

# Redesigning dementia care

An evaluation of small-scale, homelike care environments

Hilde Verbeek

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## Chapter 1

# General introduction



This thesis focuses on a new type of institutional dementia care: small-scale and homelike environments. In the Netherlands these are called small-scale living facilities (SSLFs), also referred to as group living homes, in which usually six to eight residents live together in a familiar and homelike environment. Nursing staff in these facilities are part of the household and encourage residents to participate in meaningful activities. They have integrated tasks, meaning that they do not only focus on personal and nursing care, but also perform domestic chores such as cooking and organizing activities. The development of SSLFs was stimulated by changing attitudes towards care for older people in general and for older people with dementia in particular, in which deinstitutionalization and quality of life take a prominent place.

Although it is generally believed that SSLFs are beneficial for the well-being of residents, their family caregivers and nursing staff, evidence for this assumption is hardly available. Since the number of people with dementia is rapidly growing and care is increasingly organized in SSLFs, more research into characteristics and impact on residents, family caregivers and nursing staff is necessary.

This first chapter provides a general background on dementia, describes developments in long-term institutional care for people with dementia and addresses institutional care in the Netherlands. Furthermore, development of SSLFs in the Netherlands and research in this area is briefly discussed. The chapter ends by stating the overall aim and providing an overview of the thesis.

## Dementia

Dementia is a common, progressive and still incurable syndrome. It is characterized by a global cognitive deterioration (e.g. decline in memory functioning and language perception), decline in the performance of daily activities and behavioral and psychological symptoms (BPSD), such as agitation, depression and apathy. Dementia is caused by various diseases and conditions, all affecting the brain.<sup>1</sup> The most common cause is Alzheimer's disease (AD), which accounts for approximately 70% of the cases. Other causes include vascular dementia (VD), Parkinson's disease and Lewy body dementia. Recent studies suggest that mixed dementia, usually with symptoms of both AD and VD, are more common than previously thought and that vascular risk may contribute to AD.<sup>1,3</sup>

The number of people who suffer from dementia is rapidly increasing. Estima-



tions indicate that worldwide approximately 81 million people are affected with dementia in 2040.<sup>4, 5</sup> The risk of developing dementia increases with age. In the Netherlands, approximately 1% of people in the age of 65 to 69 suffers from dementia; this increases to 40% of people of 90 years or older.<sup>6, 7</sup> Similar prevalence rates are reported for other Western European countries.<sup>4, 8</sup> According to the Dutch Alzheimer's Association, about 235,000 people are living with dementia in the Netherlands in 2010.<sup>9</sup>

The disease and care burden of dementia is high. It is considered as the number four cause of disability adjusted life years (DALYs) in older adults (age 60+).<sup>10</sup> Dementia is not only burdensome for people themselves, but also directly affects relatives taking care of people with dementia. Caregiving for a person with dementia is often difficult and family caregivers may experience high levels of burden. This encompasses psychosocial (such as decreased self-efficacy, increased depressive and anxiety symptoms), physiological (e.g. increased stress hormones), health behavior (poor diet, lack of sleep) and general health (for example poor self-reported health and increased medication use).<sup>11, 12</sup> It is suggested that also formal caregivers are at risk for psychological distress, although lower levels were reported compared with family caregivers.<sup>13, 14</sup>

The majority (approximately 70%) of people with dementia live at home, usually with help from family and friends.<sup>1, 15</sup> However, home care often becomes insufficient as the disease progresses and long-term institutional care is then required.

### **Developments in long-term institutional care for people with dementia**

As seen in several other health care sectors (e.g. mental health and care for people with an intellectual disability), a change in care models has emerged in institutional care for people with dementia during the last decades. Traditionally, care provided in long-term care facilities was based on a medical model, aimed at residents' disability and underlying pathology.<sup>16-18</sup> Basic nursing and medical care services were emphasized in a protected setting where the resident would be safe. This care evolved from practices utilized in other institutional settings, which has resulted in hospital-like care settings with large wards and long corridors. Typically, the routines of the organization determined daily life for residents enforced by a hierarchical management structure.<sup>19</sup> Since there is no cure for dementia yet, the medical model of care provides little guidance in care.<sup>16</sup> Nowadays, a paradigm shift has emerged towards

psychosocial and person-centered models of care. These models emphasize individualized care, build on residents' personal strengths and support the overall well-being of residents. The most important element is providing a high quality of life (QoL).<sup>18</sup> Values such as autonomy, individualization, preservation of the individual's sense of identity and personhood are of vital importance to realize this goal. In the United States this paradigm shift is called the cultural change movement.<sup>19-21</sup>

Alongside a change in care concept, there is a growing body of evidence that the environment influences residents' outcomes, such as physical and psycho-social functioning.<sup>22, 23</sup> The environment should therefore be seen as a active component of care. Lawton (e.g. 1973, 1991) was one of the first to relate the environment to behavior and later QoL for people with dementia.<sup>24-26</sup> During the late 1980's research again explored the role of the environment, both at home and in institutional care. Several recent reviews have summarized its evidence.<sup>22, 23, 27</sup> Quite strong evidence was found for features such as unobtrusive safety measures, varying ambience of size and shape, and single rooms.<sup>22, 23</sup> Also positive effects were suggested for small-scale and homelike facilities, although evidence was not as strong due to methodological limitations (e.g. small sample sizes, a lack of comparison group or baseline differences among residents).

Both the change in care concept and increased recognition of the importance of environment in care has resulted in the development of new dementia care facilities, all aimed at proving care for residents in a small-scale and homelike environment. Current policies in many countries advocate this aim.<sup>28</sup>

## **Institutional nursing care in the Netherlands**

In the Netherlands, institutional nursing care is mainly delivered through the non-profit sector and covered by a mandatory insurance called the Exceptional Medical Expenses Act (AWBZ).<sup>29</sup> In general, institutional nursing care can be divided into residential care (also referred to as home for the elderly) and nursing home care, depending on the level of care people require. People in residential care are still able to do most of the activities of daily living (ADL) themselves, although they often have some disabilities.<sup>29</sup> Contrary, nursing homes provide complex nursing care and monitoring to people with a chronic illness who are not able to do their ADLs.<sup>29, 30</sup> The level of care is determined by a standardized assessment procedure, carried out by a governmental agency. Admission to institutional nursing care (whether residential

care or nursing home care) is based on this assessment alongside residents' family or legal guardian preferences. In the Netherlands, 6.3% of people aged 65 years and older lived in institutional nursing care in 2007.<sup>31</sup> The majority lived in residential care (i.e. 3.7%) and 2.5% lived in nursing homes.

In 2009, there were approximately 480 nursing homes in the Netherlands.<sup>32</sup> Nursing homes have separate wards for people requiring rehabilitation, primarily somatic (i.e. physical) diseases and psychogeriatric wards for people with dementia.<sup>29</sup> Furthermore, many nursing homes also provide crisis intervention and respite care services.<sup>30</sup> Contrary to other countries, nursing homes in the Netherlands employ their own staff, including specially trained physicians (i.e. elderly care physician),<sup>33</sup> physical therapists, psychologists, occupational therapist, speech therapist, dietician and social workers. This allows for a multidisciplinary approach to long-term care.<sup>29</sup>

### Small-scale living facilities in dementia care

In the Netherlands, the first SSLFs were developed during the mid 1980's. During the last five to 10 years, there is a strong increase in SSLFs. Estimations indicate that in 2010 approximately 25% of all institutional dementia care is organized in SSLFs.<sup>34</sup> The Dutch government encourages its development, both conceptually and financially, and aims at 33% of SSLFs within five years.<sup>35, 36</sup> A recent program invests 80 million Euros for development of SSLFs, both in the community as well as in larger institutions.<sup>36</sup> Furthermore, a part of the budget will be invested in domotica and smart house technology to support care service delivery.

Despite these developments, very little is known about the effects of SSLFs. Only one Dutch study has been reported, which suggested positive effects for residents (e.g. having more to do and enjoyed more from their environment)<sup>37</sup> and nursing staff (e.g. increased job satisfaction).<sup>38</sup> No effects were found for family caregivers.<sup>39</sup> Another Dutch study is currently conducted at Tilburg University by the Tranzo institute comparing SSLFs in the Netherlands and Belgium.<sup>40</sup> Furthermore, some studies have been conducted in other countries, also showing mixed results. Both positive (e.g. higher QoL)<sup>21</sup> and negative effects (e.g. more behavioral problems)<sup>41</sup> have been reported.

Previous studies often suffered from methodological limitations, such as small sample sizes, no or short follow-up period and a lack of control group or baseline differences between residents in control and experimental groups. Moreover, results of

studies conducted abroad are difficult to translate to the Dutch situation, due to differences in concept, residents' characteristics and general health care system and policy. Furthermore, a previous study conducted in the Netherlands by Te Boekhorst and colleagues focused on pioneering facilities, providing care within the community to a maximum of 36 residents per location.<sup>37,42</sup> Current developments aim at slightly larger facilities, clustered at the area of a (former) nursing home or adjacent to other care services (e.g. residential care, welfare services).<sup>36</sup> Therefore, more research into SSLFs and their effect on residents, their family caregivers and nursing staff is necessary.

## Objectives and outline of the thesis

This thesis' main objective is to evaluate SSLFs for older people with dementia, especially focusing on effects for residents, their family caregivers and nursing staff. Since little is known about the concept and characteristics of small-scale living, two explorative studies were conducted first. These are described in chapter 2 (literature review) and 3 (cross-sectional study). Chapters 4 up to 8 address the design and results of the main quasi-experimental study evaluating SSLFs.

*Chapter 2* presents an international overview of concepts that have implemented small-scale and homelike facilities for older people with dementia, based on a literature review. It compares and describes concepts in terms of five main characters: the physical setting, number of residents, residents' characteristics, domestic characteristics and care philosophy. The main similarities and differences are discussed, as well as costs and development over time.

*Chapter 3* describes the results of a cross-sectional study into residents' characteristics of SSLFs and regular wards (RWs) in nursing homes in the Netherlands, especially focusing on functional and cognitive status. In total, 769 residents were included and assessed as part of a screening procedure of the quasi-experimental study into effects of SSLFs.

*Chapter 4* provides the design of the main study into effects of SSLFs on residents, family caregivers and nursing staff, using a quasi-experimental, longitudinal design. It describes the selection process of facilities and participants, measurements and procedures in detail.

*Chapter 5* presents the results regarding the main outcomes of the effectiveness study for residents (QoL and total neuropsychiatric symptoms), family caregivers (burden, involvement and satisfaction with care) and nursing staff (job satisfaction

and motivation).

*Chapter 6* addresses results on the effects of SSLFs on residents' secondary outcome measures. These include residents' behavioral symptoms (i.e. neuropsychiatric symptoms, agitation, social engagement and depressive symptoms) and the use of physical restraints and psychotropic drugs.

*Chapter 7* presents results on the effects of SSLFs on nursing staff's secondary outcome measures; that is burnout symptoms and several job characteristics: workload, physical demands, social support and job autonomy.

*Chapter 8* reports on the findings of a process evaluation into experiences of family caregivers and nursing staff with SSLFs. This process evaluation was conducted alongside the study into the effects.

Finally, *Chapter 9*, presents the main findings of this thesis and discusses methodological and theoretical considerations. Furthermore, future directions for research and practice are addressed.

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## Chapter 2

# Small, homelike care environments for older people with dementia: an overview of the literature



This chapter was published as:

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a literature review. *International Psychogeriatrics*, 21, pp. 252-264.

## Abstract

**Background:** There is a large cross-national variation in characteristics of small, domestic-style care settings. However, a systematic overview of existing types is lacking. This study provides an international comparison of concepts, which have adopted a homelike philosophy in a small-scale context. Insight into their characteristics is vital for theory, planning and implementation of such dementia care settings.

**Method:** A literature search was performed using various electronic databases, including PubMed, Medline, CINAHL and PsycINFO. In addition, “gray” literature was identified on the internet. Concepts were analyzed according to five main characteristics, i.e. physical setting, number of residents, residents’ characteristics, domestic characteristics and care concept.

**Results:** 75 papers were included covering 11 concept types in various countries. Similarities among concepts reflected a focus on meaningful activities centered around the daily household. Staff have integrated tasks and are a part of the household and archetypal home-style features, such as kitchens, are incorporated in the buildings. Differences among concepts were found mainly in the physical settings, number of residents and residents’ characteristics. Some concepts have become regular dementia care settings, while others are smaller initiatives.

**Conclusion:** The care concepts are implemented in various ways, with a changing staff role. However, many aspects of these small, homelike facilities remain unclear. Future research is needed, focusing on residents’ characteristics, family, staff and costs.

## Introduction

The majority of people with dementia are cared for at home.<sup>1</sup> However, when home care becomes inadequate, institutional care is necessary. Traditionally, institutional care for older people with dementia has been arranged according to the medical model.<sup>2</sup> In this model, emphasis is given to the treatment of the underlying pathology that causes the disease.<sup>3</sup> However, the medical model provides little guidance in the care of dementia patients since there is no cure for dementia yet. Nowadays, the medical approach has become outmoded and a shift towards a psychosocial model of care has been developed.<sup>2</sup> In this approach, the care is person-centered and aimed at the well-being of the individual. The therapeutic milieu is arranged to support the remaining strengths of older people with dementia.

Together with interest in this new care approach, it is increasingly recognized that the design of the physical environment has an important influence on dementia care.<sup>4</sup> Some studies have suggested that a small, homelike environment is beneficial for older people with dementia.<sup>4,7</sup> As a result of these developments, new therapeutic environments have been created for older people with dementia, emphasizing normalization of daily life: the environment is small and homelike and the care is person-centered with respect for residents' needs and choices. In the literature, these environments are sometimes referred to as a "Housing model"<sup>8</sup> or "Home model"<sup>9</sup> as opposed to "Hotel", "Resort" or "Medical" models of care. In Sweden, almost 20% (14,000) of people with dementia residing in institutional care lived in group living facilities in 2000.<sup>10</sup> Estimates indicate that in the Netherlands around 25% of the long term nursing home care in 2010 is realized in these small-scale, homelike facilities.<sup>11</sup>

Currently, a common and desirable policy principle in many countries is to delay residency in an institution by enabling older people with dementia to remain at home for as long as possible.<sup>12</sup> Furthermore, when institutional care is required, this should be as homelike as possible. In addition, present health care ethics emphasizes respect for residents' autonomy.<sup>13</sup> Small-scale, homelike care concepts for older people with dementia are in line with these policy and moral principles. Although their underlying core philosophy is similar, there seems to be a large cross-national variation in characteristics of such care settings and insight in the requirements of the physical and social environment is unknown. A systematic international overview of small-scale homelike concepts for older people with dementia is lacking. Marshall (1993) has reported several small-scale domestic style facilities.<sup>14</sup> Since then,

various new developments have been reported in this rapidly changing field of care. Moreover, Warren, Janzen and McKim (2002) describe some residential style facilities but they focus on the impact of the environment on residents, not on characteristics.<sup>15</sup> Insight in these characteristics is essential to improve our understanding of the concept, planning and implementation of small-scale homelike facilities in dementia care.

The aim of this study is to present an international overview of concepts regarding small-scale and homelike facilities for older people with dementia. It seeks to compare and describe them in terms of five main characteristics: the physical setting, number of residents, resident's characteristics, domestic characteristics and care philosophy. Overall similarities and differences among and within concepts are emphasized. An overview of concepts and their characteristics provides tools for scientists as well as clinicians to improve dementia care settings. This is relevant in the light of the ongoing debate about enhancing domesticity in dementia care and for future planning of care settings.

## Methods

### Search procedure

To identify the possible concepts, different search strategies were performed systematically. First, various electronic databases were searched for references, including Medline, PsycINFO, Cumulative Index to Nursing and Allied Health Literature (CINAHL) and PubMed. English, German and Dutch publications from 1970 until May 2008 were included in the review. Search terms included dementia, group living, group home, collective living, group dwelling, small units, special care unit, special care facility, homelike environment. Because of the large amount of publications found in PubMed, the key word "nursing home" was added to limit the results of the search in this database. Articles were screened for relevance based on title and abstract. Furthermore, reference lists were explored to identify additional relevant studies. Finally a "gray" literature search was performed using the world wide web. All types of publications were included in the search procedure, i.e. articles, books, chapters, reports, non-empirical studies and commentaries.

### Selection criteria

Publications needed to fulfill three criteria to be eligible for this review. First, they

had to describe projects specifically designed for older people with dementia. Second, publications needed to describe projects which were small-scale, meaning that a maximum of 15 residents live together in one group or unit.<sup>16, 17</sup> Third, the philosophy of care as well as the design of the therapeutic milieu, had to emphasize a homelike, normalized way of living. Those studies of group living concepts which did not include all of these three criteria were excluded from the review.

### **Analyses**

Concepts were analyzed and described according to the following five main characteristics:

- physical setting: description of location and building features (e.g. physical design, positioning of rooms);
- number of residents per house or unit;
- residents' characteristics: specification of the project's target group (e.g. level of dementia, activities of daily living (ADL) capacities and behavioral disturbances);
- domestic characteristics: features which constitute a homelike environment;
- care concept: description of the project's philosophy of care, including organizational and social aspects of care.

These five characteristics are based on a conceptual framework for organization of a person-environment system, as expressed by Cohen and Weisman.<sup>18</sup> In this framework, the environment for older people with dementia is conceptualized according to different components, including characteristics of the patient population, the physical setting and organizational and social aspects. These last two aspects are represented in the care concept. In addition, international recurring themes including smallness of the environment (reflected in the number of residents per house or group) and familiarity (reflected in domestic characteristics) are included in the analyses.<sup>6, 8</sup> Finally, a time scale of concepts was constructed and costs were analyzed.

### **Results**

The search in electronic databases yielded 859 publications. Based on title and abstract, 77 were selected for further reading, of which 46 were included in the final selection of publications (*see Figure 1*). Reference tracking yielded another 18 relevant publications. The gray literature search resulted in another 11 publications. Altogether

ther, 75 publications were included in the review.

The 75 publications describe 11 types of concepts in 11 countries: “CADE units” (Australia), “Cantou” (France), “Care Housing” (Scotland), “Domuses” (United Kingdom), “Green Houses®” (United States), “Group Home” (Japan), “Group Living” (Sweden), “Residential groups” (Germany), “Small-scale living” (Netherlands/Belgium), “Special Care Facility” (Canada) and “Woodside place” (United States/Canada). Concepts were identified based on name, country and characteristics as provided in the publications. Table 1 provides a short summary of the 11 concept types, based on the five main characteristics.

### **Physical setting**

The concepts’ location varies between units situated within a larger nursing home (e.g. “Residential groups” in Germany) to stand alone facilities (e.g. “Green Houses” in the United States or “Special Care Facility” in Canada).<sup>19,21</sup> In addition, there are differences within projects. For instance “Small-scale living” in the Netherlands/Belgium and “Group living” in Sweden can be located in ordinary houses in the community or may be part of a larger assisted living facility.<sup>10,11</sup> Stand alone facilities may prevent institutional characteristics from gaining hold in the project.<sup>20, 21</sup> However, such facilities are often not feasible owing to pressures of financing arrangements and the organization of health care. Some concepts, such as “CADE units” in Australia, are located in the local community, because this increases residents’ opportunity to maintain their social network.<sup>22</sup>

Concepts’ building features resemble a homelike environment with archetype symbols such as a kitchen, dining room, living room and a laundry area.<sup>20, 23</sup> The kitchen often has an important function as a meeting centre.<sup>24</sup> Almost all residents have private rooms, and in some cases, a private bathroom. In addition, some concepts use technology to support care in many different ways. For instance, “Green Houses” in the United States use smart house technology, consisting of prosthetic, communication and educational devices.<sup>20</sup> This includes, for example, an interactive television to bring distant family and residents in contact with each other.



**Figure 1.** Flow chart of the publication search.

**Table 1.** Concepts' characteristics (concepts are presented in alphabetical order)

Concept*	Physical setting	No. of residents	Resident's characteristics	Domestic characteristics	Care Concept
CADE units norma(Australia)	<ul style="list-style-type: none"> <li>- Purpose built 'prosthetic environment'</li> <li>- Proximity to local community</li> </ul>	8 – 10/14	<ul style="list-style-type: none"> <li>- Moderate to severe dementia</li> <li>- Ambulant, with no significant physical problems</li> <li>- Behaviorally disturbed</li> <li>- Few psychiatric problems</li> </ul>	<ul style="list-style-type: none"> <li>- Opportunity to participate in household activities</li> <li>- Familiar decor</li> </ul>	<ul style="list-style-type: none"> <li>- Based on normalization</li> <li>- Staff work patiently at the resident's pace</li> <li>- Needs of the resident take precedence over needs of the unit</li> <li>- Staff: registered nurses, enrolled nurses and residential care assistants</li> </ul>
Cantou (France)	<ul style="list-style-type: none"> <li>- Community living in a separate enclosed area</li> <li>- Large kitchen and living room, with adjacent individual rooms</li> </ul>	12 – 15	<ul style="list-style-type: none"> <li>- Senile dementia</li> <li>- Mean MMSE score: 9.29 (SD 8.17)<sup>25</sup></li> </ul>	<ul style="list-style-type: none"> <li>- Resident's own furniture</li> <li>- Activities centered around tasks of daily living</li> <li>- Active participation of family in daily life</li> </ul>	<ul style="list-style-type: none"> <li>- Non-medical, communal care</li> <li>- Stable multipurpose staff</li> <li>- Home for life</li> </ul>



Care Housing (Scotland)	8 – 12 - Located in residential home/ part of sheltered accommodation	- Mild to moderate dementia - Mean MMSE score: 13.4 (range 6 – 20) <sup>26</sup> - Modified Crichton Royal Behavior Rating Scale (MCRBRS, range 0 – 38) Total score: 12.5 (range 8 – 16) <sup>26</sup>	- Participation in daily activities - Flexible and individual tailored care - Maximizing independence
Domus philosophy (United Kingdom)	9 – 12 - Purpose built facility or conversion of existing wards - Private bedroom - Shared bathroom, toilet and living room	- Dementia, requiring intensive nursing care - Elderly psychiatric patients - Mean Organic Brain Syndrome (OBS) score 7.1 (SD 2.6) <sup>27</sup>	- 'Home-for-life' principle - Psychological / emotional needs above physical aspects - Emphasis on maintaining independence and residual capacities
Green House® (United States)	7 – 10 - Stand alone quality - Self-contained semi attached bungalows - Private bedrooms with en-suite bathrooms	- Dementia-specific or general nursing home level of care Minimum Data Set scores (MDS); <sup>28</sup> * Cognitive Performance Scale (CPS; range 0 – 6) Mean: 2.8 (SD: 1.92) * ADLs (range 0 – 16), Mean: 7.0 (SD: 5.7)	- Social model with necessary clinical care - Emphasis on competence - Universal workers

<p>Group Homes (Japan)</p>	<p>- Attached to larger facility or self-containing residences</p> <p>5 – 9</p>	<p>- Mild to moderate dementia - MMSE score: 13.2 (SD: 6.1) <sup>29</sup> - Barthel index (range 0 – 20): Mean score: 16.2 (SD: 3.4) <sup>29</sup></p>	<p>- Participation of the residents in daily housekeeping if possible</p>	<p>- Care around daily life - Specialized in-home care services with mutual support for elderly with dementia</p>
<p>Group Living<sup>†</sup> (Sweden) <sup>†</sup>Also known as Collective living or Group Dwelling</p>	<p>- Ordinary blocks of flats or part of larger assisted living facility - Private combined living-/ bedroom, shower, toilet - Shared kitchen, dining room, laundry</p> <p>5 – 9</p>	<p>- Dementia Alzheimer's type or Vascular dementia - Mild to moderate form of dementia, inclusion: Berger scale scores II-IV, ADL Katz scale, incl. max. level E - Mean MMSE: 16.7 (SD: 5.9), Mean Berger scale: 3.0 (SD: 0.5), Mean Katz ADL score: 1.6 (SD: 1.2) <sup>30</sup> - Mean MMSE: 17.8 (SD: 5.6) <sup>31</sup> - Mean MMSE: 14.0 (SD: 5) <sup>32</sup> - Mean MMSE: 7.1 (rang 0 – 23) <sup>33</sup> - Mean MMSE: 9.0 (SD: 6.2) Mean Katz ADL: E (range A–G) <sup>34</sup></p>	<p>- Domestic furnishing and color schemes - Resident is stimulated to take part in all normal activities of life, e.g. housework, shopping, cleaning</p>	<p>- Care should profit from group dynamics in the small homogeneous group - Integrated staff; staff ratio: 10 *assisted nurses: 0.91 * registered nurses: 0.04 * others: 0.06 - Intermediate form of care</p>

Residential groups (Germany)	- Smaller units within 6 – 15 a larger nursing home	- Segregated: middle to late stage dementia; Mean MMSE: 8.8 <sup>35</sup> and Mean MMSE: 10.3 <sup>19</sup> - Integrated: with & without dementia; Mean MMSE: 17.0 <sup>35</sup>	- Social environment reflects a family structure - Participation in daily activities	- Encouraging and training environment - Integrated role of the staff - Person-oriented care
Small-scale Living (Netherlands / Belgium)	- Variety in location - Shared kitchen and living area; private bedrooms	- Middle- to late stage dementia	- Participation in daily activities - Familiar decor	- Emphasis on normalization of living - Integrated staff; education: 38 * nursing assistants: 11% * certified nursing ass.: 79% * registered nurse: 10%
Special Care Facility (SCF) (Canada)	- 6 bungalows, purpose built - Private bedrooms with en-suite bathrooms	- Middle to late stage dementia - Mean score Global Deterioration Scale (GDS): 6.1 (range 5 – 7) <sup>21</sup>	- Biodiverse environment: multigenerational, live-in pets, plants - Physical environment, daily activities like a typical home	- Integrated role of the staff including personal care, leisure and rehabilitation activity

<p>Woodside place' (Canada / United States)</p> <p>8 – 15</p> <ul style="list-style-type: none"> <li>- Main building connected to three individual houses</li> <li>- Each house has a shared kitchen and living room, private bed-/bathrooms</li> </ul>	<ul style="list-style-type: none"> <li>- Mild to moderate dementia</li> <li>- Mean MMSE: 11.1 (SD: 6.1)<sup>36</sup></li> <li>- Mean MMSE: 15.4 (SD: 5.0)<sup>37</sup></li> </ul>	<ul style="list-style-type: none"> <li>- Maximum engagement in activities</li> <li>- Homelike sitting spaces (e.g. kitchen, library)</li> </ul>	<ul style="list-style-type: none"> <li>- Program and staffing patterns around social model</li> <li>- Emphasis on independence</li> <li>- No physical and minimal psychotropic restraints</li> </ul>
<p><b>* Publications</b></p> <p>CADE units: 8, 14, 22, 39, 40</p> <p>Cantou: 14, 25, 41</p> <p>Care Housing: 6, 14, 26, 39</p> <p>Domus: 14, 27, 42-47</p> <p>Green House: 20, 28, 48</p> <p>Group Home: 29, 49-52</p> <p>Group Living: 23, 30, 31, 53-64, 10, 14, 32, 34, 46, 65-74</p> <p>Residential groups: 19, 24, 35, 46, 75</p> <p>Small-scale living: 11, 14, 17, 24, 38, 76-80</p> <p>Special Care Facility: 21, 81</p> <p>'Woodside': 15, 36, 37, 82-86</p>			

### Number of residents

The number of residents per house or unit varies from five to nine (e.g. “Group Homes” in Japan, “Group living” in Sweden and “Small-scale living” in the Netherlands/Belgium) to 13 – 15 residents (e.g. “CADE units” in Australia, “Cantou” in France).<sup>11, 22, 25, 29</sup> The main purpose of a small group is to promote social activities and to create an environment resembling a family.<sup>19</sup> There is opportunity for staff, residents and family members to become familiar with each other and allowing close contact and communication.<sup>24</sup> The group dynamics of a small group seem to be beneficial for care and residents.<sup>59</sup> In practice, however, group size is often determined by practical considerations, such as budget, available space and staffing.<sup>18</sup>

### Residents’ characteristics

Residents’ characteristics are very heterogeneous, both between and within projects (see Table 1). Mean MMSE scores range from 7.1 to 17.8, although many studies do not report such objective parameters. Some concepts are designed for residents in the early stages of their disease (e.g. “Woodside” in Canada/United states and “Group living” in Sweden). Admission criteria may include a sufficient level of participation in activities, communication skills or being ambulatory.<sup>59, 84</sup> In these concepts, residents are usually transferred to another care setting when these criteria are no longer met. They manifest themselves as an intermediate form of care between the residents’ own home and the nursing home. One concept (“CADE units” in Australia) is specifically aimed at residents with behavioral problems and no significant physical problems.<sup>22</sup> It is perceived as a complement to existing facilities and services. In contrast, concepts such as “Domuses” in the U.K. and “Cantou” in France have a “Home-for-life” principle, with residents being able to stay until they die.<sup>25, 27</sup> “Care Housing” in Scotland is intended as a home for life, except for residents who disturb the group living experience of other residents or those residents who do not benefit from the household approach.<sup>39</sup>

In practice, the principle of a home for life may vary within projects. In “Group living” in Sweden, for example, residents have become more dependent over the years than initially was intended.<sup>10, 69</sup> Nevertheless, in Sweden increased care needs and demanding behavior, such as aggression, are the most common reasons for relocations from non-specialized group living into dementia care units.<sup>73, 87</sup> In “Small-scale living” in the Netherlands, a home for life is seen as a basic principle, but many projects nevertheless use in- and exclusion criteria for selection of their residents.<sup>11</sup> Often extreme behavioral problems are an exclusion criterion, since this

is especially seen as problematic in a small group of residents.<sup>88</sup> In many parts of the Netherlands small-scale living is a relatively new concept and, due to inexperience, detailed information regarding everyday practice is often lacking. Some “Group Homes” in Japan provide end-of-life care, making them true “homes for life”, while others focus on providing accommodation for elderly people in the early stages of dementia.<sup>50</sup> Hirakawa and colleagues (2006) found that, 76% of “Group Home” facilities considered it possible to provide end-of-life care, if necessary. However, only 17% had actual experience in providing such services.<sup>50</sup> Furthermore, a survey by the Institute for Health Economics and Policy reported that in practice only 5.4% of the “Group Homes” provided end-of-life care to their residents.<sup>51</sup>

### **Domestic characteristics**

To create a homelike environment, concepts incorporate physical as well as social and organizational domestic characteristics. Physical domestic characteristics include allowing residents’ own furniture, as in the “Cantou” in France or “Small-scale living” in the Netherlands/Belgium),<sup>11, 25</sup> pets, gardens and a fireplace. In addition, some concepts such as the “Green House”, specifically exclude traditional institutional features such as long corridors, a nurses’ station and medication carts.<sup>20</sup> These are all attempts to make the physical environment familiar and appealing to the residents. However, the physical setting alone is not sufficient to create a homelike environment, it can only facilitate this.<sup>18</sup> Organizational and social aspects of the environment are necessary components in the development of a small, homelike therapeutic setting. In all concepts residents are encouraged to participate in the household as far as possible (e.g. “Care Housing” in Scotland),<sup>39</sup> with activities of daily life planned according to the residents’ wishes. They have opportunity to choose their meals, sleep, rest, personal care and activities whenever they want,<sup>20, 29</sup> and are thereby able to continue their own lifestyle to varying degrees.<sup>11</sup>

### **Social care concept**

In all concepts a social model of care is applied, focusing on residents’ psychosocial well-being rather than their physical needs. To realize this, the physical and organizational environment has been fundamentally changed in comparison with the traditional setting in nursing homes.<sup>28</sup> Improvement of residents’ quality of life is the main priority,<sup>20</sup> with the family often being involved in the care program (e.g. “Woodside” in United States/Canada, “Cantou” in France and “Small-scale living” in the Netherlands/Belgium).<sup>11, 25, 84</sup> Care staff have integrated tasks and are part of the

household (e.g. “Residential Groups” in Germany).<sup>19</sup> They live together with the residents and provide individually tailored care. Residents are stimulated, encouraged and supported, emphasizing autonomy and choice. Daily life is organized around meaningful activities, such as cooking, with a lot of personal contact. This requires the care staff to have specific skills, such as high levels of social and communication skills.<sup>11</sup> The care staff usually comprises nursing assistants and a limited number of nurses. Detailed information regarding education and staff ratio was only available from the Netherlands and Sweden (*see Table 1*). Involvement of other staff members varies among projects. Some concepts (e.g. “Green House” in the United States) use a multidisciplinary team, including a medical doctor, social worker, dietician and activity workers, while other projects (e.g. “Cantou” in France) are essentially non-medical, providing additional care only if necessary.<sup>20, 25</sup> In “Domuses”, special attention and training is given to anxieties and attitudes staff may experience to improve quality of care.<sup>27</sup>

### **Concepts over time**

The “Cantou” in France was identified in this study as the first small, homelike concept for older people with dementia.<sup>25</sup> During the 1980’s similar concepts appeared, such as “Group living” in Sweden,<sup>59</sup> “Small-scale living” in the Netherlands<sup>76</sup> and “Domuses” in the U.K.<sup>27</sup> Some of these have become regular dementia care settings, such as “Group Living” in Sweden and “Small-scale living” in the Netherlands. In both countries, the government has stimulated the development of small, homelike facilities by adjusting their policy and financial support.<sup>53, 88</sup> In contrast, other facilities, such as “Domuses” in the U.K., are smaller initiatives.<sup>45</sup> “Domuses” appear to be a more costly form of care<sup>42</sup> and in the U.K. a more widespread model of care is the “multi-purpose nursing home”, in which long-term care as well as shorter-stay, day and/or respite care are provided.<sup>45</sup> This suggests that government policies may have a large influence on dissemination of the concept.

