

**GROUP LIVING HOMES FOR OLDER PEOPLE  
WITH DEMENTIA**

**CONCEPT AND EFFECTS**

**Selma te Boekhorst**

The studies described in this thesis were performed at the Program on Aging of the Netherlands Institute of Mental Health and Addiction in Utrecht, and the EMGO Institute for Health and Care Research (EMGO+) of the VU University Medical Center in Amsterdam. EMGO+ participates in the Netherlands School of Primary Care Research (CaRe), which has been re-acknowledged in 2005 by the Royal Dutch Academy of Science (KNAW).

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**Group living homes for older people with dementia**  
**Concept and effects**

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                         dr. J. de Lange

**VOOR MIJN OUDERS**



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**1**

**GENERAL INTRODUCTION**

*Group living homes for older people with dementia*

## **INTRODUCTION**

Group living home care is an innovative form of nursing home care for older people with dementia. It has been developed in reaction to the hospital model on which nursing homes are traditionally based and aims to offer small groups of people with dementia a homelike environment in which they lead a daily life as normal as possible. Modeled after Swedish example, the first Dutch group living homes were created in the mid 1980s. Its popularity increased enormously in the following decades and nowadays (2010), approximately 25% of the psychogeriatric nursing home population lives in group living homes (Kenniscentrum Wonen-Zorg Aedes-Actiz, 2008). Looking at these numbers, it is not surprising that many consider group living home care the new standard for Dutch nursing home care. However, although public opinion sees definite advantages of group living home care over traditional nursing home care, no thorough scientific research has been done to support this view. Moreover, there exists much uncertainty about the contents of the concept of group living home care itself. The objective of this thesis therefore is to bring clarification to both concept and effects of group living home care for older people with dementia, in particular compared to modern traditional nursing home care.

In the next paragraphs, important concepts related to group living home care and this study are explained. Subsequently, the research questions, methods and outline of this thesis are presented.

### **Dementia**

Dementia (literally ‘deprived of mind’) is a generic term for a large number of medical and neurological conditions which come often, but certainly not always, with advancing age. The underlying causes of dementia can range from cerebrovascular to degenerative diseases, leading to many different dementia subtypes such as Alzheimer’s disease, vascular dementia or Pick’s disease. Although neuropathological evidence is considered the golden standard for diagnosing dementia, several clinical diagnostic criteria have been developed. According to the DSM-IV-TR (2000) the ‘essential feature of a dementia is the development of multiple cognitive deficits that include memory impairment and at least one of the following cognitive disturbances: aphasia, apraxia, agnosia or a disturbance in executive functioning. The cognitive deficits must be sufficiently severe to cause impairment in occupational or social functioning and must represent a decline from a previously higher level of functioning’. This deterioration is often accompanied by dramatic changes in behavior and emotions, making dementia an extremely difficult process for both sufferer and caregiver.

A consensus study by Ferri et al. (2005) estimated the worldwide prevalence of dementia to be 24,3 million at the time, with 4,6 million new cases emerging every year. The number of

people with dementia will double every 20 years to 81,1 million in 2040. Rates of increase are not uniform around the world. In developed countries the increase in people with dementia is forecast to be 100% between 2001 and 2040, but in lower and middle income countries like India, China and their south Asian and Pacific neighbors this increase will be more than 300%.

The prevalence of dementia increases sharply with age. Lobo et al. (2000) estimated the European prevalence of dementia to be 0.8% in 65-69 year-olds and 28.5% in people 90 years and older. A recent American study presented USA dementia prevalences of 13.3% in 71-79 year-olds and 37.4% in people 90 years and older (Plassman et al., 2007). Although less precisely measured, the prevalence of dementia in the Netherlands seems to be more or less similar, with 1% of 65 year olds and more than 40% of 90 year olds affected (Gezondheidsraad, 2002).

### **Nursing home care in the Netherlands**

The majority of people with dementia are cared for at home. However, due to a combination of factors such as severe behavioral problems or exhaustion of the informal caregiver, admittance into a nursing home is sometimes inevitable (Yaffe et al., 2002). It is estimated that in 2000, approximately 35% of Dutch people with dementia lived in either residential or nursing home care (Gezondheidsraad, 2002).

Dutch nursing homes are publicly funded institutions in which people with psychogeriatric complaints, mainly dementia, receive separate care from those with somatic complaints. They 'provide temporary or permanent multidisciplinary treatment, guidance, support and nursing care, mainly for elderly patients with long term, complex health problems, expressed primarily in term of functional disorders and handicaps' (Ribbe, 1993). In 2004, there were 345 nursing homes in the Netherlands, housing 35,635 people with psychogeriatric complaints and 27,392 people with somatic complaints (VWS, 2005). However, the 1340 Dutch residential homes often provide nursing home care as well. One study estimated that 29.000 of the 114.00 people living in residential homes has dementia, which is over 25% (Boersma et al., 1995).

Dutch nursing homes employ specifically trained nursing home physicians, which is unique in the world. They are responsible for the multidisciplinary treatment of residents, together with nurses, certified nursing assistants, psychologists, physiotherapists, occupational therapists, recreational therapists, speech therapists and social workers (Ribbe, 1993; Hoek et al., 2000).

### **Group living home care**

In the Netherlands as well as in other countries, nursing home care was traditionally modeled on hospital care. However, in the last decades of the 20<sup>th</sup> century, realization grew that, unlike

hospitals, nursing homes needed to serve as *homes* in the literal sense of the word. An institutional setting is particularly unsuited for people with dementia, who have unique needs such as a sense of security and easy orientation (Hammer, 1999). As a reaction to this the concept of group living home care arose. It was originally developed in Sweden, after which countries such as Great Britain (Lindesay et al., 1992), France (Ritchie et al., 1992), Japan (Funaki et al., 2005) and the Netherlands followed suit.

### ***Sweden***

According to Annerstedt (1997), the first group living homes started in the area around Malmö in the South of Sweden in the late 1970s and early 1980s. Following governmental subsidizing, group living homes emerged all over the country in the 1990s and in 1997, approximately 14,000 people lived in group living homes. It was estimated that this number would rise to 20,000-25,000 at the turn of the century. The development and consequences of group living home care is described extensively in Annerstedt (1993) and Malmberg & Zarit (1993).

Swedish group living can be defined according to Lawton's (1980) four of the five environmental dimensions (Annerstedt, 1997). In the *personal environment* dimension, group living home care expects significant people such as family and friends to cooperate in care and care planning. In the dimension *group environment*, group living home care needs staff who are trained and supervised in the treatment of people with dementia and a homogenous group of residents. This homogeneity is achieved by selecting 8-9 residents of a certain age, type and level of dementia. Only people with late onset dementia of the Alzheimer type, vascular dementia or a combination of these two are admitted. Residents also need to be able to communicate meaningfully on admittance and to get out of bed by themselves. This mostly corresponds with moderately to moderately-severe dementia. Group living in Sweden is therefore intended for people with dementia between home care and institutional care (Häggström & Norberg, 1996). Lawton's third dimension, the *social environment*, is conceptualized in group living home care by normalizing daily life according to the resident's cultural values and traditions, with common contrasts such as weekday-holiday and day-night. The dimension *physical environment* in Swedish group living home care is designed to be well-known, homelike, small and safe.

### ***The Netherlands***

Dutch group living home care for people with dementia was first created in the early 80s. Sources of inspiration were not only the Swedish model described above, but also the Dutch model of group living home care for people with psychiatric disorders and mental disabilities (Wennink, 1989; Otten & Hoekman, 1999).

The first group living home opened its doors in 1981, after which its popularity increased steadily. However, the real growth did not occur until the last years of the 20<sup>th</sup> century.

Nowadays (2010), the Netherlands have 432 group living homes with more than 12,000 residents. This corresponds to almost 25% of the nursing home population with psychogeriatric complaints. Moreover, it is an increase of 178% compared to 2005, when there were little over 4,000 people living in group living home care (kenniscentrum Wonen-Zorg, 2008).

Despite this explosive growth, adequate descriptions of group living home care were scarce. Branche and building corporation Aedes-Arcare (now Actiz) defined group living home care as follows:

*In group living home care a small group of people who need intensive care and support lives together in a group home, which enables them to live a life as normal as possible.*

Definitions of this kind are clearly insufficient. They are too short to provide a full account of group living home care and therefore leave a lot to be explained. What is meant by a “group home”? How exactly *can* residents “live a life as normal as possible”? How many residents form a “small group”? However, perhaps the most important issue is that such short definitions say nothing on the underlying principles of group living home care, which may have widely divergent practical consequences.

