be seen as a promising program that can provide a basis for implementation in current nursing home practice to facilitate staff-family partnership.

#### *Dissemination of findings*

This dissertation's findings are disseminated for scientific purposes and for practice. As a start, our research was disseminated through publication in peer-reviewed, international journals, and presented at several international conferences. Furthermore, as the research was embedded in the Living Lab, regular updates on findings were given through quarterly meetings with policy makers, experts, and client councils. In addition, findings were presented at the wards that participated in the research. Also,

interviews were given for local magazines published by the nursing home care organizations. Next, results were disseminated by collaborating with an innovative network platform that encourages improvement of Dutch nursing home care (LOC). Presentations on findings were held during national meetings initiated by the LOC.

In order to further disseminate this dissertation's findings, a fact sheet will be made and distributed among all care organizations that take part in the Living Lab. People from outside of the Living Lab can take notice of the findings by reading this dissertation, or the summary of this dissertation that will be published on the website of the Living Lab in Aging and Long-Term Care (<http://www.academischewerkplaatsouderenzorg.nl>).

Finally, in order to encourage the practical use of the developed instrument and program, efforts will be made to further develop the guidelines for the observation method and the partnership program, including that of the process facilitators.





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## **ABOUT THE AUTHOR**





Linda J.M. Hoek, born on November 15, 1989, in Geesteren, finished her bachelor physiotherapy at Hogeschool Saxion in 2012 and finished her master health psychology at Universiteit Twente in 2015. During her study, Linda worked as a student assistant at the faculty of Behavioural Management and Social sciences, and research assistant at Medisch Spectrum Twente, Enschede. In September 2015, she started as a PhD candidate at the Maastricht University, at the department of Health Services Research within the CAPHRI Care and Public Health Research Institute. Her research was conducted from the Living Lab in Ageing and Long-Term Care, a structural and interdisciplinary partnership between Maastricht University, Zuyd Hogeschool, Gilde Zorgcollege, VISTA college, and 7 long-term care organizations: MeanderGroep Zuid-Limburg, Sevagram, Envida, Cicero Zorggroep, Zuyderland, Mosae Zorggroep en Vivantes. Hoek focused on the support of autonomy of nursing home residents with dementia through establishing a partnership between family and nursing home staff. Her research aimed on gaining insight in how and to what extent the autonomy of residents with dementia living in nursing homes is supported, and how a partnership can be created between family and nursing staff to increase resident autonomy. Linda developed, conducted and reflected upon the research in co-creation with nursing home residents, their family members, nursing home staff, client councils and other experts in the field. She focused on integrating relational autonomy, which entails respecting residents' individuality within the social context and relationships, in practice. Linda presented her work at different national and international conferences. During her PhD project, she was involved in the organization of the European Doctoral Conference in Nursing Science (EDCNS) in Maastricht in 2018. She was also involved in education as a tutor and supervised Bachelor students during their thesis at the faculty of Health, Medicine and Life Sciences.

Linda is married to Krijn, and recently, they became loving parents of their little baby boy Hugo. Together with their dog, they live in Enschede.



# SCIENTIFIC PUBLICATIONS



## ARTICLES

**Hoek LJM**, Van Haastregt JCM, Backhaus R, Hamers JPH, Verbeek H. "Because we both care": Process evaluation of a program to create family-staff partnership in the care for nursing home residents with dementia. *Submitted for publication*

Backhaus R, **Hoek LJM**, De Vries E, Van Haastregt JCM, Hamers JPH, Verbeek H. Interventions to Foster Family Inclusion in Nursing Homes for People with Dementia: A Systematic Review. *Accepted for publication in BMC Geriatrics*

**Hoek LJM**, Van Haastregt JCM, De Vries E, Backhaus R, Hamers JPH & Verbeek H. Partnerships in Nursing Homes: How Do Family Caregivers of Residents with Dementia Perceive Collaboration with Staff? *Dementia*, 2020. <https://doi.org/10.1177/1471301220962235>

**Hoek LJM**, Verbeek H, De Vries E, Van Haastregt JCM, Backhaus R & Hamers JPH. Autonomy Support of Nursing Home Residents With Dementia in Staff-Resident Interactions: Observations of Care. *Journal of the American Medical Directors Association*, 2020. <https://doi.org/10.1016/j.jamda.2020.04.013>

**Hoek LJM**, van Haastregt JCM, de Vries E, Backhaus R, Hamers JPH & Verbeek H. Factors influencing autonomy of nursing home residents with dementia: the perception of family caregivers. *The Journal of Nursing Home Research*, 2019;5:33-39. <https://doi.org/10.14283/jnhrs.2019.7>

## CONFERENCE ABSTRACTS

**Hoek LJM**, Verbeek H, De Vries E, Van Haastregt JCM, Backhaus R & Hamers JPH. The Support of Autonomy for Nursing Home Residents with Dementia: Observation of Morning Care. GSA Annual Scientific Meeting, November 13-17, Austin, TX, USA.

**Hoek LJM**, Verbeek H, Van Haastregt JCM, De Vries E, Backhaus R & Hamers JPH. Factors influencing autonomy of nursing home residents with dementia: the perception of family caregivers. GSA Annual Scientific Meeting, November 14-18, Boston, MA, USA.

**Hoek LJM**, van Haastregt JCM, de Vries E, Backhaus R, Hamers JPH & Verbeek H. Contributing factors to autonomy for Nursing home residents: a qualitative study to explore the perception of family caregivers of relatives with dementia. Nursing home research International working group, Long-term care research, September 13-14, 2018, Rome, Italy.

**Hoek LJM**, Van Haastregt JCM, Verbeek H, De Vries E, Backhaus R & Hamers JPH. Factors influencing autonomy of nursing home residents with dementia: the perception of family caregivers. European Doctoral Conference in Nursing Science, June 22-23, 2018, Maastricht, The Netherlands.



# **LIVING LAB IN AGEING AND LONG-TERM CARE**





### **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, seven long-term care organizations (Cicero Zorggroep, Envida, Mosae Zorggroep, MeanderGroep Zuid-Limburg, Sevagram, Vivantes and Zuyderland), 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 ZUID-LIMBURG**

Dit proefschrift is onderdeel van de Academische Werkplaats Ouderenzorg Zuid-Limburg, een structureel, multidisciplinair samenwerkingsverband tussen de Universiteit Maastricht, zeven zorgorganisaties (Cicero Zorggroep, Envida, Mosae Zorggroep, MeanderGroep Zuid-Limburg, Sevagram, Vivantes en Zuyderland), 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 ouderen zorg 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.

**PHD-THESES LIVING LAB IN AGEING AND LONG-TERM CARE/PROEFSCHRIFTEN ACADEMISCHE WERKPLAATS OUDERENZORG ZUID-LIMBURG**

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- Sandra Zwakhalen. Pain assessment in nursing home residents with dementia. 2007

