# **PROTOCOL**



# Nursing home care for people with dementia: Update of the design of the Living Arrangements for people with Dementia (LAD)-study

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## **Abstract**

**Aim:** The aim of the current study is to describe the extended design of the Living Arrangements for people with Dementia (LAD)-study.

**Background:** The demand for long-term care in care homes increases with the growing number of people with dementia. However, quality of care in care homes needs improvement. It is important to monitor quality of care in care homes for the purposes of conducting scientific research, providing input for policy, and promoting practice improvement.

**Design:** The Living Arrangements for people with Dementia -study monitors changes in - quality of - care in care homes since 2008. With its extended design, the Living Arrangements for people with Dementia -study now also focuses on additional topics that are considered to improve quality of care: implementation of person-centred care, involvement of family carers and volunteers and reducing psychotropic drugs and physical restraints using a multidisciplinary approach.

**Methods:** The data collection of the Living Arrangements for people with Dementia -study entails an interview with the manager and questionnaires are completed by care staff, family carers, volunteers, and multidisciplinary team members. This study is partly funded by the Dutch Ministry of Health, Welfare and Sports, grant number 323,088 and partly funded by the participating care homes.

**Discussion:** Results of the Living Arrangements for people with Dementia -study will shed more light on variables related to quality of care in care homes for people with dementia.

**Impact:** Based on the obtained information, appropriate efforts to improve quality of care can be discussed and implemented. Furthermore, the results of this study guide policy making, because it expands knowledge about the effects of changing policies and exposes topics that need further attention.

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#### KEYWORDS

care home, dementia, informal care, long-term care, nursing, person-centred care, physical restraints, psychotropic drugs, quality of care, study protocol

#### 1 | INTRODUCTION

The number of people with dementia is rapidly increasing worldwide. In 2015, there were 47 million people living with dementia and this number will increase up to 132 million in 2050 (World Health Organization, 2017a). Along with this increase, the demand on longterm healthcare services for people with dementia at home and in care homes increases (World Health Organization, 2012). However, quality of care in many care homes needs improvement (Prince, Comas-herrera, Knapp, Guerchet, & Karagiannidou, 2016; Tolson et al., 2011). The Living Arrangements for people with Dementia (LAD-) study monitors and evaluates trends in quality of care for people with dementia in care homes and related variables since 2008 (Willemse, Smit, de Lange, & Pot, 2011). This is important for improving quality of care and substantiating and guiding policy (Prince, Prina, & Guerchet, 2013). The extended design of the LAD-study, focusing on three important themes that improve quality of care, is described in this paper.

#### 2 | BACKGROUND

National policies on dementia care have focused on several themes to improve quality of care for people with dementia in the last decade. These themes include the implementation of person-centred care, involvement of family carers and volunteers and reducing psychotropic drugs and physical restraints using a multidisciplinary approach (Brooker, 2007; International Psychogeriatric Association, 2012; Van Rijn, 2015; World Health Organization, 2012; Zwijsen et al., 2014). These themes are prominent in the later measurement rounds of the LAD-study and will be further described below.

Providing person-centred care in care homes has received considerable attention over the past years, because it is associated with high quality care (Simmons & Rahman, 2014). Therefore, this subject has become one of the main themes in the LAD-study. Person-centred care not only seems to benefit residents, but also care staff. For example, it has been found to reduce challenging behaviour and depression and improve quality of life in people with dementia (Kim & Park, 2017). In addition, a systematic review has shown a positive influence of person-centred care on job satisfaction and working conditions of care staff (Brownie & Nancarrow, 2013). However, the implementation of person-centred care is a considerable challenge for many long-term care service providers (Grabowski, Elliot, Leitzell, Cohen, & Zimmerman, 2014; World Health Organization, 2012).

Implementing person-centred care in care homes requires a culture change (Grabowski et al., 2014; Koren, 2010). This demands a shift in the philosophy of care from a medical to a person-centred model, which focuses on psychological needs, well-being, and quality of life of people with dementia (Grabowski et al., 2014; White-Chu, Graves. Godfrey, Bonner, & Sloane, 2009; World Health Organization, 2012). Research has revealed several key values, attitudes, and behaviours that contribute to successfully implementing person-centred care (Killet et al., 2014). For example, leadership and management changes, having a shared vision on providing good person-centred care (i.e. philosophy of care), making sure residents engage in meaningful activities, empowering care staff and changes in the physical environment (i.e. a more home-like environment) (de Boer, Hamers, Zwakhalen, Tan, & Verbeek, 2017; Brownie & Nancarrow, 2013; Grabowski et al., 2014; Killet et al., 2014; Kim & Park, 2017; Koren, 2010; Te Boekhorst, Depla, De Lange, Pot, & Eefsting, 2009; Verbeek, van Rossum, Zwakhalen, Kempen, & Hamers, 2009). It is important to study both the actual person-centredness of the care provided and these key values, attitudes, and behaviours to advance and improve the implementation of person-centred care in care homes.