To summarize, the existing definitions did not give both researchers and managers much to go on. It is therefore little wonder that there was much uncertainty on the exact content of the concept of group living home care.

### **Research on group living home care**

The development of group living home care in Sweden naturally led to Swedish scientific research assessing its effects. One study showed that group living home care raised residents' quality of life for a period of 2-2.5 years in comparison to traditional nursing home care (Annerstedt, 1994). Another study by Annerstedt et al. (1993) found that psychosocial stimulation and therapy offered in group living home care had positive effects on emotional symptoms and performance of residents of group living home care compared to residents in traditional nursing home care. However, these positive effects diminished as the dementia progressed. Elmståhl et al. (1998) found that polypharmacy seemed to increase in the two years after admission into group living home care. Furthermore, depressive symptoms in particular were present in about 80% of residents, while only 12% received medication for this. Another study by Elmståhl et al. (1997) on the design of group living units showed that in order to reduce psychiatric symptoms of its residents a group living home should facilitate easy perception, for example with wide corridors, but without reducing other communal area as this offers large benefits as well. Another study on the design of group living units focusing on the organizational work climate, found that residents spent much more time with staff and each

other instead of spending it alone when staff worked in a creative organizational climate (Norbergh et al., 2002). In another study on staff it was found that after completing a training program on group living home care, staff had higher competence and professional conduct towards patients as well as increased motivation, job satisfaction and quality of work compared to staff in traditional nursing home care (Alfredson & Annerstedt, 1994). Research on family burden showed that total burden of family caregivers of residents in group living units decreased after 12 months, but degree of isolation was unchanged and feelings of disappointment even increased. This was independently predicted by residents' lack of vitality on admission (Elmståhl et al., 1998). Finally, a cost analysis found that group living home care was significantly cheaper than traditional nursing home care (Wimo et al., 1991).

While all these studies offer valuable insights into group living home care, there are several methodological and conceptual issues which make it difficult to extrapolate the results to the Dutch situation. For example, the two studies comparing residents of group living home care with residents of traditional nursing home care (Annerstedt, 1993; 1994) had small sample sizes of  $n=21$  and  $n=23$  respectively, thereby creating a major statistical power problem. The same applies to the study on staff satisfaction of Alfredson & Annerstedt (1994), which had sample sizes of  $n=34$  and  $n=19$  respectively. Moreover, it might measure the effectiveness of a staff training program more than the effects of group living home care itself. The studies on pharmacological treatments of residents (Elmståhl et al., 1998) and family burden (Elmståhl et al., 1998) did not have control groups at all, which makes it impossible to draw conclusions on the effectiveness of group living home care.

As mentioned earlier, thorough scientific research on Dutch group living home care had not yet been done. However, several small studies as well as anecdotal evidence showed that group living homes may have beneficial effects. An edition of the Dutch journal on psychogeriatric care 'Denkbeeld' was dedicated to group living home care and described the concept and its advantages in great detail (Denkbeeld, 2003). A report on one of the first group living homes, the "Anton Pieck Hofje" in Haarlem showed that high quality care could indeed be offered in a small setting (Plaisier et al., 1992). A report on another group living home found that residents experienced less apathy and anxiety than a control group of residents living in a residential home (Van Linschoten et al., 1995). Finally, a report on another group living home showed a positive as well as a negative effect: activities of daily life (ADL) increased but so did behavioural problems (Ludwig, 1997).

## **RESEARCH QUESTIONS**

The existing uncertainty on the concept of group living home care and the indecisive literature findings on its effectiveness led to five research questions. Two of these investigated the concept of group living home care:

1. *What are the ideals of group living home care for people with dementia?*
2. *Are the ideals of group living home care for people with dementia as described in the first research question, actually practiced in group living homes as compared to traditional nursing homes?*

The other three research questions assessed the effects of group living home care:

3. *What are the effects of group living home care for people with dementia on its residents' functioning, quality of life and use of psychotropic drugs and physical restraints as compared to residents of traditional nursing homes?*
4. *What are the effects of group living home care for people with dementia on informal caregivers' psychological distress –conceptualized as psychopathology, caregiver burden and subjective caregiver competence - as compared to informal caregivers of residents of traditional nursing homes?*
5. *What are the effects of group living home care for older people on job satisfaction and burnout of professional caregivers compared to professional caregivers of traditional nursing homes and are differences in these outcome measures explained by differences in three psychosocial job characteristic - autonomy, control and social support – between the two groups?*

## **Sample**

### ***Locations***

With the exception of the first research question, which defined group living home care with the Concept Map method (Trochim, 1989), all studies took place in group living homes, the experimental group and traditional nursing homes, the control group. Group living homes had to meet five eligibility criteria to participate:

1. A maximum of six residents per unit
2. A maximum of six units
3. Situated more than 200 metres of the nursing home to which they belonged
4. Prepared their own meals
5. Built more than two years prior to the start of the studies

To ensure that group living home care was compared with the best traditional nursing home care the Netherlands already had to offer, participating traditional nursing homes had to meet two eligibility criteria:

1. Built according to the Dutch 1997 Building Regulations for Nursing Homes
2. A minimum of 20 residents per unit



### *General introduction*

Twenty group living homes and fourteen traditional nursing homes met these criteria. Nineteen and seven participated in the studies respectively, resulting in a response of 96% and 50%. The group living homes and traditional nursing homes were located in similar geographic areas, with participating facilities in urban areas such as Amsterdam and Rotterdam in the West of the Netherlands as well as rural areas in the North and East. Because group living home care was practically non-existent in the South of the Netherlands, traditional nursing homes from this region were excluded from the studies.

#### ***Participants***

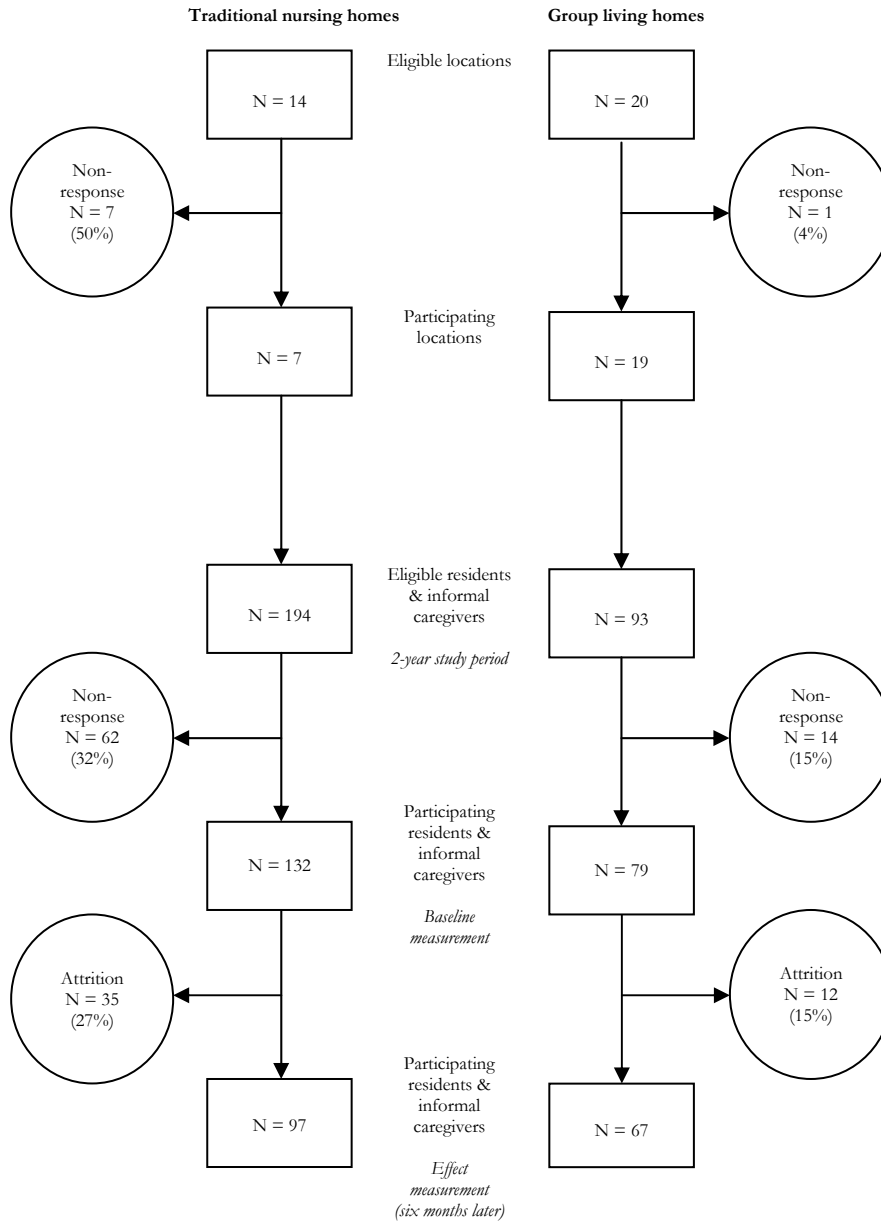
Newly admitted residents in both group living homes and modern traditional nursing homes were eligible for the study if they had a primary informal caregiver who could provide the necessary information about their relative and themselves. Response rates varied from 42% to 100% per unit with an average of approximately 68% in modern traditional nursing homes and 85% in group living homes. The main reason for not participating in the study was that it would be too stressful for residents and/or informal caregivers.