Over time, there are some indications that the concept of “Group Living” in Sweden has changed with regard to the residents’ characteristics and physical design. Originally, it was developed for residents with mild to moderate forms of dementia and sufficient ADL-capacities, situated in ordinary flats, as a form of intermediate care.<sup>23, 59</sup> Nowadays, group living facilities tend to become part of larger assisted-living facilities and residents’ functional dependence is increasing,<sup>10, 69</sup> which implies that these are more likely to become “homes for life”. This shift is also seen within the concept of “Small-scale living” in the Netherlands.

### Costs

Concepts' costs were analyzed in only four studies. Costs of "Group Living" in Sweden were analyzed in three studies,<sup>32, 71, 74</sup> while another study investigated the costs of "Domuses" in the U.K.<sup>42</sup> The latter concluded that Domus care is more costly than regular hospital care. However, a detailed evaluation was not possible due to a small sample size and lack of variation in individual costs.<sup>42</sup>

A study by Wimo and colleagues (1991) suggests that "Group Living" is cheaper compared to the costs of nursing home care.<sup>74</sup> However, this study is based on a small population (two group living facilities, housing 24 residents) and regards "Group Living" primarily as a non-institutional form of care. Costs such as hospital days and extra support from social services were not included. In addition, residents of both settings were not comparable in care dependency. Based on a study by Wimo and colleagues (1995), "Group Living" seems a cost-effective form of dementia care, although the differences were small. If residents' care dependency level increases, the costs of "Group Living" would increase as well since institutional care would be required.<sup>32</sup> Svensson and colleagues (1996) suggests that the average costs per patient might be higher in "Group Living" than in old people's homes, although the costs of care vary both with the physical design and functional ability of residents. Cost comparisons are therefore difficult to make. Svensson and colleagues (1996) have investigated 106 "Group Living" units, housing 765 residents. Costs tend to be lower when the number of residents per unit increases and when units are attached to other institutional facilities. In addition, units housing residents with a higher level of functional disability have a higher staff ratio.<sup>71</sup>

### Discussion

This study is the first to present a comparative international overview of concepts that have implemented small-scale homelike facilities for older people with dementia. Based on our review of the literature, 11 concepts were identified in 11 different countries. Some concepts have become regular dementia care facilities, while others are smaller initiatives. Similarities among concepts reflect a common social care concept, with a focus on meaningful activities around the daily household. The implementation among concepts, however, varies with differences in residents' characteristics, number of residents and physical setting and might be influenced by cultural and organizational differences among countries.



This review has some limitations. It is likely that not all initiatives will have been identified for different reasons. A standard definition of a small-scale, homelike concept of dementia care is lacking. We used many search terms that relate to the topic of small-scale, homelike facilities, but it does not guarantee that all studies and projects were identified. In addition, the search was restricted to publications in German, Dutch or English only, and some initiatives, particularly smaller ones, may not have been reported at all and therefore not identified. However, where initiatives are widespread within a country, it is likely that they have been included in this review. Since this research is solely based on a literature search, it is difficult to assess to what extent a concept's philosophy is implemented in practice and therefore to what extent differences exist among concepts in daily practice. With regard to objective parameters, such as residents' characteristics (e.g. scores on cognition, ADL functioning and behavior) very limited data were available.

### **Clinical implications**

During the implementation process of a concept's core philosophy, it is very important to translate the care concept into every day practice clearly and unambiguously.<sup>8,39</sup> Appropriate staff training and education is essential.<sup>59</sup> There is, however, a tension between the focus on everyday life and the medical needs of older people with dementia.<sup>24</sup> When too much emphasis is given to normalization of living for older people with dementia, there is a risk that professionalism in dementia care may be lost.<sup>59</sup> This aspect of care should not be neglected when implementing small, homelike settings.

Furthermore, the role of caregiving staff is changing. In small-scale projects care is person- or resident oriented, with emphasis on individual well-being. This requires different capacities and skills, for example social and communication skills, compared with traditional task-oriented care.<sup>11</sup> Moreover, the responsibility of care staff increases.<sup>75</sup> Living together with older people with dementia and creating a household is a very intensive and complex process. The use of technology may support staff in this process and may increase job satisfaction.<sup>89</sup>

### **Research implications**

Although the interest in small-scale, homelike facilities in dementia care has increased, many aspects regarding this development remain unclear. The characteristics of residents in these facilities are relatively unknown. We have tried to collect data based on the literature, but this was insufficient to gain a complete understanding

of objective parameters concerning residents' characteristics such as cognition, ADL functioning, quality of life and behavioral patterns. Some studies report a few of such measures, but they frequently suffer from methodological limitations, such as the inclusion of a limited number of residents. Moreover, outcomes are not comparable among studies due to the use of different measurement scales. Future research should investigate characteristics of residents in small-scale and homelike facilities and regular large-scale nursing homes in a longitudinal context, focusing on outcome measures such as behavior, functional status, quality of life and medication use. A comparison of characteristics in both settings provides insight into suitable accommodation for older people with dementia, and how to meet the needs of possible subgroups. In addition, follow-up measurements allow comparison of the development and course of characteristics among residents. In this way, knowledge about effects of the concept will be obtained. Recent studies have made first attempt to realize this.<sup>28, 29, 76</sup> However, organizational structures of dementia care varies among countries and probably have an effect on these evaluations. Therefore, comparison among concepts is only valuable when these structures and organization of dementia care setting are taken into account.

Besides residents' characteristics, attention should be paid to experiences of family and caregiving staff. Family members appear more satisfied with the provided care, although no differences in burden and health is reported.<sup>76</sup> Positive outcomes for staff have been suggested, such as an increased job satisfaction, while negative results, for instance a higher workload, have also been reported.<sup>75</sup> A recent study by te Boekhorst and colleagues (2008) proposes that nursing staff in small-scale living are more satisfied with their jobs and report lower burnout symptoms than staff working in traditional nursing homes.<sup>90</sup> However, the skills and competences of staff working in small-scale and homelike facilities have not yet been investigated. Since the role of care staff is changing in this concept, further research is needed.

A final important aspect that needs further investigation are the costs of small-scale, homelike facilities. In this overview, a few cost-analyses have been reported showing contrasting results.<sup>32, 42, 71, 74</sup> However, there is little understanding as yet of the interplay of costs and finance structures on these concepts, particularly in terms of the services provided, staff education, residents' care dependency and organization of care provision. The concepts identified in our overview lack a detailed description of these factors. A cost-based comparison would be valuable, though difficult, given the diverse financial structures of health care systems across countries, and particularly in dementia care. Comparisons should provide a detailed description of orga-

nization of dementia care and residents' characteristics in relation to costs.

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## Chapter 3

# Small-scale, homelike facilities versus regular psychogeriatric nursing home wards: a cross-sectional study into residents' characteristics



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## Abstract

**Background:** Nursing home care for people with dementia is increasingly organized in small-scale and homelike care settings, in which normal daily life is emphasized. Despite this increase, relatively little is known about residents' characteristics and whether these differ from residents in traditional nursing homes. This study explored and compared characteristics of residents with dementia living in small-scale, homelike facilities and regular psychogeriatric wards in nursing homes, focusing on functional status and cognition.

**Methods:** A cross-sectional study was conducted, including 769 residents with dementia requiring an intensive level of nursing home care: 586 from regular psychogeriatric wards and 183 residents from small-scale living facilities. Functional status and cognition were assessed using two subscales from the Resident Assessment Instrument Minimum Data Set (RAI-MDS): the Activities of Daily Living-Hierarchy scale (ADL-H) and the Cognitive Performance Scale (CPS). In addition, care dependency was measured using Dutch Care Severity Packages (DCSP). Finally, gender, age, living condition prior to admission and length of stay were recorded. Descriptive analyses, including independent samples t-tests and chi-square tests, were used. To analyze data in more detail, multivariate logistic regression analyses were performed.

**Results:** Residents living in small-scale, homelike facilities had a significantly higher functional status and cognitive performance compared with residents in regular psychogeriatric wards. In addition, they had a shorter length of stay, were less frequently admitted from home and were more often female than residents in regular wards. No differences were found in age and care dependency. While controlling for demographic variables, the association between dementia care setting and functional status and cognition remained.

**Conclusions:** Although residents require a similar intensive level of nursing home care, their characteristics differ among small-scale living facilities and regular psychogeriatric wards. These differences may limit research into effects and feasibility of various types of dementia care settings. Therefore, these studies should take residents' characteristics into account in their design, for example by using a matching procedure.

## Background

The number of people who suffer from dementia is rapidly increasing worldwide, with estimates around 80 million persons in 2040.<sup>1,2</sup> Its prevalence increases exponentially with age.<sup>2</sup> Dementia is characterized by a variety of symptoms such as cognitive and functional decline and has often a progressive course. The disease burden of dementia is high. It is regarded as the number four cause of disability adjusted life years (DALYs) in older adults (age 60+).<sup>3</sup> As the disease progresses, nursing home care is often required.

Within nursing home care for people with dementia, there is a trend towards deinstitutionalization.<sup>4</sup> Large nursing homes are transformed into or replaced with small-scale and homelike care settings.<sup>5</sup> In these small-scale care settings, normal daily life is emphasized and residents are encouraged to participate in meaningful activities, centered around the daily household. This opposes against traditional large nursing homes, in which daily life is primarily organized around routines of the nursing home and which have often an institutional character.<sup>6</sup>

In various countries, small-scale and homelike care settings have been developed for people with dementia who require a nursing home level of care.<sup>5</sup> Examples include small-scale living in the Netherlands,<sup>6,7</sup> group living in Sweden,<sup>8</sup> group homes in Japan<sup>9</sup> and Green Houses<sup>®</sup> in the United States.<sup>10</sup> Small-scale living in the Netherlands and group living in Sweden have become widespread models of care. In the Netherlands, it is expected that around 25% of all nursing home care for people with dementia in 2010 will be organized in small-scale living facilities, partly stimulated by the Dutch government. In Sweden, group living facilities housed almost 20% of people with dementia living in institutional care in 2000.<sup>11</sup> Furthermore, group homes in Japan are increasing rapidly, up to 4,775 in 2004.<sup>9</sup>

Despite this transformation, little is known about residents' characteristics in small-scale living facilities and whether these differ from residents in traditional nursing homes. Residents' characteristics are an important factor in exploring whether small-scale living serves a specific subgroup of people with dementia requiring nursing home care. Especially information regarding objective parameters such as functional status and cognition is scarce.<sup>5</sup> Since institutional nursing home care is increasingly organized in small-scale, homelike facilities, knowledge about residents' functional status and cognition is necessary. Some studies investigating effects, including functional status and cognition, had relatively small sample sizes.<sup>4, 12, 13</sup> Other studies focused on comparison of behavioral problems<sup>14</sup> or only investigated

residents in small-scale, homelike facilities without making a comparison with other care facilities.<sup>15, 16</sup>

In addition, residents' characteristics have important implications for future research, particularly regarding effects and feasibility of dementia care settings. Since randomization in this type of research is difficult to accomplish due to practical and ethical considerations, comparability of resident groups at baseline is essential for interpretation of results. Functional status and cognition appear strongly related to dementia severity<sup>17</sup> and are therefore important baseline residents' characteristics that may influence other outcomes in longitudinal studies, such as quality of life, neuropsychiatric symptoms and social functioning.

This study, therefore, investigated functional status and cognition of residents with dementia requiring a nursing home level of care in two settings: small-scale living facilities and regular psychogeriatric wards in nursing homes. Functional status and cognition were assessed and residents' profiles were constructed. In addition, other resident characteristics such as care dependency, age, gender, length of stay and living condition prior to admission were recorded. These background characteristics were regarded as most important in our study and of potential influence on the outcome measures. The relationship between these variables and the two dementia care facilities was explored in more detail. Findings could contribute to optimal design of and future research into dementia care settings.

## Methods

### Design

A cross-sectional study was conducted in the southern part of the Netherlands, as part of the screening in a longitudinal study investigating effects of small-scale living facilities on residents, family caregivers and nursing staff. The design of this study has been reported elsewhere.<sup>6</sup> The screening was carried out between April 2008 and December 2008. A registered nurse (RN) in charge of the regular psychogeriatric ward or house in a small-scale living facility assessed the residents. Data were collected from questionnaires.

The study was approved by the Medical Ethical Committee of the University Hospital Maastricht and Maastricht University. In addition, local Ethical Committees of participating facilities/wards and their boards gave consent for the study.

**Study population**

The study population consisted of 769 residents, all requiring a similar level of intensive nursing home care. Nursing home care in the Netherlands is mainly provided for people with chronic somatic (i.e. physical) diseases, people who require rehabilitation care and people with dementia. They are cared for in specialized somatic, rehabilitation or psychogeriatric wards respectively. This level of care is determined by a standardized assessment procedure, carried out by a government agency. Admission to a nursing home facility, either a small-scale living facility or regular psychogeriatric ward, is based on this assessment and in accordance with the residents' family or legal guardian.

In total, 183 residents in small-scale living facilities were included and 586 residents living in regular psychogeriatric wards of nursing homes. Small-scale living facilities had to fulfill six criteria in order to be eligible for the study:

1) a maximum of eight residents per house or unit, 2) residents, family and staff form a household together, 3) nursing staff perform multiple tasks, such as medical and personal care, organizing activities and domestic chores 4) a small, fixed team of nursing staff who care for the residents 5) daily life is largely organized by residents, their family members and nursing staff and 6) the facility resembles a typical home-like environment.<sup>6</sup> Five small-scale living facilities were selected and included in the study, with 28 houses in total.

Regular psychogeriatric wards in nursing homes were selected based on the following criteria: 1) a minimum of 20 residents per ward, 2) staff have differentiated tasks, focusing on residents' medical and personal care and 3) the routines of the nursing home largely determine residents' daily life. In total, seven nursing homes were selected and participated in the study, with 21 psychogeriatric wards.

**Measures*****Functional status***

Functional status was measured using the Activities of Daily Living-Hierarchy (ADL-H) subscale<sup>18, 19</sup> from the Resident Assessment Instrument Minimum Data Set (RAI-MDS), version 2.1.<sup>20</sup> This seven category hierarchical scale comprises four items assessing ADL activities personal hygiene, toilet use, locomotion and eating. These items are found most consistent with various stages of loss of functioning: early (personal hygiene), middle (toilet use and locomotion) and late (eating) loss of functioning.<sup>18</sup> Scores range from zero (independent) to six (totally dependant).

### ***Cognition***

Cognition was assessed using the Cognitive Performance Scale (CPS),<sup>19, 21</sup> another subscale from the RAI-MDS, version 2.1.<sup>20</sup> The CPS includes five items, addressing cognitive and communication aspects (short-term memory, decision making and making oneself understood), presence of coma and eating dependency. The items form a hierarchical scale, consisting of seven categories and ranging from zero (intact) to six (very severe impairment). Based on a decision tree, total CPS scores are calculated.<sup>21</sup> Previous research has shown that CPS scores correspond strongly to scores on the widely used Mini-Mental State Examination.<sup>19, 21-24</sup>

### ***Care dependency***

Care dependency was assessed using the Dutch Care Severity Packages (DCSP) scores (in Dutch 'ZorgZwaartePakketten' (ZZPs)). This is a standardized assessment which is used in all Dutch nursing homes to assess the amount and type of care that a resident needs. It consists of a 54-item questionnaire, covering several care domains, such as (psycho)social functioning, personal and nursing care, mobility and behavioral problems. An algorithm is used to calculate DCSP scores. There are 10 DCSP scores available in nursing home care, which are divided in three categories: long-term care (DCSP scores 1 – 8), care aimed at rehabilitation (DCSP score 9) and end-of-life care (DCSP score 10).<sup>25</sup> Within long-term care, a higher DCSP score indicates a higher care dependency.

### ***Background characteristics***

Residents' age, gender, living condition prior to admission (e.g. home, residential care or nursing home) and length of stay were recorded using a questionnaire. Furthermore, it was assessed whether residents had a (probable) diagnosis of dementia (yes or no).

Functional status and cognition were assessed on-site by a registered nurse (RN) in charge of the regular psychogeriatric ward or house in a small-scale living facility, specifically for this study. Care dependency and background characteristics were derived from residents' record by the RN. All care dependency scores were recently assessed prior to data collection as part of an annual registration.

### ***Statistical Analysis***

The Statistical Package for Social Sciences (SPSS) version 15.0 was used for data analy-



sis. Descriptive statistics were computed to present residents' characteristics per setting. In addition to mean scores on functional status and cognition, a residents' profile was constructed for detailed analyses. To obtain a profile for residents regarding functional status and cognition, scores on these measures were dichotomized. For cognition, the three highest scores (i.e. 4 – 6) were regarded as a low cognitive level; the remaining categories (i.e. 0 – 3) formed a relatively high level of cognition. For functional status, the three lowest scores (i.e. 0 – 2) were combined as a relatively high functional status; the four other categories (i.e. 3 – 6) were considered as a low level of functional status.<sup>26</sup> Cross-tabs were calculated to compare profiles between residents in small-scale living and regular psychogeriatric wards.

Differences between the two dementia care facilities were tested using independent samples t-tests for the variables functional status, cognition, age and length of stay; care dependency, gender and living condition prior to admission were analyzed using chi-square-tests. Since length of stay was not normally distributed in both groups, a log transformation was used in the analyses.

To explore the relationship between residents' characteristics and care setting in more detail, multivariate logistic regression analysis was performed, with type of care setting (small-scale living facilities versus regular psychogeriatric ward) as dependent variable and residents' characteristics as independent variables. In all tests, a significance level  $\alpha$  of .05 was used.

## Results

Table 1 presents descriptive and test statistics for all residents' measurements in both dementia care settings.

### Background characteristics

Significant differences (all  $P < .01$ ) were found in gender, living condition prior to admission and length of stay. Relatively more women lived in small-scale living facilities compared with traditional nursing homes. Furthermore, more residents in regular psychogeriatric wards had lived at home prior to admission, whereas residents in small-scale living facilities had more often been transferred from a regular ward. In addition, residents in traditional nursing homes had lived longer at their ward than those in small-scale living facilities (*see Table 1*). No differences were found for age, diagnosis of dementia and care dependency.

**Table 1.** Residents' characteristics: small-scale living and regular psychogeriatric wards.

	Small-scale living	Regular wards	P – Value
Age, mean $\pm$ SD (range)	82.72 $\pm$ 0.57 (61 – 101)	82.50 $\pm$ 0.30 (57 – 101)	.73*
Gender, n (%)			.01 <sup>†</sup>
Male	36 (19.7)	175 (29.9)	
Female	146 (79.8)	407 (69.5)	
Unknown	1 (0.5)	4 (0.4)	
Living condition prior to admission			.00 <sup>†</sup>
Home	53 (29.0)	362 (61.8)	
Home for the elderly	31 (16.9)	61 (10.4)	
Other / Unknown	22 (12.0)	76 (13.0)	
Length of Stay <sup>‡</sup> , mean $\pm$ SD (range)	15.43 $\pm$ 0.57 (1 – 37)	32.56 $\pm$ 1.09 (1 – 190)	.00*
Diagnosis of dementia			.33 <sup>†</sup>
Yes	176 (96.2)	556 (94.9)	
No	2 (1.1)	10 (1.7)	
Unknown	5 (2.7)	20 (3.4)	
Care dependency <sup>§</sup>			.33 <sup>†,¶</sup>
DCSP $\geq$ 1 $\leq$ 5	121 (66.2)	386 (65.9)	
DCSP $\geq$ 6 $\leq$ 8	46 (25.1)	177 (30.2)	
DCSP = 9	3 (1.6)	1 (0.2)	
DCSP = 10	0 (0.0)	12 (2.1)	
Unknown	13 (7.1)	10 (1.6)	
Cognition <sup>#</sup> , mean $\pm$ SD (range)	3.52 $\pm$ 0.11 (0 – 6)	4.40 $\pm$ 0.06 (0 – 6)	.00*
Functional Status <sup>#</sup> , mean $\pm$ SD (range)	3.26 $\pm$ 0.13 (0 – 6)	4.14 $\pm$ 0.06 (0 – 6)	.00*

\* Data were analyzed using independent t-tests. <sup>†</sup> Data were analyzed using Chi-Square tests.

<sup>‡</sup> as measured in months <sup>§</sup> DCSP = Dutch Care Severity Package; scores 1 – 5 represent a relatively low level of care dependency, scores 6 – 8 represent a relatively high level of care dependency, score 9 represents rehabilitation care and score 10 represents terminal care. <sup>¶</sup> Chi-square is calculated for two groups: DCSP  $\geq$  1  $\leq$  5 and DCSP  $\geq$  6  $\leq$  8 since categories 9 and 10 contained too little cases for valid testing. <sup>#</sup> Normal range: 0 – 6; a lower score indicates a better performance.

### Functional status and cognition

Significant differences (all  $P < .01$ ) were found in both functional status and cognition. Residents in small-scale living facilities had a better cognitive and functional status, as reflected in lower CPS and ADL-H scores than residents of traditional nursing homes.

Table 2 presents residents' profile regarding cognition and functional status. It shows that residents with both a high level of cognition and functional status were overrepresented in small-scale living facilities compared with regular psychogeriatric wards (30.7% and 10.6% respectively). Additionally, residents with a relatively low cognitive and functional status were overrepresented in regular psychogeriatric wards: 66.0% compared with 42.5% in small-scale living facilities.

In both types of facilities, the majority of residents had a low functional status, although for regular psychogeriatric wards this is far more prominent with a total of 87.7% having a low functional status versus 65.9% in small-scale living facilities. Level of cognition was almost equally distributed in small-scale living, with slightly more residents having a relatively high cognition (i.e. 54.2%). However, in regular psychogeriatric wards, residents with a relatively high cognitive level were outnumbered: approximately two out of three residents (67.8%) had a low cognitive level.

**Table 2.** Cognition and ADL profile: small-scale living facilities and regular psychogeriatric wards compared.

	Functional Status, n (%)		
	High (ADL-H score 0 – 2)	Low (ADL-H score 3 – 6)	Total
<b>Small-scale living</b>			
Cognition, n (%)			
High (CPS score 0 – 3)	55 (30.7)	42 (23.5)	97 (54.2)
Low (CPS score 4 – 6)	6 (3.4)	76 (42.5)	82 (45.8)
Total	61 (34.1)	118 (65.9)	179 (100)
<b>Regular psychogeriatric wards</b>			
Cognition, n (%)			
High (CPS score 0 – 3)	62 (10.6)	126 (21.6)	188 (32.2)
Low (CPS score 4 – 6)	10 (1.7)	385 (66.0)	395 (67.8)
Total	72 (12.3)	511 (87.7)	583 (100)

### Multivariate logistic regression

Table 3 shows the results of the final regression model. Nagelkerke  $R^2$  was 0.31.  $R^2$  is a measure that indicates how well the dependent variable, in this case dementia care setting, can be determined by the independent variables and ranges from zero to one.<sup>27</sup>

Regression analysis confirmed significant associations (all  $P < .01$ ) for dementia care setting and functional status, cognition, gender, living condition prior to admission and length of stay. The chance of living in a regular psychogeriatric ward increased with almost 30% per one point increase on the scales measuring cognition and ADL. This means that residents who were more cognitive and ADL impaired, lived more often in a regular psychogeriatric ward. In addition, the chance that men lived at a regular psychogeriatric ward was almost 2.5 times higher than for women (range 1.5 – 3.9). Residents admitted from a home for the elderly or another regular psychogeriatric ward had a higher chance of being admitted at a small-scale living facility, compared with residents admitted directly from home. Finally, the chance of living on a regular psychogeriatric ward increased with around 88% per 10 months of length of stay.

**Table 3.** Results of logistic regression analysis, final model.\*

Residents' characteristics	B (SE)	Odds Ratio	95% CI for Odds Ratio
Gender <sup>†</sup>	0.89 (0.25)	2.42	1.49 – 3.94
Living condition prior to admission <sup>‡</sup>			
Home for the elderly	-1.39 (0.29)	0.25	0.14 – 0.45
Nursing home	-2.06 (0.24)	0.13	0.08 – 0.21
Other	0.85 (0.51)	2.33	0.85 – 6.36
Length of stay	0.63 (0.23)	1.88	1.20 – 2.96
Cognition	0.26 (0.09)	1.30	1.09 – 1.54
Functional status	0.24 (0.09)	1.27	1.07 – 1.50

\* Nagelkerke  $R^2 = 0.31$ ; dependent variable is dementia care setting: small-scale living facility = 0, regular psychogeriatric ward = 1. <sup>†</sup> Gender: Female = 0, Male = 1. <sup>‡</sup> Reference group is 'Home'.

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## Discussion and Conclusions

This study showed that residents' characteristics differ in small-scale living facilities and regular psychogeriatric wards, although all residents required a similar nursing home level of care. Residents in small-scale living facilities had a higher cognitive and functional status than residents in regular wards. Demographic characteristics such as living condition prior to admission and length of stay could explain these results to some extent. Length of stay in small-scale living facilities was inevitably shorter, since these are relatively new facilities (newest facility was open for one year), whereas regular nursing home wards are located in long established facilities. This explains the large difference (i.e. 17 months) in mean length of stay between the two care settings. However, while controlling for this and other demographic variables, the association remained between dementia care setting and cognition and functional status. Although some studies have found similar results regarding functional status<sup>12, 14, 28</sup> and cognition,<sup>13</sup> other studies did not find significant differences.<sup>4, 29</sup>

An explanation for our findings may be that selection has occurred in allocating residents to small-scale living facilities, despite similar admission criteria for both dementia care settings as determined by a standardized assessment procedure performed by a governmental agency. Most of these residents were transferred from a regular psychogeriatric ward. As residents in small-scale living had better cognitive and ADL performance, it seems that residents with the best cognitive and functional abilities were selected for the small-scale living facilities. A recent study by te Boekhorst and colleagues (2009) confirms this explanation.<sup>7</sup> They found that residents admitted in small-scale living facilities were in a slightly earlier stage of dementia than residents admitted in traditional nursing homes, as reflected in significantly higher cognitive performance and functional abilities.

A selection process is probably related to the innovative concept of small-scale living facilities. Although small-scale living facilities are currently expanding in the Netherlands, these facilities are still relatively new compared with traditional nursing homes. Over time, residents' characteristics may change, resulting in an increased care dependency and decreased cognitive and functional status. Research conducted in Sweden supports this assumption. In Sweden, group living is a long-established dementia care setting, in which residents have become more ADL dependent over the years.<sup>11, 16</sup> These results support a clinical experience in Sweden that over time, residents were admitted in a later stage in their dementia.<sup>16</sup> However, our

study identified that already 42.5% of residents in small-scale living had a low level of cognition and functional status. These results highlight the importance of research into suitability of small-scale living facilities for residents with more cognitive and functional impairments.

In our study, the level of care dependency, as measured with DCSP scores, did not differ between the two settings. This is in line with the standardized assessment procedure to determine the level of care: all residents in our study require a similar intensive nursing home level of care. However, we found that residents in small-scale living facilities were more independent in ADL and had a better cognitive performance. Since we derived DCSP scores from the medical record, this might not correspond completely in time with the assessment of ADL and cognition during the screening. Therefore residents might have deteriorated due to the progressive nature of their disease which could explain the differences. Moreover, care dependency constitutes more than just cognition and ADL dependency, including behavioral problems for example. In the DCSP scores, behavioral problems are incorporated among others, where a higher score indicates more (behavioral) problems. However, previous research suggested that DCSP items relating to behavior were possibly more difficult to interpret and had a lower reliability than other DCSP items.<sup>30</sup> The overall DCSP scores' validity or reliability was not studied. More research is needed to confirm that DCSP scores are a valid and reliable measure of care dependency and how this measure is related to other validated measures of care dependency.

Additionally, health care policy and economic issues might have had an influence, since financing of care settings is based on these DCSP scores. An adequate score on the DSCP measure might have been a selection criterion for intake in a small-scale living facility, without residents really being as care-dependant as in a regular nursing home ward. Most residents in our sample, approximately two third in both care settings, had a relatively low level of care dependency (DCSP scores 1 – 5). It might be that for small-scale living facilities, this is an underestimation and that actually residents now classified as having a relatively high care dependency (DSCP scores 6 – 8) are actually in a lower need of care.