Another theme that has developed to become an eminent theme in the LAD-study is the involvement of family carers and volunteers in care homes. Their involvement has also been demonstrated to contribute positively to quality of care, for example by improving person-centred care (Gaugler, 2005; Gilster, Boltz, & Dalessandro, 2018; van der Ploeg, Walker, & O'Connor, 2014; Pot & Petrea, 2013; World Health Organization, 2017b). Research indicates that family carers can contribute to creating a home-like environment in a care home which improves well-being and quality of life of people with dementia (Gaugler, 2006; Greene & Monahan, 1982; Mitchell & Kemp, 2000). Most family carers maintain their role as care provider after the admission of their family member with dementia to a care home (Bowers, 1988; Gaugler, Pearlin, & Zarit, 2003; Gladstone, Dupuis, & Wexler, 2006). Concurrently, family carers continue to experience high levels of stress and burden caused by, amongst other things, conflict with care staff (Chen, Sabir, Zimmerman, Suitor, & Pillemer, 2007; Gaugler, Pot, & Zarit, 2007). This might lead to dissatisfaction of family carers with the care home (Tornatore & Grant, 2002). A protective factor of decreased psychological well-being of family carers seems to be the cognitive mechanism self-efficacy. This mechanism refers to the belief in the family carers' own capacity to adequately and confidently act in various situations with regards to their family member with dementia (Bandura, 1977; Grano, Lucidi, & Violani, 2017). Long-term care providers often struggle to on the one hand involve family carers as much as possible in - decisions about - the care for and the life of their relative with dementia, but on the other hand prevent them from perceiving high levels of caregiver burden. In the past years, the interest in involving volunteers in care homes has also increased. Some studies have shown promising results, for example, volunteers can build relationships, enhance occupation, preserve personhood and engage in personcentred one-on-one interactions with residents with dementia (Damianakis, Wagner, Bernstein, & Marziali, 2007; van der Ploeg, Mbakile, Genovesi, & O'Connor, 2012). More research is needed into the characteristics and work experiences of volunteers to examine how they are associated with quality of care.

Finally, there has been increasing attention in the LAD-study for a multidisciplinary approach around the use of psychotropic drugs and physical restraints. Reason for this is that they are still frequently prescribed for the treatment of challenging behaviour of residents with dementia in care homes, even though adverse effects are well-known (de Bellis et al., 2013; Hofmann & Hahn, 2014; Kirkham et al., 2017; Lapeyre-Mestre, 2016; Zdanys, Carvalho, Tampi, & Steffens, 2016). Several studies have therefore underlined the need for the reduction of psychotropic drugs and physical restraints and various campaigns have attempted to achieve this (de Bellis et al., 2013; Feng et al., 2009; Kirkham et al., 2017). To first consider psychosocial interventions and implement a multidisciplinary decision-making process for the prescription of psychotropic drugs and physical restraints is known to improve treatment of challenging behaviour and is therefore seen as an aspect of good quality of care (de Casterlé, Goethals, & Gastmans, 2014; International Psychogeriatric Association, 2012; Macaden, 2016; Zwijsen et al., 2014). Further research is needed to discover motivations for using these means for the treatment of challenging behaviour and to aim for the implementation of a multidisciplinary decision-making process when approaching challenging behaviour.

#### 3 | THE STUDY

# 3.1 | Aims

The aims of the LAD-study are: to provide input for and evaluate policy on important themes for improving quality of care in care homes and to provide insight in positive and worrisome developments in the provided care in care homes for people with dementia; to conduct scientific research and add to the knowledge on what variables contribute to achieving high quality care in care homes and; to instigate practice improvement by providing participating care homes with a benchmark as a source of information for internal quality improvement.

# 3.2 | Design

The LAD-study is a cross-sectional monitoring study. Data collection is carried out in different care homes throughout the

Netherlands. The study has been repeated every two or three years since 2008 (Willemse et al., 2011) and is still ongoing. During the first (2008-2009), second (2010-2011), third (2013-2014) and fourth (2016-2017) measurement cycles, respectively 136, 144, 47, and 49 care homes participated in the study. The decreased number of participants in the two most recent measurement cycles is caused by a change in the funding of the study. Previously, the study was completely financed by the Ministry of Health. Welfare and Sport, whereas during the last two measurement cycles, care homes needed to co-finance their participation. An advisory board, consisting of researchers, representatives of care homes and representatives of the Ministry of Health, Welfare and Sports, contributes to the design of the study in each measurement cycle and reviews the research protocols before the start of the data collection. Every measurement cycle, all care homes providing nursing home care to people with dementia in the Netherlands, including previouslyparticipating care homes, are approached to participate in the new measurement cycle. In the current paper, the extended design of the fourth measurement cycle (2016-2017) is described.