During the two-year study period, 132 residents and informal caregivers in modern traditional nursing homes participated in the study upon admission, of which 97 (73.5%) residents survived to participate in the second measurement six months later together with their informal caregiver. In group living homes 79 residents and their informal caregivers participated in the study upon admission, of which 67 (84.8%) residents survived to participate in the second measurement six months later together with their informal caregiver. Multilevel survival rate after six months did not differ significantly between the two groups, but there was a trend towards a higher survival rate in group living homes ( $X^2 = 3.92$ ,  $p = .059$ ).

Figure 1 shows a flowchart of the number of locations and participants, both potential and realized, on the baseline measurement and the effect measurement six months later.

In the study on the effects of group living home care on professional caregivers, nursing staff were eligible for the study if they performed all care tasks (washing, dressing, bathroom visits, transfers, eating and drinking). 183 nurses in group living homes and 197 nurses in traditional nursing homes participated, resulting in a response of 60% and 45% respectively.

Figure 1. Flowchart study residents and informal caregivers



## **OUTLINE**

The two research questions on the concept of group living home care are answered in chapter 2 and 3. **Chapter 2** describes and discusses the results of the construction of a Concept Map (Trochim, 1989), which was held to clarify the ideals of group living home care. **Chapter 3** describes the study that assessed to what extent group living homes incorporated the ideals of group living home care as described in the Concept Map.

The studies assessing the three research questions on the effects of group living home care are presented in chapter 4, 5 and 6. In **chapter 4**, the study on the effects of group living home care on functioning and quality of life of its residents is presented. **Chapter 5** describes the study investigating the effects of group living home care on informal caregivers' psychological distress. **Chapter 6** presents the study on the effects of group living home care on professional caregivers' job satisfaction and burnout and the influence of psychosocial job characteristics autonomy, control and social support.

In **Chapter 7**, the main findings of the studies are summarized. It also describes several methodological considerations. Last, relevance for clinical practice and health policy are discussed and recommendations for further research are given.

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*Group living homes for older people with dementia*



# 2

## **THE IDEALS OF GROUP LIVING HOMES FOR OLDER PEOPLE WITH DEMENTIA:**

### **A CONCEPT MAP**

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**ABSTRACT**

This article discusses the results of a Concept Mapping, held to clarify the concept of small-scale group living for elderly with dementia. Seventeen experts from different backgrounds formulated 91 statements about small-scale group living. These were subsequently depicted on a concept map with two dimensions: care versus living and individual versus context. The statements were then divided into six clusters by hierarchical clusteranalysis. Five of these clusters centred around the arrangements of the individual lives of the residents and the collective lives of residents and staff, while only one held statements about the physical characteristics of small-scale group living. Therefore, it can be concluded from this Concept Map that small-scale group living is not so much determined by the physical characteristics but by the organisational features of the care context.

## **INLEIDING**

Het aantal mensen met dementie in Nederland zal de komende decennia verdubbelen van ongeveer 200.000 op dit moment naar meer dan 400.000 in 2050 (Gezondheidsraad, 2002). Jaarlijks moeten er zes verpleeghuizen van tenminste 210 bedden elk worden bijgebouwd om deze enorme toename het hoofd te kunnen bieden (Gezondheidsraad, 2002). Het wonen in een grootschalig instituut is echter niet goed verenigbaar met de woonwensen van ouderen (Ettema, 2001). Het blijkt voor velen moeilijk er een gevoel van thuis zijn te ervaren (Hammer, 1999). Kleinschalig wonen wil hier verandering in brengen door in een huiselijke omgeving verpleeghuiszorg te bieden aan een kleine groep ouderen met dementie.

Kleinschaligheid is geen nieuw begrip in de zorgsector: chronisch psychiatrische patiënten en verstandelijk gehandicapten wonen al jaren in kleinschalige voorzieningen (Wennink, 1989; Otten & Hoekman, 1999). In de ouderenzorg ligt dat echter anders. Hoewel Ter Haar al in 1968 opmerkte dat in de zorg voor 'geestelijk gestoorde bejaarden' zoveel mogelijk een normaal gezin moest worden geïmiteerd (Ter Haar, 1968), is de bouw van zorgvormen met een soortgelijk concept pas de laatste twintig jaar op gang gekomen. Bovendien verliep deze ontwikkeling aanvankelijk zeer traag. Volgens de Databank Wonen-Zorg van Aedes-Arcares (geciteerd op 8 augustus 2003) opende de eerste kleinschalige woonvorm, de Mussengang in Groningen, in 1986 haar deuren. Drie jaar later, in 1989, volgde het Anton Pieck Hofje in Haarlem. Daarna groeide de populariteit van kleinschalige woonvormen gestaag, met een grotere toename vanaf het jaar 2000. Werden in de periode 1990-1999 nog 29 kleinschalige woonvormen gebouwd, in 2000-2004 verdubbelde dat aantal tot 64. Bovendien is nu al bekend dat er tot 2008 nog minstens 31 kleinschalige projecten gerealiseerd worden.

Een aantal kleinschalige woonvormen heeft al onderzoek laten uitvoeren naar het eigen functioneren. Daaruit bleek onder andere dat kwalitatief hoogstaande zorg geboden kon worden in een kleinschalige setting (Plaisier et al., 1992) en dat bewoners van een kleinschalige woonvorm minder apathie en angst vertoonden dan een referentiegroep, gevormd door ouderen met dementie in een verzorgingshuis (Van Linschoten et al., 1995). Uit ander onderzoek bleek dat de desbetreffende woonvorm zowel een negatieve als een positieve invloed had op de bewoners: zij hadden een hoger activiteitsniveau dan een vergelijkbare groep ouderen met dementie in een verpleeghuis, maar tegelijkertijd namen ook de gedragsproblemen toe (Ludwig, 1997). Deze resultaten vormden de aanleiding voor de start van een landelijk wetenschappelijk onderzoek naar de effecten van kleinschalig wonen voor ouderen met dementie door het Trimbos-instituut en het Vrije Universiteit medisch centrum. Tijdens de voorbereiding van dit onderzoek werd al snel duidelijk dat er geen eenduidige afbakening bestond van het concept kleinschaligheid. Dat blijkt ook uit de gegevens uit de databank van Aedes-Arcares (geciteerd op 8 augustus 2003). Hoewel alle projecten zich

scharen onder de noemer kleinschalig wonen, worden zij vooral gekenmerkt door een enorme verscheidenheid. Eén zo'n opvallend verschil is de groeps grootte: de meeste huizen hebben zes bewoners, maar het aantal bewoners kan variëren van vier tot acht bewoners. Een ander verschil betreft de locatie van de kleinschalige woonvormen: ongeveer 60% bevindt zich op het terrein van het verpleeghuis, terwijl de overige 40% tot meer dan vijf kilometer daarvan verwijderd is. Fahrenfort stelt vast dat de variatie in de immateriële kenmerken, zoals de financiële structuur of het personeelsbeleid, eveneens zeer groot is (Fahrenfort, 2003).

Er is al een aantal beschrijvingen van het concept kleinschalig wonen gegeven (Krijger, 2002). Het kenniscentrum Wonen-zorg van Aedes-Arcare hanteert bijvoorbeeld de volgende definitie: "We spreken van kleinschalig wonen als een kleine groep mensen, die intensieve zorg en ondersteuning nodig heeft, met elkaar in een groepswoning woont waardoor het voor hen mogelijk is een zo normaal mogelijk leven te leiden" (geciteerd op 26 augustus 2003). Deze en andere definities zijn te algemeen om het complexe begrip kleinschaligheid adequaat te beschrijven. Bovendien wordt niet duidelijk wat de *essentie* van kleinschalig wonen is. Welk ideaal streeft men er mee na? Gaat het primair om huiselijkheid? De geborgenheid van een kleine groep? Of wordt met een zo normaal mogelijk leven een leven bedoeld waarin de oudere met dementie nog zoveel mogelijk zelf kan doen? In dat geval zouden zelfredzaamheid en maatschappelijke participatie de leidende principes moeten zijn.