Some limitations regarding this study must be considered. This study focused on cognition and functional status and therefore assessed only a limited number of variables. Other relevant characteristics such as behavioral problems and social functioning need to be investigated as well. Additionally, residents in other care settings could be included, for example residential care, to cover the whole continuum of dementia care in the Netherlands. Furthermore, a cross-sectional design was used,

since this study's objective was to compare residents in two dementia care settings. This design limits causal interpretation of our results. For example, it might be possible that at admission ADL and cognition were the same for residents in both care settings, which may imply a positive effect of small-scale living facilities. However, in our sample no standardized information regarding these patient characteristics at admission was present, which is a drawback. Therefore no inferences can be drawn regarding effects of small-scale living facilities regarding the variables ADL and cognition. Longitudinal research is needed to investigate effects of dementia care setting on residents, addressing several important outcome measures such as quality of life, functional status, behavioral problems and social functioning. This is important, since dementia care settings are increasingly directed towards small-scale and homelike facilities. A few studies have been reported regarding these measures showing promising results.<sup>4, 7, 12, 13, 28</sup> However, methodological limitations such as small sample sizes, differences at baseline between groups or a relatively short follow-up period, hinder interpretation of results.

Our results suggest that functional status and cognition of residents living in small-scale, homelike facilities is better than in regular psychogeriatric wards of nursing homes. These differences in baseline characteristics have implications for research and practice. Effectiveness of new dementia care settings is hard to predict. Research focusing on effects of care settings on residents, family members and nursing staff should take baseline differences in residents' characteristics into account, since these could influence outcome measures. Matching of residents based on a profile of functional status and cognition could form a solution for this challenge. This procedure will increase a study's internal validity and therefore enhance the prognostic comparability of the study groups. In addition, statistical analyses can be used to correct for remaining baseline differences between groups.

Furthermore, development of small-scale living facilities may influence daily practice in more traditional nursing homes. Our results suggest that residents with better cognitive and functional abilities were transferred from traditional nursing homes. As a result, care dependency in traditional nursing homes may increase. Our results highlight the importance of research into optimal environments in the continuum of dementia care.

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## Chapter 4

# The effects of small-scale, homelike facilities for older people with dementia on residents, family caregivers and staff: design of a longitudinal, quasi-experimental study



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## Abstract

**Background:** Small-scale and homelike facilities for older people with dementia are rising in current dementia care. In these facilities, a small number of residents live together and form a household with staff. Normal, daily life and social participation are emphasized. It is expected that these facilities improve residents' quality of life. Moreover, it may have a positive influence on staff's job satisfaction and families involvement and satisfaction with care. However, effects of these small-scale and homelike facilities have hardly been investigated. Since the number of people with dementia increases, and institutional long-term care is more and more organized in small-scale and homelike facilities, more research into effects is necessary. This paper presents the design of a study investigating effects of small-scale living facilities in the Netherlands on residents, family caregivers and nursing staff.

**Methods/Design:** A longitudinal, quasi-experimental study is carried out, in which two dementia care settings are compared: small-scale living facilities and regular psychogeriatric wards in traditional nursing homes. Data is collected from residents, their family caregivers and nursing staff at baseline and after six and 12 months of follow-up.

Approximately two weeks prior to baseline measurement, residents are screened on cognition and activities of daily living (ADL). Based on this screening profile, residents in psychogeriatric wards are matched to residents living in small-scale living facilities. The primary outcome measure for residents is quality of life. In addition, neuropsychiatric symptoms, depressive symptoms and social engagement are assessed. Involvement with care, perceived burden and satisfaction with care provision are primary outcome variables for family caregivers. The primary outcomes for nursing staff are job satisfaction and motivation. Furthermore, job characteristics social support, autonomy and workload are measured. A process evaluation is performed to investigate to what extent small-scale living facilities and psychogeriatric wards are designed as they were intended. In addition, participants' satisfaction and experiences with small-scale living facilities are investigated.

**Discussion:** A longitudinal, quasi-experimental study is presented to investigate effects of small-scale living facilities. Although some challenges concerning this design exist, it is currently the most feasible method to assess effects of this relatively new dementia care setting.

## Background

It is estimated that around 24 million people suffered from dementia worldwide in 2001 and this number will double every 20 years.<sup>1</sup> Most people suffering from dementia are cared for at home, but institutional care is often inevitable as the disease progresses. Institutional dementia care is increasingly organized in small-scale and homelike facilities. These are facilities in which a small number of residents live together in a homelike environment. Normalization of daily life with person-centered care is a central theme in these facilities.<sup>2</sup> In the literature, this care concept is also referred to as a 'home' model<sup>3</sup> or 'housing' model<sup>4</sup> as opposed to the medical model of care. Traditionally, institutional care for people with dementia has been organized to this medical model<sup>5, 6</sup> and this has resulted in large-scale institutional nursing homes. Nowadays, policy principles emphasize that institutional care should be as homelike as possible.<sup>7</sup> Small-scale and homelike facilities are the result of this shift in dementia care concept. Differences with traditional nursing homes exist at a physical, social and organizational level. Table 1 presents a summary of main differences.<sup>3, 8-10</sup>

In many countries small-scale and homelike facilities have been established, such as group living in Sweden,<sup>11</sup> Green Houses<sup>®</sup> in the United States,<sup>12</sup> and residential groups in Germany.<sup>13</sup> In the Netherlands, there is nowadays a large increase of small-scale living facilities, also referred to as group living.<sup>10</sup> It is expected that in 2010, approximately 25% of Dutch nursing home care for older people with dementia is organized in small-scale living facilities. In Sweden, almost 20% (14,000) of people with dementia residing in institutional care lived in group living facilities in 2000.<sup>14</sup>

Despite these developments, little is known yet about effects of a small-scale and homelike environment on residents, family and professional caregivers.<sup>2</sup> Some studies report positive findings for residents.<sup>15-18</sup> It is suggested that residents in small and homelike facilities have a better mobility,<sup>15</sup> more social capacities,<sup>16</sup> and a higher quality of life<sup>17, 18</sup> than residents living in traditional nursing homes. However, more behavioral problems have also been reported for residents in small, homelike facilities.<sup>19</sup> Family members in small-scale living facilities appear to be more satisfied with care<sup>20</sup> and seem to experience less burden than family in traditional nursing homes.<sup>21</sup> Findings from staff members indicate that they may have a higher job satisfaction and motivation than in traditional nursing home care,<sup>22, 23</sup> although negative results such as a higher workload have also been reported.<sup>22</sup>

Most studies regarding the effects of small-scale living facilities for older people

with dementia suffer from several methodological limitations, such as inclusion of a small number of residents,<sup>15</sup> no follow-up measurements,<sup>19</sup> differences at baseline between residents in small-scale living facilities and traditional nursing home care<sup>17</sup> or no control group at all. These drawbacks limit the interpretation of results. Since the number of people with dementia will increase worldwide<sup>1, 24</sup> and dementia care will be more and more organized in small-scale and homelike facilities, more research and knowledge regarding effects of this environment is necessary.

**Table 1.** Physical, social and organizational characteristics: traditional nursing homes vs. small-scale living facilities.

	<b>Traditional nursing home</b>	<b>Small-scale living facility</b>
Physical	<ul style="list-style-type: none"> <li>- Large-scale wards (&gt;20 residents)</li> <li>- Long corridors</li> <li>- Institutional character</li> </ul>	<ul style="list-style-type: none"> <li>- Small units (six to eight residents)</li> <li>- Homelike character, based on a archetype house</li> </ul>
Social	<ul style="list-style-type: none"> <li>- Many fellow residents and nursing staff working at one ward</li> </ul>	<ul style="list-style-type: none"> <li>- Emphasis on family situation</li> <li>- Residents form a group</li> <li>- Nursing staff is part of the household</li> </ul>
Organizational	<ul style="list-style-type: none"> <li>- More 'Top-down': organization/nursing home decides daily routine</li> <li>- Task-differentiation: many different functions and staff</li> </ul>	<ul style="list-style-type: none"> <li>- More 'bottom-up': residents and family caregivers have a large influence on daily routine</li> <li>- Nursing staff have integrated tasks: i.e. medical, personal care, activities and household</li> </ul>

### **Aim and research questions**

The current paper presents the design of a Dutch longitudinal, quasi-experimental study, investigating the effects of small-scale living facilities for older people with dementia. Residents, their family and nursing staff of small-scale living facilities are

compared with those living in regular psychogeriatric wards of traditional nursing homes on several outcome measures. The three research questions are:

1. What are the effects of small-scale living facilities on residents' quality of life, behavioral problems and social engagement?
2. What are the effects of small-scale living facilities on family caregivers' involvement, satisfaction with care delivery and perceived burden from informal care?
3. What are the effects of small-scale living facilities on staff's job satisfaction, motivation and work perception, such as perceived social support, autonomy and burden?

In addition, a process evaluation is performed with two main goals: 1) to investigate to what extent both types of dementia care settings are designed as they were intended and 2) to investigate participants' satisfaction and experience with small-scale living facilities.

## Methods/Design

An longitudinal, quasi-experimental study is carried out (April 2008 – January 2010). Two types of dementia care settings are compared: small-scale living facilities (experimental group) and psychogeriatric wards in traditional nursing homes (control group). Outcome measures regarding residents, family caregivers and nursing staff are measured at three moments in time: a baseline measurement (T1) and after six (T2) and 12 months (T3) after baseline. To enhance comparability of groups at baseline, residents are matched, using a screening procedure approximately two weeks prior to T1. Figure 1 presents a flow chart of the design and data collection. In addition to the effect study, a process evaluation is performed.

The study design and protocols are approved by the Medical Ethics Committee of the University Hospital Maastricht and Maastricht University. In addition, local Ethical Committees of participating institutions have given their consent to the study protocols and procedures.



**Figure 1.** Flow-chart design and measurement.



**Target population**

The target populations of this study are older people with dementia, who receive institutional nursing home care, their family caregivers and nursing staff working at their unit. They are recruited in two types of dementia care settings: small-scale living facilities and psychogeriatric wards in traditional nursing homes, all in the southern part of the Netherlands.

**Residents**

All residents in small-scale living facilities are eligible for participation in this study, if they 1) have a primary diagnosis of dementia, based on criteria established by the *Diagnostic and Statistical Manual of Mental Disorders*, fourth edition<sup>25</sup> and 2) have been living in the care setting for at least 4 weeks prior to data collection. The type and severity of the dementia syndrome may vary. Residents with a primary psychiatric disease or those with Korsakoff's syndrome are excluded, because they usually differ from other residents with dementia (e.g. have a better mobility and are younger) and live often in special wards. Residents living in psychogeriatric wards in traditional nursing homes are eligible if they meet the above mentioned criteria and in addition match the cognition and ADL-profile of residents in small-scale living facilities. This is assessed in a screening prior to the baseline measurements.

**Family caregivers**

A family caregiver is in this study defined as someone who has or takes the responsibility for a resident with dementia at a voluntary basis. All main family caregivers providing informal care for participating residents in this study are eligible. The number is limited to one main family caregiver per resident.

**Staff**

All nursing staff (i.e. nursing assistants, certified nursing assistants and registered nurses) working on a permanent basis in either the selected small-scale living facilities or regular psychogeriatric wards in which the residents live are eligible to participate in the study. Temporary staff, such as trainees, are excluded from the study.

### **Small-scale living facilities: experimental group**

Small-scale living facilities had to fulfill the following criteria to be eligible for this study:

1. A maximum of eight residents per house or unit. This number is considered in the Netherlands as a maximum number for small-scale living facilities.<sup>10</sup>
2. Staff, residents and their family form a household together: activities are centered around the daily life and household. An important requirement is that staff prepare all meals together with residents and/or their family caregivers.
3. Staff perform integrated tasks: this means that one person may fulfill multiple tasks such as medical and personal care, domestic chores and activities.
4. Residents are cared for by a small, fixed team of professional caregivers, which are part of the household.
5. Daily life is organized completely or in a large amount by residents, their family caregivers and nursing staff.
6. Archetype home: a physical setting that resembles a homelike environment.

These criteria are based on a concept map, designed by te Boekhorst and colleagues (2007)<sup>10</sup> and on characteristics as presented in Table 1.

### **Psychogeriatric wards in traditional nursing homes: control group**

In the Netherlands, usual care for older people with dementia consists of care in psychogeriatric wards in traditional nursing homes. Inclusion criteria for these wards are:

1. A minimum of 20 residents per ward.
2. Staff have differentiated tasks: their main tasks entail medical and personal care for residents. Other tasks, such as domestic chores and (social) activities are provided by other specialized disciplines.
3. Residents and their family members have little control over the organization of daily life within the ward. Daily life is mainly organized around the routines of the nursing home.

### **Measures**

Table 2 presents all outcome and additional measures, their operationalization and timing of measurements.

### **Residents**

The primary outcome measure for residents is quality of life (QoL), as assessed by the

QUALIDEM.<sup>26-28</sup> The QUALIDEM is a dementia-specific QoL instrument, developed for use in residential care and is rated by professional caregivers or proxies. It is a multi-dimensional scale and consists of 37 items, divided in nine homogeneous subscales: Care relationship (seven items), Positive affect (six items), Negative affect (three items), Restless tense behavior (three items), Positive self image (three items), Social relations (six items), Social isolation (three items), Feeling at home (four items) and Having something to do (two items). Of these subscales, six can be used in very severe dementia (Global Deterioration Scale stage seven)<sup>29</sup> using approximately half of the items.<sup>26</sup> Items describe observable behaviors present last week and comprises four response options each: never, seldom, sometimes and often. The reliability (coefficient Rho 0.60 – 0.90) and validity are found to be appropriate for evaluation of interventions.<sup>26, 27</sup>

**Table 2.** Data collection: outcome, operationalization and time of measurement.

Outcome measure	Operationalization	Time of measurement			
		S	T1	T2	T3
<b>Residents</b>		<b>S</b>	<b>T1</b>	<b>T2</b>	<b>T3</b>
<i>Primary outcome</i>					
Quality of Life	QUALIDEM <sup>26-28</sup>	Q	Q	Q	
<i>Secondary outcome</i>					
Neuropsychiatric symptoms	NPI-NH <sup>30-33</sup>	Q	Q	Q	
	CMAI <sup>34,35</sup>	Q	Q	Q	
Depression symptoms	CSDD <sup>36,37</sup>	Q	Q	Q	
Social Engagement	Subscale ISE and RISE from RAI MDS <sup>38,39</sup>	Q	Q	Q	
<i>Additional variables</i>					
ADL-capacity	Subscale ADL-H from RAI MDS <sup>40,41</sup>	SQ	Q	Q	
Cognition	MMSE <sup>42</sup>		Q		
	Subscale CPS from RAI MDS <sup>40,43</sup>	SQ	Q	Q	
Use of physical restraint	Number of times physical restraints are used		Q	Q	Q
			Q	Q	Q
Psychotropic medication	ATC classification system <sup>44</sup>		Q	Q	Q
Use of health care services	Visits to e.g. Nursing home physician, psychologist etc.		Q	Q	Q
Dementia type	Alzheimer's dementia vascular dementia,				
	Other (e.g. Parkinson's disease)		MR		
Stage of dementia	GDS <sup>29</sup>	Q	Q	Q	

Outcome measure	Operationalization	Time of measurement
Comorbidity	International classification of diseases, version 10 <sup>45</sup>	MR MR MR
<i>Socio-demographic variables</i>		
Age	Years	SQ
Gender	Male or Female	SQ
Length of Stay	Number of months	SQ
Living prior to admission	At home, Residential care, Regular Nursing home care, Other	SQ
<b>Family caregivers</b>		
<i>Primary outcome</i>		
Involvement with care	Frequency, length, activities and motivation for visits	Q Q Q
Perceived burden	SPPIC <sup>46</sup>	Q Q Q
Satisfaction with care	27 items	Q Q Q
<i>Additional variables</i>		
Age	Years	Q Q Q
Gender	Male or Female	Q Q Q
Sense of competence	SSCQ <sup>47</sup>	Q Q Q
Relationship with resident	E.g. Spouse, Child, Sibling or Other	Q Q Q
<b>Nursing staff</b>		
<i>Primary outcome</i>		
Job satisfaction & motivation	[45]	Q Q Q
<i>Secondary outcome</i>		
Social support	Subscale from JCQ <sup>48,49</sup>	Q Q Q
Autonomy	MAQ <sup>50</sup>	Q Q Q
Workload	[45]	Q Q Q
<i>Additional variable</i>		
Age	Years	Q Q Q
Gender	Male or Female	Q Q Q
Education level	Type of education and level (e.g. level 1 – 5)	Q Q Q

Contract working hours	Hours	Q	Q	Q
Years of employment	Years	Q	Q	Q

S = Screening, approximately two week prior to baseline measurement; T1 = Baseline measurement  
T2 = Follow-up after six months T3 = Follow-up after 12 months Q = Questionnaire, SQ = Screening  
Questionnaire, MR = Medical Record

Secondary outcome measures are: neuropsychiatric symptoms (Neuropsychiatric Inventory, Nursing Home version (NPI-NH)<sup>30-33</sup> and Cohen-Mansfield Agitation Inventory, CMAI),<sup>34, 35</sup> depressive symptoms (Cornell Scale for Depression in Dementia, CSDD),<sup>36, 37</sup> and social engagement (Index for Social Engagement (ISE), a subscale from the Resident Assessment Instrument (RAI) Minimum Data Set (MDS, version 2.1)<sup>39</sup> and Revised Index for Social Engagement, RISE).<sup>38</sup>

Furthermore, several health-related variables are measured: ADL-capacity (ADL-Hierarchy (ADL-H), a subscale from the RAI-MDS, versions 2.1),<sup>40, 41</sup> cognition (standardized Mini-Mental State Examination (MMSE)<sup>42</sup> and Cognitive Performance Scale (CPS), a subscale from the RAI-MDS, version 2.1),<sup>40, 43</sup> use of physical restraints, psychotropic medication (classified according to the anatomical therapeutic chemical (ATC) classification system),<sup>44</sup> use of health care services (e.g. record of visits to the nursing home physician, psychologist and physiotherapist), comorbidity (classified according to classification of diseases in nursing home patients, CvZ-V),<sup>51</sup> compatible with the international classification of diseases, version 10 (ICD-10),<sup>45</sup> dementia type and stage of dementia (Global Deterioration Scale, GDS).<sup>29</sup> In addition, socio-demographic variables are assessed: gender, age, length of stay and living condition prior to admission.

### **Family caregivers**

Primary outcome measures for family caregivers are: perceived burden, involvement with care and satisfaction with care provision. Perceived burden is measured with the 'Self-Perceived Pressure from Informal Care' (SPPIC) scale, a self-reported questionnaire consisting of nine items.<sup>46, 52</sup> Items are scored at a five-point scale and form a one-dimensional Rasch scale, varying from less pressure to more pressure. Reliability (Rho = 0.79) and validity are found satisfactory for use in evaluation of intervention. Involvement with care is assessed by a self-report questionnaire, in which family caregivers report their frequency and length of visits, activities during a visit

(based on the RAI-MDS subscale activities, version 2.1) and motivation for visiting. Satisfaction with care is assessed, using a self-reported questionnaire, which comprises 27 items, regarding care provided during the last two to four weeks. In addition, gender, age, relationship with the resident and sense of competence (Short Sense of Competence Questionnaire, SSCQ)<sup>47</sup> are measured.

### **Nursing Staff**

Job satisfaction and work motivation are the primary outcome measures for nursing staff. These are assessed using a self-reported questionnaire, consisting of 6 items.<sup>50</sup> Items are measured on a five-point Likert scale, ranging from one 'totally disagree' to five 'totally agree'. Secondary outcome measures are: workplace social support (eight-item scale from the Job Content Questionnaire),<sup>48, 49</sup> job autonomy (Maastricht Autonomy Questionnaire)<sup>50</sup> and workload.<sup>50</sup> Finally, background variables age, gender, education level, contract working hours per week and employment years in institution type are recorded, as well as absentee rate.

### **Process evaluation**

To investigate to what extent both types of dementia care settings are designed as they were intended, data is collected by researchers' observations and questionnaires at all three measurements. Observations regarding the selection criteria (e.g. joint household, staff tasks) are recorded in a logbook. The questionnaire comprises items relating to the organizational, social and physical environment of the unit and are measured at a five-point Likert scale, ranging from one 'not at all' to five 'completely'. Item examples are: 'To what extent is nursing staff part of the household?' and 'To what extent resembles the design of the unit an archetype house?'

To examine participants' satisfaction and experiences with small-scale living facilities, self-report questionnaires (filled in by family caregivers and staff), are administered at the end of all measurements, i.e. T3. In addition, in-depth interviews are conducted with a selection of participants.

### **Procedure**

Data from residents, family caregivers and nursing staff are collected at three moments: a baseline measurement (T1) and six months (T2) and 12 months (T3) after baseline. Approximately two weeks prior to T1, a screening among residents is conducted to match residents at baseline (see Figure 1). The managing directors of the nursing homes and small-scale living facilities all provide consent to conduct the

study. Written informed consent is obtained for all residents by their registered legal representative before participation. In addition, written informed consent is obtained for family caregivers and nursing staff in order to participate in the study.

### **Screening**

The screening procedure to match residents at baseline, consists of two MDS subscales to assess cognition (CPS) and ADL-capacity (ADL-H).<sup>40, 41, 43</sup> In addition, age, gender, length of stay and living condition prior to submission are measured. All residents in small-scale living facilities and psychogeriatric wards are assessed by the registered nurse (RN) of their unit. Cognition and ADL-scores are both dichotomized. Cut-off points are based on previous studies.<sup>39, 53</sup> For cognition, the three lowest scores (i.e. 4, 5 and 6) are combined as a relatively low level of performance (category '-'); the remaining scores (i.e. 0 – 3) form a relatively high level of performance (category '+'). For ADL, the 4 lowest scores (i.e. 3 – 6) are considered as a relatively low level of functioning (category '-'). The other three scores (i.e. 0, 1 and 2) form a relatively high level of functioning (category '+'). Then, a cognition/ADL profile was constructed for each resident. Based on the profile of residents in small-scale living facilities, residents in psychogeriatric wards in traditional nursing homes with a relatively similar profile are recruited. This procedure is conducted to enhance comparability of groups at baseline with respect to cognition and ADL-capacity.

### **Data collection**

The primary outcome measure for residents, QoL (QUALIDEM), is assessed by two registered nurses (RNs) or certified nursing assistants (CNAs), as well as by residents' main family caregiver. Neuropsychiatric symptoms (NPI-NH and CMAI), social engagement (ISE and RISE), ADL-capacity (ADL-H), cognition (CPS), use of physical restraints and use of services are assessed by RNs and CNAs. The nursing home physician or a psychologist administer the GDS, MMSE and CSDD. In addition, data regarding diagnosis and type of dementia, comorbidity and medication use are derived from medical records, as provided by the nursing home physician. Outcomes regarding family caregivers and nursing staff are based on self-report questionnaires.

### **Sample size considerations**

Sample size calculations are based on the primary outcome measure for residents, that is QoL, as measured by the QUALIDEM.<sup>26-28</sup> Using an effect size ( $\delta$ ) of 0.33, a significance level of .05 (two sided) and a power of 90%, 84 residents are needed in each

group. Based on previous research, the drop-out rate for residents in small-scale facilities appears to be lower than those in traditional nursing homes.<sup>17</sup> Taking these drop-out rates into account, we aim at including 120 residents in small-scale living facilities at baseline and 140 in traditional nursing homes to have a sufficient number of residents after 12 months (*see also Figure 1*).

### **Statistical Analysis**

Descriptive statistics are computed to describe background variables and characteristics of all participants, i.e. residents, family caregivers and staff. Baseline variables will be compared to investigate the comparability of residents at baseline. Multivariate regression analyses will be applied to estimate the differences in outcomes over time. Data will be analyzed according to the intention-to-treat principle, i.e. including all participants with valid data, regardless of whether they remained in the setting in which they were measured at baseline. In addition, on-treatment analyses will be performed, to investigate effects on participants who remained in the same care setting during all three measurements. In all analyses there will be correction for potential baseline differences. Drop-outs, relocations and losses to follow-up will be described. In addition, subgroup analyses will be performed to investigate participants' characteristics, who gain more benefits from small-scale living facilities than others. Data collected during the process evaluation will be mainly analyzed using descriptive techniques.

### **Study Progress**

Screening and inclusion of residents, family caregivers and professional caregivers started in April 2008 and will end in December 2008. Baseline measurements also started in April 2008. Follow-up measurements are planned for October 2008 – May 2009 and April – December 2009. In October 2008, baseline measurements have been performed for 106 residents living in small-scale living facilities and 93 residents living in psychogeriatric wards. In addition, 171 family caregivers are included (91 from small-scale living facilities and 80 from psychogeriatric wards) and 134 nursing staff members (71 in small-scale living and 63 from psychogeriatric wards). Dissemination of results is planned for 2010.



## Discussion

This paper presents the design of a longitudinal, quasi-experimental study to investigate the effects of small-scale living facilities for older people with dementia. Although some challenges concerning this design exist, it is currently the most feasible method to assess the effects of this relatively new dementia care setting.

Randomization in this study is difficult to realize due to ethical and practical drawbacks. Institutional care for people with dementia is seen in the Netherlands as a home for life. As a consequence, residents and their family members, together with clinicians, decide which accommodation suits their own wishes and beliefs best. This makes a random allocation of residents to a dementia care setting complicated, as seen in a study by Maas and Buckwalter (1990), reported in Saxton and colleagues (1998).<sup>15, 54</sup> Maas and Buckwalter tried to randomly assign residents to nursing home or special care unit, but family members had problems with accepting a random group allocation. In addition, it could take several years to acquire a moderate sample size of residents in small-scale living facilities by using random assignment of residents. In the Netherlands, traditional nursing homes outnumber small-scale living facilities and the latter seem to have a lower turnover rate,<sup>17</sup> which makes random assignment difficult to realize.

To prevent selection bias, we have used a matching procedure in this study to enhance comparability of resident groups at baseline, with respect to cognition and ADL-capacity. We consider cognition and functional capacity as most important characteristics for matching, since these appear strongly related to dementia severity,<sup>55</sup> especially discriminating between moderate and severe dementia.<sup>56</sup> A previous study has shown that residents living in small-scale living facilities had a higher cognitive and functional status at baseline, compared to those in regular psychogeriatric wards.<sup>17</sup> This emphasizes the need for creating comparable groups at baseline in order to study effects of the dementia care setting. Furthermore, the environment of both dementia care settings is well documented during the process evaluation, using registration, observation, questionnaires and in-depth interviews. As a result, differences and similarities between the two settings can be taken into account during the interpretation of results.

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## Chapter 5

# Dementia care redesigned: effects of small-scale living facilities on residents, their family caregivers and staff



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## Abstract

**Objective:** The purpose of this study was to evaluate the effects of small-scale living facilities in dementia care on residents, family caregivers and staff.

**Design:** This was a quasi-experimental study including two types of institutional nursing care: small-scale living facilities (experimental group) and regular psychogeriatric nursing home wards (control group). Three measures were conducted: at baseline and follow-ups after six and 12 months.

**Setting:** Twenty-eight houses in small-scale living facilities and 21 regular psychogeriatric nursing home wards.

**Participants:** In total, 259 residents were included in study: 124 in small-scale living facilities and 135 controls, matched on cognitive and functional status. Furthermore, 229 family caregivers were included and 305 staff members.

**Measurements:** For residents, main outcome measures were quality of life, neuropsychiatric symptoms and agitation. Main outcome measures for family caregivers included perceived burden, satisfaction and involvement with care. Main outcome measures for staff were job satisfaction and motivation.

**Results:** No effects were found for residents' total quality of life, neuropsychiatric symptoms and agitation. Family caregivers in small-scale living reported significant less burden (mean difference 0.8, 95% CI 0.1 – 1.5) and were more satisfied with nursing staff (0.3, 0.2 – 0.5) than family caregivers in regular wards. No differences were found in their involvement with care. Overall, no significant differences were found for staff's job satisfaction and motivation, although subgroup analyses using contrast groups (regarding typical small-scale living and regular wards) revealed more job satisfaction (2.0, 0.5 – 3.5) and motivation (0.6, 0.0 – 1.3) in small-scale living facilities compared with regular wards.

**Conclusion:** This study was unable to demonstrate convincing overall effects of small-scale living facilities. Since governmental policies and, in some countries, financial support, are increasingly aimed at providing small-scale, homelike care, it is suggested that this may not be a final solution to accomplish high-quality dementia care and that other options should be considered.



## Introduction

Dementia care is currently being redesigned and deinstitutionalization has become common policy. A recent study conducted by the Organization for Economic Cooperation and Development (OECD), for example, stated that policies should be aimed at enabling people with dementia to remain at home for as long as possible. Furthermore, when required, institutional dementia care should be as homelike as possible.<sup>1</sup> Dementia is still an incurable syndrome and causes progressive deterioration in cognition, functional abilities and behavior. As the disease progresses, institutional nursing care is often inevitable. The World Health Organization regards dementia as the number four cause for disability adjusted life years in people aged 60 or older.<sup>2</sup> Worldwide, the number of people with dementia is rapidly increasing to an estimated 81 million by 2040.<sup>3</sup> This burden challenges all people involved: those suffering from dementia, their families and professional caregivers. Since current treatments cannot cure or even stop the progression of dementia and the development of new drugs takes years to be tested and developed, provision of high-quality care and good practice must be a priority.<sup>4, 5</sup>

Promoting overall well-being of residents is nowadays leading in institutional dementia care. Values such as preserving autonomy, enabling residents to continue their own lifestyle and focusing on quality of life (QoL) are of vital importance. Integrated dementia care programs, like person-centered care, tailored to individual needs of residents are designed to support these values.<sup>5, 6</sup> Moreover, outcomes relating to family caregivers and staff (e.g. caregiver burden and satisfaction) are also essential processes suggested to contribute to residents' QoL.<sup>7</sup> The focus on deinstitutionalization and well-being has resulted in the development of new dementia care settings by combining changes in both physical environment and care programs, directed towards small-scale and homelike care environments.<sup>8, 9</sup> Various countries have implemented this, for instance group living in Sweden,<sup>10</sup> group homes in Japan,<sup>11</sup> the Green House<sup>®</sup> project in the United States<sup>12</sup> and small-scale living in the Netherlands,<sup>13, 14</sup> all aimed at providing nursing care in small groups (six to 10 residents per house) emphasizing normalization of daily life and encouraging residents to participate in meaningful activities. In some countries, such as the Netherlands, governmental policies and financial support have encouraged its development which brought small-scale living facilities to form a significant part (e.g. approximately 25% in the Netherlands) of institutional care.<sup>8</sup>

Despite its increase, research into the effects of small-scale living facilities on

residents, family and staff is hardly available and suffers from methodological limitations such as small sample sizes, lack of comparison groups, no or short periods of follow-up and large variation in cognitive and functional abilities of residents.<sup>8</sup> Evidence from controlled studies on best-care practices is therefore urgently needed.

Therefore, this study investigated the effects of small-scale living facilities compared with regular care in nursing homes in the Netherlands, focusing especially on residents' QoL and behavior, family caregivers' experienced burden, involvement with care and satisfaction and nursing staff's job satisfaction and motivation. Unique to this study is the combination of a large sample size, baseline resident matching, a long follow-up period of 12 months and simultaneous assessment of both resident, family caregivers and nursing staff outcomes.