#### 3.3 | Ethical considerations

For the purposes of the LAD-study, the usual daily practice in care homes is studied. There are no experimental conditions and data on residents is gathered through observations of care staff, meaning that the study does not cause any inconvenience for residents. The LAD-study therefore does not come in the scope of the Medical Research Involving Human Subjects Act (WMO) (Willemse et al., 2011). This is confirmed by the medical-ethics committee of the University Medical Center Utrecht (reference number WAG/ om/13/055932). The ethical committee of the research institute has furthermore determined that the study meets the ethical standards. Research Ethics Committee approval has been received every measurement cycle. Care staff, family carers, multidisciplinary team members, volunteers and managers voluntarily and anonymously participate in the study. Data containing personal information is never obtained and can therefore never be used to identify an individual participant.

Participants receive an information letter or email with a description of the aim of and general information about the study. In this letter, it states that the participant can choose not to take part in the study by not returning or not completing the questionnaire, without any consequences. All family members and care workers are also informed about the study in general by information flyers, which are sent to the care homes to distribute.

# 3.4 | Recruitment

First, in October 2015, 1,728 care homes belonging to 363 care organizations were approached by mail with an invitation to participate in the fourth measurement cycle of the LAD-study. These care homes were all listed by the Dutch Ministry of Health, Welfare and Sport because they have a 'Psychiatric Hospitals

Compulsory Admissions Act' (BOPZ) acknowledgement. In addition, care homes without this acknowledgement were approached through the existing network of the researchers and through an umbrella organization by telephone. When several care homes belonged to a broader care organization, the management of the care organization was approached instead of all individual care homes. In addition, social media was used to inform care homes about the study.

# 3.5 | Study population

Managers of participating care homes were interviewed by trained research assistants. Care staff (e.g. (certified) nursing assistants) and multidisciplinary team members (e.g. physicians, psychologists and paramedics) at units for people with dementia were asked to participate in the study and invited to complete an online questionnaire. Care staff in training and nutrition assistants were excluded from the study.

Subsequently, residents and their first representatives were randomly selected. A minimum of twelve participants (per unit) and a maximum of one third of the residents in the care home (or unit) were selected. When there were less than twelve residents living in the care home, they were all selected to participate in the study. Which residents were in the sample, was unknown to managers and care staff. The primary care worker of each resident was invited to complete an online questionnaire about the resident. It was possible that one primary care worker completed more than one questionnaire, because they were responsible for multiple residents. The first representative of the resident in the sample was invited to complete a paper-and-pencil questionnaire, which could be returned by mail. In addition, physicians of the participating care homes were asked to complete a questionnaire on prescribed psychotropic drugs and physical restraints for each of the residents in the sample and for all residents of the care home together.

Further, activity involvement of a random sample of four residents per care home (or per unit) was observed by two care workers. Finally, volunteers who were involved with residents with dementia in the care homes were invited to participate in the study, with a minimum of twelve participants (per unit) and a maximum of one third of the volunteers working in the care home (or unit). When there were less than twelve volunteers working in the care home, they were all selected.

# 3.6 | Procedure

Data collection took place from May 2016–February 2017. Data were collected by researchers and research assistants of the research institute. Research assistants were master students - Psychology and Contemporary Social Problems - from various universities that were trained by the researchers. Furthermore, they received an elaborate written instruction and various checklists to ensure that the procedure of data collection was carried out correctly. The first two times research assistants visited a care home,

they were accompanied by one of the researchers or another experienced research assistant. After that, they visited the care homes by themselves. Research assistants had regular supervision sessions with the researchers.

During the visit, the research assistant conducted an interview with the manager, randomly selected residents and sent questionnaires to care staff, family carers, volunteers, and multidisciplinary
team members. Care staff and multidisciplinary team members received an information- and invitation letter with login information for
the online questionnaire. Family carers and volunteers were invited to
complete a paper-and-pencil questionnaire. Care staff, family carers,
multidisciplinary team members, and volunteers who participated in
the study, could send their contact information to the researchers to
win a gift card. One gift card per unit or per care home, in case there
were no separate units, was randomly awarded to the different participant groups (one for care staff, one for family carers, etc.). The research
assistant observed the physical environment in the care home using a
checklist and instructed two members of care staff (per unit) to observe the activity involvement of residents in the sample.