Kortom, het concept vereist een nauwkeurige omschrijving, zeker nu ondanks de hierboven beschreven onduidelijkheid kleinschalig wonen als nieuwe standaard voor de zorg voor ouderen met dementie wordt gepropageerd. Het doel van dit artikel is dan ook om de betekenis van het begrip kleinschalig wonen te verhelderen.

## **METHODE**

### **Concept Mapping**

Voor het definiëren van het begrip kleinschalig wonen voor ouderen met dementie is gebruik gemaakt van het Concept Mapping traject van Trochim (Trochim, 1989a, 1989b). Concept Mapping is een computerondersteunde methode die een groep mensen in staat stelt om binnen korte tijd een complex begrip te expliciteren. Deze methode wordt wereldwijd toegepast op zeer uiteenlopende onderwerpen (Trochim et al., 1994; Burke et al., 2005; Trochim et al., 2003). In Nederland zijn met behulp van Concept Mapping onder andere kwaliteitsaspecten van de acute psychiatrie (De Ridder et al., 1989) en het denken over de gezondheidszorg en omgaan met ziekte (Ketelaars et al., 1993) in kaart gebracht. De betrouwbaarheid van Concept Mapping kan als goed worden beschouwd (Trochim, 1993).

Concept Mapping is een bottom-up procedure met vijf opeenvolgende stappen: brainstormen, prioriteren, clusteren, verwerken en interpreteren. Deze stappen leiden de

deelnemers van concrete uitspraken naar meer abstracte concepten, die samen een goed beeld geven van de verschillende aspecten van het begrip en de samenhang daartussen.

### **Deelnemers**

Voor deze Concept Map werden in eerste instantie de pioniers van kleinschalig wonen in Nederland uitgenodigd: personen die nauw betrokken waren bij de opzet en begeleiding van de eerste kleinschalige woonvormen. Deze mensen werden benaderd via een aantal overlegorganen rondom kleinschaligheid, waarin zij participeerden. Via het sneeuwbaaleffect werden hieruit ook andere deskundigen geselecteerd, zodat uiteindelijk 22 personen op persoonlijke titel een uitnodiging ontvingen. Dat gebeurde per brief waarin ook een folder met informatie over Concept Mapping was bijgesloten. Zeventien personen gingen op de uitnodiging in en vormden de uiteindelijke deelnemersgroep. De drie sectoren die een belangrijke rol spelen bij de vormgeving van kleinschalig wonen, huisvesting, zorguitvoering, en zorgbeleid, waren in deze groep als volgt vertegenwoordigd:

- Huisvesting: 2 personen (beiden architect)
- Zorguitvoering: 12 personen (1 verpleegkundige, 1 verpleeghuisarts, 10 directeuren/managers van verpleeghuizen)
- Zorgbeleid: 3 personen (1 medewerker kenniscentrum, 1 medewerker landelijke koepelorganisatie, 1 directeur adviesbureau)

### **Procedure**

De Concept Map vond plaats op 5 oktober 2003 onder begeleiding van een onafhankelijke voorzitter, een medewerker van het Trimbos-instituut die zich gespecialiseerd heeft in deze methode.

In de eerste stap (*brainstorm*) werden de deelnemers uitgenodigd om associaties te vormen over het te definiëren onderwerp. Zij moesten daarvoor de volgende zin afmaken: 'we spreken pas van kleinschalig wonen als...'. Het was hen, zoals gebruikelijk bij brainstormen, niet toegestaan om met elkaar in discussie te gaan. Alle gedane uitspraken werden in de computer ingevoerd.

In de tweede stap (*prioritering*) moesten de deelnemers de uitspraken die tijdens de brainstorm gegenereerd waren, rangschikken op volgorde van belangrijkheid. Deze stap werd individueel uitgevoerd. Om te voorkomen dat de deelnemers alle uitspraken als even belangrijk waardeerden, moesten zij de uitspraken evenredig over vijf categorieën verdelen, lopend van minst belangrijk (score 1) tot meest belangrijk (score 5). De uitspraken werden op aparte kaartjes uitgereikt, zodat de deelnemers stapeltjes konden maken voor de verschillende categorieën.

In de derde stap (*clustering*) moesten de deelnemers de uitspraken bij elkaar voegen die naar hun mening inhoudelijk bij elkaar aansloten. Ook deze stap werd individueel uitgevoerd. Elke uitspraak mocht slechts één keer worden gebruikt maar het aantal clusters dat men kon creëren was vrij. Net als bij de vorige stap werd iedere uitspraak op een apart kaartje uitgedeeld, zodat de deelnemers stapeltjes konden maken voor de verschillende clusters.

In de vierde stap (*verwerking*) werden de individuele ordeningen uit de tweede en derde stap door een statistisch computerprogramma samengevoegd tot een groepsproduct. De resultaten van dit groepsproduct werden vervolgens via een meerdimensionale schaaltechniek weergegeven in een begrippenkaart, de concept map. Uitspraken die door de deelnemers bij het ordenen naar inhoud vaak bij elkaar geplaatst waren (de derde stap) werden op de landkaart dicht bij elkaar geprojecteerd. Uitspraken die op basis van inhoud zelden of nooit bij elkaar geplaatst waren, lagen op de landkaart ver van elkaar verwijderd. Met behulp van een hiërarchische clusteranalyse werden uitspraken die op de landkaart dicht bij elkaar lagen, in clusters van onderling samenhangende uitspraken samengevoegd. De keuze voor het exacte aantal clusters werd bepaald door de onderzoekers en de onafhankelijk voorzitter. Op basis van de prioriteiten die de deelnemers aan de uitspraken hadden toegekend (de tweede stap), werd vervolgens van elk cluster het gemiddelde belang berekend. Dit kwam grafisch tot uiting in hoogteverschillen tussen de clusters.

In de vijfde en laatste fase (*interpretatie*) werd de landkaart samen met de deelnemers geïnterpreteerd. De verschillende clusters werden benoemd en aan de prioriteiten van de clusters werden conclusies verbonden. Ook de assen van de landkaart kregen in deze stap een betekenis. De onderzoekers hebben de namen van de clusters na afloop van de Concept Map nog enigszins aangepast, maar hun oorspronkelijke betekenis is daarbij behouden gebleven.

## **RESULTATEN**

### **Brainstorm en prioritering**

De zin “we spreken pas van kleinschalig wonen als...” werd door de deelnemers 91 maal afgemaakt. Een overzicht van deze uitspraken, onderverdeeld in de clusters, is te vinden in Bijlage 1. De tien uitspraken waar de deelnemers de hoogste prioriteit aan gaven staan in tabel 1. De belangrijkste uitspraak luidt dat er pas sprake van kleinschalig wonen is als “er een vast team medewerkers is”.

De 10 belangrijkste uitspraken hebben alle betrekking op de organisatie van het dagelijks leven; fysieke kenmerken van de woonvorm, zoals groepsgrootte en huisvesting, werden niet hoog geprioriteerd. De afwezigheid van een uitspraak over de ideale groepsgrootte in de top tien kan echter ook worden verklaard doordat de deelnemers tijdens de brainstorm niet één, maar twee uitspraken deden over de groepsgrootte: zij noemden zowel een maximum van zes

als van negen bewoners. Tijdens de prioritering bleek de groep vervolgens verdeeld over het belang van elke uitspraak, waardoor uiteindelijk geen van beide een hoge prioriteit kreeg.