## Methods

### Design and Sample

A quasi-experimental study was conducted during April 2008 – January 2010 (recruitment period April 2008 – December 2008), including three measurements: at baseline and follow-ups after six and 12 months. A detailed report of the rationale and study design was published elsewhere.<sup>14</sup>

Two types of long-term institutional nursing care settings were included: small-scale living facilities and regular psychogeriatric wards in nursing homes. The experimental condition consisted of 28 houses in small-scale living facilities, which were selected on: 1) at most eight residents per house, 2) a joint household, with activities centered around daily life and all meals prepared by staff together with residents and/or family caregivers, 3) staff performing multiple tasks (e.g. medical and personal care, organizing activities and domestic chores), 4) a small, fixed team of staff caring for residents 5) organization of daily life mainly by residents, family and staff and 6) facilities' resemblance of an archetypal home. The control condition consisted of 21 regular wards selected on: 1) at least 20 residents per ward, 2) staff having differentiated tasks, focusing on residents' medical and personal care and 3) organization of residents' daily life largely by routines of the nursing home.

Residents were eligible if they had a primary diagnosis of dementia, based on the criteria established by the *Diagnostic and Statistical Manual of Mental Diseases*, fourth edition,<sup>15</sup> resided for at least one month in the facility and their legal guardian had

provided written informed consent. Residents in regular wards had to match the cognitive and functional status profile of residents in small-scale living, as assessed by two subscales from the Resident Assessment Instrument Minimum Data Set (RAI-MDS), i.e. Cognitive Performance Scale (CPS) and Activities of Daily Living-Hierarchy scale (ADL-H).<sup>14, 16-18</sup> This matching procedure increased the comparability of groups at baseline. A family caregiver in this study was defined as someone who voluntarily had responsibility for a resident. All nursing staff involved in direct care and working on a permanent basis were eligible to participate.

The Medical Ethics Committee of the University Hospital Maastricht/Maastricht University and all local ethical committees of participating facilities approved the study.

### **Measures**

The primary outcome measures for residents were QoL, neuropsychiatric symptoms and agitation. QoL was assessed with QUALIDEM, a validated dementia-specific QoL instrument designed for use in institutional care and rated by proxies.<sup>19, 20</sup> QUALIDEM focuses on observable behaviors, contains 37 items rated on a four-point scale (never-seldom-sometimes-often; range 0 – 3) and comprises nine subscales: care relationship (seven items), positive affect (six items), negative affect (three items), restless tense behavior (three items), positive self image (three items), social relations (six items), social isolation (three items), feeling at home (four items) and having something to do (two items). Higher scores indicate a higher QoL. A mean total score (range 0 – 27) was calculated by adding the mean score of each subscale (range 0 – 3; i.e. total subscale score divided by the number of its items). Neuropsychiatric symptoms were assessed with the neuropsychiatric inventory, nursing home version (NPI-NH),<sup>21</sup> which measures frequency and severity of 12 domains (range 0 – 144): delusions, hallucinations, aggression/agitation, depression, anxiety, euphoria, apathy, disinhibition, irritability, aberrant motor behavior, sleep and eating disturbances. Higher scores indicate more symptoms. Agitation was measured with the Cohen-Mansfield Agitation Inventory (CMAI),<sup>22</sup> containing 29 items which assess frequency (from never, one, to several times an hour, seven) of agitated behaviors during the past two weeks (range 29 – 203), with a higher score indicating more agitation. Furthermore we recorded socio-demographic (age, gender, living condition prior to admission and length of stay) and clinical information (dementia severity, type of dementia, psychotropic drug use, comorbid diseases, cognition, functional status). Dementia severity was measured with the global deterioration scale (range 1 – 7),<sup>23</sup> with higher scores indicating more severe dementia. Type of dementia,

psychotropic drug use (according to the anatomical therapeutic chemical classification system)<sup>24</sup> and number of comorbid diseases (International Classification of Diseases, version 10) was derived from medical records. Cognition was assessed with the Mini-Mental State Examination (MMSE; range 0 – 30, higher scores indicate better cognitive performance)<sup>25</sup> and CPS.<sup>16</sup> Functional status was measured with the ADL-H.<sup>17</sup>

The primary outcome measures for family caregivers were perceived burden, involvement and satisfaction with care. Perceived burden was assessed with the Self Perceived Pressure From Informal Caregiving (SPPIC), a nine item scale (range: 0 – 9).<sup>26</sup> A higher score indicates more burden. Involvement with care was defined as frequency (number of visits) and length of visits (minutes) in the past two weeks and number of activities during a visit. Satisfaction with resident contact and nursing staff contact was measured on a four-point scale, with higher scores indicating more satisfaction. Furthermore, age, gender and relationship with resident were assessed.

The primary outcome measures for nursing staff were job satisfaction and motivation, assessed by six items,<sup>27</sup> scored on a five-point scale ranging from totally disagree to totally agree. Total scores ranged from four to 20 (job satisfaction) and two to 10 (motivation), with higher scores indicating more satisfaction and motivation respectively. Finally, socio-demographic variables (age, gender, education level, months of employment in facility type and years working in elderly care and contract hours per week) were measured.

The QUALIDEM was rated both by family caregivers and two nursing staff members, i.e. registered nurses (RNs) or certified nursing assistants (CNAs), who were in charge of the residents and were most involved in their care. These RNs/CNAs also rated the NPI-NH and CMAI. Data concerning family caregivers and nursing staff were collected using self-report questionnaires. To measure contrast between experimental and control group, an 18-item questionnaire was developed which measured the extent to which a nursing home facility fulfilled the criteria for small-scale living.<sup>14</sup> Items relate to a units' organizational, social and physical environment and were measured on a five-point scale, ranging from one 'not at all' to five 'completely' (range 18 – 90) and rated by two observers independently. An example item is: 'To what extent is the staff part of the household?' Higher scores indicate more adherence to small-scale living.

### **Statistical Analyses**

Differences in characteristics between the two groups at baseline were tested with

$\chi^2$ -tests for categorical variables, individual sample t-tests for normally distributed continuous variables and Kruskal-Wallis tests for continuous variables with skewed distributions. Study hypotheses were tested with mixed-model multi-level analyses, according to the intention-to-treat principle. Multi-level analyses are robust against missing data on outcome variables. Therefore all participants having a baseline measurement were included, regardless of availability of data at follow-up. All socio-demographic characteristics of participants (see Table 1 for specification per participant group) were included as covariates in the model. Missing data for only these covariates were imputed using multiple imputation. First, fixed effects for group by time interaction were tested for significance. If this interaction was not significant, it was removed from the model and only fixed effects for group and time were tested. Based on a priori sample size calculation, the power for these analyses was sufficient, as a number of 84 participants per group was required.<sup>14</sup>

Subgroup analyses were conducted. Based on their median score on the contrast questionnaire two groups were created: highest scoring small-scale living (contrast group one) versus lowest scoring regular wards (contrast group two). Contrast group one consisted of 14 houses with total scores above the median (>66); contrast group two consisted of 10 regular wards with total scores below the median (<40). The power for these analyses is limited, due to an insufficient number of participants in the contrast groups (less than 84 participants per group), resulting in an increased chance of type-II errors. All tests used a two-sided significance level of .05. All statistical analyses were conducted using Predictive Analytics SoftWare (PASW) version 17 from SPSS.

## Results

Figure 1 describes the number of participants at each stage of the study, including reasons for non-participation. In total, 259 residents were included, 124 in small-scale living facilities and 135 in regular wards. Family caregivers were available for 253 residents, of whom 229 were willing to participate: 114 in small-scale living facilities and 115 in regular wards. Finally, 305 nursing staff members participated in the study, 114 from small-scale living facilities and 191 from regular wards.

Participants' baseline socio-demographic characteristics are presented in Table 1. Groups were comparable on baseline characteristics, except for living condition prior to admission, length of stay and use of psychotropic drugs (residents' level),



\* Main reasons for non-response of family caregivers was drop-out due to death of residents, not returning questionnaires and moving. † Main reasons for non-response for nursing staff were not returning questionnaires, transfer to another ward or nursing home and maternity/sickness leave.

gender and years of employment in nursing home type (staff's level).

Unadjusted means for all outcome measures are shown in Table 2 (residents) and Table 3 (family caregivers and nursing staff). Figure 2 (residents), Figure 3 (family caregivers) and Figure 4 (nursing staff) present adjusted scores for both groups (small-scale living facilities versus regular wards) at three measurements.

Subgroup analyses (data not shown) based on the contrast questionnaire confirmed overall outcomes, except for nursing staff's job satisfaction and motivation. For these outcome measures, results for both overall and contrast analyses are presented.

**Table 1.** Participants' baseline characteristics.

	Small-scale living	Regular wards
<b>Residents</b>	n = 124	n = 135
Age (years)	82.4 (7.9)	83.1 (6.5)
Women	99 (80)	95 (70)
Living condition prior to admission*		
At home	37 (30)	80 (59)
Other institution / unknown	7 (70)	55 (41)
Length of Stay in months <sup>†</sup>	15.7 (11.3)	24.4 (22.0)
Dementia type		
Alzheimer's Disease	33 (27)	44 (32)
Vascular Dementia	19 (15)	24 (18)
Other	20 (16)	27 (20)
Not Otherwise Specified / unknown	52 (42)	40 (30)
Global Deterioration Scale	5.3 (1.1)	5.1 (1.0)
Mini Mental State Examination	11.1 (7.0)	10.5 (6.6)
Cognitive Performance Scale	3.5 (1.4)	3.4 (1.4)
Activities of Daily Life – Hierarchy Scale	3.1 (1.7)	3.3 (1.4)
Comorbid diseases	4.3 (2.3)	3.8 (1.9)
Use of psychotropic drugs <sup>‡</sup>		
Yes ( 1 or more)	72 (58)	100 (74)
No	37 (30)	28 (21)
Unknown	15 (12)	7 (5)
<b>Family caregivers</b>	n = 106	n = 100
Age in years	58.1 (9.7)	57.9 (11.2)
Women	77 (75%)	66 (66%)
Relationship with resident		
Spouse	11 (10%)	14 (14%)
Child	66 (63%)	65 (65%)
Other / unknown	29 (27%)	21 (21%)
<b>Nursing staff</b>	n = 114	n = 191
Age in years	40.7 (11.5)	42.8 (10.1)
Women <sup>§</sup>	110 (97)	170 (89)
Level of education		
Level 1 basic nursing aids	6 (5)	3 (2)



Level 2 NA	18 (16)	29 (15)
Level 3 CNA	64 (57)	128 (67)
Level 4 RN	21 (19)	26 (14)
Level 5 RN	3 (3)	3 (2)
Employment in nursing home type in months <sup>¶</sup>	23.1 (18.4)	85.2 (72.8)
Years working in elderly care	14.7 (10.3)	16.7 (10.7)
Contract hours per week	26.4 (7.0)	26.9 (6.6)

Data are mean (SD) or number (%).  $P = *.001$  †.047 ‡.038 §.021<sup>¶¶</sup> .001.  
 NA= nursing assistants, CNA= certified nursing assistants, RN= registered nurses.

### Residents

No significant group by time interaction effects were found for all subscales and the total score of QUALIDEM. No differences were found in total QoL, as scored by nursing staff (Figure 2). Group effects were found on two subscales scored by nursing staff: negative affect and having something to do. Residents in small-scale living facilities had a higher QoL with respect to having something to do (adjusted mean difference 0.9, 95% CI 0.5 – 1.2;  $P < .001$ ) and a lower QoL regarding negative affect than residents in regular wards (0.7, 0.2 – 1.2;  $P = .01$ ). Total QoL scored by family caregivers was slightly higher for residents in small-scale living than in regular wards, but this difference did not reach significance (adjusted mean difference 1.0, 95% CI - 0.1 – 2.1;  $P = .076$ ). Group effects were found on three subscales: feeling at home (1.0, 0.1 – 2.0;  $P = .023$ ), having something to do (0.5, 0.1 – 0.9;  $P = .018$ ) and social relations (1.1, 0.2 – 2.0;  $P = .02$ ), with residents in small-scale living facilities having a higher QoL on these aspects.

No significant differences were found in neuropsychiatric symptoms (NPI-NH). Both groups scored rather low. A group by time interaction effect was found for agitation ( $P = .04$ ). Total agitation scores (CMAI) for residents in small-scale living remained stable over time, while these scores for residents in regular wards decreased. Only at measurement three (follow up after 12 months) this did result in a significant difference between groups (adjusted mean difference 4.6, 95% CI 0.3 – 8.9;  $P = .035$ ) (Figure 2).

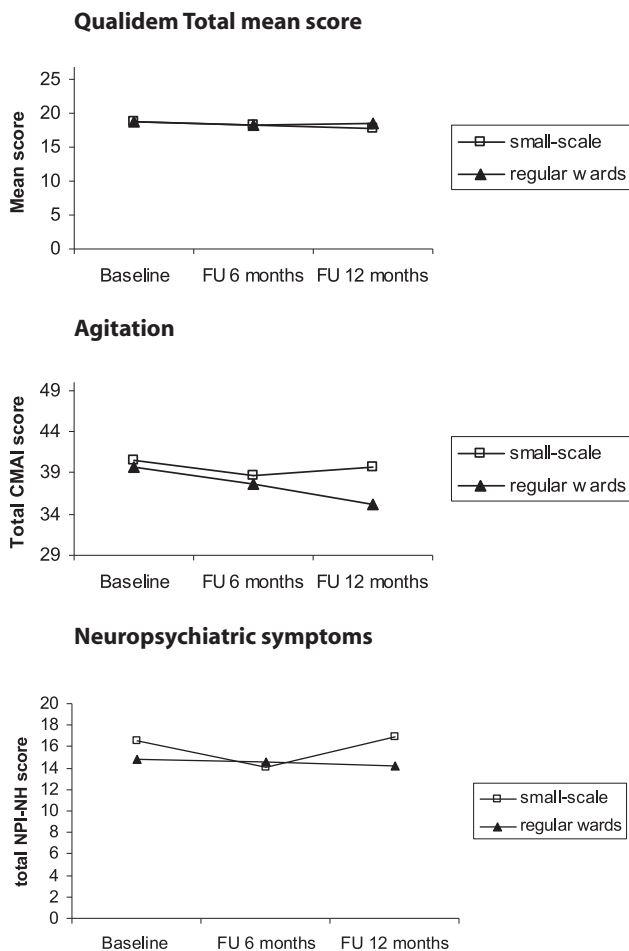
**Table 2:** Primary outcomes for residents.

	Baseline	FU 6 months	FU 12 months
<b>Residents*</b>			
total score Qualidem subscale Care relationships (range 0 – 21)			
Small-scale	15.0 (4.5)	14.6 (4.4)	14.5 (4.4)
Regular ward	15.5 (4.6)	15.8 (4.8)	15.8 (4.6)
total score Qualidem subscale Positive affect (range 0 – 18)			
Small-scale	14.5 (3.7)	13.8 (3.9)	13.7 (3.7)
Regular ward	14.0 (4.0)	13.8 (3.7)	13.7 (4.1)
total score Qualidem subscale Negative affect (range 0 – 9)			
Small-scale	6.6 (1.9)	6.6 (2.3)	6.6 (2.4)
Regular ward	5.8 (2.2)	5.7 (2.4)	5.7 (2.3)
total score Qualidem subscale Restless behavior (range 0 – 9)			
Small-scale	5.4 (2.8)	5.3 (2.8)	4.8 (2.8)
Regular ward	5.7 (2.7)	5.5 (3.0)	5.8 (2.8)
total score Qualidem subscale Social isolation (range 0 – 9)			
Small-scale	6.6 (2.0)	6.4 (2.3)	6.1 (1.9)
Regular ward	6.8 (2.3)	6.8 (2.3)	6.9 (2.2)
total score Qualidem subscale Positive self image (range 0 – 9)			
Small-scale	7.1 (2.1)	7.2 (2.3)	7.1 (2.2)
Regular ward	7.4 (2.1)	7.6 (2.1)	7.7 (2.0)
total score Qualidem subscale Having something to do (range 0 – 6)			
Small-scale	2.7 (2.1)	2.3 (2.0)	2.2 (2.0)
Regular ward	1.9 (2.0)	1.6 (1.7)	1.4 (1.6)
total score Qualidem subscale Feeling at home (range 0 – 12)			
Small-scale	9.7 (2.7)	9.8 (2.5)	9.5 (2.9)
Regular ward	9.8 (2.6)	10.1 (2.4)	10.4 (2.0)
total score Qualidem subscale Social relations (range 0 – 18)			
Small-scale	12.4 (3.8)	10.7 (3.9)	11.0 (3.9)
Regular ward	11.3 (4.1)	11.6 (3.8)	10.3 (3.7)
mean total Qualidem score (range 0 – 27)			
Small-scale	18.8 (3.5)	18.3 (3.7)	17.5 (3.8)
Regular ward	18.8 (3.8)	18.6 (3.9)	18.4 (3.6)
total score NPI-NH (range 0 – 144)			
Small-scale	16.2 (14.0)	13.5 (12.0)	16.6 (14.9)

Regular ward	15.7 (13.7)	14.3 (12.7)	14.8 (12.1)
total score CMAI (range 29 – 203)			
Small-scale	40.3 (14.2)	37.3 (11.5)	39.6 (13.5)
Regular ward	40.6 (14.0)	38.5 (11.7)	35.3 (8.0)

Data are unadjusted scores (SD). \* n<sub>small-scale</sub> = 124, n<sub>regular wards</sub> = 135; Follow-up after 6 months

n<sub>small-scale</sub> = 111, n<sub>regular wards</sub> = 111; Follow-up after 12 months n<sub>small-scale</sub> = 93, n<sub>regular wards</sub> = 97.



**Figure 2.** Adjusted mean scores for residents' outcome measures, as assessed by nursing staff.

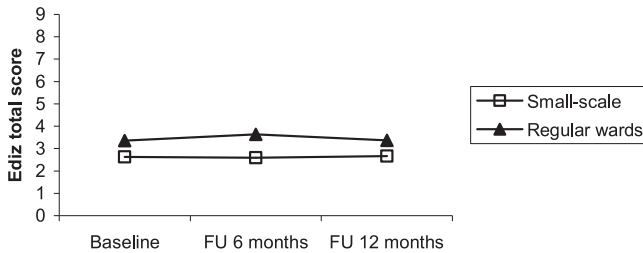
**Table 3:** Primary outcomes for family caregivers and nursing staff.

	Baseline	FU 6 months	FU 12 months
<b>Family caregivers*</b>			
Perceived Burden (range 0 – 9)			
Small-scale	2.8 (2.9)	2.6 (2.8)	2.7 (2.6)
Regular ward	3.5 (2.8)	4.0 (3.2)	3.5 (3.2)
Number of visits (range 0 – 14)			
Small-scale	5.3 (4.0)	4.8 (3.4)	4.4 (3.5)
Regular ward	5.6 (4.1)	5.6 (4.2)	5.0 (3.2)
Duration of visits (in minutes)			
Small-scale	99.9 (52.7)	104.9 (71.2)	97.5 (43.5)
Regular ward	100.8 (46.3)	90.6 (45.0)	92.4 (47.4)
Number of activities during visit (range 0 – 14)			
Small-scale	3.0 (1.6)	3.1 (1.8)	3.2 (2.0)
Regular ward	2.7 (1.4)	2.8 (1.5)	2.6 (1.3)
Satisfaction with contact resident (range 0 – 4)			
Small-scale	3.2 (0.7)	3.1 (0.8)	3.1 (0.8)
Regular ward	3.1 (0.8)	2.9 (0.8)	3.0 (0.8)
Satisfaction with contact nursing staff (range 0 – 4)			
Small-scale	3.7 (0.5)	3.6 (0.7)	3.5 (0.9)
Regular ward	3.3 (0.6)	3.3 (0.5)	3.4 (0.7)
<b>Nursing Staff†</b>			
Job satisfaction (range 4 – 20)			
Small-scale	16.5 (2.8)	16.5 (2.9)	16.2 (2.8)
Regular ward	15.8 (2.7)	16.3 (2.4)	16.2 (2.8)
Job motivation (range 2 – 10)			
Small-scale	8.3 (1.5)	8.4 (1.4)	8.3 (1.3)
Regular ward	8.1 (1.3)	8.4 (1.2)	8.4 (1.3)
Data are unadjusted total scores (SD).			
*Family caregivers: n <sub>small-scale</sub> = 106, n <sub>regular wards</sub> = 100; Follow-up after 6 months n <sub>small-scale</sub> = 75, n <sub>regular wards</sub> = 64; Follow-up after 12 months n <sub>small-scale</sub> = 67, n <sub>regular wards</sub> = 51.			
†Nursing staff: n <sub>small-scale</sub> = 114, n <sub>regular wards</sub> = 191; Follow-up after 6 months n <sub>small-scale</sub> = 72, n <sub>regular wards</sub> = 109; Follow-up after 12 months n <sub>small-scale</sub> = 69, n <sub>regular wards</sub> = 87.			

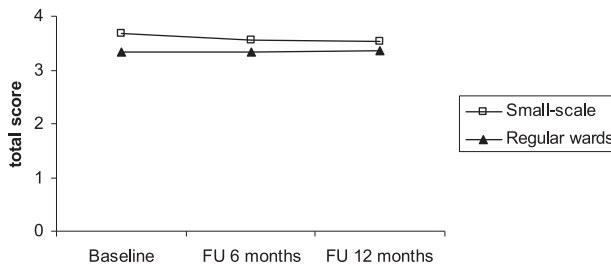
### Family caregivers

No group by time interaction effect was found for perceived burden; both groups remained stable over time. A significant group effect was found (Figure 3): family caregivers in small-scale living facilities experienced less burden than family caregivers in regular wards (adjusted mean difference 0.8, 95% CI 0.1 – 1.5;  $P = .034$ ). Furthermore, a significant group effect was found in satisfaction with nursing staff (adjusted mean difference 0.3, 95% CI 0.2 – 0.5;  $P < .001$ ). Family caregivers in small-scale living facilities were more often very satisfied than family caregivers in regular wards, who were more often fairly satisfied. No effects were found for involvement with care. No significant differences were found for frequency and length of visits and amount of activities during a visit between groups in the last two weeks (Figure 3). No differences were found for satisfaction with resident contact (Figure 3).

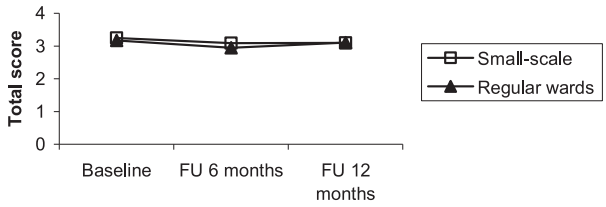
#### Family caregivers' perceived burden



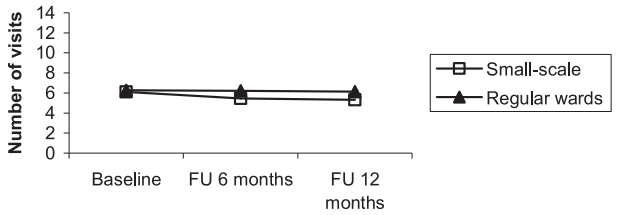
#### Family caregivers' satisfaction with nursing staff



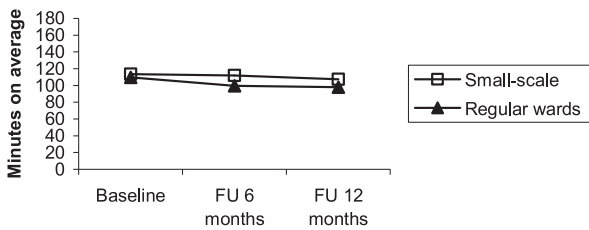
**Family caregivers' satisfaction with resident contact**



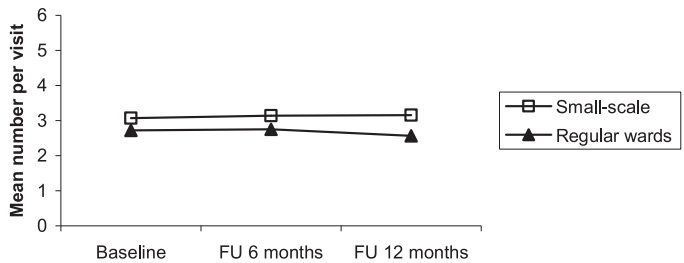
**Involvement: number of visits past 14 days**



**Involvement: length of visit past 14 days**



**Involvement: number of activities during visit**

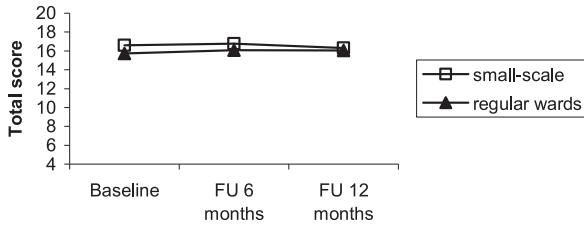


**Figure 3.** Adjusted mean scores for outcomes on family caregivers.

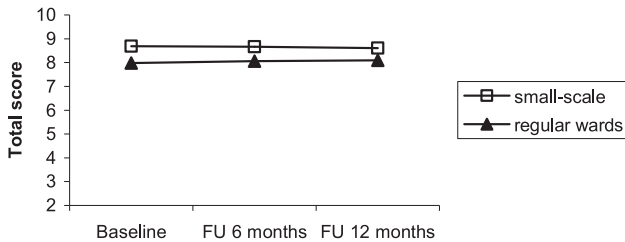
### Nursing staff

No significant differences were found for job satisfaction and motivation. Both groups scored relatively highly on these scales. However, subgroup analyses using contrast groups revealed significant differences. Nursing staff in contrast group one, typical small-scale living facilities, were significantly more satisfied with their job (adjusted mean difference 2.0, 95% CI 0.5 – 3.5;  $P = .009$ ) and showed a significantly higher motivation (0.6, 0.0 – 1.3;  $P = .05$ ) than nursing staff working in contrast group two, typical regular wards (Figure 4).

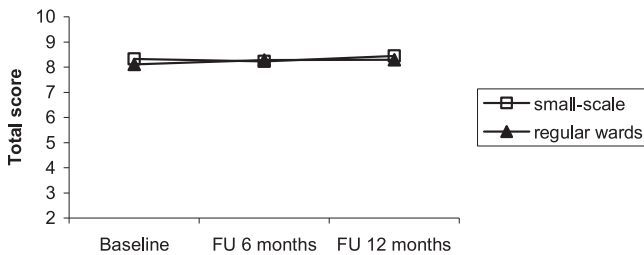
#### Job satisfaction (overall)

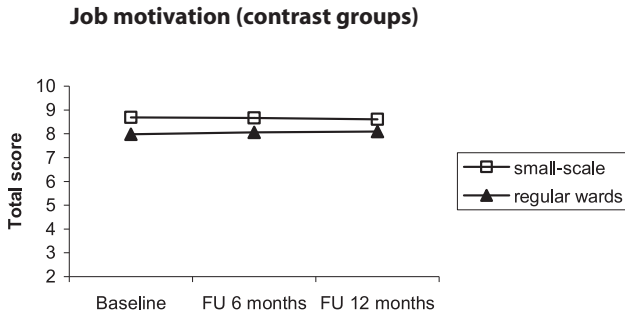


#### Job satisfaction (contrast groups)



#### Job motivation (overall)





**Figure 4.** Adjusted mean scores for outcomes on staff.

## Discussion

We were unable to demonstrate convincing overall effects of small-scale living facilities for our primary outcome measures. No difference in residents' total QoL was found and only few dimensions significantly differed. No effects were found for neuropsychiatric symptoms and agitation. Family caregivers in small-scale living facilities were less burdened and were more satisfied with nursing staff contact than family caregivers in regular wards. No effect was found for nursing staff's job satisfaction and motivation in the total group, although contrast analyses with respect to small-scale living facilities versus regular wards showed higher satisfaction and motivation for nursing staff working in typical small-scale living facilities compared with typical regular wards.

Some limitations regarding this study must be considered. We did not conduct a randomized controlled trial, due to major ethical and practical drawbacks making random assignment of residents, their family and staff to a care setting impossible. This study's major strength, over previously conducted studies, is the successful matching of resident groups on baseline cognition and ADL-capacity, which has resulted in resident groups who are on average in an equal stage of dementia. Participants in both groups were also comparable on other baseline characteristics. We would prefer to restrict inclusion to newly admitted residents, but this would have increased the study period substantially. Furthermore, QUALIDEM is quite a new instrument to measure residents' QoL. Despite its proven reliability and validity,<sup>19, 20</sup> responsiveness to change over time has not been studied yet.

For nursing staff, a natural selection process could have biased our results. Nur-



sing staff are free to choose a facility to work at and probably choose the type in which they thrive best. This may result in an underestimation of effects, especially since results from the contrast analyses suggest higher job satisfaction and motivation for nursing staff in typical small-scale living. Nursing staff in small-scale living facilities are suggested to have more job control, less demands and more social support from their co-workers,<sup>28</sup> which may account for these results. Future research should examine this in more detail.

Contrary to other studies,<sup>12, 29, 30</sup> we did not find convincing effects for small-scale living facilities when compared with regular wards. Dutch policy and organization of nursing home care may partly account for this, since the government encourages small-scale living, both financially and conceptually. As a result, regular institutional care is in a transition towards small-scale, homelike environments. Therefore it may be more difficult to detect differences between both care settings, since all outcome measures are rather positive in both groups. For example, in our study neuropsychiatric symptoms and agitation are rather low for both groups and in fact comparable to a successful intervention implementing person-centered care in an Australian study on institutional care.<sup>6</sup> We believe that generalization of our results is appropriate to countries with a similar level of healthcare and organizational system to the Netherlands.

Our results have important implications for dementia care policy and practice and show that small-scale living facilities are not necessarily a better care setting for all residents with dementia. Since governmental policies and, in some countries, financial support are increasingly aimed at providing small-scale, homelike care, we suggest that small-scale living facilities are not a final solution and other options should be considered. Policy makers and healthcare professionals should contemplate carefully what they regard as good care and QoL for people with dementia and not blindly focus on small groups or a homelike environment. Both a care program focusing on family and staff's attitudes towards residents in combination with environment and appropriate medical care is needed to improve dementia care. More research is required to disentangle this challenge.

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## Chapter 6

# Effects of small-scale, homelike facilities in dementia care on residents' behavior and the use of physical restraints and psychotropic drugs: a quasi-experimental study



This chapter has been submitted for publication as:

Verbeek, H, Zwakhalen, SMG, Van Rossum E, Ambergen T, Kempen GIJM and Hamers JPH. Effects of small-scale, homelike facilities in dementia care on residents' behavior, use of physical restraints and psychotropic drugs: a quasi-experimental study.

## Abstract

**Objectives:** To determine the effects of small-scale living facilities on behavior of residents with dementia and use of physical restraints and psychotropic drugs.

**Design:** Quasi-experimental study comparing residents in two types of long-term institutional nursing care (i.e. small-scale living facilities and regular psychogeriatric wards) on three measurements: at baseline and follow-ups after six and 12 months.