Prior to the visit, the manager received information from the researchers regarding the study and a checklist with preparations (consisting of a request for e.g. an overview of names of care staff, residents and family carers). Approximately six months after the visit, the care homes received a benchmark report, where the results of the care home were presented in combination with (aggregated) results of other participating care homes and, if applicable, with results of the care home from previous measurement cycles. In the benchmark report, additionally, a comparison between units was made when multiple units had participated in the study. The benchmark report was presented and discussed in a separate meeting by the researchers in the respective care homes (e.g. to the board of directors, management, care staff, volunteers, etc.). The care homes remained anonymous for other participating care homes in the benchmark reports and in other publications about the study.

#### 3.7 | Measures

Table 1 provides an overview of all variables that were investigated during the four measurement cycles of the LAD-study, regarding the themes of interest: implementation of person-centred care, involvement of family carers and volunteers and reducing psychotropic drugs and physical restraints using a multidisciplinary approach. These variables will be described in detail in the following paragraphs.

# 3.7.1 | Implementation of person-centred care

To measure the level of person-centred care in the care home from different perspectives, the Person Centered Care questionnaire (PCC; Porock & Chang, 2013) was completed by family carers (30 items), care staff (34 items) and multidisciplinary team members (25 items). The PCC is scored on a 5-point Likert scale, ranging from 1 'almost none of the time' to 5 'almost all of the time'. A higher score indicates more person-centred care.

 TABLE 1
 Measures and operationalizations in four measurement cycles of the LAD-study, regarding the three prominent themes

			suremen		Respondent	
Measure	Operationalization	1	2	3	4	type
Person-centred care						
Approach to dementia	ADQ (74)	Χ	Χ	X	Χ	CS, MTM
Level of person-centred care in	PCC care staff (34-items) (47)			Х	Х	CS
the long-term care home	PCC family carers (30-items) (47)			X	Χ	FC
	PCC care staff (25-items) (47)				Χ	MTM
Person-centredness of care staff	P-CAT (75)		Χ	Х		CS
Group living home characteristics	Characteristics of group living home care questionnaire (76)	Χ	Х	Х	Χ	IM
Characteristics of the physical	Physical environment evaluation		Χ	Χ		OBS
environment	Component of dementia care mapping (PEEC-DCM; Chaudhury, Cooke, Frazee, Rowles, & Bernard, 2013; Smit, Willemse, de Lange, & Pot, 2014)					
	Checklist for standardized observations of the environment (55)				Χ	OBS
Satisfaction with team collaboration	13-item Satisfaction with team collaboration questionnaire				Χ	CS
Transformational leadership	Global transformational leadership scale (51)		Χ	Χ	Χ	CS
Leadership characteristics	23-item Leadership characteristics questionnaire (52)				Χ	CS
Unity in philosophy of care	7-item unity in care philosophy questionnaire (53,54)		Χ	Χ	Χ	CS, MTM
Involvement in activities	Type of activities (48,79) and duration			Х	Χ	QR
Well-being during activities	Level of well-being (positive mood-negative mood)			Χ	Χ	QR
Level of attention during activities	Level of attention (much attention-no attention)			Х	Χ	QR
Involvement in activities during previous 3 days	Subscale from MDS:RAI (49)	Х	Χ	Х	Χ	QR
Activities of family carer with their family member (and other residents)	Type of activities			X	Х	FC
Emotional demands and emotional	al resources of care staff					
Emotional demands and emotional resources	DISC (58)		Х	Х	Х	CS
Engagement of care staff						
Engagement in long-term care home	LQWQ subscale engagement (57)		Х	Х	Χ	CS
nvolvement of family carers and vo	lunteers					
Perceived pressure	EDIZ (59)		Х	Х	Х	FC
Self-efficacy	30-item self-efficacy questionnaire			Χ	Χ	FC
Satisfaction of family carers						
Satisfaction	Grade 0-10		Χ	Χ	Χ	FC
	Likelihood-to-recommend question		Χ	Χ	Χ	FC
Perceptions of the caregiv- ing role	FPCR (64,65)		Х	Χ	Χ	FC
Involvement of family carer in long-term care home	Number of hours per week and type of activities	Х	Х	Х	Χ	IM, FC
Involvement of volunteer in long-term care home	Hours per week and type of activity	Х	Х	Χ	Χ	IM, VQ