**Tabel 1. De tien belangrijkste uitspraken (gemiddelde prioriteit en standaarddeviatie)**

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We spreken pas van kleinschalig wonen als..	
<hr/>	
1.	er sprake is van een vast team medewerkers (4.67; .36)
2.	er zelf gekookt wordt (4.56; .62)
3.	je kunt opstaan, naar het toilet gaan en naar bed gaan wanneer je zelf wilt (4.50; .50)
4.	je er mag blijven tot aan de dood (4.50; .50)
5.	de inrichting van de woning van jezelf is (4.31; .84)
6.	bewoners, familie en team samen de dagelijkse gang van zaken bepalen (4.31; .71)
7.	personeel niet in uniform loopt (4.19; 1.03)
8.	er een visie aan ten grondslag ligt die uitgaat van de behoeften van mensen met dementie (4.13; 1.73)
9.	de zorgorganisatie analoog is aan een huishouden (4.13; .98)
10.	je een team hebt/kunt maken dat competent is een huiselijke sfeer te creëren (4.06; 1.43)

---

### **Interpretatie van de clusters**

In de clusteranalyse bleek een aantal van zeven clusters de meest bruikbare begrippenkaart op te leveren (zie figuur 1 en Bijlage 1). Het zevende cluster bevatte slechts twee uitspraken, waarvoor de deelnemers geen gemeenschappelijke noemer konden vinden. Dit cluster laten we dan ook verder buiten beschouwing. Het resultaat van de clusteranalyse is afgebeeld in figuur 1. De clusters staan hieronder beschreven in volgorde van belangrijkheid (gemiddelde prioriteit):

#### **1. Een bewoner blijft in voor- en tegenspoed een bewoner (3.6)**

Dit cluster bestaat uit vier uitspraken en kreeg van de deelnemersgroep gemiddeld de hoogste prioriteit. De uitspraken in dit cluster hebben betrekking op het gevoel van 'ergens thuis zijn' of 'op je plek zijn', ook als het om wat voor reden dan ook slechter met de bewoner gaat. De belangrijkste uitspraak in het cluster is hier het beste voorbeeld van: er is pas sprake van kleinschalig wonen als de bewoner mag blijven tot aan de dood. Deze uitspraak hoort tevens tot de tien belangrijkste uitspraken van de begrippenkaart.

**2. Er wordt een gewoon huishouden gevoerd (3.2)**

Dit cluster bevat zes uitspraken, die alle gaan over het leven in een zo normaal mogelijk huishouden. De bewoners horen dus rechten en plichten te hebben die ook in een gewoon huishouden gelden, zoals het kunnen ontvangen van bezoekers in de eigen kamer maar ook het deelnemen aan de gemeenschappelijke maaltijd. De belangrijkste uitspraak in dit cluster is dat er pas sprake is van kleinschalig wonen als er zelf gekookt wordt. Ook deze uitspraak staat in de top-tien van hoogst geprioriteerde uitspraken.

**3. De bewoner heeft regie over de inrichting van zijn dagelijks leven (3.1)**

Dit cluster heeft 21 uitspraken en beschrijft allerlei vormen van zelfbepaling en keuzevrijheid die de bewoner moet hebben bij de dagelijkse gang van zaken. Dit varieert van zaken als het kunnen kiezen van een eigen kapper tot het voeren van een eigen budget en het mogen ruzie maken met andere bewoners. Kortom, dit cluster gaat over baas-zijn in eigen huis en leven. De belangrijkste uitspraak is dat er pas sprake is van kleinschalig wonen als de bewoner opstaat, naar het toilet gaat en naar bed gaat wanneer hij/zij dat zelf wil. Deze uitspraak hoort samen met de uitspraak dat bewoners, familie en team samen de dagelijkse gang van zaken bepalen, bij de tien belangrijkste uitspraken.

**4. Het personeel is onderdeel van het huishouden (3.1)**

Dit cluster bestaat uit 22 uitspraken, die alle te maken hebben met de organisatie van de zorg in een kleinschalige woonvorm. Hierbij geldt de mening dat de zorg zoveel mogelijk geïntegreerd moet worden in het dagelijks leven van de bewoners en bovendien moet plaatsvinden in de sfeer van een normaal huishouden. Dit heeft allerlei gevolgen voor de houding en de taken van het personeel. Zo wordt van de verzorgenden verwacht dat zij een huiselijk sfeer creëren en dat zij het levensverhaal van de bewoners goed kennen, maar ook dat zij de huishoudelijke taken op zich nemen. In tegenstelling tot het verzorgend personeel moeten medici en paramedici zich juist terugtrekken uit het dagelijks leven van de bewoners: de verpleeghuisarts moet fungeren als een huisarts en er hoort geen aparte activiteitenbegeleiding te zijn. De uitspraak met de hoogste prioriteit in dit cluster is dat er pas sprake is van kleinschalig wonen als er een vast team medewerkers is. Dit is tevens de belangrijkste uitspraak van de begrippenkaart. Naast deze uitspraak behoren nog vier andere uitspraken van dit cluster bij de tien belangrijkste uitspraken, het hoogste aantal van alle zes clusters. Omdat dit cluster echter ook een aantal uitspraken bevat met een lage waardering, kreeg het als geheel niet een hoge prioriteit.



**5. Bewoners vormen met elkaar een groep (3.0)**

Dit cluster bevat 17 uitspraken, die net als de uitspraken van het vierde cluster te maken hebben met de praktische organisatie van een kleinschalige woonvorm. Terwijl in het vierde cluster het personeel centraal staat, wordt in dit cluster de rol van bewoners en de familie beschreven. Cruciaal hierbij is dat de bewoners wonen en leven als een gezin waarin hun familie altijd welkom is. Het moet familieleden dan ook toegestaan zijn om mee te eten, te overnachten en te helpen in de zorg. De belangrijkste uitspraak in dit cluster is dat er pas sprake is van kleinschalig wonen als er geen bezoektijden zijn. Opvallend is dat deze uitspraak, evenals andere uitspraken van dit cluster, niet terug te vinden is bij de tien hoogst geprioriteerde uitspraken. Misschien heeft de eerder genoemde onenigheid over de groeps grootte hierin ook een rol gespeeld: de uitspraken over de verschillende groeps groottes horen alle in dit cluster thuis.

**6. Een kleinschalige woonvorm is gevestigd in het archetype huis (2.8)**

Dit cluster met 19 uitspraken beschrijft de omgeving en inrichting van kleinschalige woonvormen, waarbij geldt dat deze zoveel mogelijk gelijk moeten zijn aan die van een gewoon huis. Zo hoort een kleinschalige woonvorm in een woonwijk te liggen, een voordeur aan de straat te hebben en herkenbaar te zijn als huis. Ook binnenshuis moet de kleinschalige woonvorm worden ingericht als een gewoon huis met een kapstok in de gang, een wasmachine en maar één eettafel in de kamer. De belangrijkste uitspraak in dit cluster is dat er pas sprake is van kleinschalig wonen als de inrichting van de woning van jezelf is. Deze uitspraak is terug te vinden bij de tien belangrijkste uitspraken van de begrippenkaart.