**Setting:** 28 houses in small-scale living facilities and 21 psychogeriatric wards in regular nursing homes.

**Participants:** In total, 259 residents were included; 124 in small-scale living facilities and 135 controls, matched on cognitive and functional status.

**Intervention:** Small-scale living facilities differ in physical (small-scale, based on archetypal housing including kitchen), social (residents, family and staff form a household) and organizational (staff have integrated tasks) characteristics from regular wards.

**Measurements:** Nurses assessed neuropsychiatric and depressive symptoms, agitation, social engagement and use of physical restraints using questionnaires. Psychotropic drug use was derived from residents' medical records.

**Results:** Significantly fewer physical restraints and psychotropic drugs were used in small-scale living facilities compared with regular wards. Residents in small-scale living facilities were significantly more socially engaged, at baseline and after six months follow-up, and displayed more physically non-aggressive behavior after 12 months than residents in regular wards. No other differences were found.

**Conclusion:** Although the study suggests some positive effects of small-scale living facilities on the use of physical restraints and psychotropic drugs, the results for behavior were inconclusive. More research is needed to gain an insight in the relationship between dementia care environment and other residents' outcomes.

## Introduction

Cultural change has taken a prominent place in long-term institutional care and is especially relevant for people with dementia residing in nursing homes. The cultural change movement promotes resident-directed care and quality of life. It involves a shift in the philosophy of care and practice.<sup>1</sup> Important characteristics of this process are the provision of autonomy, enabling residents to make their own choices, and encouraging social interaction and participation in meaningful activities. Traditionally, institutional care is based on a medical model of care with an emphasis on basic custodial care, safety, uniformity and medical issues.<sup>1,2</sup> Both chemical and physical restraints are consequently still highly prevalent in nursing homes and residents with dementia are particularly at risk.<sup>3,4</sup> Restraints are a common response to behavioral and psychological symptoms (BPSD) in dementia, although evidence of their ineffectiveness and adverse effects is accumulating.<sup>3,5</sup>

Several new care models have been developed to implement a process of cultural change, by adapting the physical, social and organizational environment.<sup>6</sup> One of these models focuses on small-scale, homelike care environments, in which the normalization of daily life is emphasized. This model has been implemented in various countries, such as group living in Sweden,<sup>7</sup> group homes in Japan,<sup>8</sup> the Green House<sup>®</sup> model in the United States<sup>9</sup> and small-scale living facilities in the Netherlands.<sup>10,11</sup> In some countries, governmental policies encourage the development of small-scale, homelike care environments, making them a substantial part of long-term institutional care.<sup>6</sup> For example, estimations indicate that currently in the Netherlands approximately 25% of all institutional dementia care is arranged in small-scale living facilities. Despite these developments, little evidence is available on the effects of small-scale environments on residents.<sup>12</sup> Some promising results have been reported, especially related to residents' quality of life.<sup>9,11,13</sup> However, more behavioral problems for residents have also been found.<sup>8</sup>

Since the number of people with dementia is increasing exponentially and long-term dementia care is increasingly directed towards small-scale homelike environments, more knowledge into the effects on residents is required. This information is necessary for planning and policy purposes in order to design evidence-based dementia care settings. The current study aimed to examine the effects of small-scale living facilities on residents' behavior, especially focusing on neuropsychiatric behaviors and social engagement, and the use of physical restraints and psychotropic drugs. Since it is expected that the extent to which facilities adhere to the principles

of small-scale homelike care influence outcome measures, subgroup analyses were conducted based on a proxy measure of organizational culture, specifically designed to measure adherence to principles of small-scale, homelike care.

## Method

### Design

A quasi-experimental study was conducted in the Netherlands during April 2008 – January 2010 (recruitment period April 2008 – December 2008), including three measurements: at baseline and follow-ups after six and 12 months. A detailed report of the rationale and study design was published elsewhere.<sup>14</sup> In short, two types of long-term institutional dementia care were included: small-scale living facilities (experimental group) and regular psychogeriatric wards in nursing homes (control group).

### Setting

Both types of settings in this study housed residents requiring a similar level of nursing care. This level of care in The Netherlands is determined by a standardized assessment procedure, carried out by a governmental agency. Admission to the dementia care setting (either small-scale living facilities or regular wards) was based on this assessment and in accordance with the residents' family or legal guardian. All dementia care settings in this study were funded by the government.

### *Small-scale living facilities*

The experimental group consisted of 28 houses in small-scale living facilities. These facilities were selected based on the following six characteristics:<sup>14</sup>

1. eight residents per house or unit at most;
2. a joint daily household of residents, their family caregivers and staff: activities were centered around daily life and all meals were prepared in the unit's kitchen by nursing staff together with the residents and/or their family caregivers;
3. staff performed integrated tasks: alongside medical and personal care, they also carried out household chores and organized activities;
4. a small team of staff took care of the residents;
5. daily life was largely determined by the residents, family caregivers and nursing staff;



6. the physical environment resembled an archetypal house.  
All houses were located in the southern part of the Netherlands.

### **Regular psychogeriatric wards in nursing homes**

Twenty-one regular wards in nursing homes were included as the control group. These wards were selected on the following criteria:

1. at least 20 residents or more per ward;
2. staff had specialized tasks and focused on the medical and personal care of residents;
3. daily life was mainly organized by institutional routines with little influence by the residents, their family caregivers and staff.

Furthermore, nursing homes were located in similar areas to the small-scale living facilities.

### **Participants**

Residents were eligible for the study if they had a diagnosis of dementia according to the criteria of the *Diagnostic and Statistical Manual of Mental Diseases* fourth edition,<sup>15</sup> and had resided in the facility for at least one month. To increase comparability of groups at baseline, residents in regular wards were matched to residents in small-scale living facilities based on their cognitive and functional status.<sup>14</sup> These were assessed using two subscales of the Resident Assessment Instrument Minimum Data Set (RAI-MDS):<sup>16</sup> the Cognitive Performance Scale (CPS)<sup>17</sup> and the Activities of Daily Life- Hierarchy scale (ADL-H).<sup>18</sup> Written informed consent was obtained for all eligible residents by their legal guardian.

### **Measures**

Behavior Neuropsychiatric symptoms were measured using the neuropsychiatric inventory, nursing home version (NPI-NH), a scale specifically developed for assessment by professional caregivers in institutional care.<sup>19</sup> The NPI-NH assesses 12 domains: delusions, hallucinations, aggression/agitation, depression, anxiety, euphoria, apathy, disinhibition, irritability, aberrant motor behavior, sleep and eating disturbances. For each domain, the frequency (F) and severity (S) of symptoms is rated on a four-point (1 – 4) and three-point (1 – 3) scale respectively and a total score is calculated by multiplying the frequency and severity scores (F\*S score). The F\*S score ranges from zero to 12 for each symptom, with higher scores indicating more severe symptoms.

Agitation was assessed using the Cohen-Mansfield agitation inventory (CMAI).<sup>20</sup> The CMAI assesses the frequency (ranging from never, one, to several times an hour, seven) of 29 agitated behaviors during the previous two weeks. Symptoms can be clustered into three types of agitation:<sup>21</sup> physically non-aggressive behavior (e.g. pacing/aimless wandering, hiding things, hoarding things, trying to get to a different place, handling things inappropriately, general restlessness and inappropriate dressing/disrobing; total score range 7 – 49), physically aggressive behavior (hitting, pushing, scratching, cursing/verbal agitation, grabbing, screaming, spitting and making strange noises; total score range 8 – 56) and verbally agitated behavior (constant unwarranted requests for attention/help, complaining, repetitive sentences/questions and negativism; total score range 4 – 28).

Depressive symptoms were assessed using the Cornell Scale for Depression in Dementia (CSDD).<sup>22</sup> This is a 19-item scale, specifically designed to assess symptoms of depression in people with dementia. The severity of each symptom is graded on a three-point scale ranging from absent (0), mild or intermittent (1) to severe (2). The total score ranges from zero to 38, with higher scores indicating more depressive symptoms. A cut-off point of 10 is generally indicative of major depressive symptoms. Social engagement was measured using the Index of Social Engagement (ISE), a subscale of the RAI-MDS,<sup>16</sup> which reflects both social involvement and autonomy.<sup>23</sup> This subscale consists of six dichotomously scored (present or absent) items, with a total score ranging from zero (lowest level of social engagement) to six (highest level of social engagement).

### ***Physical restraints***

Five types of physical restraints were measured in this study: belts (in bed and/or chair), (wheel)chair with a locked table or chair on a board, deep or overturned (wheel)chair, sleep suits, and bilateral fully enclosed bedrails. The presence or absence of these devices during the week of assessment was measured using a questionnaire.

### ***Psychotropic drug use***

Psychotropic drugs were classified according to the Anatomical Therapeutic Chemical (ATC) classification<sup>24</sup> into five types: anti-psychotics (N05A), anxiolytics (N05B), sedatives (N05C), anti-depressants (N06A) and anti-dementia drugs (N06D). Prescriptions were assessed as present (including incidental use, i.e. “pro re nata (PRN)”) or absent during the week of assessment.

**Other variables**

Socio-demographic variables of age, gender, length of stay and living condition prior to admission were assessed. Furthermore, dementia severity, cognitive and functional status, type of dementia and comorbid diseases were measured. Dementia severity was assessed at all moments using the Global Deterioration Scale (GDS), ranging from one to seven, with a higher score indicating more severe dementia.<sup>25</sup> Baseline cognitive status was assessed using the Mini-Mental State Examination (MMSE).<sup>26</sup> Scores range from zero to 30, with higher scores indicating less cognitive impairment. Furthermore, the CPS was used at all three measurement moments.<sup>17</sup> Functional status was assessed at all moments with the ADL-H.<sup>18</sup> The type of dementia was categorized into Alzheimer's disease, vascular dementia or other. Comorbid diseases were classified according to the International Classification of Diseases (ICD), version 10.

A questionnaire was developed to measure the degree of adherence to principles of small-scale homelike care, as a proxy measure of organizational culture.<sup>14</sup> It contained 18 items which assessed aspects of the physical, social and organizational environment on a 5-point Likert scale, ranging from 1 'not at all' to 5 'completely' (range 18-90). Higher scores indicated greater adherence to small-scale living. An example item is: 'To what extent is the staff part of the household?' Every ward (either a regular ward or a house in small-scale living) was independently rated by two observers using this scale.

**Procedures**

The study was approved by the Medical Ethics Committee of the University Hospital Maastricht/Maastricht University. Furthermore, local Ethical Committees of participating facilities and their boards gave consent for the study. Data were collected during April 2008 – January 2010.

All measures regarding behavior (i.e. NPI-NH, CMAI, CSDD and ISE) and physical restraints were assessed by registered nurses (RN) or certified nursing assistants (CNA), who were in charge of the residents and were most involved in their care specifically for this study's purposes. Psychotropic drug use, type of dementia and comorbid diseases were derived directly from the medical chart. The MMSE and dementia severity were assessed by a psychologist or nursing home physician.

**Statistical analysis**

Differences in residents' characteristics at baseline were tested with  $\chi^2$ -tests for categorical variables, two sample t-tests for normally distributed continuous variables

and Kruskal-Wallis tests for continuous variables with skewed distributions. Study hypotheses on all behavior outcomes were analyzed using mixed-model multi-level analyses, according to the intention-to-treat principle. All residents with a baseline measurement were included in the analyses, regardless of availability of data at follow-up, since multi-level analyses are robust for missing values for the outcome variables. Several variables were included as covariates in the analyses: i.e. age, gender, length of stay, living condition prior to admission, functional status, cognitive status as measured with the CPS, dementia severity, number of comorbid disease and psychotropic drug use. Missing data for these covariates only were imputed using multiple imputations. Since data for two outcome measures (agitation and neuropsychiatric symptoms) were skewed (skewness statistic > 2.5), log transformations were performed in order to analyze these measures.

First, fixed effects regarding group by time interactions were tested for significance. If these interactions were not significant, they were removed from the model and only fixed effects for group and time were tested. All analyses used a significance level  $\alpha$  of .05. A priori it was calculated that 84 residents per group were needed for sufficient power.<sup>14</sup> Analyses of continuous outcome measures (i.e. all measures of behavior) were conducted using Predictive Analytics SoftWare (PASW) version 17 from SPSS. For the dichotomous outcome measures (use of physical restraints and psychotropic drugs) generalized estimating equations (GEE) was used, as conducted in Stata 11 (StataCorp). For the connection between the dichotomous dependent variables for the three measurements and the independent variables, the logit link was used.

Subgroups analyses were performed, in which two groups were created based on their median scores on the questionnaire measuring the degree of adherence to principles of small-scale homelike care. Contrast group one consisted of the 14 highest scoring houses in small-scale living facilities, all with total scores above the group median (> 66); group two consisted of the 10 lowest scoring regular wards, all with total scores below the group median (< 40). These subgroup analyses allow for investigation of effects comparing the most typical small-scale living facilities with most typical regular wards (i.e. comparison of most and least adherence to principles of small-scale living facilities).

## Results

### Sample

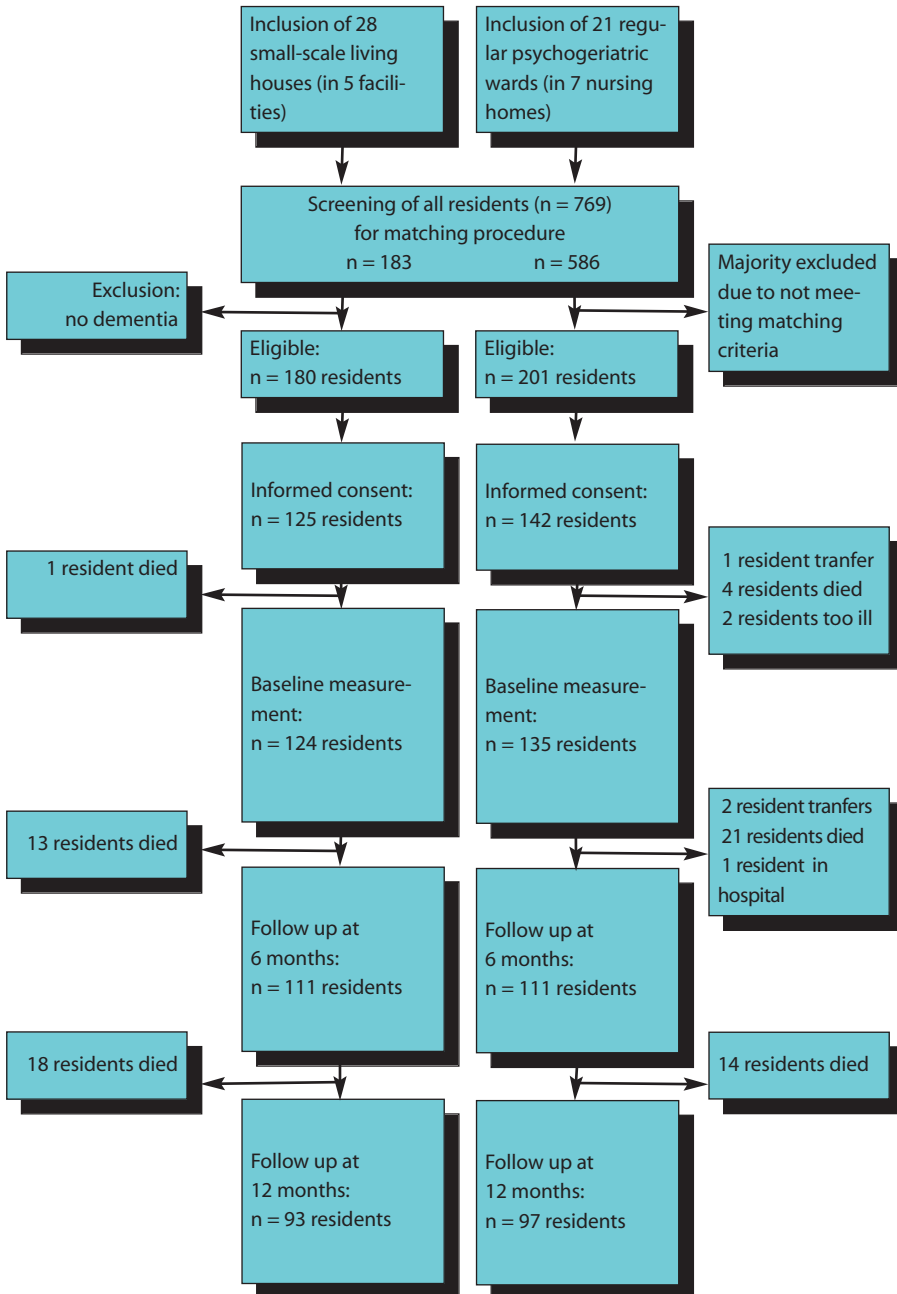
In total, 259 residents were included: 124 in small-scale living facilities and 135 in regular wards. Figure 1 describes the number of residents per group at each measurement. For subgroup analyses based on the contrast questionnaire, 134 residents were included in total: 70 in small-scale living facilities and 64 in regular wards.

Table 1 shows residents' baseline characteristics. Two significant differences were found; residents in small-scale living facilities were less often admitted directly from home and had a shorter length of stay compared with residents in regular wards.

### Effect on residents' outcome measures

Unadjusted means are presented in Tables 2 (behavior) and 3 (physical restraints and psychotropic drug use). Regarding neuropsychiatric symptoms, total scores (i.e. frequency\*severity) are highest for apathy and irritability in both settings, followed by depression and agitation/aggression. CSDD scores show that on average residents in both settings do not display symptoms of a major depressive disorder, i.e. all mean scores are below the cut-off point of 10 (Table 2). Differences between settings on use of physical restraints and psychotropic drugs appear to be large, varying between 12-14% (Table 3).

Subgroup analyses (data not shown) based on the contrast questionnaire confirmed the overall analyses, except for social engagement and physically non-aggressive behavior. Both the total and subgroup analyses of these outcome measures are presented.



**Figure 1.** Number of residents per group at each measurement.

**Table 1.** Characteristics of residents at baseline.

	Small-scale living	Regular wards
Sample size, n	124	135
Age, years (SD)	82.4 (7.9)	83.1 (6.5)
Women, %	80	70
Living condition prior to admission*, %		
At home	30	59
Other institution / unknown	70	41
Length of Stay†, months (SD)	15.7 (11.3)	24.4 (22.0)
Dementia type, %		
Alzheimer's Disease	27	32
Vascular Dementia	15	18
Other	16	20
Not Otherwise Specified / unknown	42	30
Global Deterioration Scale‡, mean (SD)	5.3 (1.1)	5.1 (1.0)
Mini Mental State Examination§, mean (SD)	11.1 (7)	10.5 (6.6)
Cognitive Performance Scale  , mean (SD)	3.5 (1.4)	3.4 (1.4)
Activities of Daily Life - Hierarchy Scale, mean (SD)	3.1 (1.7)	3.3 (1.4)
Comorbid diseases, mean number (SD)	4.3 (2.3)	3.8 (1.9)

*P* = \*.001; †.047

‡ range 1 – 7; a higher score indicates more severe dementia

§ range 0 – 30; a higher score indicates a better cognitive status

|| range 0 – 6; a higher score indicates poorer functioning.

### Behavior

A significant group by time interaction was found for social engagement in the total group. Residents in small-scale living facilities were significantly more engaged at baseline (adjusted mean difference 0.93, 95% Confidence Interval (CI) 0.48 – 1.38;  $P < .001$ ) and after 6 months (0.50, 95% CI 0.03 – 0.98;  $P = .038$ ) compared with residents in regular wards. After 12 months, no significant differences were found. In subgroup analyses using contrast groups, however, residents in small-scale living facilities were more engaged at all three measurements than residents in regular wards (adjusted mean difference for the group effect 1.04, 95% CI 0.50 – 1.59;  $P < .001$ ).

Furthermore, a significant group by time interaction was found for the agitation subscale physically non-aggressive behavior. After 12 months, residents in small-scale living facilities displayed significantly more physically non-aggressive behavior than residents in regular wards (adjusted mean difference 2.58, 95% CI 1.00 – 4.17;  $P = .001$ ). This difference after 12 months was slightly smaller between groups in the sub group analysis using contrast groups and did not reach significance (1.90, 95% CI -0.53 – 4.33;  $P = .126$ ). No effects were found on the other subscales of agitation.

**Table 2.** Unadjusted scores (SD) for residents' behavior.

	Baseline	FU 6 months	FU 12 months
<b>Social Engagement</b> (total scores; range 0 – 6*)			
Small-scale	3.87 (1.67)	3.44 (1.83)	3.26 (1.86)
Regular ward	2.93 (1.81)	3.06 (1.64)	2.89 (1.64)
<b>Agitation</b>			
Physically non-aggressive behavior (total scores; range 7 – 49*)			
Small-scale	10.75 (5.72)	10.39 (5.62)	11.09 (6.34)
Regular ward	10.50 (5.85)	9.45 (4.27)	8.42 (3.13)
Physically aggressive behavior (total scores; range 8 – 56*)			
Small-scale	10.47 (4.93)	10.14 (3.72)	10.38 (4.68)
Regular ward	11.53 (5.54)	10.28 (4.71)	9.93 (3.59)
Verbally agitated behavior (total scores; range 4 – 28*)			
Small-scale	7.90 (5.23)	6.62 (4.47)	6.82 (4.93)
Regular ward	7.28 (3.92)	6.02 (2.92)	5.82 (3.43)
<b>Neuropsychiatric symptoms</b> Frequency*Severity score (range 0 – 12*)			
A. Delusions			
Small-scale	1.18 (2.95)	0.86 (2.37)	1.34 (3.14)
Regular ward	1.07 (2.61)	1.14 (2.62)	1.21 (2.48)
B Hallucinations			
Small-scale	0.86 (2.35)	0.57 (1.54)	0.88 (2.34)
Regular ward	0.79 (2.25)	0.57 (1.90)	0.46 (1.63)
C Agitation / aggression			
Small-scale	1.90 (3.05)	1.14 (2.21)	1.45 (2.87)
Regular ward	2.10 (3.20)	1.77 (3.02)	2.00 (3.13)



	Baseline	FU 6 months	FU 12 months
D. Depression			
Small-scale	1.98 (2.99)	1.99 (3.22)	1.88 (3.35)
Regular ward	1.67 (3.03)	1.51 (2.81)	1.55 (2.72)
E. Anxiety			
Small-scale	1.03 (2.49)	1.00 (2.66)	.97 (2.62)
Regular ward	1.16 (2.62)	0.89 (2.22)	1.37 (2.72)
F. Euphoria			
Small-scale	0.30 (1.22)	0.14 (1.76)	0.37 (1.59)
Regular ward	0.38 (1.43)	0.26 (1.05)	0.11 (0.58)
G. Apathy			
Small-scale	2.06 (3.27)	1.88 (3.10)	2.75 (3.65)
Regular ward	2.29 (3.68)	2.43 (3.40)	2.46 (3.68)
H. Disinhibition			
Small-scale	1.27 (2.56)	0.65 (1.69)	1.15 (2.63)
Regular ward	1.09 (2.49)	0.79 (2.25)	0.63 (2.01)
I. Irritability			
Small-scale	2.12 (3.07)	2.28 (3.10)	2.37 (3.28)
Regular ward	2.00 (2.91)	1.65 (2.77)	1.88 (3.27)
J. Aberrant motor behavior			
Small-scale	1.55 (3.18)	1.48 (2.81)	1.60 (2.94)
Regular ward	0.81 (2.31)	1.17 (2.63)	0.99 (2.72)
K. Night-time behavior			
Small-scale	1.02 (2.46)	.64 (1.71)	0.97 (2.20)
Regular ward	1.10 (2.48)	.66 (1.82)	0.97 (2.17)
L. Eating change			
Small-scale	0.94 (2.55)	1.06 (2.87)	1.42 (3.42)
Regular ward	1.21 (3.17)	1.40 (3.29)	1.10 (2.77)
<b>Depressive symptoms</b> (total score; range 0 – 38*)			
Small-scale	5.49 (4.75)	4.24 (4.24)	3.46 (4.71)
Regular ward	5.25 (4.53)	3.41 (2.85)	3.28 (4.06)
*A higher score indicates more social engagement, agitation, neuropsychiatric and depressive symptoms.			

A group effect was found for one domain of neuropsychiatric symptoms. Residents in small-scale living facilities showed more aberrant motor behavior than residents in regular wards (adjusted mean difference 0.19, 95% CI 0.02 – 0.35;  $P = .020$ ). No other significant effects were found for neuropsychiatric or depressive symptoms.

### **Physical restraints**

A significant group effect was found for the total use of physical restraints. In small-scale living facilities, significantly fewer physical restraints were used at all three moments compared with regular wards (adjusted OR 0.40, 95% CI 0.22 – 0.73;  $P = .003$ ). Three out of five devices were used significantly less in small-scale living facilities compared with regular wards: belts (in chair and/or in bed) (adjusted OR 0.08, 95% CI 0.02 – 0.34;  $P = .001$ ), a (wheel)chair with a locked table/chair on a board (adjusted OR 0.23, 95% CI 0.08 – 0.68;  $P = .008$ ), and bilateral enclosed bedrails (adjusted OR 0.28, 95% CI 0.15 – 0.51;  $P < .001$ ).

### **Psychotropic drug use**

A significant group effect was found for psychotropic drug use. Residents in small-scale living facilities used significantly fewer psychotropic drugs compared with residents in regular wards for all three measurements (adjusted OR = 0.50, 95% CI 0.28 – 0.91;  $P = .023$ ).

**Table 3.** Prevalence for use of physical restraints and psychotropic drug use (unadjusted).

	Baseline	FU 6 months	FU 12 months
<b>Use of Physical restraints</b>			
Total, % (including belts, (wheel)chair with a locked table / chair on a board, deep or overturned chair, sleepsuits, bilateral full enclosed bedrails)			
Small-scale	30	31	33
Regular ward	44	44	46
Belts (in bed and / or in a chair), %			
Small-scale	1	3	1
Regular ward	11	9	9
(Wheel)Chair with a locked table / chair on a board, %			
Small-scale	4	6	4
Regular ward	10	9	12

	Baseline	FU 6 months	FU 12 months
Deep or overturned chair, %			
Small-scale	6	13	15
Regular ward	8	5	7
Sleepsuits, %			
Small-scale	6	8	10
Regular ward	16	14	11
Bilateral full enclosed bedrails, %			
Small-scale	24	21	25
Regular ward	40	42	44
<b>Psychotropic drug use (ATC classification)</b>			
Total, %			
Small-scale	66	63	67
Regular ward	78	76	79

## Discussion

This study examined the effects of small-scale living facilities on residents. The results show that fewer physical restraints and psychotropic drugs were used in small-scale living facilities compared with regular wards for all three measurements. Effects on behavior were mixed and suggest more social engagement for residents in small-scale living facilities, although this effect disappeared over time in the total group of residents. Furthermore, physically non-aggressive behavior was more present after 12 months, and more aberrant motor behavior was found for all measurements in small-scale living facilities compared with regular wards. No effects were found for the other neuropsychiatric or depressive symptoms.

Some limitations regarding this study must be addressed. Residents could not randomly be assigned to a dementia care facility due to ethical and practical drawbacks. This may have biased our sample and results. In order to increase the comparability of groups, residents were matched at baseline. This is a major strength over previously conducted studies. Residents were similar with respect to many important characteristics such as cognitive and functional status and dementia severity. Nevertheless, the sample differed in terms of length of stay and living condition prior to admission. Furthermore, it would have been better to include only newly admitted residents, although this would have increased the inclusion period sub-

stantially. Since some differences in our outcome measures (e.g. physical restraints and psychotropic drug use) already existed at baseline, causal interpretation is limited. Finally, measurement of physical restraints was based on nurses' self-reports instead of independent observers, which may have increased the risk of underreporting. This is, however, unlikely, since prevalence rates of the use of physical restraints in the current study are comparable to those reported in international literature.<sup>3</sup>

An important finding from this study is that fewer physical restraints and psychotropic drugs were used in small-scale living facilities compared with regular wards. Differences in the organizational culture may account for these effects in favor of small-scale living facilities. Previous studies pointed out that besides federal legislation and residents' characteristics (such as dementia severity, functional and cognitive status), differences at organizational level related to institutional policy and staff attitudes among facilities are important predictors of the use of physical restraints and psychotropic drug use.<sup>4, 27</sup> Since in the current study legislation and residents' characteristics did not differ between groups, the results suggest that differences in organizational differences related to cultural change and staff attitudes could have accounted for the positive effects of small-scale living facilities on use of physical restraints and psychotropic drug use. A resident-oriented culture, emphasizing individualized and psychosocial care was shown to decrease psychotropic drug use.<sup>28</sup>

The effects on behavior in this study were mixed. Our results suggests positive effects of small-scale living facilities on social engagement, although after 12 months these were only still present in a subgroup of small-scale living units which adhered at most to the small-scale criteria. These results are in line with recent studies emphasizing that environmental stimuli can influence social engagement, especially when related to real-world tasks.<sup>29, 30</sup> Small-scale living facilities may offer a more attractive environment for people with dementia to encounter meaningful stimuli, thereby enhancing social engagement. Other studies also reported more social engagement for residents in small-scale, homelike environments.<sup>9, 11</sup>

On the other hand, this study also found more physically non-aggressive behavior (such as aimless wandering) and aberrant motor behavior for residents in small-scale living facilities compared with those in regular wards. This is consistent with previous literature which suggested more restlessness for people residing in non-institutional environments.<sup>29</sup> The lack of convincing behavioral effects may also be related to the low scores of BPSD in both groups, comparable to successful interventions, as reported in other studies.<sup>14, 30</sup>

Small-scale living facilities for people with dementia differ on various levels from regular wards in nursing homes. The physical, social and organizational environment of institutional care has changed tremendously, aimed at deinstitutionalization. This has far-reaching consequences for daily practice in dementia care. Changes do not only affect residents, but also their families, nursing staff and managing directors. Roles are changing, with integrated tasks for staff, emphasizing skills such as flexibility and creativity. Many policies are aimed at providing small-scale and homelike care, although the effects of small-scale living facilities on residents, family caregivers and nursing staff remain mixed.<sup>12</sup> Healthcare professionals should carefully consider how to optimally design nursing home environments and should not blindly focus on one model. More research is therefore imperative in order to identify the interplay between environmental elements (physical, social and organizational) and their effects on resident-related and caregivers' outcomes. Studies need to determine which elements of small-scale living facilities are essential for improving outcome measures and how they work together.

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## Chapter 7

# Working in small-scale, homelike dementia care: effects on staff's burnout symptoms and job characteristics



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Zwakhalen SMG, Verbeek H, Van Rossum E, Ambergen T, Kempen GIJM & Hamers JPH. Working in small-scale, homelike dementia care: effects on staff's burnout symptoms and job characteristics.

## Abstract

**Aims:** This paper is a report of a study of the effects of working in a new type of dementia care facility on staff's burnout symptoms and job characteristics (job autonomy, social support, physical demands and workload).

**Background:** Long-term psychogeriatric care is increasingly organized in small-scale living facilities. Despite the increase of small-scale facilities, relatively little is known about the effects of work environments on nursing staff's well-being.