TABLE 1 (Continued)

			suremer			
				Respondent		
Measure	Operationalization	1	2	3	4	type
Satisfaction with volunteer work	33-item satisfaction with volunteer work questionnaire				Х	VQ
Multidisciplinary approach for redu	icing psychotropic drugs and physical restraints					
Psychotropic drugs	Type and number of times used per resident	Χ	Χ	Χ	Χ	MTM
Physical restraints	Type and number of times used per resident	Χ	Χ	Χ	Χ	IM
Description of psychotropic drugs, only after considering psychosocial interventions	1 item with response categories 'never', 'rarely', 'sometimes', 'often' and 'always'			Х	Х	MTM
Prescription of psychotropic drugs and physical restraints even though in the opinion of the physician it would be better not to	2 items with response categories 'always', 'often', 'sometimes', 'rarely' and 'never'			Х	X	МТМ
Neuropsychiatric symptoms	NPI-Q (80)	Χ	Χ	Χ	Χ	QR
Treatment of challenging behaviour	Approach, treatment and multidisciplinary co-operation				X	IM, CS, FC, VQ, MTM
Satisfaction with collaboration with multidisciplinary team	Satisfaction with temporary admission- and treatment unit- questionnaire (3 items) (68)		Х			FC
members	Satisfaction with temporary admission- and treatment unit- questionnaire (8 items) (68)			X	Х	FC, CS
Satisfaction with collaboration within the multidisciplinary team	Grade (1-10)			Х	Х	МТМ

Abbreviations: CS, care staff questionnaire; FC, family carer questionnaire; IM, interview with the manager; MTM, multidisciplinary team member questionnaire; OBS, observations by research assistant; QR, questionnaire about the resident completed by primary care worker; VQ, volunteer questionnaire;

Activity involvement of residents was measured through observations of care staff. First, residents' occupation was scored and coded in 21 standardized occupation types, based on Dementia Care Mapping and the Activity Pursuit Patterns (Bradford Dementia Group, 2005; interRAI, 2005; Smit, Willemse, de Lange, Tuithof, & Pot, 2017). Every hour residents' occupation was measured and their well-being, operationalized by the mood of the resident. Mood was scored on a 6-point Likert scale ranging from 1 'extremely positive mood' - 6 'extremely negative mood' and level of attention during the activity, which was scored on a 5-point Likert scale ranging from 1 'very focused' - 5 'no focus'. This observation was carried out during three 8-hr shifts in a 2-week period.

The Global Transformational Leadership scale (GTL) was used to measure the level of transformational leadership of the direct supervisor of care staff (Carless, Wearing, & Mann, 2000). The GTL consists of 7 items on a 5-point Likert scale ranging from 1 'rarely or none of the time' - 5 '(almost) all of the time', with a higher score indicating more transformational leadership characteristics. Additionally, a newly developed questionnaire was used to evaluate the more general leadership characteristics of the direct supervisor of the care staff. This 23-item questionnaire was based on The Aged care Clinical Leadership Qualities Framework using a 4-point Likert scale ranging from 1 'totally disagree' - 4 'totally

agree' (Jeon et al., 2015). The GTL and the new questionnaire was filled in by care staff.

A questionnaire to measure unity in care philosophy was developed by the research group based on previous findings of the LAD-study (Smit, de Lange, Willemse, & Pot, 2017). The questionnaire consists of 7 items regarding various subjects linked to the philosophy of care, such as challenging behaviour, responding to the individual needs of the resident and communication with family carers (Trimbos-institute, 2010a). Items are scored on a 5-point Likert scale, ranging from 1 'none of the time' to 5 'all of the time', with a higher score indicating more unity. The questionnaire was completed by care staff.

To measure the care environment in the care homes, a check-list was filled in by the research assistant (de Boer et al., 2018). The checklist in the current study consisted of 69-items using a 5-point Likert scale - ranging from 1 'totally disagree' – 5 'totally agree' - divided into six themes: privacy and autonomy, sensory stimulation, view and nature, facilities, orientation and routing and small-scale living homes characteristics. It is assumed that higher scores represent more positive effects from the physical environment on the residents.

The experiences of care staff with collaboration in the care staff team was measured with a newly developed, 13-item questionnaire.

The questionnaire is based on previous research (te Nijenhuis, 2012) and items are scored on a 4-point Likert scale with a range from 1 'totally disagree' – 4 'totally agree'. A higher score indicates more constructive collaboration in the team.

One subscale form the Leiden Quality of Work Questionnaire (LQWQ) was used to measure development opportunities of care staff (5 items) (van der Doef & Maes, 1999). Items are scored on a 4-point Likert scale ranging from 1 'totally disagree' – 4 'totally agree', with a higher score indicating more development opportunities. The LQWQ subscales were filled in by care staff.