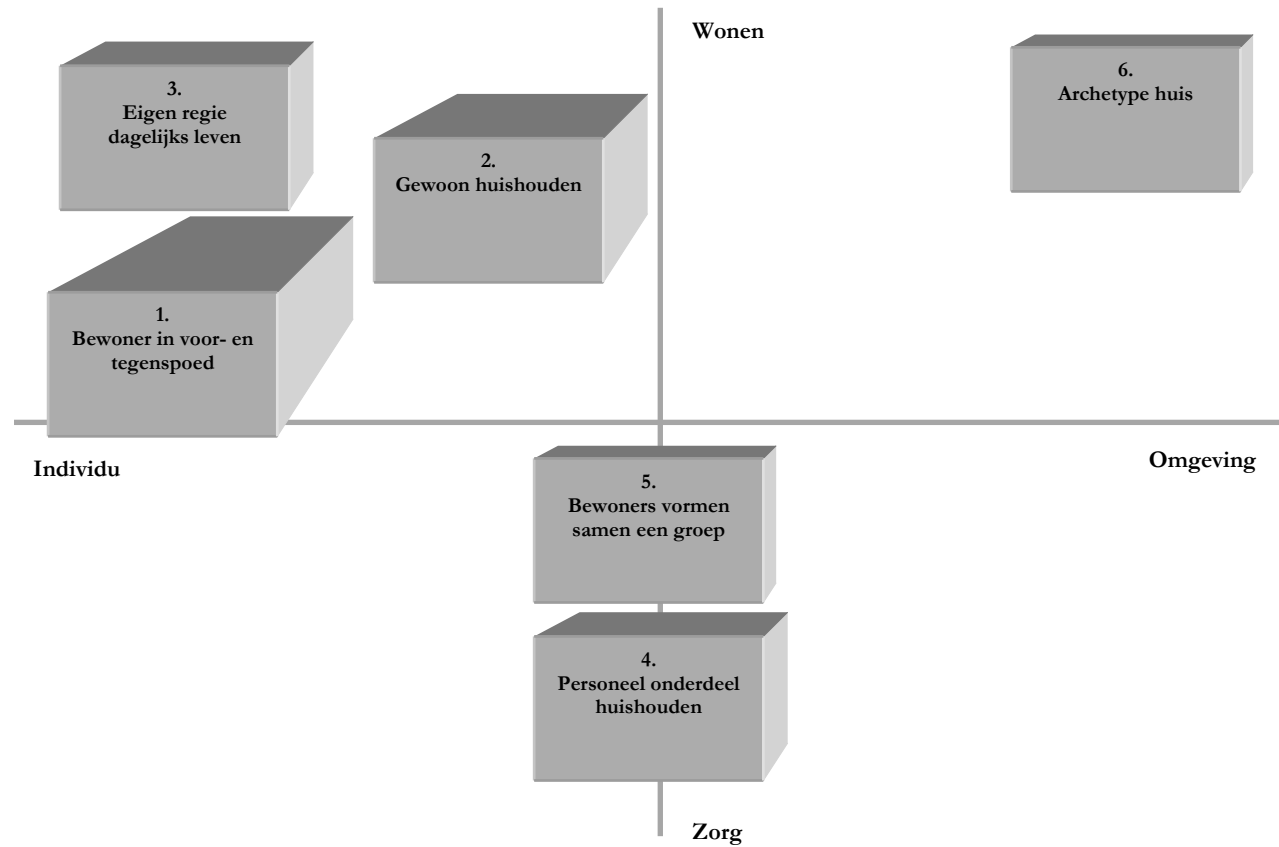
**Interpretatie van de assen**

In figuur 1 is met behulp van Bijlage 1 te zien dat aan de linkerzijde van de y-as (verticale as) uitspraken over de individuele bewoner staan, terwijl aan de rechterzijde van de y-as uitspraken over de omgeving afgebeeld zijn. Boven de x-as (horizontale as) zijn voornamelijk uitspraken over het wonen te vinden, terwijl onder de x-as de uitspraken over de zorg staan. De deelnemers werden het er dan ook over eens dat de x-as het continuüm tussen het individu en zijn omgeving vormt, terwijl de y-as het continuüm tussen wonen en zorg representeert. In deze begrippenkaart wordt kleinschalig wonen dus getypeerd door de dimensies individu-omgeving en wonen-zorg.

De clusters zijn niet evenredig verdeeld over deze dimensies. De clusters in de dimensie wonen (boven de x-as) liggen verspreid op de dimensie individu-omgeving. Met andere woorden, uitspraken over het wonen in een kleinschalige woonvorm hebben zowel betrekking

op de individuele bewoner als op zijn/haar omgeving. Bij de twee clusters in de dimensie zorg (onder de x-as) bestaat deze onderverdeling niet: zij blijven gecentreerd rond de dimensie zorg. Een mogelijke verklaring hiervoor is dat de verdeling van zorg over de dimensie individu en omgeving niet betekenisvol is omdat zorg altijd bestaat uit een interactie tussen het individu en zijn/haar omgeving.

Figuur 1. Begrippenkaart met interpretaties van clusters en assen



## **CONCLUSIE**

Met behulp van de methode Concept Mapping is de onderstaande verheldering van het begrip kleinschalig wonen voor ouderen met dementie tot stand gekomen. Er is pas sprake van kleinschalig wonen als:

1. een bewoner in voor- en tegenspoed een bewoner blijft;
2. er een gewoon huishouden gevoerd wordt;
3. de bewoner regie over de inrichting van zijn dagelijks leven heeft;
4. het personeel onderdeel van het huishouden is;
5. de bewoners met elkaar een groep vormen;
6. een kleinschalige woonvorm in het archetype huis is gevestigd.

Op grond van hun ligging op de kaart zouden we deze zes dimensies van kleinschalig wonen ook kunnen samenvatten tot drie thema's die bepalend zijn voor kleinschalig wonen. Het eerste thema betreft de fysieke kenmerken van kleinschalig wonen en bestaat alleen uit het zesde cluster (woonvorm is archetype huis). Het tweede thema gaat over het gezamenlijke leven van de bewoners en personeel in kleinschalig wonen en bevat het tweede (gewoon huishouden), vierde (personeel onderdeel huishouden) en vijfde cluster (bewoners vormen een groep). Het derde thema betreft het individuele leven van de bewoners in kleinschalig wonen en bevat het eerste (bewoner in voor- en tegenspoed) en het derde cluster (regie over dagelijks leven).

## **DISCUSSIE**

De drie bovengenoemde overkoepelende thema's leiden tot een aantal interessante gevolgtrekkingen. Zo geeft de lage prioriteit van het eerste thema over de fysieke kenmerken aan dat een kleinschalige woonvorm niet per se een archetypisch huis hoeft te zijn. Dit sluit goed aan bij de resultaten van een studie, waarin onderzocht werd of de tien belangrijkste uitspraken van deze Concept Map aansloten bij de dagelijkse praktijk van kleinschalig wonen (Van der Wel & Van Ijperen, 2005). Hoewel het een klein onderzoek betrof, gaven de uitkomsten aan dat de mate van kleinschaligheid van een project inderdaad niet zozeer bepaald werd door fysieke omgeving en de inrichting van de woning, maar vooral door de inrichting van de zorgverlening. Toch betekent dat waarschijnlijk niet dat kleinschalige woonvormen helemaal niet aan de kenmerken van een gewoon huis hoeven te voldoen: de juiste fysieke omgeving is mogelijk een zeer belangrijke scheppende voorwaarde voor het verlenen van kleinschalige zorg. De fysieke omgeving raakt naar de mening van de deelnemers van deze Concept Map echter niet aan de essentie van kleinschalig wonen.

Deze essentie moet gezocht worden in de twee andere thema's in deze Concept Map die kleinschalig wonen karakteriseren. Het feit dat er zoveel belang wordt gehecht aan het

gezamenlijke leven van bewoners, familieleden en verzorgenden (tweede thema) impliceert dat kleinschalig wonen breekt met het medisch model waarin het personeel zich buiten het dagelijks leven van de bewoners plaatst. Kleinschalig wonen staat inderdaad voor ‘zo normaal mogelijk’ uit de definitie van Aedes-Arcare, in de zin dat er geen scheiding wordt aangebracht tussen zorg en huishouding, tussen zorg en dagelijks leven, oftewel tussen het dagelijks leven van de verzorgenden en dat van de bewoners. Een consequentie van deze verschuiving is dat de gespecialiseerde (para)medische disciplines uit de dagelijkse routine moeten verdwijnen, terwijl verzorgenden juist daarin moeten worden opgenomen. Zij zijn er niet alleen om voor de bewoners te zorgen, maar om samen met de bewoners en hun familieleden het dagelijks leven ‘te leven’. Dit is overigens geen gemakkelijke opgave: verschillende uitspraken op de begrippenkaart tonen aan dat verzorgenden over specifieke vaardigheden moeten beschikken om in kleinschalig wonen te werken. Ander onderzoek laat zien dat kleinschalig wonen vooral hoge eisen stelt aan de communicatieve vaardigheden van verzorgenden (Royers, 2005). Omdat zij het grootste gedeelte van de tijd alleen met de bewoners zijn, moeten zij aan collega’s, maar vooral aan familie goed gestructureerde inhoudelijke informatie geven over de geboden zorg.

Het belang van het tweede thema over het gezamenlijk leven van verzorgenden, bewoners en familieleden blijkt ook uit de tien hoogst geprioriteerde uitspraken. Maar liefst zes van de tien uitspraken horen bij dit thema. Vijf daarvan zijn terug te vinden in het vierde cluster, dat de rol van het personeel in kleinschalig wonen beschrijft. In dit cluster hoort ook de belangrijkste uitspraak van de begrippenkaart thuis: er is pas sprake van kleinschalig wonen *als er een vast team medewerkers is*. Deze uitspraak wekt enige verbazing, omdat op een traditionele verpleeghuisafdeling ook een vast team verzorgenden werkt. Mogelijk moeten we deze uitspraak daarom interpreteren als dat kleinschalig wonen primair betekent dat de bewoners door *een klein team* medewerkers worden begeleid. Terwijl de discussie rondom kleinschalig wonen vooral gefocust was op het aantal bewoners in een groep, is het aantal verzorgenden wellicht hetgeen waar het om draait. Misschien is dat wel de belangrijkste kernwaarde van kleinschalig wonen: dat de bewoners (en hun familieleden) zich gekend voelen en zich daardoor veilig weten.

Het feit dat de deelnemers ook veel belang hechten aan het individuele leven van de bewoners (derde thema) betekent dat men met kleinschalig wonen beter tegemoet wil komen aan individuele behoeften van de bewoners. Bij deze dimensie van kleinschalig wonen ligt het accent daarmee op het eerste woord van het begrip. Door de zorg op kleine schaal aan te bieden kan de mens maatgevend zijn in plaats van de organisatie. Door de zorg op kleine schaal aan te bieden kan er meer ruimte zijn voor de persoon van de bewoner; voor zijn

wensen, voor zijn voor- en afkeuren, voor zijn verhaal. Een ‘zo normaal mogelijk leven’ (definitie van Aedes-Arcare) betekent dus ook een leven naar je eigen normen.