**Methods:** Two types of long-term institutional nursing care settings in the Netherlands were included in this quasi-experimental, longitudinal study: 28 houses in small-scale living facilities and 21 regular psychogeriatric wards in nursing homes. At baseline and at follow-ups after six and twelve months nursing staff were assessed by means of self report questionnaires.

**Results/Findings:** In total, 305 nursing staff members were included; 114 working in small-scale living facilities (intervention group) and 191 in regular wards (control group). No overall effects on burnout symptoms were detected, although subgroup analyses using contrast groups revealed significantly lower levels of burnout symptoms for nursing staff working in most typical small-scale living facilities. Significantly fewer physical demands and fewer workload were experienced by staff working in small-scale living facilities compared with staff in regular wards. They also experienced more job autonomy. No significant effect was found for overall social support in the total group, although subgroup analyses showed that staff working in most typical small-scale living facilities experienced more social support.

**Conclusion:** This study suggests positive effects of work environment on several work characteristics. Organizational climate differs in the two conditions, which might account for our results. Future studies should enhance our understanding of the influence of job characteristics on outcomes.

## Introduction

Long-term institutional nursing home care for people with dementia is shifting in terms of philosophy and practice from a medically-oriented care environment towards a resident-centered, individualized care environment.<sup>1</sup> The worldwide trend towards deinstitutionalization fits within this shift. When the dementia progresses and care demands increase, admission to a long-term care facility often becomes inevitable. Long-term psychogeriatric care is increasingly organized in small-scale living facilities.<sup>2</sup> These facilities emphasize the importance of well-being and differ from regular wards with respect to physical, social and organizational characteristics.<sup>2</sup> Small-scale living facilities aim to offer a homelike environment to a small number of residents per group. Residents are encouraged to participate in domestic tasks and the pattern of daily life is determined by residents, their family caregivers and nursing staff. Besides incentives and consumers demands, increased awareness of older persons needs have supported the development of these new care settings.<sup>3</sup>

Nursing staff employed in small-scale living facilities have different roles and tasks compared with staff employed in more traditional facilities. Overall, staff working in small-scale living facilities inclines more towards integrated care: nursing staff members are part of the household and have integrated tasks, including personal and medical care, organizing activities and daily household chores.<sup>2, 4, 5</sup> One would expect this to affect job characteristics (such as autonomy, social support, workload and demands). For example, in small-scale living facilities daily nursing activities are characterized by working all-round and independently, whereas nursing staff in traditional wards collaborate with each other and have differentiated tasks.

Despite the increase of small-scale facilities, relatively little is known about the effects of work environments on nursing staff's well-being (such as job stress) and job characteristics. The few studies that focused on staff's well-being in small-scale living in comparison with regular wards<sup>6-8</sup> showed that working in small-scale living facilities may offer nursing staff an attractive work environment. Although most of the studies showed some positive effects on job characteristics like autonomy and workload, study findings on burnout symptoms were inconsistent. Methodological flaws (i.e. cross-sectional designs) complicate the interpretation of findings, however. It is important to be aware of the impact of staff's work environment and how this influences nursing job stress and care for residents.<sup>9</sup> Environmental and organizational aspects have been reported as being important in relation to burnout.<sup>10</sup> In turn, low levels of burnout and work environment attributes impact on quality of care.<sup>11, 12</sup>

Furthermore, there is growing evidence that residents' quality of life is positively related to non-patient-related factors like organizational climate<sup>13</sup> and nursing staff's job characteristics.<sup>14-16</sup> Positive associations between non-institutional environment and staff morale were mentioned by Parker and colleagues.<sup>17</sup>

The fact that healthcare policy needs to be evidence-based received worldwide attention and support.<sup>18</sup> Small-scale living facilities became one of the developments implemented while little convincing scientific evidence.

Therefore, the present study examines the effect of working in small-scale living facilities on staff's burnout symptoms and various job characteristics (job autonomy, social support, physical demands and workload). It is hypothesized that nursing staff working in small-scale facilities experience fewer burnout symptoms, more autonomy and social support and fewer symptoms of physical demands and workload compared with staff in regular wards. These job characteristics were selected since they are mentioned by many theoretical models of stress as important factors in relation to outcomes like nurses' job satisfaction and burnout.<sup>19, 20</sup>

## Method

### Design

A longitudinal, quasi-experimental study was carried out during April 2008 – January 2010 (recruitment period April 2008 – December 2008) which compared two types of long-term institutional nursing care settings for people with dementia: small-scale living facilities and regular psychogeriatric wards. The design is described in more detail elsewhere.<sup>21</sup>

### Specifications of the setting: the two nursing home conditions

In the experimental condition, 28 houses in small-scale living facilities were characterized by the following criteria:<sup>21</sup> 1. a maximum of eight residents per house or unit; 2. staff, residents and their family formed a household together and activities are centered around the daily life and household. Staff performed domestic tasks and prepared meals together with residents and/or their family caregivers; 3. staff performed integrated tasks which means that one person may fulfill multiple tasks such as medical and personal care, domestic chores and activities; 4. residents were cared for by a small, fixed team of nursing staff; 5. daily life was organized completely or to a large extent by residents, their family caregivers and nursing staff;

6. archetypal home: a physical setting that resembled a homelike environment.

In the control condition, 21 regular nursing home wards were characterized by the following criteria: 1. a minimum of 20 residents per ward; 2. staff members had differentiated tasks with a main focus on medical and personal care for residents; 3. residents and their family members had little control over the organization of daily life within the ward as it was mainly organized around the routines of the nursing home.

### **Participants**

Nursing staff (i.e. nursing aids, nursing assistants, certified nursing assistants and registered nurses) directly involved in care tasks and working on a permanent basis in either the selected small-scale living facilities or regular psychogeriatric wards were eligible to participate in the study. Temporary staff (such as trainees), permanent nightshift workers and team managers were excluded from the study.

### **Measures and outcomes**

#### ***Burnout symptoms***

Burnout symptoms as an outcome of job stress were measured by a five-item self-reported questionnaire.<sup>22</sup> Previous studies determined its validity, reliability and internal consistency.<sup>22, 23</sup> Current analyses confirmed good internal consistency (Cronbach's alpha = 0.89). Items ranged from "never" to "always" on a seven-point Likert scale. Total score ranged theoretically from five to 35. Higher scores indicated more burnout symptoms. A sample item is: "I feel burned-out by my job."

Job characteristics (job autonomy, social support, workload, and physical demands) were measured by a self-reported questionnaires. Previous studies determined its validity, reliability and internal consistency.<sup>22, 23</sup> Current study findings confirmed good internal consistency.

#### ***Job autonomy***

Job autonomy was assessed by the Maastricht Autonomy Questionnaire (MAQ)<sup>22</sup> which consists of 10 items scored on a five-point Likert scale ranging from very little to very much. Its total score ranges from 10 to 50. Higher scores indicate

more job autonomy. The questionnaire includes information on job control and freedom in work tasks and methods. It measures the opportunity for staff to determine a variety of task elements, such as the pace of work and the work goals. A sample item is: "My work offers me the opportunity to interrupt my job whenever I want." Current study findings confirmed good internal consistency (Cronbach's alpha = 0.90).

Workplace **social support** was measured by the eight-item scale from the Job Content Questionnaire.<sup>19, 24</sup> The questionnaire inventories work-related social support, both instrumental and emotional support, by colleagues and supervisors. One subscale of four items refers to support from colleagues whereas the other subscale of four items refers to support by supervisors. It uses a four-point Likert scale with items ranging from "completely disagree" to "completely agree". The total score ranges from eight to 32 and a higher score represents more social support. A sample item is: "My colleagues help get the work done." Current study findings confirmed good internal consistency of the total scale (Cronbach's alpha = 0.81) and both subscales (Cronbach's alpha, both subscales = 0.85).

### **Workload**

(psychological demands) was measured by an eight-item scale that includes qualitative and quantitative demanding aspects such as working under time pressure, strenuous work and job complexity.<sup>22</sup> Items range from "never" to "always" on a five-point Likert scale. Total score ranges from eight to 40, with higher scores indicating more symptoms of workload. A sample item is: "In the unit where I work, work is too complex." Current study findings confirmed good internal consistency (Cronbach's alpha = 0.91).

### **Physical demands**

were assessed by a seven-item questionnaire ranging from "never" to "always" on a five-point Likert scale.<sup>25</sup> A total score is calculated and ranges from seven to 35, with higher scores representing more physical demands. Items refer to heavy physical demands like standing and carrying heavy weights. A sample item is: "In my work, I have to bend forward with my upper body." Current study findings confirmed good internal consistency (Cronbach's alpha = 0.87).

In addition, the following background variables were assessed: age, sex, education

level, months of employment in facility type, years working in elderly care and contract hours per week.

### **Environmental characteristics**

A contrast questionnaire was used to measure environmental characteristics in both the experimental and the control group. More specifically, the extent to which a nursing home facility fulfilled the criteria for small-scale living was assessed.<sup>21</sup> This questionnaire consists of 18 items that relate to a unit's organizational, social and physical environment. These were measured on a five-point scale, ranging from one = "not at all" to five = "completely" (range 18 – 90) and rated by two observers independently. Higher scores indicate greater adherence to the criteria of small-scale living facilities. A sample item is: "To what extent are staff and family members part of the household?"

### **Procedure**

Data on nursing staff were gathered at baseline (T1), and after six months (T2) and 12 months of follow-up (T3) by means of self-report questionnaires. After staff received oral and written information about the study and was assured of confidentiality, informed consent was obtained for nursing staff to participate in the study voluntarily. To guarantee confidentiality nursing staff returned the questionnaires directly to the researchers.

### **Ethical considerations**

The Medical Ethics Committee of a University Hospital approved the study. In addition, all local ethical committees of participating facilities and the managing directors of the regular nursing homes and small-scale living facilities approved of and provided consent to the study.

### **Statistical analysis**

All statistical analyses were conducted using Predictive Analytics SoftWare (PASW) version 17 from SPSS. Differences in characteristics between the two groups at baseline were tested with  $\chi^2$ -tests for categorical variables, individual sample t-tests for normally distributed continuous variables and Kruskal-Wallis tests for continuous variables with skewed distributions. Study hypotheses were tested with mixed-model multi-level analyses, according to the intention-to-treat principle. All nursing staff with a baseline measurement were included in the analyses, regardless of availabi-

lity of data at follow-up, since multi-level analyses are robust for missing values in the outcome variables.

All selected background characteristics of participants were included as covariates in the model. Missing data for only these covariates were imputed by multiple imputation. First, fixed effects for group by time interaction were tested for significance. If this interaction was not significant, it was removed from the model and only fixed effects for group and time were tested.

Subgroup analyses were conducted. On the basis of their median score in the contrast questionnaire two groups were created: highest-scoring small-scale living facilities (contrast group one) versus lowest-scoring regular wards (contrast group two). Contrast group one consisted of 14 houses with total scores above the median (>66); contrast group two consisted of 10 regular wards with total scores below the median (<40). Subgroup analyses have to be interpreted with caution since the number of participants in these subgroups was suboptimal (based on the number of respondents and an effect size of 0.4, the power = 0.936). All tests used a two-sided significance level of .05.

## Results

### Sample

The total number of eligible staff at baseline was 581; 178 in small-scale living and 403 in regular wards. In total, 305 nursing staff members participated: 114 (response rate 64%) nursing staff from small-scale living and 191 (response rate 47%) from regular wards. For subgroup analyses based on the contrast questionnaire, 137 nursing staff members were included: 57 working in small-scale living facilities and 80 working in regular wards.

Participants' baseline socio-demographic characteristics are presented in Table 1. Groups were comparable, except that nursing staff members working in small-scale living facilities were employed for a shorter time and were more often women compared with staff working in regular wards.



**Table 1.** Characteristics of nursing staff participants.

	Small-scale living (n = 114)	Regular wards (n = 191)
Age in years	40.7 (11.5)	42.8 (10.1)
Women*	110 (97)	170 (89)
Level of education		
Level 1 basic nursing aids	6 (5)	3 (2)
Level 2 NA	18 (16)	29 (15)
Level 3 CNA	64 (57)	128 (67)
Level 4 RN	21 (19)	26 (14)
Level 5 RN	3 (3)	3 (2)
Employment in nursing home type in months <sup>†</sup>	23.1 (18.4)	85.2 (72.8)
Years working in elderly care	14.7 (10.3)	16.7 (10.7)
Contract hours per week	26.4 (7.0)	26.9 (6.6)

Data are mean (SD) or number (%)

$P = *0.021; †0.001$

NA= nursing assistants, CNA= certified nursing assistants, RN= registered nurses.

Unadjusted means on burnout symptoms and job characteristics of overall and subgroup analyses are presented in Table 2. Subgroup analyses confirmed overall analyses (data not shown), except for the outcome burnout symptoms and job characteristic social support. For these outcome measures, results for both overall and subgroup analyses are presented.

### Effects on burnout symptoms

No significant effects on burnout symptoms were found in the analyses of the total participants' group (adjusted mean difference 0.72, 95% CI -1.19 - 2.64,  $P = .458$ ). Subgroup analyses based on the contrast questionnaire showed a significant group effect. Nursing staff in typical small-scale living facilities experienced less burnout symptoms compared with staff in typical regular wards (adjusted mean difference 3.20, 95% CI 0.58 - 5.83,  $P = .017$ ). These differences were already present at baseline and remained stable over time.

**Table 2.** Staffs' outcomes on burnout symptoms and job characteristics job autonomy, social support, workload and physical demands in total groups and subgroups.

	Baseline	FU 6 months	FU 12 months
<b>Nursing Staff*</b>			
<i>Outcome: Job stress</i>			
Burnout symptoms total group (range 5 – 35)			
Small-scale	12.4 (5.0)	13.0 (4.6)	12.7 (4.2)
Regular	13.4 (5.2)	12.3 (4.5)	13.2 (4.7)
Burnout symptoms subgroup			
SG1 > small-scale	10.8 (4.2)	11.0 (4.3)	11.1 (3.7)
SG 2 > regular	14.4 (5.7)	15.0 (5.4)	15.1 (5.6)
<i>Job characteristics</i>			
Job autonomy (range 10 – 50)			
Small-scale	30.7 (6.5)	29.1 (6.8)	29.9 (7.7)
Regular	26.7 (6.8)	26.9 (7.6)	26.8 (7.5)
Job autonomy subgroup			
SG 1 > small-scale	33.2 (6.0)	31.6 (6.4)	33.5 (7.1)
SG 2 > regular	26.9 (6.9)	28.7 (6.1)	29.3 (7.0)
Social support (range 8 – 32)			
Small-scale	24.5 (3.3)	23.9 (3.6)	23.9 (3.9)
Regular ward	24.1 (3.0)	24.1 (3.3)	24.4 (2.8)
Social support subgroup			
SG 1 > small-scale	25.5 (3.1)	25.2 (3.3)	26.1 (3.7)
SG 2 > regular	23.9 (2.8)	23.9 (3.1)	24.6 (2.6)
Workload (range 8 – 40)			
Small-scale	23.4 (7.1)	25.1 (5.8)	24.1 (5.2)
Regular ward	28.5 (5.0)	27.4 (4.4)	27.9 (4.3)
Workload subgroup			
SG 1 > small-scale	20.1 (5.8)	22.7 (5.3)	22.3 (5.7)
SG 2 > regular	28.5 (4.9)	29.1 (4.1)	28.8 (3.6)
Physical demands (range 7 – 35)			
Small-scale	19.4 (5.3)	20.2 (4.9)	20.0 (4.9)
Regular ward	23.0 (4.8)	22.9 (4.8)	22.9 (4.4)
Physical demands subgroup			
SG 1 > small-scale	18.5 (5.5)	20.1 (4.9)	19.6 (5.1)
SG 2 > regular	23.8 (4.5)	23.6 (4.5)	23.7 (4.3)

Data are unadjusted means (SD).

\* Nursing staff: Baseline  $n_{\text{small-scale}} = 114$ ,  $n_{\text{regular wards}} = 191$ ; Follow-up (FU) after 6 months  $n_{\text{small-scale}} = 72$ ,  $n_{\text{regular wards}} = 109$ ; Follow-up after 12 months  $n_{\text{small-scale}} = 69$ ,  $n_{\text{regular wards}} = 87$  Nursing staff subgroup (=SG) analysis: Baseline  $n_{\text{small-scale}} = 57$ ,  $n_{\text{regular wards}} = 80$ ; Follow-up (FU) after 6 months  $n_{\text{small-scale}} = 36$ ,  $n_{\text{regular wards}} = 29$ ; Follow-up after 12 months  $n_{\text{small-scale}} = 32$ ,  $n_{\text{regular wards}} = 33$

Higher score indicates more burnout symptoms, autonomy, support, workload, and physical demands.

## Effects on job characteristics

### **Job autonomy**

A statistically significant group effect was found for job autonomy (adjusted mean difference 3.88, 95% CI 1.17 – 6.59;  $P = .005$ ), demonstrating that nursing staff in small-scale living facilities experienced more job autonomy than staff in regular wards for all measurements. Differences were stable over time.

### **Social support**

No significant effect was found for overall social support in the total participants' group (adjusted mean difference 0.51, 95% CI 0.68 – 1.71;  $P = .401$ ). Both groups scored relatively highly on social support but subgroup analyses did show a significant group effect. Nursing staff in most typical small-scale living facilities experienced more overall social support than staff in typical regular wards (adjusted mean difference 1.87, 95% CI 0.67 – 3.07;  $P = .004$ ). Differences were present at baseline and stayed stable over time.

Additional analyses found a significant effect for social support by co-workers for the total group of participants. Nursing staff in small-scale living facilities experienced more social support by their co-workers than staff in regular wards (adjusted mean difference 0.71; 95% CI 0.16 – 1.26;  $P = .012$ ). No significant effects were found for social support by supervisors (adjusted mean difference 0.24; 95% CI -0.79 – 1.26;  $P = .652$ ). Subgroup analyses of both subscales for social support confirmed the findings. The difference between groups on social support experienced by co-workers was even higher (adjusted mean difference 1.14; 95% CI 0.45 – 1.82;  $P = .001$ ).

### **Workload**

A significant group by time interaction was found for workload. In small-scale living facilities, less workload was experienced for all three measurements compared with

regular wards. Staff in regular wards reported significantly more workload at baseline (adjusted mean difference 5.25; 95% CI 2.39 – 8.11;  $P = .001$ ), after six months (adjusted mean difference 3.12; 95% CI .031 – 5.93;  $P = .030$ ) and after twelve months (adjusted mean difference 4.12; 95% CI 1.27 – 6.97;  $P = .005$ ) compared with staff in small-scale living facilities.

### **Physical demands**

A significant group effect was found for physical demands.

In small-scale living facilities, significantly fewer physical demands were experienced by nursing staff compared with regular wards (adjusted mean difference 3.22, 95% CI 1.27 – 5.17;  $P = .001$ ).

## **Discussion**

This study examined the effects of working in a new type of dementia care facility (i.e. small-scale living facilities) on staff's burnout symptoms and various job characteristics. Although subgroup analysis using contrast groups revealed significant lower levels of burnout symptoms, it showed no overall effect on burnout symptoms for nursing staff in the total group. Differences in job characteristics (e.g. job autonomy, workload and physical demands) were found.

Some limitations of this study need to be acknowledged. Clearly we need to be careful in interpreting our findings. It remains questionable what causes differences in nursing staff working in small-scale living facilities compared with regular wards. For most variables notable differences between both care conditions were already observed at baseline and remained consistent over time. Therefore, no causality could be determined. Personality characteristics of nursing staff may account for differences in job characteristics. A recent study by Pot and de Lange<sup>28</sup> also suggested staff characteristics (e.g. age, cultural background) play a role in differences in job characteristics like autonomy. Furthermore, although groups baseline characteristics were comparable in the present study, except for gender and time of employment in the facility, groups may differ in terms of other characteristics and/or competences which were not assessed. Nursing staff are free to choose a facility to work at and probably choose the type in which they feel most comfortable. This may have biased our findings. Furthermore, the proportion of non-responders was higher in nursing staff working in regular wards than staff in small-scale facilities. Reasons for not

returning the questionnaire remain unclear, but non-response may be influenced by the social work group cohesion and involvement of small teams working in the small-scale-living facilities.

These findings are in line with our previous study findings into effects of small-scale living facilities on staff's well-being by Verbeek and colleagues.<sup>26</sup> This study did not demonstrate effects with respect to the outcome measures job satisfaction and motivation in the total group of nursing staff. Again, subgroup analyses showed higher satisfaction and motivation for nursing staff working in typical small-scale living facilities compared with most typical regular wards.<sup>25</sup>

Previous studies on burnout symptoms comparing both care conditions are mixed. While Reggentin & Dettbarn-Reggentin (2004) found no differences in burnout symptoms, Te Boekhorst and colleagues (2008) found differences in levels of reported burnout symptoms in favor of nursing staff working in small-scale living facilities.<sup>7, 8</sup> These studies suggested that differences in job characteristics (i.e. more job control, fewer demands and more social support) may account for these results.<sup>7, 8</sup> Burnout symptoms have been found to be significantly higher in jobs that combine higher demands and lower autonomy.<sup>27</sup> The findings of the present study though could not confirm this suggestion. While differences in job characteristics were present for the total group of participants, no differences were found for burnout symptoms. Subgroup analyses did find effects for burnout symptoms, suggesting that work environment may be related to job stress. The exact role needs to be determined.

With regard to job characteristics, in this study nursing staff experienced significantly more autonomy and fewer physical demands and workload in small-scale living facilities compared with staff in regular wards. These findings are consistent with those of other studies, suggesting that demands were lower in small-scale living facilities whereas control/autonomy was higher.<sup>7, 8</sup> Although overall analyses in total social support showed no differences, staff working in small-scale living facilities experienced more social support by co-workers. This finding may seem somewhat surprising, since small-scale living facilities offer an environment in which only a small fixed team of nursing staff is responsible for a small group of residents in contrast to the large teams in regular wards. It might be explained by a stronger team cohesion of staff working in these new care environments. Future work should address how these care environments need to be arranged in order to create the most optimal and efficient working environment conditions for nursing staff.

An important finding from this study is that staff members working in small-

scale living facilities experienced significantly fewer physical demands and lower workload. Previous studies on small-scale living facilities in the Netherlands demonstrated that residents living in small-scale living facilities were fewer ADL dependent and had better cognition compared with residents in regular wards.<sup>29, 30</sup> Differences between residents in small-scale living facilities and regular ward may indeed affect nursing staff working at these facilities. Since residents are more ADL dependent and experience higher cognitive dysfunction in regular wards, this could result in a higher workload/ higher demands. A recent study by Miyamoto and colleagues<sup>31</sup> confirmed that low ADL functioning was one of the predictors of nursing staff stress and burden.

## Conclusions

Since this study showed that job characteristics differed, other competences may be required. More attention should be given to the nursing competences required for working in either one of both care settings. If these can be indentified, recruitment and selection of staff would be improved and tailored to the skills of nursing staff. Furthermore, educational programs could be tailored to train nursing staff for work in small-scale living facilities.

Nursing homes offer complex working environments that are influenced by numerous factors. A leading model, originally developed by Karasek (1979) called the Job-Demand-Control model, states that two job characteristics (demands and control) influence well-being and job satisfaction.<sup>32</sup> A combination of high job demands and low job control is particularly suggested to have a negative impact such as low job satisfaction. Johnson and Hall (1988) extended the model with social support, since they assume that support received from supervisors and co-workers could buffer the impact of demands and control.<sup>33</sup> In addition, Spoor and colleagues<sup>34</sup> mentioned that job resources and recovery opportunities have to match with job demands if outcomes are to be optimized. It remains unclear how these can contribute to interventions focusing on improving staffs well-being.<sup>34</sup> Further research is needed to examine underlying mechanisms for an understanding of possible relationships between working conditions, job characteristics and outcomes such as job satisfaction and burnout and to reveal mediating effects in both nursing home care conditions.

The findings of this study on job characteristics suggest that organizational climate could differ between both nursing home conditions and may influence nur-

sing staff's well-being. This has important implications for nursing home managers and policymakers. In order to achieve a healthy work environment for nursing staff it is important to be well aware of nursing staff's experienced well-being, especially since staff's well-being may directly influence the quality of nursing home care<sup>35</sup> and job stress has been linked with turnover rates.<sup>36</sup> Future studies should enhance our understanding of the influence of job characteristics on outcomes.

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## Chapter 8

# Small-scale, homelike facilities in dementia care: a process evaluation into the experiences of family caregivers and nursing staff



This chapter has been submitted as:

Verbeek H, Zwakhalen SMG, Van Rossum E, Kempen GIJM & Hamers JPH. Small-scale, homelike facilities in dementia care: a process evaluation into the experiences of family caregivers and nursing staff experiences.

## Abstract

**Background:** Current developments in institutional dementia care aim at the downsizing of facilities and increasing their homelike appearance. Small-scale living facilities are an example of this movement, in which a small group of residents (usually six to eight) live together in a homelike environment. Residents are encouraged to participate in normal daily activities and nursing staff is part of the household with integrated tasks. Despite the increase of these facilities, little is known about experiences of family caregivers of residents and nursing staff.

**Objective:** To gain an in-depth insight into the experiences of family caregivers and nursing staff with small-scale living facilities.

**Design:** A process evaluation was conducted alongside the final measurement of an effectiveness study, using a cross-sectional, descriptive design.

**Settings:** Two types of institutional dementia care in the Netherlands: small-scale living facilities and regular wards in nursing homes.

**Participants:** In total, 130 family caregivers and 309 nursing staff workers in both care settings participated in a survey questionnaire. Additional in-depth interviews were conducted with a random selection of 24 participants in small-scale living facilities: 13 family caregivers and 11 nursing staff workers.

**Methods:** Survey questions for family caregivers focused on care service delivery; questions for nursing staff were related to skills. The interviews especially related to positive and negative aspects of small-scale living facilities and skills for nursing staff.

**Results:** Both family caregivers and staff mainly reported positive experiences with small-scale living facilities, especially the personal attention that nursing staff provides to residents, their involvement with residents and the emphasis on autonomy in daily life. Barriers mainly related to nursing staff working alone during a large part of the day. Family caregivers in small-scale living facilities were more satisfied with the care facility and nursing staff than those in regular wards.

**Conclusion:** The findings of the study revealed several positive aspects of small-scale living facilities related to physical, social and organizational aspects that could be used as tools to implement changes in institutional dementia care settings.

## Introduction

Dementia is a common syndrome, including progressive deterioration in cognition, abilities to perform activities of daily living (ADL) and behavioral symptoms (e.g. apathy, agitation and depressive symptoms). Alongside the ageing of the population, dementia is rapidly increasing. Estimations indicate that from 2001 the number of people affected by dementia will double every 20 years up to 81 million worldwide by 2040.<sup>1</sup> Effective treatments for dementia are lacking, placing a high burden on all people directly involved in caregiving.

Due to the progressive nature of dementia, admission to a long-term care facility is usually inevitable in the long run. Currently, a common policy in long-term institutional care is to create small-scale and homelike care environments.<sup>2</sup> Worldwide this concept has been implemented in various settings.<sup>3,5</sup> Similarities among care concepts reflect person-centred care with normalisation of daily life by focusing on meaningful activities centred on daily household chores. Nursing staff is often part of the household. All concepts emphasise values such as quality of life, well-being, preserving autonomy and enabling residents to maintain their own lifestyle as much as possible.<sup>2</sup>

Studies investigating small-scale living facilities are scarce and have mainly focused on its effects, with contrasting results. Promising results were reported for residents (e.g. increased quality of life and less use of physical restraints) and nursing staff (e.g. higher job satisfaction and fewer burnout symptoms) compared with traditional care.<sup>4,6,7</sup> However, other studies found no convincing effects.<sup>5,8</sup> Hardly any research has been conducted into daily experiences with care processes in small-scale living facilities.

The decision for family caregivers to house their relative in a long-term care facility is very challenging. They often experience feelings of guilt and distress.<sup>9</sup> Small-scale living facilities are considered as an efficient way to reduce informal caregiver burden, although these are often seen as a form of respite care.<sup>10,11</sup> In the Netherlands, however, small-scale living facilities are perceived as an alternative to institutional care in nursing homes (i.e. regular psychogeriatric wards), and not as respite care. Facilities thus have a home-for-life principle and admission is based on an assessment performed by a governmental agency, taking family caregivers' wishes into account. More knowledge and understanding of family caregivers to improve service delivery is therefore highly warranted.

It is also important to gain an understanding of nursing staff's experiences, since

their role is changing in small-scale living facilities.<sup>12</sup> Nursing staff here have integrated tasks, not only focusing on nursing care but also organization of activities, cooking and other household work. Furthermore, the hierarchy in small-scale living facilities is often flattened.<sup>13</sup> This may require other skills and competencies than working at a regular ward, although evidence for this is lacking.

This study aims to provide an in-depth insight into the experiences of family caregivers and nursing staff with small-scale living facilities in the Netherlands. For family caregivers, it specifically addresses experiences with care service delivery, description of the facility and positive and negative aspects of the caregiving process in small-scale living facilities. For nursing staff, the study focuses on skills and positive and negative experiences with working in a small-scale living facility. The study was conducted as a process evaluation as part of a quasi-experimental, longitudinal study into the effects of small-scale living facilities on residents, their family caregivers and nursing staff.<sup>8, 14</sup> In this effectiveness study, two types of dementia care settings (i.e. small-scale living facilities and regular psychogeriatric wards in nursing homes) were compared at three measurements (baseline and follow-up after six and 12 months), addressing a variety of outcome measures for residents (e.g. quality of life), family caregivers (e.g. burden) and nursing staff (e.g. job satisfaction).

## Methods

Both quantitative and qualitative data were collected during April 2009 – January 2010, alongside the last measurement of the effectiveness study (i.e. 12 months after baseline). All study participants provided informed consent.

### Setting and participants

This study's survey was conducted in two long-term institutional nursing care settings for older people with dementia: small-scale living facilities and psychogeriatric wards in regular nursing homes.<sup>14</sup>

In total, 28 houses from five small-scale living facilities were included. These facilities were selected based on the following criteria: 1) at most eight residents per house; 2) a joint household, with activities centred around daily life and all meals prepared by staff together with residents and/or family caregivers; 3) staff performing multiple tasks (e.g. medical and personal care, organising activities and domestic chores), 4) a small, fixed team of staff caring for residents; 5) residents, their

family caregivers and nursing staff mainly determined organization of daily life; 6) a facility resembling an archetypal home. Twenty-one regular wards from seven nursing homes were included selected on: 1) at least 20 residents per ward; 2) staff having differentiated tasks, focusing on residents' medical and personal care; 3) the routines of the nursing home largely determine organisation of residents' daily life.

Questionnaires were sent to all family caregivers (n=184) of residents in both dementia care settings, who had provided informed consent to participate in the effectiveness study. This resulted in 130 family caregivers participating in this study: 67 in small-scale living facilities and 63 in regular wards. Furthermore, questionnaires were sent to all nursing staff involved in direct care working in the participating small-scale living facilities and regular wards. In total, 309 nursing staff workers participated: 101 in small-scale living facilities (response rate 60.4%) and 208 from regular wards (response rate 59.2%).