Emotional job demands and emotional job resources were measured with two subscales of the Demand Induced Strain Compensation Questionnaire (DISQ) (de Jonge, Willemse, & Spoor, 2011). The two subscales both consist of three items and are scored on a 5-point Likert scale with a range from 1 '(almost) none of the time' – 5 '(almost) all of the time'. A higher score indicates either more emotional demands or more emotional resources. The DISQ questionnaire was completed by care staff. Engagement with the organization of care staff was measured using the 5-items subscale 'engagement' of the LQWQ (van der Doef & Maes, 1999).

### 3.7.2 | Involvement of family carers and volunteers

Family carers' feelings of role overload by caregiving was measured with the Self-Perceived Pressure from Informal Care (EDIZ) instrument (Pot, van Dyck, & Deeg, 1995). The EDIZ consists of 10 items, scored on a 5-point Likert scale ranging from 1 'No!' – 5 'Yes!'. A total score ranging between 0–9 and a higher score indicating more perceived pressure.

Self-efficacy of family carers was measured with a newly developed instrument based on the Dutch General Self-efficacy Scale (Teeuw, Schwarzer, & Jerusalem, 1994), Revised Scale for Caregiving Self-Efficacy (Steffen, McKibbin, Zeiss, Gallagher-Thompson, & Bandura, 2002) and Sense of Competence in Dementia Care Staff questionnaire (Schepers, Orrell, Shanahan, & Spector, 2012). The instrument consists of 37 items, scored on a 4-point Likert scale with a range from 0 'not at all' – 3 'very well'. A higher score indicates more self-efficacy.

Satisfaction of family carers with the care home was measured by a grade between 0 (terrible) – 10 (excellent). Also, family carers were asked whether they would recommend the care home to someone else when they experienced similar circumstances. This 'likelihood-to-recommend question is based on the Net Promotor Score and aims to measure customer satisfaction (Reichheld & Markley, 2011).

Perceived caregiving role of family carers was measured with the Dutch version of the Family Perceptions of Caregiving Role instrument (FPCR; Maas & Buckwalter, 1990; Trimbos-institute, 2010c). The used questionnaire consists of 15 items that are scored on a 7-point Likert scale with a range from 1 'strongly disagree' – 7 'strongly agree'. A higher score indicates that family carers perceive to have a greater role in the care for the resident.

The frequency of visits of family carers was measured by the registration of how frequently they visit their relative and what type of activities they carry out during their visits. Activities were coded in 20 standardized occupation types based on Dementia Care Mapping and the Activity Pursuit Patterns (Bradford Dementia Group, 2005; interRAI, 2005; Smit, Willemse, et al., 2017). Next, the number of hours per week that family carers are involved in the daily routines in the care home and the type of activities they carry out - coded in 17 standardized occupation types - were registered during the interview with the manager.

The involvement of volunteers was measured by registration of the number of hours per week and the type of activities volunteers carry out. Activities were coded in 17 standardized occupation types based on Dementia Care Mapping and the Activity Pursuit Patterns (Bradford Dementia Group, 2005; interRAI, 2005; Smit, Willemse, et al., 2017). Additionally, the number of hours per week that volunteers are involved in the care home and the type of activities they carry out - coded in 17 standardized occupation types - were registered during the interview with the manager.

Satisfaction with volunteering was measured using a newly developed questionnaire with 21 items that is based on the Volunteer Satisfaction Index (VSI; Galindo-Kuhn & Guzley, 2002) and a questionnaire of the federation of patient organizations about the volunteers' satisfaction with their volunteer work (Dutch patient consumer federation, 2007). The items are scored on a 4-point Likert scale ranging from 1 'totally disagree' – 4 'totally agree', with a higher score indicating more satisfaction.

# 3.7.3 | Reducing psychotropic drugs and physical restraints using a multidisciplinary approach

Physicians and psychologists were asked whether psychotropic drugs were only prescribed after considering psychosocial interventions and/or involving other professionals. Response categories were: 'never', 'rarely', 'sometimes', 'often', and 'always'. In addition, physicians were asked whether they prescribed psychotropic drugs or physical restraints for treating depressive symptoms, anxiety, or challenging behaviour under duress, even though in their opinion it would be better not to. The response categories were 'never', 'rarely', 'sometimes', 'often', and 'always'.

To evaluate whether guidelines for the treatment of challenging behaviour were being applied in care homes for people with dementia, questions were asked to the manager, care staff, family carers, and multidisciplinary team members about the approach, treatment and multidisciplinary collaboration for dealing with challenging behaviour in residents with dementia.