Resumerend heeft de Concept Map duidelijk gemaakt dat volgens de deelnemers bij kleinschalig wonen twee verschuivingen ten opzichte van de traditionele verpleeghuiszorg moeten worden gerealiseerd: 1. van een medisch model naar een woon-model; 2. van grootschalige zorg naar kleinschalige zorg. Bij de keuze voor kleinschalig wonen moet men een visie ontwikkelen op deze twee dimensies. Hoe breng ik de zorg onder het primaat van het wonen? En hoe borg ik de menselijke maat? Hoe zorg ik er met andere woorden voor dat de noden van een efficiënte organisatie niet die van de bewoners en hun familie gaan overheersen?

Met het slechten van het spanningsveld tussen de organisatie en het individu treedt er in de kleinschalige woonvormen mogelijk een nieuw spanningsveld naar voren: tussen de groep en het individu. Door zo duidelijk het gezamenlijke leven én het individuele leven van de bewoners te thematiseren hebben de deelnemers aan de Concept Map duidelijk gemaakt dat de verzorgenden voor de lastige opgave staan beider belangen met elkaar te verzoenen. Mogelijk gaat het zelfs om deels botsende idealen. Inherent aan het kleinschalige model is de relatief beperkte ruimte van een normale woning, waardoor bewoners weinig gelegenheid hebben om alleen te zijn of elkaar te ontlopen. Eénpersoonskamers waar de bewoner zich desgewenst aan het groepsleven kan onttrekken lijken daarom gewenst. Bovendien zouden er kleinschalige woonvormen met verschillende leefstijlen ontwikkeld kunnen worden, waarin mensen met dezelfde achtergrond met elkaar samenleven. Het is goed voor te stellen dat het leven in een kleine groep daardoor wordt veraangenaamd. Verder zou men op dit punt ook naar differentiatie kunnen streven: kleinschalige woonvormen waarin relatief veel in het groepsleven wordt geïnvesteerd, en huizen waarin de eigen regie op de voorgrond staat.

Tot slot een paar kanttekeningen. Om tot een verheldering van het begrip kleinschalig wonen te komen formuleerde een geselecteerde groep deelnemers opinies over kleinschalig wonen. De nadruk ligt daarbij ten eerste op *opinies*. Het gaat dus om idealen en niet om een weergave van de werkelijke gang van zaken in kleinschalige woonvormen. Een treffend voorbeeld hiervan is het hoogst geprioriteerde cluster “een bewoner blijft in voor- en tegenspoed een bewoner”. De deelnemers geven met dit cluster aan dat zij vinden dat alle ouderen met dementie welkom moeten zijn in kleinschalig wonen en dat zij daar ook mogen blijven tot aan hun dood. Gezien de opname- en overplaatsingscriteria van een groot aantal kleinschalige woonvormen<sup>5</sup> lijkt dit in de praktijk niet altijd toegepast te worden. Het Trimbos-instituut en het VUmc voeren momenteel vervolgonderzoek uit om de praktijk van kleinschalig wonen in Nederland te toetsen aan de resultaten van deze Concept Map.

De tweede kanttekening betreft de *geselecteerde groep deelnemers*. Hoewel de methodiek van Concept Mapping waarborgt dat concrete persoonlijke uitspraken opgaan in meer abstracte algemene clusters, blijft het een feit dat de begrippenkaart vormgegeven wordt door de meningen van de deelnemersgroep. De achtergrond van de panelleden kleurt dus de resultaten. De deelnemers aan deze Concept Map waren voor het overgrote deel de pioniers van kleinschalig wonen in Nederland. Hun unieke combinatie van idealisme van het eerste uur en uitgebreide ervaringskennis heeft uiteindelijk de begrippenkaart vormgegeven. Wij willen daarom niet beweren dat de resultaten van deze Concept Map een volledige, algemeen geldende verheldering geven van het begrip kleinschalig wonen. De selectie van de deelnemers kan ervoor gezorgd hebben dat bepaalde aspecten niet voldoende aandacht hebben gekregen, of zelfs ontbreken. Een herhaling van de Concept Map met een totaal andere deelnemersgroep, zoals verzorgenden of familieleden van ouderen met dementie, is dan ook ten zeerste aan te bevelen.

<sup>a</sup> De meest recente cijfers over kleinschalig wonen staan op pagina 6 van dit proefschrift.

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## **Bijlage 1. Clusters met bijbehorende uitspraken**

### **Cluster 1. Een bewoner blijft in voor- en tegenspoed een bewoner (gem. prioriteit 3.59)**

Er is pas sprake van kleinschalig wonen als... (gem. prioriteit, standaarddeviatie)

1. ... je er mag blijven tot aan de dood (4.50, .50)
2. ... je het gevoel hebt dat je thuis bent (3.88, 1.98)
3. ... er na overlijden mogelijkheid is tot opbaren (3.06, 1.31)
4. ... elke vorm van externe dwang ontbreekt (2.94, 1.93)

### **Cluster 2. Er wordt een gewoon huishouden gevoerd (gem. prioriteit 3.22)**

Er is pas sprake van kleinschalig wonen als... (gem. prioriteit, standaarddeviatie)

1. ... er zelf gekookt wordt (4.56, .62)
2. ... er in principe sprake is van gemeenschappelijk eten (3.56, 1.25)
3. ... je veilig en onbegeleid het huis in en uit kan (3.44, 1.87)
4. ... familie in de eigen kamer ontvangen kan worden (3.13, 1.11)
5. ... de tafel gedekt wordt (2.38, 1.61)
6. ... je je eigen linnengoed gebruikt (2.25, 1.31)

### **Cluster 3. De bewoner heeft de regie over de inrichting van zijn dagelijks leven (gem. prioriteit 3.09)**

Er is pas sprake van kleinschalig wonen als... (gem. prioriteit, standaarddeviatie)

1. ... je kunt opstaan, naar het toilet gaan en naar bed gaan wanneer je dat zelf wilt (4.50, .50)
2. ... bewoners, familie en team samen de dagelijkse gang van zaken bepaalt (4.31, .71)
3. ... je je eigen budget hebt (4.00, 1.25)
4. ... je mag eten en drinken wat je wil (3.81, 1.15)
5. ... je je eigen huisdier mag meenemen (3.75, 1.44)
6. ... je eigen boodschappen kunt doen (3.63, 1.36)
7. ... je ten alle tijden naar je eigen kamer mag (3.38, .98)
8. ... je de baas bent in huis (3.25, 2.06)
9. ... je niet mee hoeft te doen (3.19, 1.40)
10. ... je kunt kiezen wat je gemeenschappelijk doet en alleen (3.07, 1.40)
11. ... er heel veel ruimte is voor persoonlijke hobby's en liefhebberijen (2.88, 1.86)
12. ... je je eigen tandenborstel in de badkamer kunt zetten (2.75, 1.44)
13. ... er keuzemogelijkheid is met wie je wilt wonen (2.69, 1.71)
14. ... je je eigen kapper kunt kiezen (2.69, .84)
15. ... per woning bepaald wordt of er huisdieren aanwezig zijn (2.50, 1.13)
16. ... er keuze is over wel of niet de naam op de voordeur (2.50, .88)
17. ... je ruzie mag maken met je medebewoners (2.50, 1.00)
18. ... je zelf de dokter kunt bellen (2.50, .75)
19. ... per woning bepaald wordt of er gerookt mag worden (2.38, 1.48)

20. ... je zelf de temperatuur kunt regelen (2.31, 1.59)
21. ... je 's nachts de koelkast kunt plunderen (2.31, 1.59)

**Cluster 4. Het personeel is onderdeel van het huishouden (gem. prioriteit 3.09)**

Er is pas sprake van kleinschalig wonen als... (gem. prioriteit, standaarddeviatie)