Additionally, in-depth interviews (n=24) were conducted in small-scale living facilities. A random sample was selected of family caregivers and nursing staff, stratified per location (with a minimum of two per location). In total, 13 family caregivers and 11 nursing staff participated. Family caregivers were eligible if they participated in the effectiveness study. Furthermore, all nursing staff who were the head or coordinator of a house in a small-scale living facility (usually one per house) were eligible for the interviews.

### **Data collection**

Data were collected via questionnaires (both in small-scale living facilities and regular wards) and semi-structured interviews (only in small-scale living facilities).

### ***Questionnaire for family caregivers***

The questionnaire for family caregivers contained two questions regarding general satisfaction with the dementia care facility and nursing staff. These were rated on a 10-point scale, ranging from one (very dissatisfied) to 10 (very satisfied).

Furthermore, 24 questions were added, derived from the "Questionnaire Care Services".<sup>15</sup> This questionnaire assesses the extent to which care services are provided by a small-scale and homelike approach, comparable to the inclusion criteria used in this study. Items are clustered around five main themes: 1) having an ordinary daily household (five items); 2) residents having control over their own daily life (five items) 3) nursing staff being part of the household (five items); 4) residents forming a group together (four items); 5) the facility resembling an archetypal house (five

items). All items are rated on a five-point Likert scale, ranging from never (zero) to always (four), with higher scores indicating more adherence to the principles of small-scale and homelike care services delivery. Finally, the background characteristics of age, gender, relationship with residents and marital status were assessed.

### **Questionnaire for nursing staff**

Questionnaires for nursing staff in both settings were asked in an open-ended question to state the two skills they consider as most important to do their job properly. Nursing staff in small-scale living facilities were specifically asked, in two open-ended questions, what they perceived as advantages and disadvantages of working in a small-scale living facility.

Several background variables were assessed. Socio-demographic variables consisted of age, gender, education level and years of experience in elderly care. Furthermore, nursing staff from regular wards were asked whether they would like to work in a small-scale living facility and nursing staff from small-scale living facilities whether they would like to return to working in a regular ward, using closed questions (yes/no/do not know).

### **Interviews**

A topic list was used to structure the interviews (*see Box 1*). All interviews were tape recorded and transcribed afterwards.

#### **Box 1.** Topic list for semi-structured interviews in small-scale living facilities

##### **Family caregivers**

- Do you have experiences with nursing care in traditional nursing home wards?  
If yes, what are your experiences there?
- Have you noticed any differences between traditional facilities and small-scale facilities?  
If yes, which differences do you notice?
- If you had to concisely define the home environment of your relative, which three characteristics would you name?
- Do you have a predominantly positive, neutral or negative impression of your relative's nursing care environment? Can you amplify your answer?
- Would you recommend the facility type to others? Why would or would you not?
- Did you particularly choose to accommodate your relative in a small-scale homelike



setting?

- Why did you choose that facility type in particular?
- Do you still support your choice?
- Was the environment in line with your expectations?
- Does your relative feel himself/herself at home in the facility?
- Do you feel involved with the care and the facility of your relative?
- Why do or do you not feel involved?
- How is your contact with the facilities' staff?
- Do you think that the small-scale facility is homelike? Why do or do you not?
- What are the pros of a small-scale homelike facility?
- What are the cons of a small-scale homelike facility?

#### **Nursing staff**

- How did you picture working in a small-scale living facility in advance?
- Have these expectations come true while working in a small-scale living facility?
- What is it like to work closely with a small group of residents?
- What is it like to be part of the household?
- What is it like to perform several activities next to personal and nursing care such as preparing meals, organizing activities etc?
- Have you ever worked at a psychogeriatric ward in a regular nursing home?
- If yes, what do you think is the biggest difference with working in a small-scale living facility?
- What do you consider the pros of working in a small-scale living facility?
- What do you consider the cons of working in a small-scale living facility?
- Which skills are required do your job well a small-scale living facility?

#### **Data analysis**

All quantitative data from the questionnaires were processed with the Statistical Package for Social Sciences (SPSS), version 17.0. Descriptive statistics were calculated. To test differences between the two groups, independent sample t-tests were conducted for continuous variables and Chi-square tests for nominal and ordinal variables. All qualitative data (including data on open-ended items of the questionnaires) were categorized by two authors independently (HV and SZ). Themes and patterns emerging from the answers were discussed until consensus was reached on the major

recurrent topics.

## Results

Participants' characteristics are presented in Table 1. No significant differences were found between groups on background variables. Although relatively more women worked in small-scale living facilities compared with regular wards, this difference did not reach significance ( $P = .06$ ).

**Table 1.** Participants' characteristics for questionnaires and interviews.

	Small-scale living	Regular wards
<b>Family caregivers - Questionnaires</b>	<i>n</i> =67	<i>n</i> =63
Age	59.30 (9.2)	59.11 (10.6)
Range	31 – 82	40 – 86
Gender		
Female	50 (74)	40 (64)
Male	17 (26)	23 (36)
Relationship to resident		
Spouse	7 (10)	11 (17)
Child	48 (72)	48 (76)
Other	12 (18)	4 (7)
Marital status		
Married/living together	30 (45)	29 (46)
Married/living together, with children	15 (22)	15 (24)
Single	6 (9)	13 (21)
Single, living with children	6 (9)	2 (3)
Unknown	10 (15)	4 (6)
<b>Family caregivers - Interviews</b>	<i>n</i> =13	-
Age	59.8 (11.6)	-
Range	6 – 79	-
Gender		
Female	9 (70)	-
Male	4 (30)	-

	Small-scale living	Regular wards
<b>Relationship to resident</b>		
Spouse	1 (8)	-
Child	11 (84)	-
Other	1 (8)	-
<b>Marital status</b>		
Married/living together	7 (56)	-
Married/living together, with children	2 (15)	-
Single	2 (15)	-
Single, living with children	1 (7)	-
Unknown	1 (7)	-
<b>Nursing staff - Questionnaires</b>		
	<i>n=101</i>	<i>n=208</i>
Age	41.7 (10.7)	40.7 (10.8)
Range	20 – 60	19 – 67
<b>Gender</b>		
Female	97 (96)	187 (90)
Male	4 (4)	21 (10)
<b>Education level</b>		
Level 1	4 (4)	1 (1)
Level 2	17 (17)	27 (13)
Level 3	52 (51)	133 (64)
Level 4	16 (2)	32 (15)
Level 5	2 (2)	6 (3)
Unknown	10 (10)	9 (4)
Years of experience in elderly care	15.4 (9.3)	16.8 (10.2)
Range	1 – 36	0 – 41
<b>Nursing staff - Interviews</b>		
	<i>n=11</i>	
Age	33.6 (11.4)	-
Range	21 – 52	-
<b>Gender</b>		
Female	8 (73%)	-
Male	3 (27%)	-
<b>Education level</b>		
Level 1 basic nursing aid	0 (0)	-
Level 2 NA	0 (0)	-
Level 3 CNA	10 (91)	-

Level 4 RN	1 (9)	-
Level 5 RN	0 (0)	-
Years of experience in elderly care	12.5 (11.3)	-

Data represent mean (SD) or number (%).

NA = nursing assistant, CNA = certified nursing assistant, RN = registered nurse.

### **Family caregivers**

First, the results of the questionnaires on (satisfaction with) care service delivery in both care settings are presented. Subsequently, results from the interviews are presented around three main themes: facilities' description, and positive and negative experiences with small-scale living facilities.

### **Care services delivery**

Although family caregivers in both care settings were generally satisfied, family caregivers in small-scale living facilities were significantly more satisfied with the setting ( $P < .001$ ) and with nursing staff ( $P < .001$ ) compared with family caregivers in regular wards. Family caregivers rated small-scale living facilities with an average score of 8.5 (with a range between one and 10) for the setting in general and 8.4 for nursing staff, where regular wards were rated with scores of 7.2 and 7.7 respectively. Family caregivers rated small-scale living facilities significantly higher in the provision of small-scale and homelike care than those in regular wards (mean difference 23.2, SE = 1.43;  $P < .001$ ). Significant differences were found for all five themes (see Table 2). The largest difference was found for "having an ordinary household" (mean difference 6.9, SE = 0.65;  $P < .001$ ); the smallest difference for "facility resembling an archetypal home" (mean difference 2.0, SE = 0.46;  $P < .001$ ).

### **Description of small-scale living facilities**

"Homelike" was a main theme in the description of small-scale living facilities during the interviews. But what makes a facility homelike? Some family caregivers pointed at physical aspects of the environment: design of the facility that resembled an archetypal house (i.e. kitchen, living room, separate bedrooms, entrance), a small group (max. seven residents) and the opportunity to bring own furniture, both in private bedrooms and in the shared living room. Privacy also contributed. The facili-

**Table 2.** Differences in care-service delivery as experienced by family caregivers.

	Small-scale living	Regular wards	P - value
	(n=67)	(n=63)	
Having an ordinary household (range 0-20)	11.9 (3.0)	5.0 (4.2)	<.001
Residents having control over their own daily life (range 0-20)	12.6 (3.0)	7.1 (2.7)	<.001
Nursing staff being part of the household (range 0-20)	13.0 (2.7)	7.3 (2.4)	<.001
Residents forming a group together (range 0-16)	6.9 (2.3)	3.9 (2.4)	<.001
The facility resembling an archetypal house (range 0-20)	12.6 (2.5)	10.6 (2.8)	<.001
Total score	57.0 (7.4)	33.8 (9.0)	<.001

Data are means (SD).

ties provided freedom, since spaces were open and easily accessible and residents could retire to their own bedroom.

Furthermore, aspects related to activities were mentioned by family caregivers as increasing a homelike feeling, especially preparing meals as a domestic activity, with residents having a choice to participate. Family caregivers felt that this increased residents' autonomy, giving them control over daily life activities. Moreover, family caregivers appreciated that they were highly involved in everyday life and not left to the strict routines of the facility. The role of nursing staff with integrated tasks was crucial to this process. Family caregivers experienced that tasks in daily work were fluently connected, which contributed to the facilities' homeliness.

*"Well, you don't realize they are staff. They come and sit with you, cosily chat away. For example, X, she needs to do a lot of paper work. She joins the residents, chats with them and in the meantime she does her other work, updating files. Tasks are fluently transferred and that is really homelike. Like she is doing her homework while visiting her grandmother."*

(DAUGHTER, 48 YEARS OLD)

***Positive aspects of small-scale living facilities***

In general, family caregivers unanimously expressed positive experiences with small-scale living facilities in the interviews. These were predominantly related to the contact with nursing staff (both with residents and family caregivers), personal attention, freedom in making one's own choices and a sense of involvement.

Family caregivers indicated that nursing staff's attitude was open, friendly and involved. The whole team was responsible for and well informed about all residents, not just one contact person. Therefore, family caregivers felt heard. Furthermore, nursing staff was open to matters that family caregivers brought up and showed a lot of empathy. This was closely related to the theme of personal attention. Family caregivers indicated that nursing staff were highly attentive to the personal needs of individual residents, approaching them with patience and sympathy, beyond providing only nursing care. The limited number of residents per house provided an opportunity to build a personal relationship between staff members and residents and also for residents among each other. Residents often saw familiar faces which increased recognition.

Moreover, nursing staff really encouraged residents to participate in daily household activities. Tailored to individual wishes and needs, they looked specifically for strengths and capacities that residents still had. This increased autonomy and enabled residents to continue their own lifestyle for as far as possible.

*"There [regular ward] you had to go along with the rhythm of the ward. And here [small-scale living facility] people themselves decide the daily rhythm. Nursing staff adjust to residents... very spontaneously."*

(DAUGHTER, 61 YEARS OLD)

Family caregivers also felt involved with daily life and care provided. Some of them played an active role in activities in the household, for example assisting during dinner, helping prepare meals or reading the paper. Some family caregivers had to become accustomed to this process.

Deciding to place their relative in long-term dementia care was a challenging decision for all family caregivers. Few family caregivers indicated that their relative felt nowhere at home anymore, due to the dementia disease. The reported positive experiences were of the utmost importance for family caregivers.

*"When you are confronted with that decision [admittance to care setting], this is very difficult. If you feel that someone is where he/she still has that sense of autonomy, can participate in a group, feels at home, that makes it easier for you to make the decision...it gives you a bit of peace."*

(DAUGHTER, 50 YEARS OLD)

### **Negative aspects of small-scale living facilities**

Although the majority of family caregivers were overall very satisfied with small-scale living facilities, some negative aspects were mentioned in the interviews. These were mainly related to the amount of staff and the provision of activities and services. Family caregivers pointed out that the houses in small-scale living facilities were sometimes understaffed. Nursing staff worked alone during a large part of the day, especially in the evening and night. Residents were left alone at some times, because staff had to help other residents or assist another house. Regular wards seemed more flexible with staffing issues, for example replacement for sickness absence. Two small-scale living facilities had many temporary workers. This complicated tailor-made care, since they were not well-acquainted with the residents.

Some family caregivers experienced that too little activities and other services (e.g. garden, meeting room, restaurant or shop) were available in the facility. They appreciated if they could go out with residents. They also noted that staff had a great influence in this process since residents depended on their initiatives and skills. Few family caregivers felt that staff's encouragement was not sufficient and indicated that residents were bored. In their opinion, the large amount of tasks of nursing staff was partly responsible for this.

### **Nursing staff**

Results from the questionnaires showed that of staff working in small-scale living facilities, only 7% indicated that they would like to go back to working at a regular ward. On the other hand, 56% of the staff working in regular wards reported that they would like to work in a small-scale living facility, whereas 33% stated that they did not want to work in such a care setting.

First, results from the questionnaires on skills are presented, with additional information from the interviews in small-scale living facilities. Then, results from the interviews are presented, focusing on positive and negative experiences of working in a small-scale living facility.

### **Skills**

In both dementia care settings, “patience” and “empathy” were reported in the questionnaires as the most important skills for working in a dementia care setting. Nursing staff in small-scale living facilities additionally mentioned “client-centeredness”, whereas nursing staff from regular wards reported “cooperation”. Moreover, nursing staff from regular wards addressed more often practical conditions (such as knowledge, proper materials and good physical health) than nursing staff in small-scale living facilities.

During the interviews conducted in small-scale living facilities, nursing staff elaborated on the skills and competencies specifically required for working in such a facility. A sense of self-assurance and responsibility were mentioned most often. Nursing staff needed to be able to make decisions on their own, since they worked alone for long periods of time. Therefore, they indicated that capability and competence to observe residents and to identify problems quickly is a precondition.

### **Positive aspects of working in a small-scale living facility**

Nursing staff reported three aspects most frequently in the questionnaire regarding positive aspects of working in a small-scale living facility: 1) involvement and personal contact with residents; 2) a feeling of being able to spend more time and attention on the residents; 3) autonomy in day structure and the related responsibility and self-confidence. These aspects were also the main themes during the interviews.

*“It is nice to closely collaborate with residents. You can divide your attention a little. At a regular ward residents who are quiet fall outside your scope and here [small-scale living facility] everybody gets the attention they need. I really enjoy that.”*  
(NURSE, 21 YEARS OLD)

Results from the interviews indicated that the feeling of having more time for residents could be related to the extension of nursing staff’s tasks. In small-scale living facilities nursing staff encouraged residents to participate in daily activities. This increased their opportunities to interact with residents outside standard nursing care moments. Daily household chores served as a handle for undertaking activities. Nursing staff perceived themselves as universal workers with integrated tasks.

Nursing staff indicated that they experienced high levels of autonomy in deciding on the day structure, which was also mentioned as one of the biggest difference with working at a regular ward. This was also related to the integrated way of wor-



king. Nursing staff were free to plan their own day, taking into account their residents' individual needs and preferences. Since they could adjust their own pace of work, the work was also physically less demanding. For example, a nurse indicated that not all residents had to be bathed in the morning, but she spread this out over the day. This increased the feeling of providing tailor-made care for residents. Management played a crucial role in facilitating this process of autonomy, mainly by empowering nursing staff to focus on the needs of residents rather than to focus on the performance of scheduled tasks. Furthermore, nursing staff could give more of their own identity in their work, which was highly appreciated.

*"Because you can plan your own day, you have a more relaxed attitude towards residents. You don't have to think about the time pressure of now I have to do this and now I have to do that. No, if you assist a resident with toileting and dinner has to be prepared, I think that could also be done in about 10 minutes...you can sit with residents, chat, go outside. You have that peace, that freedom."*

(NURSE, 28 YEARS OLD)

### **Negative aspects of working in a small-scale living facility**

Nursing staff mentioned fewer negative than positive aspects with working in small-scale living facilities, both in the questionnaires and during the interviews. The two most frequently reported negative aspects related to working alone and staffing shortages.

Results from the interviews showed several reasons why often working alone was experienced as negative by nearly half of the nursing staff members. Some said that they missed a team to discuss care issues, to share responsibility during the everyday job and to ask for help. They often had to make difficult decisions alone. This required a lot of responsibility and self-confidence. Furthermore, they sometimes had to leave residents alone while assisting others. Staff indicated that at a regular ward it was easier to split tasks.

*"Here [small-scale living facility] you have to do everything. When something rankles you, you cannot ask someone to take over. You cannot walk away for a moment. At a regular ward you can ask another, [nursing staff] could you assist that resident today...but here you are the one person to take care of everything and organize... once in a while I would like for someone to take over my tasks."*

(NURSE, 52 YEARS OLD)

Furthermore, nursing staff indicated that small-scale living facilities were sometimes short on staff. Due to this shortage, some felt that they could not spend enough time with residents. Another disadvantage that was mentioned is the emotional burden. Nursing staff felt highly involved with residents. When something happened to them, this had an increased impact. Additionally, staff members experienced difficulties when residents displayed behavioural problems, since this had a great impact on the small group of residents and was difficult to handle.

## Discussion

This study shows that family caregivers and nursing staff have mainly positive experiences with small-scale living facilities in dementia care and their experiences show many similarities with each other. Both family caregivers and staff highly appreciate the personal attention that nursing staff spends on residents, their involvement with residents and the emphasis on autonomy in daily life. Barriers are also experienced though, mainly related to nursing staff working alone during a large part of the day. Nursing staff and family caregivers experienced small-scale living facilities as more vulnerable to shortages in staffing than regular wards. Nursing staff indicated that the skills required for working specifically in small-scale living facilities relate to client-centeredness, in addition to responsibility and a sense of self-assurance.

One limitation of our study is that questionnaires were assessed in both small-scale living facilities and regular wards, whereas interviews investigating in-depth experiences were only conducted in small-scale living facilities. This complicates the interpretation of the interview findings, since it is not assured that all experiences are specific to small-scale living facilities and could also apply to other dementia care facilities such as regular wards. Furthermore, we have only included a limited number of participants in the interviews, since we attempted to gain an in-depth insight of experiences. These participants may not be representative of the total group. However, by combining data from the questionnaires with the interviews, we aimed to increase the representativeness of the study. Finally, due to the cross-sectional design of the study no inferences can be drawn regarding the effects of small-scale living facilities.

Although the current study showed mainly positive experiences of family caregivers and nursing staff with small-scale living facilities, this does not necessarily result in more positive outcomes for both groups. The effectiveness study revealed

no effects of these small-scale living facilities for nursing staff's job satisfaction and motivation.<sup>8</sup> Only in a subgroup of nursing staff working in most typical small-scale living facilities were higher job satisfaction and motivation detected compared with typical regular wards. Furthermore, no differences were found for family caregivers' involvement in care.<sup>8</sup> Frequency and length of visits were comparable between both groups (i.e. small-scale living facilities and regular wards) and also the number of activities did not differ. However, family caregivers in small-scale living facilities reported less burden and a higher satisfaction with nursing staff than family caregivers in regular wards. All differences were present at baseline and remained stable over time.

A promising result from this study is the feeling of nursing staff that they are able to spend more time with residents in small-scale living facilities. Findings point out that this could be related to nursing staff's autonomy and the extension's of their tasks, providing opportunities to interact with residents beyond basic nursing tasks, in which daily household tasks (e.g. cooking, reading the newspaper, chatting) serve as a basis. Previous studies have shown that the institutional policy of small-scale living facilities, with staffing patterns focusing on meaningful activities and integrated tasks in a non-hierarchical structure, is important in establishing meaningful social interactions with residents, development of a sense of community and preserving community roles, thereby creating a supportive environment.<sup>16-18</sup> Furthermore, some studies have suggested that small-scale living facilities may also provide a more attractive work climate, due to a higher level of control and lower level of demands.<sup>6, 19</sup> It is worthwhile to investigate whether these features of small-scale living facilities related to institutional policy and staffing could also be implemented in regular wards in nursing homes. This may have a positive impact on family caregivers and nursing staff working in various types of dementia care settings.

Barriers related to small-scale living facilities were also experienced by participants. Both family caregivers and nursing staff regarded small-scale living facilities are more vulnerable to shortages in staff, especially since nursing staff worked alone during a long period of the day. This could be related to the group size. In the Netherlands, small-scale living facilities usually have six or seven residents per house, as in the current study. In practice, this could hamper their financial feasibility, although research investigating these issues (e.g. cost-effectiveness studies) are lacking. Some explorative studies suggest that a clustering of units or slightly larger groups (e.g. 10 to 12 residents) could improve the facilities' financial feasibility.<sup>2, 20, 21</sup>

Although the respondents in our study pointed to the quantity of nursing staff,

quality and adequate education and training of nursing staff is essential in dementia care.<sup>22, 23</sup> Several studies have found that higher educational levels of nursing staff have a positive effect on quality of care.<sup>23, 24</sup> Especially in small-scale living facilities education and training should have a prominent place, since the role of nursing staff changes with the extension of tasks. Nursing staff in our study reported a sense self-assurance and responsibility as important skills for working in small-scale living facilities, especially since they often work alone. This could also reflect knowledge and skills of how to observe residents, interpret their signals and report to other staff for which education and training is imperative.

### Conclusion

The current study shows that many aspects of small-scale living facilities related to the physical, social and organizational climate are appreciated by family caregivers and nursing staff. These aspects, such as personal contact and autonomy in day structure, could provide tools to implement changes in all institutional dementia care settings.

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Chapter 9

# General Discussion



The main goal of this thesis was to evaluate small-scale living facilities (SSLFs) in dementia care, focusing on residents, their family caregivers and nursing staff. Although it is generally believed that SSLFs are beneficial for the well-being of those involved, evidence for this assumption is largely lacking. Since the number of people with dementia is rapidly increasing and care is increasingly organized in SSLFs, especially in the Netherlands, more research was urgently needed.

This final chapter summarizes the main findings of the evaluation of SSLFs for residents, family caregivers and nursing staff. Furthermore, it discusses methodological strengths and limitations of the research presented in this thesis and reflects on theoretical considerations regarding interpretation of effects. The chapter ends with future directions for practice and research.

### Main findings

Since little was known about the concept and characteristics of SSLFs, two explorative studies were conducted first. Findings from a *literature review* identified 11 concepts regarding SSLFs worldwide (e.g. USA, Japan, Europe). Similarities among concepts showed a focus on meaningful activities centered around the daily household. Residents were encouraged to participate in everyday activities, emphasizing normalization of daily life with person-centred care. Nursing staff had integrated tasks, focusing on more than one category (i.e. nursing, personal care, household chores).

A *cross-sectional study* showed that on average residents in SSLFs had a better cognitive and functional status than residents in regular wards (RWs) of traditional nursing homes. This pointed to the need for a matching procedure in the effectiveness study to increase comparability of groups at baseline.

The main study of this thesis investigated effects of SSLFs on residents (n=259), their family caregivers (n=209) and nursing staff (n=305). A quasi-experimental, longitudinal study was conducted in which two types of institutional dementia care were compared: (28) houses in SSLFs and (21) RWs in nursing homes. Three measurements were performed: at baseline and follow-ups after six and 12 months. Due to a matching procedure, residents in both care settings were similar at baseline regarding cognitive and functional status and stage of dementia.

For *residents*, no effects were found for the primary outcome measures: quality of life (QoL), neuropsychiatric symptoms and agitation. Residents' total QoL did not differ between care settings and group effects were found for only a few dimensions.



Results on secondary outcome measures showed that residents in SSLFs were less physically restrained and received less psychotropic drugs compared with residents in RWs. These differences existed at baseline and remained stable over time. Secondary outcomes on behavior showed mixed results. Residents in SSLFs were more socially engaged than residents in RWs at baseline and after six months. Only in a subgroup of residents living in the most typical SSLFs this difference was still present after 12 months compared with residents living in the most typical RWs. In contrast, residents in SSLFs displayed more aberrant motor behavior than residents in RWs at all three measurements and showed more physically non-aggressive behavior after 12 months.

*Family caregivers* of residents in SSLFs reported significant less burden and more satisfaction with nursing staff than family caregivers of residents in RWs. All differences existed at baseline and remained stable over time. No effects were found for satisfaction with resident contact and involvement with care (i.e. frequency, length of visits and activities during visit).

For *nursing staff*, no effects were found for the primary outcome measures job satisfaction and motivation. However, subgroup analyses comparing nursing staff working in the most typical SSLFs with staff working in the most typical RWs, found more job satisfaction and motivation in SSLFs. This pattern was similar for the secondary outcome measure burnout symptoms. All differences in the subgroup analyses were present at baseline and remained stable over time. Results from secondary outcomes further revealed effects on several job characteristics. Nursing staff in SSLFs experienced more autonomy and less workload and physical demands than nursing staff in RWs. Perceived social support was similar for the total group of nursing staff in both care settings, although subgroup analyses revealed more social support for nursing staff working in typical SSLFs.

Alongside the effectiveness study, a process evaluation was conducted to gain an in-depth insight into *experiences* of family caregivers and nursing staff with SSLFs. Family caregivers and nursing staff were overall highly satisfied with SSLFs. Homeliness, familiarity, autonomy and involvement with daily life were mentioned of great importance to this satisfaction. Personal attention towards residents is highly appreciated. Some negative aspects were experienced as well. These mainly relate to the amount of staff, since nursing staff worked alone during a great extent of the day.

## Methodological considerations

This section will address methodological considerations, regarding strengths and limitations, specifically related to conducting research in long-term dementia care settings.

The randomized controlled trial (RCT) is viewed as the most powerful design to test interventions in clinical studies. Traditionally originated from pharmacological research, RCTs are also applied in health care services research, public health and nursing research. Due to several ethical and practical constraints, an RCT is often not feasible in studies investigating effects of long-term care settings for older people with dementia.<sup>1-3</sup> Quasi-experimental study designs form a solution, although they are more susceptible to bias. This section addresses three main reasons for bias in these studies: selection bias due to non-equivalent groups at baseline, cross-site variation and differences in exposure duration to conditions. Furthermore, it discusses briefly issues related to assessment of outcome measures.

### **Selection bias: nonequivalent groups at baseline**

One of this study's strengths over previously conducted studies is matching of residents on cognitive and functional status, resulting in equivalent groups regarding stage of dementia at baseline. This is important since stage of dementia is one of the most important variables related to the outcomes in this study (e.g. QoL, behavior, use of physical restraints). Via the matching procedure selection bias resulting from nonequivalent groups for residents has decreased. Furthermore, additional analyses showed that the rate of decline in cognitive and functional abilities due to the progressive nature of dementia was equal for both groups of residents during the one year follow up (*see Table 1*). This contributes to the evidence that effects found for residents are more related to the differences in care setting (SSLFs vs. RWs) than to differences in residents' characteristics.

A drawback of the matching procedure is a limitation of the study's external validity, since the included residents at RWs are not representative for the total group of residents living in RWs. In our sample, 22.2% of residents in RWs have a high level of cognitive functioning and functional status and 28.9% had a low level of cognitive functioning and functional status, whereas for the total group of residents in RWs this was 10.6% and 66%, respectively.<sup>4</sup> Therefore, the effectiveness study targeted on average on a better functioning resident group and it remains unclear what effects for more cognitive and physically demanding resident groups would be.

**Table 1.** Outcomes for activities of daily life, cognition and stage of dementia.

	Baseline	FU 6 months	FU 12 months
Activities of daily life* (range 0 – 6)			
Small-scale living	3.1 (1.7)	3.3 (1.7)	3.4 (1.6)
Regular wards	3.3 (1.4)	3.4 (1.4)	3.6 (1.4)
Cognition* (range 0 – 6)			
Small-scale living	3.5 (1.4)	3.6 (1.8)	3.7 (1.7)
Regular wards	3.4 (1.4)	3.3 (1.9)	3.9 (1.7)
Stage of dementia# (range 1 – 7)			
Small-scale living	5.3 (1.1)	5.4 (0.9)	5.4 (0.8)
Regular wards	5.1 (1.0)	5.1 (1.1)	5.4 (0.9)

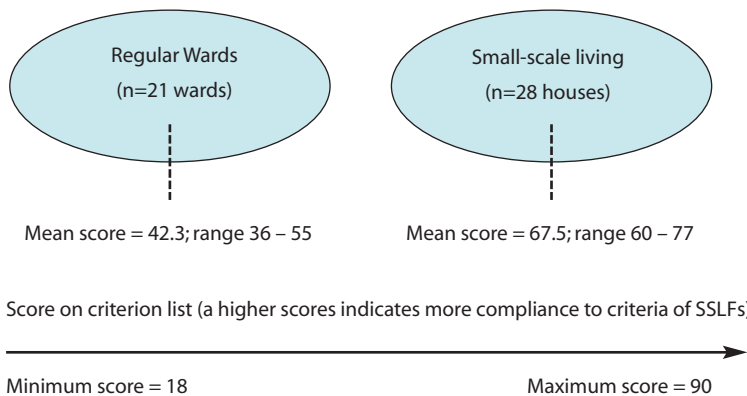
Data represent unadjusted mean scores (SD). \*As measured with two subscales from the Resident Assessment Instrument-Minimum Data Set (RAI-MDS): ADL-Hierarchy scale and Cognitive Performance Scale (CPS). Higher scores indicate more dependency. # As measured with the Global Deterioration Scale. Higher scores indicate a more severe stage of dementia.

Selection bias could still be present though for family caregivers and nursing staff. Although several baseline characteristics (e.g. age, gender) were similar between settings, these groups might differ on aspects which were not assessed, such as personality characteristics. This problem is especially relevant in interpreting effects on outcome measures for nursing staff (e.g. job satisfaction and motivation). Nursing staff are free to choose where they want to work and it is very likely that they choose a setting in which they thrive best. It could therefore be expected that a specific type of nursing staff choose to work in SSLFs because they are attracted to this new care concept and related way of working (e.g. integrated tasks, being part of the household). On the other hand, also nursing staff in RWs may deliberately choose to work in traditional homes. This might explain that no effects were found in the total group of nursing staff on outcomes such as job satisfaction and motivation. However, subgroup analyses did find significant group effects, which suggests that some aspects of SSLFs seem to have a positive influence on outcomes for nursing staff. Family caregivers often choose a care setting based on availability and proximity (to

the residents' or family caregivers' community), although selection bias could still be present. For example, it is speculated that family caregivers with higher levels of emotional involvement are more susceptible of placing their relative in SSLFs, since these are regarded as the most innovative forms of care.<sup>5</sup>

**Cross-site variation**

RWs increasingly implement characteristics of SSLFs, whereas SSLFs may still have characteristics of RWs in their way of working. A strength of the current study is therefore the observation of all participating dementia care sites by two raters independently, based on the most important characteristics of SSLFs as stated at the start of the study (including physical, social and organizational characteristics). These results showed that there is substantial contrast between SSLFs and RWs: SSLFs's mean score is significantly higher than the mean score of RWs, with no overlapping scores (mean difference 25 points;  $P < .001$ ). This contrast remained stable over time (mean difference after 12 months 26 points;  $P < .001$ ). Despite these findings, a continuum of the extent to which characteristics of SSLFs are implemented was also found (see Figure 1). This points to need for subgroup analyses, using contrast groups to compare effects between the most typical SSLFs with the most typical RWs. Hereby, cross-site variation was partly corrected, although this could never fully be accomplished.