Satisfaction of family carers and care workers with contact with multidisciplinary team members was measured with 8 items based on the 'Satisfaction with temporary admission- and treatment unit-questionnaire', previously developed by the research institute (Trimbos-institute, 2010b). The items are scored on a 4-point Likert scale (ranging from 1 'none of the time' to 4 'all of the time') and a higher score indicating more satisfaction.

 TABLE 2
 Primary measures and operationalizations in four measurement cycles of the LAD-study

		Measurement cycle					
						Responden	
Measure	Operationalization	1	2	3	4	type	
Demographics							
Age	Years	Χ	Х	Х	Х	CS, QR, FC VQ, MTM	
Gender	Male or female	Х	Х	Χ	Х	CS, QR, FC VQ, MTM	
Marital status	Married or single	Χ	Χ	Х	X	CS, QR, VC MTM	
Referral status	Low versus high referral status (1–10)	Χ	Χ	Χ	Χ	QR	
Length of stay	Number of months	Χ	Χ	Χ	Χ	QR	
Gender of the relative with dementia	Male or female		Χ	Χ	Χ	FC	
Nationality	Dutch or other	Χ	Χ	Х	Χ	CS, VQ, MTM	
Length of service	Years	Χ	Χ	Х	Χ	IM, CS, VC MTM	
Length of employment in profession	Years	Χ	Х	Х	Χ	CS, MTM	
Educational level	No education/primary school, secondary education, or high education		Χ	Х	Χ	IM, FC, VC	
Nursing education	Type of education and level	Χ	Χ	Χ	Χ	IM, CS	
Travelling distance to the relative with dementia	Hours		Χ	Х	Χ	FC	
Relationship with the relative with dementia	Spouse, child, or other		Χ	Χ	Χ	FC	
Personal living situation	Living alone or together with someone		Χ	Χ	Χ	FC	
Sharing of the care task	Yes (with children, siblings, volunteers, or others) or no		Х	Х	Х	FC	
Function	Physician, psychologist, or other			Χ	Χ	MTM	
Participation in multidisciplinary meetings	Yes or no			Χ	Χ	MTM	
Characteristics of long-term care homes							
Demographics							
Time of existence of long-term care home	Months	Χ	Χ	Χ	Χ	IM	
Number of residents in long-term care home, per unit and per living room	Number of residents	Χ	Χ	Х	Χ	IM	
Inclusion criteria at admission	Type of criteria and number of residents refused	Χ	Х	Х	Х	IM	
Transferring criteria	Type of criteria and number of residents transferred	Х	Х	Х	Х	IM	
Use of technological aids in care and housing	Type and number of aids	Χ	Х	Х	Х	IM	
Staff ratio							
Direct care staff	Hours per week per resident	Х	Х	X	Χ	IM	
Education of direct care staff	Hours per week per educational level per resident	Х	X	Х	Х	IM	
Sickness leave during the past 6 months	Percentage	Х	Х	Х	Χ	IM	
Resignation rate	Percentage			Χ	Χ	IM	
Current vacancies	Number of vacancies		Χ	Х	Χ	IM	
Facilitating services	Fulltime equivalent per resident	Χ	Χ	Χ	Χ	IM	
Management services	Fulltime equivalent per resident	Χ	Χ	Х	Χ	IM	
Healthcare professionals services	Fulltime equivalent per resident	X	Χ	Χ	Χ	IM	

TABLE 2 (Continued)

		Measurement cycle				
Measure	Operationalization	1	2	3	4	Respondent type
Working hours of care staff	Hours per week	Х	Х	Х	Х	CS
Type of employment of care staff	Permanent appointment or flexible contract	Χ	Χ	Χ	Χ	CS
Management						
Number of managers in long-term care home	Number of managers				Χ	IM
Self-directing teams within long-term care home	Six statements about the degree in which teams are self-directing				Χ	IM
Residents						
Quality of life						
Quality of life	QUALIDEM (81)	Χ	Χ	Χ	Χ	QR
Cognitive functioning						
Cognitive functioning	CPS (82)		Χ	Χ	Χ	QR
ADL-dependency						
ADL dependency	KATZ (83)	Χ	Χ	Χ	Χ	QR
Care staff						
Well-being						
Burnout complaints	UBOS (84)	Χ	Х	Χ	Χ	CS
Job satisfaction	LQWQ subscale job satisfaction (57)	Χ	Χ	Χ	Χ	CS
Job characteristics						
Job characteristics	Four subscales of the LQWQ: job demands, autonomy, social support from manager, social support from co-workers (57)	Χ	X	X	X	CS
Intention to leave the long-term care home						
Intention to leave the long-term care home	LQWQ subscale intention to leave (57)	Χ	Χ	Χ	Χ	CS

Abbreviations: CS, care staff questionnaire; FC, family carer questionnaire; IM, interview with the manager; MTM, multidisciplinary team member questionnaire; OBS, observations by research assistant; QR, questionnaire about the resident completed by primary care worker; VQ, volunteer questionnaire;

Satisfaction with the collaboration in the entire multidisciplinary team was measured with a grade between 1 (very dissatisfied) – 10 (very satisfied), which was provided by the multidisciplinary team members.

An overview of the primary measures in the LAD-study is presented in Table 2. A detailed description of variables that were measured in the first measurement cycle has been provided by Willemse et al. (2011).

# 3.8 | Sample

A total of 49 care homes from 12 different care organizations participated in the fourth measurement cycle of the LAD-study. In Table 3, an overview is provided of the number of participating care homes, family carers, care staff, residents, multidisciplinary team members, and volunteers in the four measurement cycles.

### 4 | DISCUSSION

In this paper, the extended design of the fourth measurement cycle of the Living Arrangements for people with Dementia (LAD-)study is

**TABLE 3** Number of participants in four measurement cycles of the LAD-study

	Measurement cycle					
Participants	1	2	3	4		
Long-term care homes	136	144	47	49		
Care staff	1,180	1,145	501	589		
Residents	1,327	1,390	546	542		
Family carers	-	888	431	401		
Multidisciplinary team members	_	_	53	43		
Volunteers	_	_	_	44		

described, where 49 care homes participated between May 2016–February 2017. The extended design of the fourth measurement cycle incorporated important subjects relating to quality of care in care homes: implementation of person-centred care, involvement of family carers and volunteers and a multidisciplinary approach to reduce psychotropic drugs and physical restraints. Important topics that relate to quality of care that have not yet been covered, are for example: effects of person-centred care on quality of life of residents

and quality of care; predictors for and consequences of the involvement of family carers and volunteers in care homes and predictors for and consequences of psychotropic drugs and physical restraint use.

The results of the ongoing monitoring LAD-study will not only contribute to the scientific literature on quality of care in care homes, but are also highly relevant for policy guidance and practice improvement. Moreover, monitoring and evaluating dementia care is profoundly important and is part of the global action plan on the public health response to dementia (World Health Organization, 2017c). With the collected data, important information can be provided on quality of care for policy makers, service providers and care staff in care homes. This has already been demonstrated by previous research based on data from the LAD-study on predictors of well-being and person-centredness of care staff and activity involvement and quality of life of residents (Smit, 2018; Willemse, 2016).

# 5 | CONCLUSION

The results of the LAD-study will provide insight in trends and developments regarding important factors contributing to quality of care in care homes. Barriers and facilitators for care homes in achieving high quality care might be revealed (e.g. reasons that care homes struggle to implement person-centred care, differences in involvement of family carers and volunteers and explanations for the undiminished prescription of psychotropic drugs). Also, the study will expose issues that need further consideration. In addition, because many topics that are relevant for delivering high quality care are measured in the LAD-study since the first measurement cycle, knowledge about the effects of changing policies in long-term care for people with dementia in care homes is extended throughout the years. The LAD-study provides insight in whether or not governmental investments and changing policies have the anticipated effects. Finally, the outcomes of the LADstudy influence decisions of the government and policy makers about topics in the care in care homes that need more attention and improvement. When in the future the quality of care in care homes improves, these care homes might be able to meet the growing demand and at the same time still be able to provide high quality care.

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#### **CONFLICT OF INTEREST**

No conflict of interest has been declared by the author(s).

#### **AUTHOR CONTRIBUTIONS**

M.P., C.H.H., B.M.W., A.M.P.: Have made substantial contributions to conception and design, or acquisition of data, or analysis and interpretation of data; M.P., C.H.H., B.M.W., A.M.P.: Been involved in drafting the manuscript or revising it critically for important intellectual content; M.P., C.H.H., B.M.W., A.M.P.: Given final approval of the version to be published. Each author should have participated sufficiently in the work to take public responsibility for appropriate portions of the content; M.P., C.H.H., B.M.W., A.M.P.: Agreed to be accountable for all aspects of the work in ensuring that questions related to the accuracy or integrity of any part of the work are appropriately investigated and resolved. Contributions from anyone who does not meet the criteria for authorship should be listed, with permission from the contributor, in an Acknowledgments section (for example, to recognize contributions from people who provided technical help, collation of data, writing assistance, acquisition of funding, or a department chairperson who provided general support). Prior to submitting the article all authors should agree on the order in which their names will be listed in the manuscript.

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