**Figure 1.** Diagram representing the contrast between small-scale living facilities and regular wards.

**Exposure duration**

One important limitation of this study is that the exposure time to the condition (i.e. experimental vs. control) differs between settings. The average length of stay for residents and their family caregivers in SSLFs is much shorter than in RWs, since SSLFs are newer care settings. This is similar for nursing staff, although their average number of years working in elderly care does not differ between groups. Many differences in outcome measures (e.g. use of physical restraints and psychotropic drugs) between SSLFs and RWs were already present at baseline and remained stable over time, which complicated causal interpretation of results. A question that remains is therefore: are differences between groups in this study caused by SSLFs or by other (unmeasured) variables? At the one hand, observed differences could be due to a selection of residents, family caregivers and nursing staff at admission. On the other hand, differences between study participants in both care settings could also be a result of SSLFs, which has been established before the study's baseline measurement. One solution would be to only include residents and their family caregivers directly from home and only newly working nursing staff (i.e. all 'incident cases'), although this would have increased the study period substantially.

**Proxy assessment**

People with dementia residing in institutional care are in an advanced stage of their disease. In this thesis, therefore, proxy reports were used to assess outcomes on residents, such as QoL and behavior. These proxies were mainly nursing staff, who were most involved with care for the individual residents. Since the care concept in SSLFs is different from RWs, emphasizing person-centered care with integrated tasks for nursing staff and encouragement of residents to participate in daily life, this may be reflected in nursing staff's attitude towards residents and how they perceive good care for people with dementia. This might be a potential bias for their ratings on residents' outcome. However, this thesis has not measured nursing staff's attitude towards care. Recently, several instruments have been developed to measure this concept, for example the Approaches to Dementia Questionnaire (ADQ).<sup>6</sup> An assessment of staff's attitude could be used in the future to investigate such influences on their ratings of residents' well-being and functioning.

## Theoretical considerations

This section reflects on the results of the evaluation of SSLFs from a theoretical point of view. First, it discusses possible reasons for the lack of convincing evidence in support of SSLFs on the primary outcome measures. Second, it reflects on interpretation of findings, focusing on residents' behavior and family caregivers' burden.

### Complex intervention

The current study was not able to demonstrate convincing overall effects of SSLFs on the primary outcome measures, especially for residents (QoL, neuropsychiatric symptoms and agitation) and nursing staff (job satisfaction and motivation). An important explanation for our findings may be the complexity of the concept of SSLFs and lack of understanding regarding active ingredients. As a result, many changes are implemented in daily practice, without knowledge and awareness what, why and how these changes are most effective. Criteria for complex interventions, as set by the Medical Research Council (MRC),<sup>7,8</sup> all apply to SSLFs. They 1) have a high number of interacting components, 2) affect many difficult behaviors for both those delivering care (nursing staff) and receiving care (residents), 3) target to a variety of groups (i.e. residents, family caregivers, nursing staff, management) and organizational levels (e.g. physical, social, organizational), 4) affect many and variable outcomes and 5) need a degree of flexibility and tailoring during implementation. Due to this complexity, important questions<sup>7</sup> regarding SSLFs have not yet been answered: which and how do presumed beneficial effects vary among target groups and care settings, what are the active ingredients of SSLFs and how do they exert their effect? More knowledge and evidence regarding these questions is essential to gain understanding if and how SSLFs have an effect on residents, their family caregivers and nursing staff.

The active ingredients of SSLFs remain unclear. The main focus in research and practice has often been on physical aspects of SSLFs, such as (group) size, location, and design features of an archetypal home (e.g. kitchen, door bell, and furniture).<sup>9,10</sup> This is understandable, since physical aspects are most visible, easy to measure and therefore provide a clear distinction with traditional nursing homes. However, physical aspects are only one part of the care philosophy of SSLFs, and social and organizational aspects are of importance as well.<sup>11</sup> Results from the contrast questionnaire measuring these aspects in the effectiveness study showed that overall SSLFs scored significantly higher on these aspects than RWs, and that all individual items signi-

ificantly differed, except for two items related to staff (i.e. to what extent do “...staff wear a uniform” and “...other staff have access to the unit”). This raises a question: are the aspects set as inclusion criteria (e.g. physical resemblance to archetypal house, residents having autonomy, nursing staff being part of the household) the most effective elements which could improve well-being of residents, family caregivers and nursing staff? Possibly not, although they may be encouraging. It is likely that other or additional and targeted interventions are needed to reach actual improvements.

The next section highlights some findings regarding residents’ behavior and family caregivers’ burden. It attempts to find explanations for results found in this thesis, relate it to the concept of SSLFs and also addresses alternative explanations.

### **Residents’ findings: social engagement and agitation**

Findings from the effectiveness study could imply that the extent to which a unit applies to criteria for SSLFs may have an influence on social engagement, since only residents in the most typical SSLFs were still more engaged after 12 months. This corresponds with recent studies, demonstrating that the environment and meaning of stimuli influences engagement of residents with dementia in nursing homes.<sup>12, 13</sup> Items related to household or office work increased residents’ engagement.<sup>12</sup> This may be due to a lifetime exposure and that these activities have meaning in itself which is an important characteristic, fulfilling residents’ desire to make oneself useful. Additionally, it is of great importance to individualize activities to residents’ self-identity roles by tapping into past experiences, hobbies and interests as this also increased engagement.<sup>14, 15</sup> It could be that in the most typical SSLFs these aspects are better addressed, thereby increasing residents’ social engagement.

An interesting and important finding from this study is that residents in SSLFs displayed more aberrant motor behavior at all measurements and more physically non-aggressive agitation (such as wandering) after 12 months than residents in RWs. This could be related to several factors. Since SSLFs are based on a different care concept, emphasizing normalization of daily life, encouraging residents’ participation and autonomy and a more person-centered attitude towards care, it could be that “aberrant” motor behavior is more accepted. Perhaps nursing staff do not perceive it as aberrant motor behavior or as agitation (especially since it is physically non-aggressive) but as a way of normal acting of the residents which should be respected. In RWs, where care is more based on a medical model of care, emphasizing safety, this

could be more often be perceived as deviant or problem behavior which should be restricted.

However, recent findings from the literature suggest that especially physically non-aggressive behaviors could be a result of residents' need for stimulation.<sup>16-18</sup> This could be actively fulfilled, for example by walking or activity programs, or passively, such as seeing, hearing and smelling activities. SSLFs are possibly at risk in providing not enough opportunity for residents to be actively involved, for example due to the small unit size. Especially active stimulation was missed by some family caregivers in SSLFs, as findings from the process evaluation showed.

### **Family caregivers' burden**

The results of this thesis suggest positive effects of SSLFs on family caregivers' burden, since in SSLFs significant less burden was experienced compared with RWs. Differences existed already at baseline and remained stable over time. Both characteristics of the facility and caregivers' characteristics may explain these results. It could be that family caregivers of residents in SSLFs experienced less burden at admission, although another study showed that family caregivers in SSLFs experienced even significantly higher levels of burden than family caregivers in RWs at admission of their relative.<sup>5</sup>

Perhaps burden of family caregivers in SSLFs is relieved by a higher confidence in the care provided in SSLF. This could be related to their higher levels of satisfaction. Family caregivers in SSLFs were more satisfied with nursing staff in this facility as shown in this thesis' effectiveness study. The process evaluation showed also a higher satisfaction with the facility type for family caregivers in SSLFs. Furthermore, it found that family caregivers of residents in SSLFs had mainly positive experiences, especially related to involvement with residents, personal contact and autonomy. Previous research revealed that when nursing staff members become more involved with family caregivers and keep open lines of communication, family caregivers' satisfaction increases, which improves their feeling of confidence that their loved one is well being cared for.<sup>19, 20</sup> SSLFs may have characteristics that improve family caregivers communication and involvement with nursing staff, such as small caseload, homelike environment, autonomy and attention for continuation of self-identity for residents.

Unmeasured characteristics of family caregivers could also have an influence on their perceived burden, such as personality characteristics, coping style and psychological distress. Sense of competence, which refers to the caregivers' ability and



resources to deal with perceived burden, was assessed in the effectiveness study, although no differences between groups were found (adjusted mean difference 0.67, 95% Confidence Interval 0.52 – 1.85;  $P = .269$ ).

## Future directions

### Practice

The results of this thesis have several implications for future practice. *First*, this thesis has shown that SSLFs are not necessarily a better care environment than RWs and therefore an automatic transition towards SSLFs is not recommended. Other options should be considered carefully. SSLFs are the result of a changing care concept that has been developed during the past decennia's in health and dementia care, in which quality of life and well-being have a prominent place. This has stimulated changes in institutional care for people with dementia in a positive way, both in regular nursing homes as well as in the development of new dementia care facilities. The key question in realizing dementia care facilities should focus on how to reach optimal well-being for residents, their family caregivers and nursing staff. This provides opportunities for residents and their family caregivers to make a choice which care facility suits their wishes and beliefs best.

*Second*, adequate training and education for nursing staff are essential for future dementia care. This is especially relevant in SSLFs since nursing staff work alone during a great extent of the day and have a large responsibility for residents' care (i.e. observing, alertness for changes and adequate response). There is a critical shortage of well-trained and highly educated nursing staff specialized in geriatric and dementia care, both in the Netherlands and abroad.<sup>21, 22</sup> Training (both in educational models as training on the job) should focus on dementia and consequences of the disease for care giving, taking into account the whole residents' system. Since multimorbidity is present in many residents, more knowledge of other chronic diseases highly prevalent in older people (such as cardiovascular diseases or diabetes) and the interplay among diseases is essential. Nursing staff need to know consequences of the disease for daily functioning and how to support this, taking into account what residents themselves are still able to do.

*Third*, dementia care facilities should take family caregivers' burden and distress into account, by providing information, support groups and counseling and additional training for nursing staff. Although caregiver burden and distress is much hig-

her for family caregivers of patients at home, recent studies showed that experienced burden remains present after admission.<sup>5, 23, 24</sup> Furthermore, in the light of current developments with increasing costs and decreasing staff, policy makers and health care organizations might be more dependant on assistance of family caregivers. Additionally, involvement of family caregivers in the care giving process after admission may have beneficial effects for their well-being as well.<sup>19, 20, 25</sup>

### **Research**

Results from this thesis point to several recommendations for future research. *First*, new studies are needed that investigate which factors or aspects of SSLFs are effective for which outcome measures, for whom (i.e. define its target group) and how effects are exerted. These insights could assist effective implementation of new SSLFs and will improve effectiveness of existing SSLFs. Furthermore, it needs to be investigated which and how effective ingredients could be transferred to other dementia care settings as well. The interplay among physical, organizational and social aspects of the care environment should be taken into account. Translational research bringing evidence from neurocognitive research into daily practice and design of dementia care settings might be helpful, emphasizing a biopsychosocial model of dementia care.

*Second*, research is necessary to investigate which skills and competencies nursing staff require for working in SSLFs and how best to support nursing staff in obtaining and maintaining these skills. Since the role of nursing staff is changing in SSLFs, one might assume that other skills or competencies are more important compared with working on RWs. For example, results from the process evaluation revealed that client-centeredness was more prominent in SSLFs compared with RWs. Furthermore, this thesis found differences in job characteristics, such as higher levels of job autonomy for nursing staff working in SSLFs, which may also require other competencies.

*Third*, there is a need for cost-analyses and cost-effectiveness studies. Hardly any data on costs for SSLFs and differences with regular dementia care is available, although a recent study suggested that care arranged to the model in SSLFs is not unfavorable in comparison with traditional care.<sup>26</sup> As the costs for dementia care will rise substantially in the near future,<sup>27</sup> with accommodation being a major cost driver,<sup>27, 28</sup> cost-analyses are highly warranted for an optimal organization of dementia care services.

*Finally*, more evidence is needed contributing to the decision under which cir-

cumstances home care or institutional care is favorable for people with dementia and their families. Dementia care is currently redesigned, focusing on deinstitutionalization. The underlying belief is that most older people, including those with complex care needs such as people with dementia, can and prefer to be cared for in their own home, thereby increasing familiarity.<sup>29</sup> To support this, home- and community-based care services are enhanced. There is, however, hardly any data available contributing to the decision under which circumstances home care or institutional care is favorable for people with dementia and their families. Little is known about specific characteristics of people with dementia who benefit most from institutional as opposed to home- and community-based research.<sup>29</sup> Some promising studies and models have been suggested, which require further development and testing.<sup>29-33</sup> As people with dementia and their caregivers are a heterogeneous group, one size probably does not fit all and availability and diversity in dementia care and care settings are of vital importance.

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Chapter 10

Summary

Samenvatting

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## Summary

This thesis evaluated small-scale living facilities (SSLFs) in institutional dementia care, focusing on residents, their family caregivers and nursing staff (*Chapter 4 – 8*). In SSLFs a small number of residents (usually six to eight) live together in a homelike environment. Since little was known about the concept and characteristics of SSLFs, two explorative studies were conducted first (*Chapter 2 and 3*). This section summarizes all studies as described in this thesis.

*Chapter 1* provides a general introduction to the study, addressing background information on dementia, institutional care and SSLFs in the Netherlands and presents the thesis' main objectives.

A review of the literature (*Chapter 2*) identified 11 care concepts like SSLFs worldwide. Similarities of concepts reflected a focus on meaningful activities centered around the daily household, with residents encouraged to participate. Nursing staff were part of the household and had integrated tasks, including personal and nursing care, organization of activities and performance of household chores. Differences among concepts were reflected in the physical environment, number of residents and resident's characteristics and may be influenced by cultural and organizational differences. These findings provided a basis for the inclusion criteria for the main study into effects of SSLFs.

A cross-sectional study was conducted (*Chapter 3*) to explore characteristics of residents living in SSLFs and compare these with residents in regular wards (RWs) in nursing homes in the Netherlands. Results showed that residents in SSLFs had on average a higher level of cognitive functioning and functional status compared with residents in RWs, although residents in both groups required a similar level of nursing care. These findings pointed at the need to take residents' characteristics into account in research. For this thesis' main study, a matching procedure was conducted to increase comparability of groups at baseline.

A quasi-experimental design (*Chapter 4*) was used to investigate effects of SSLFs on residents, their family caregivers and nursing staff. Two types of institutional care were compared, SSLFs and RWs, at three measurements: at baseline and follow-ups after six and 12 months. A matching procedure was performed to increase comparability of residents' groups at baseline regarding cognitive and functional status. Main outcome measures for residents (n=259) included quality of life (QoL) and neuropsychiatric symptoms. For family caregivers (n=206), burden, involvement and satisfaction with care was studied. Nursing staff's (n=305) primary outcome measures



included job satisfaction and motivation. A process evaluation was conducted alongside the final measurement to gain insight into experiences with SSLFs.

No convincing overall effects of SSLFs were found (*Chapter 5*). Residents total QoL was similar for both groups and only a few dimensions significantly differed. No effects were demonstrated for total neuropsychiatric symptoms and agitation. Family caregivers in SSLFs expressed less burden and were more satisfied with nursing staff than family caregivers of residents in RWs. No effects were found on job satisfaction and motivation for the total group of nursing staff, although subgroup analyses using contrast groups (regarding typical SSLFs and RWs) found higher levels for staff in SSLFs.

Secondary outcomes on residents (*Chapter 6*) showed mixed results regarding behavior. Residents in SSLFs were more socially engaged at baseline and after six months, displayed more aberrant motor behavior at all moments and more physically non-aggressive behavior after 12 months, compared with residents in RWs. Significantly fewer physical restraints and psychotropic drugs were used in SSLFs compared with RWs. These difference existed at baseline and remained stable over time.

Secondary measures for nursing staff (*Chapter 7*) revealed no effects on the outcome burnout symptoms, although subgroup analyses using contrast groups showed less burnout symptoms in typical SSLFs compared with typical RWs. Furthermore, several job characteristics significantly differed. Nursing staff in SSLFs experienced less workload and physical demands and more job autonomy than nursing staff in RWs. No effect was found for overall social support in the total group, although subgroup analyses showed that nursing staff working in most typical small-scale living facilities experienced more social support.

The process evaluation (*Chapter 8*) revealed mainly positive experiences of family caregivers and nursing staff with SSLFs. These related to the personal attention that nursing staff spends on residents, their involvement with residents and the emphasis on autonomy in daily life. Barriers were also experienced though, mainly related to nursing staff working alone during a great extent of the day.

The final chapter (*Chapter 9*) presents the main findings of the study and discusses methodological and theoretical considerations. Finally, future directions are addressed for practice and research.

## Samenvatting

Mede door onze vergrijzende samenleving zal het aantal ouderen met dementie de komende jaren sterk stijgen. Schattingen geven aan dat er momenteel in Nederland circa 235.000 mensen met dementie zijn; dit aantal zal in 2050 meer dan een half miljoen bedragen. Dementie is een syndroom dat diverse symptomen veroorzaakt, zoals cognitieve achteruitgang (o.a. in het geheugen en taalvaardigheden), problemen met de uitvoer van activiteiten in het dagelijks leven (bijvoorbeeld aankleden en wassen) en gedragsmatige problemen (zoals agitatie en apathie). Het merendeel, circa tweederde, van de mensen met dementie woont thuis. Naarmate het ziekteproces vordert, is opname in een verpleeginstelling echter vaak onvermijdelijk.

In Nederland ontwikkelt de verpleeghuiszorg voor mensen met dementie zich - mede gestimuleerd door de overheid - in sterke mate richting kleinschalige woonvormen. In 2010 was ongeveer 25% van de verpleeghuiszorg gerealiseerd in kleinschalige woonvormen. Er bestaat een grote variëteit in deze kleinschalige woonvormen, van een afzonderlijke woning in de wijk tot geschakelde woningen op het terrein van een verpleeghuis. In het algemeen wordt met kleinschalig wonen bedoeld dat een beperkt aantal ouderen (doorgaans maximaal 8) samenwoont in een huiselijke en herkenbare omgeving. Er wordt hierbij zoveel mogelijk gestreefd naar een situatie zoals thuis. Tot op heden is er slechts weinig systematisch onderzoek verricht naar kleinschalige woonvormen, waardoor de effecten voor bewoners, mantelzorgers en verzorgenden nog onduidelijk zijn.

Het primaire doel van dit proefschrift is daarom kleinschalige woonvormen voor ouderen met dementie te evalueren (*Hoofdstuk 4 t/m 8*). Vanwege de beperkte kennis in de (inter)nationale literatuur over het concept en de kenmerken van kleinschalige woonvormen, zijn voorafgaand twee exploratieve studies (*Hoofdstuk 2 en 3*) uitgevoerd.

De introductie (*Hoofdstuk 1*), geeft achtergrondinformatie over dementie en verpleeghuiszorg waarbij de Nederlandse situatie, met daarin kleinschalige woonvormen, beschreven wordt. Tevens worden in dit hoofdstuk de doelstellingen van het proefschrift weergegeven.

Een uitgebreid literatuuronderzoek (*Hoofdstuk 2*) beschrijft het concept en de kenmerken van kleinschalige woonvormen wereldwijd. In deze review zijn 11 zorgconcepten geïdentificeerd vergelijkbaar met kleinschalige woonvormen in Nederland. Overeenkomsten in concepten benadrukken betekenisvolle activiteiten rondom het dagelijkse huishouden als centraal uitgangspunt in kleinschalige woonvormen.

Bewoners worden sterk gestimuleerd om hieraan deel te nemen. Verzorgenden zijn onderdeel van het huishouden en hebben geïntegreerde taken. Zij zijn niet alleen verantwoordelijk voor persoonlijke en verpleegkundige zorg, maar zij verrichten ook huishoudelijke taken (zoals gezamenlijk koken met bewoners) en organiseren activiteiten in de woning. Verschillen tussen concepten betreffen vooral de fysieke omgeving, het aantal bewoners per wooneenheid en kenmerken van bewoners. De diversiteit wordt mogelijk beïnvloed door culturele en organisatorische verschillen tussen landen. Deze bevindingen vormden een basis voor de inclusiecriteria voor de hoofdstudie.

Een cross-sectionele studie is uitgevoerd (*Hoofdstuk 3*) om kenmerken van bewoners in kleinschalige woonvormen in kaart te brengen en deze te vergelijken met bewoners in gewone verpleegafdelingen in Nederland. Resultaten laten zien dat bewoners in kleinschalige woonvormen gemiddeld beter scoren wat betreft hun cognitieve en functionele status, in vergelijking met bewoners op gewone verpleegafdelingen. De gemiddelde behoefte aan zorg, zoals uitgedrukt in een zorgzwaartepakket (ZZP), verschilde niet tussen beide condities. Deze bevindingen geven aan dat kenmerken van bewoners in overweging genomen moeten worden bij evaluatieonderzoek in de verpleeghuiszorg.

Een quasi-experimenteel onderzoeksdesign (*Hoofdstuk 4*) is gebruikt om de effecten van kleinschalige woonvormen op bewoners, hun mantelzorgers en verzorgenden te onderzoeken. Hiervoor zijn gedurende één jaar (nulmeting en vervolgmetingen na zes en 12 maanden) twee typen verpleeghuiszorg met elkaar vergeleken: (28) kleinschalige woonvormen en (21) psychogeriatrische afdelingen in gewone verpleeghuizen. Een matchingsprocedure is toegepast om de vergelijkbaarheid van bewoners wat betreft cognitie en functionele status bij aanvang van de studie te vergroten. De belangrijkste uitkomstmaten voor bewoners (n=259 in beide condities) waren kwaliteit van leven en neuropsychiatrische symptomen. Daarnaast zijn diverse aspecten van hun gedrag en het gebruik van vrijheidsbeperkende maatregelen en psychofarmaca in kaart gebracht. Bij mantelzorgers (n=209) werden ervaren belasting, betrokkenheid en tevredenheid met de zorgverlening bestudeerd. De belangrijkste uitkomstmaten voor verzorgenden (n=304) waren arbeidstevredenheid en motivatie. Daarnaast zijn bij verzorgenden burnoutklachten onderzocht en diverse werkkenmerken zoals ervaren autonomie, sociale steun en werkdruk. Om een gedetailleerd inzicht te verkrijgen in de ervaringen met kleinschalig wonen, is aan het effectonderzoek tevens een procesevaluatie gekoppeld.

De studie heeft geen overtuigende effecten gevonden op de belangrijkste uit-

komstmaten (*Hoofdstuk 5*). De algemene kwaliteit van leven was vergelijkbaar tussen bewoners in kleinschalige woonvormen en bewoners op gewone verpleegafdelingen. Slechts op een enkele subschaal (o.a. iets om handen hebben) werden significante verschillen gevonden. Mantelzorgers van bewoners in kleinschalige woonvormen rapporteerden minder zorgbelasting dan mantelzorgers van bewoners op gewone afdelingen. Deze verschillen bestonden al bij aanvang van de studie en bleven constant in de tijd. In beide condities waren mantelzorgers redelijk tot heel tevreden over het contact met verzorgenden, ofschoon mantelzorgers in kleinschalige woonvormen vaker heel tevreden waren met dit contact. In de totale groep medewerkers werden geen significante verschillen gevonden tussen beide condities voor wat betreft arbeidstevredenheid en motivatie. Alleen in subgroepanalyses waren verzorgenden in de meest typische kleinschalige woonvormen meer tevreden en gemotiveerd dan verzorgenden in de meest typische gewone verpleegafdelingen

Secundaire uitkomstmaten voor bewoners (*Hoofdstuk 6*) laten een gemengd beeld zien wat betreft gedrag. Bewoners in kleinschalige woonvormen waren meer sociaal betrokken bij aanvang van de studie en na zes maanden, vertoonden meer doelloos gedrag op alle meetmomenten en meer fysiek non-agressief gedrag na 12 maanden in vergelijking met bewoners op gewone verpleegafdelingen. Daarnaast werden in kleinschalige woonvormen minder vrijheidsbeperkende maatregelen en minder psychofarmaca gebruikt dan op gewone afdelingen. Ook deze verschillen bestonden al bij aanvang van het onderzoek en bleven stabiel in de tijd.

Secundaire maten voor verzorgenden (*Hoofdstuk 7*) hebben geen effecten gevonden voor de uitkomstmaat burnoutklachten, alhoewel subgroep analyses lieten zien dat verzorgenden in de meest typische kleinschalige woonvormen significant minder burnoutklachten vertoonden dan verzorgenden werkzaam in de meest typische gewone verpleegafdelingen. Daarnaast worden enkele significante verschillen gevonden in werkkenmerken. Verzorgenden in kleinschalige woonvormen rapporteerden meer autonomie en minder werkdruk en fysieke inspanning dan verzorgenden op gewone verpleegafdelingen. Deze verschillen bestonden al bij aanvang van de studie en bleven stabiel in de tijd. Er werden geen verschillen gevonden in ervaren sociale steun in de totale groep verzorgenden; slechts in de subgroep analyse gaven verzorgenden van de meest typische kleinschalige woonvormen aan meer sociale steun te ervaren dan verzorgenden werkzaam op de meest reguliere afdelingen.

De procesevaluatie (*Hoofdstuk 8*) toont hoofdzakelijk positieve ervaringen van mantelzorgers en verzorgenden met kleinschalige woonvormen. Deze omvatten de persoonlijke aandacht die verzorgenden aan de bewoners besteden, betrokkenheid

en autonomie in het dagelijkse leven voor zowel bewoners, mantelzorgers als verzorgenden. Enkele knelpunten worden ook ervaren. Zo vinden sommige verzorgenden het niet prettig om overwegend alleen te werken. Zij missen vooral een team om gezamenlijk verantwoordelijkheden te delen. Hieraan gerelateerd vinden zowel verzorgenden als mantelzorgers dat de personele bezetting op kleinschalige woonvormen kwetsbaarder is, omdat ziekte van personeel bijvoorbeeld lastiger is op te vangen. Enkele mantelzorgers ervaren knelpunten in het aanbod van voorzieningen en activiteiten. Zij missen bijvoorbeeld een restaurant, gezamenlijke tuin of winkel in de buurt.

Het laatste hoofdstuk (*Hoofdstuk 9*), de discussie, vat de belangrijkste bevindingen van de studie samen en bespreekt methodologische en theoretische overwegingen in de studieopzet en interpretatie van bevindingen. Tevens worden aanbevelingen gedaan voor de praktijk en toekomstig onderzoek. Resumerend kan gesteld worden dat kleinschalige woonvormen niet per se een betere zorgvoorziening zijn dan gewone verpleegafdelingen voor ouderen met dementie. De hoofdvraag bij het realiseren van zorgvoorzieningen voor mensen met dementie moet zich blijven focussen op het realiseren van optimaal welbevinden van bewoners, mantelzorgers en verzorgenden. Om dit te kunnen realiseren is adequate training en opleiding van verzorgenden essentieel.

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Proost allemaal!



## About the author

Hilde Verbeek was born in Valkenswaard, the Netherlands, on the 14th of July 1983. After completing her secondary education (gymnasium) at the Weredi College in Valkenswaard (1995-2001), she studied psychology at Maastricht University. She obtained her Bachelor's Degree in biological psychology in September 2004 and her Master's Degree in neuropsychology in September 2006. During her Master's studies, she developed an interest in the relationship between the brain and behavior, and in particular, its implications for clinical practice. She completed an additional 12 month internship (combining research and practice) which focused on the care of people with traumatic brain injuries at Vijverdal Psychiatric Hospital's Department of Neuropsychiatry. She obtained her registration in Psychodiagnosics with the Netherlands Institute for Psychologists in October 2005 and after her graduation, worked as a teacher and research assistant at Maastricht University at various departments. In October 2006, she started her doctoral research into the use of small-scale homelike environments for people with dementia at the Department of Health Care and Nursing Science in the Faculty of Health, Medicine and Life Sciences at the same university.

Hilde currently holds an appointment as a research fellow within the CAPHRI research program "Innovations in Care for the Elderly" at Maastricht University. Since March 2010, she has been working as a co-investigator on the European FP7 project "RightTimePlaceCare". This project investigates the development of best practice strategies for the transition of people with dementia from formal professional home care to long-term residence in nursing homes. Hilde was recently awarded the Niels Stensen Stipendium to conduct research at the University of Manchester in the United Kingdom which will start in June 2011 for a 9-month period. Her future research is aimed at the optimization of dementia care environments and the further improvement of scientific research in this field.

Hilde is married to Fred Verhoeven and they live together in Eindhoven, the Netherlands.

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- Awarded with the Niels Stensen Stipendium (October 2010), a grant for talented young researchers to gain research experience abroad.
- Travel grant received from the Dutch Organization for Gerontology (Nederlandse Vereniging voor Gerontologie), to present work at the international meeting of the International Psychogeriatrics Association (Spain, September 2010).
- Travel grant received from the Internationale Stichting Alzheimer Onderzoek (ISAO), to present work at the 25th conference of Alzheimer Disease International (Greece, March 2010).
- First prize Janneke Witsenburg poster award for best poster presentation at the 9th National Gerontology Conference (Ede, the Netherlands, 2008) entitled 'Functional status and cognition in older people with dementia: a comparison between small-scale living facilities and regular nursing home wards'.











In de huidige verpleeghuiszorg voor ouderen met dementie wordt sterk ingezet op een ontwikkeling naar kleinschalige woonvormen. Dit zijn woonvormen waarin een beperkt aantal ouderen (doorgaans 6 tot 8) samenwoont in een huiselijke en herkenbare omgeving. Bewoners voeren zoveel mogelijk eigen regie en worden gestimuleerd om deel te nemen aan dagelijkse activiteiten.

In dit proefschrift beschrijft Hilde Verbeek de resultaten van haar onderzoek naar kleinschalige woonvormen. Ze gaat hoofdzakelijk in op de effecten ervan op bewoners, hun mantelzorgers en verzorgenden. Daarnaast beschrijft zij ervaringen met kleinschalige woonvormen en internationaal vergelijkbare concepten. Dit proefschrift is relevant voor onder anderen psychologen, specialisten ouderengeneeskunde, verpleegkundigen, zorgmanagers en alle anderen die regelmatig te maken hebben met mensen met dementie.



*Hilde Verbeek (1983) is als onderzoekster werkzaam op het gebied van chronische zorg en ouderen, in het bijzonder dementie, aan de Universiteit Maastricht binnen de CAPHRI School for Public Health and Primary Care.*