1. ... er sprake is van een vast team medewerkers (4.67, .36)
2. ... personeel niet in uniform loopt (4.19, 1.03)
3. ... er een visie aan ten grondslag ligt die uitgaat van de behoefte van mensen met dementie (4.13, 1.73)
4. ... de zorgorganisatie analoog is aan een huishouden (4.13, .98)
5. ... je een team hebt/kunt maken dat competent is een huiselijke sfeer te creëren (4.06, 1.43)
6. ... er geen arbeidsdifferentiatie is (3.69, 1.84)
7. ... medewerkers het levensverhaal van de bewoners goed kennen (3.69, 1.34)
8. ... de zorg niet centraal staat (3.63, 1.86)
9. ... verpleeghuiszorg is gegarandeerd (3.50, 1.88)
10. ... medewerkers specifiek worden opgeleid voor het zorgen in deze specifieke woonvorm (3.50, 1.88)
11. ... medewerkers worden aangesteld op basis van vaardigheden en niet op basis van diploma's (3.19, 1.90)
12. ... de visie bewaakt wordt (3.13, 2.11)
13. ... er zo optimaal mogelijk wordt ondersteund in wat de bewoner nog kan (3.06, 1.81)
14. ... er geen aparte activiteitenbegeleiding is (2.75, 1.06)
15. ... het personeel deel uitmaakt van het gezin (2.50, 1.63)
16. ... de huisarts weer huisarts is (2.44, 1.12)
17. ... vertroetelen mag (2.44, .62)
18. ... vrijwilligers geen vrijwilliger zijn maar vrienden (2.38, 1.73)
19. ... er 's avonds en 's ochtends evenveel personeel is als op de dag (1.94, 1.06)
20. ... het personeel eigen kinderen mee mag nemen (1.94, 1.68)
21. ... de dokter verder kijkt dan de kwaal (1.75, .69)
22. ... we spreken van een ontwikkelingsmodel (1.38, .36)

**Cluster 5. Bewoners vormen met elkaar een groep (gem. prioriteit 3.03)**

Er is pas sprake van kleinschalig wonen als... (gem. prioriteit, standaarddeviatie)

1. ... er geen bezoektijden zijn (3.94, 1.31)
2. ... de woonvorm lijkt op een gezinssituatie (3.81, 1.65)
3. ... de familie mee kan eten en mee kan helpen in de zorg (3.56, 1.62)
4. ... je met minder dan negen personen samenwoont (3.50, 2.63)
5. ... er geen groepen samengevoegd worden (3.44, 1.62)
6. ... familie niet het gevoel heeft op bezoek te komen (3.38, 1.73)
7. ... er sprake is van groepswonen (3.38, 1.73)

8. ... bewoners participeren in de huishouding (3.38, 1.86)
9. ... een familielid zegt moeder is weer thuis (3.25, 1.56)
10. ... het ziektebeeld niet bepalend is voor de woonvorm (3.00, 1.38)
11. ... je met niet meer dan zes mensen samenwoont (2.88, 2.48)
12. ... de woonvorm een gezinssituatie is (2.75, 1.81)
13. ... er geen externe kwaliteitseisen gelden (2.73, 2.06)
14. ... de keuringsdienst van waren niet op bezoek komt (2.38, 1.86)
15. ... alle protocollen in de open haard zijn gegoooid (2.13, 1.23)
16. ... familie kan overnachten (2.06, 1.06)
17. ... de wederzijdse familie betrekkingen met elkaar aangaan (1.88, .86)

**Cluster 6. Een kleinschalige woonvorm is gevestigd in een archetype huis (gem. prioriteit 2.79)**

Er is pas sprake van kleinschalig wonen als... (gem. prioriteit, standaarddeviatie)

1. ... de inrichting van de woning van jezelf is (4.31, .84)
2. ... de woning voldoet aan het archetype huis (brievenbus, telefoonrekening) (4.00, 1.63)
3. ... de woning herkenbaar is als een huis (3.69, 2.21)
4. ... er geen gescheiden ruimten zijn voor personeel en bewoners (3.44, 2.00)
5. ... je in een gedifferentieerde woonomgeving woont (woonwijk) (3.25, 1.94)
6. ... je de huiskamer binnenkomt (en niet bij de receptie) (3.13, 1.73)
7. ... er voor de voordeur ook een straat is (2.88, 1.36)
8. ... er een wasmachine aanwezig is (2.81, 1.28)
9. ... de voordeur normaal gesproken dicht zit (2.81, 1.40)
10. ... er een kapstok in de gang is (2.75, 1.56)
11. ... er geen tussendeur is tussen de woningen (2.75, 2.44)
12. ... er maar één eettafel in de kamer staat (2.69, 1.46)
13. ... er een tuin is (2.63, 1.98)
14. ... er burens zijn (2.63, .86)
15. ... er niet voor iedereen een aparte badkamer is (2.56, 2.00)
16. ... de klink bij de achterdeur staat (1.94, .56)
17. ... er een meterkast in de gang is (1.81, 1.40)
18. ... je in je eigen appartement woont (1.38, .98)
19. ... elke bewoner een eigen badkamer heeft (1.38, .98)

**Cluster 7. .... (gem. prioriteit 1.72)**

Er is pas sprake van kleinschalig wonen als... (gem. prioriteit, standaarddeviatie)

1. ... je als initiatiefnemer zelf het programma van eisen kunt vaststellen (2.00, 1.38)
2. ... er geen rechtstreekse lijn naar de brandweer is (1.44, .62)

# 3

## **THE IDEALS OF GROUP LIVING HOMES FOR OLDER PEOPLE WITH DEMENTIA:**

### **ARE THEY FOR REAL?**

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**Submitted as:**

Te Boekhorst, S., Depla, M.F.I.A., Pot, A.M., De Lange, J. & Eefsting, J.A. The ideals of group living homes for older people with dementia: are they for real?

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## **ABSTRACT**

### **Purpose of the study**

To investigate whether group living homes practice the ideals of group living home care and by doing so distinguish themselves from modern traditional nursing homes.

### **Design and Methods**

An exploratory questionnaire based on a Concept Map used to define the ideals of group living home care, was filled by managers of 17 group living homes and 16 wards of traditional nursing homes.

### **Results**

Group living homes scored significantly higher on the subscales 'normal household', 'autonomy in daily life', 'staff part of group' and 'residents form a group'. However, group living homes scored significantly lower on the most important subscale of the Concept Map: 'resident for better or worse'. They also scored lower on the most important statement of the Concept Map which states that each unit of a group living home needs to have a fixed staff.

### **Implications**

Group living homes follow the ideals of the Concept Map to a reasonable degree, but in order to fulfil the core ideals of group living home care, they need to offer residents a permanent home and only familiar faces to care for them.

## **INTRODUCTION**

In the Netherlands as well as in other countries, nursing home care has been traditionally modeled on hospital care. However, in the last decades of the 20<sup>th</sup> century, realization grew that, unlike hospitals, nursing homes needed to serve as literal *homes* where people lived out their lives. A hospital-like setting, with its long corridors and bedrooms for multiple residents, was found to be particularly unsuited for people with dementia, who have unique needs such a sense of security and easy orientation (Hammer, 1999).

As a consequence, the concept of group living home care for older people with dementia arose. It was originally developed in Sweden. According to Annerstedt (1997), the first Swedish group living homes were created in the late 1970s and early 1980s. Following governmental subsidizing, group living homes emerged all over the country in the 1990s and in 1997, approximately 14,000 people lived in group living homes. In 2002, this number had risen to 18,000, corresponding to approximately 14% of the Swedish population with dementia (Faxén-Irving et al., 2002).

Along with other countries such as Great Britain (Lindesay et al., 1992), France (Ritchie et al., 1992) and Japan (Funaki et al., 2005), the Netherlands followed the Swedish example. The first Dutch group living homes were created in the early and mid 1980s. Its popularity increased steadily after that, but the real growth occurred in the last years of the 20<sup>th</sup> century. Nowadays (2009), the Netherlands have 414 group living homes and 34 more will be built in the coming two years (kenniscentrum Wonen-Zorg, 2009). It is estimated that more than 12,000 people with dementia will be living in group living home care in 2010. This corresponds to almost 25% of the nursing home population on a psychogeriatric ward. Moreover, it is an increase of 178% compared to 2005, when there were little over 4,000 people living in group living home care (Van Waarde & Wijntjes, 2007).

### ***Definitions of group living home care***

Although matters such as a homely environment, a small group of residents and a normal daily life are generally associated with the concept of group living home care, there are few actual definitions. Annerstedt (1997) describes Swedish group living according to Lawton's (1980) four of the five environmental dimensions. In group living home care, the *personal environment* dimension is conceptualized by the collaboration in care and care planning of significant others such as family and friends. In the dimension *group environment*, group living home care needs staff who are trained and supervised in the treatment of people with dementia and a homogenous group of residents. According to Annerstedt, this homogeneity is achieved by selecting 8-9 residents of a certain age, type and level of dementia. Only people with late onset dementia of the Alzheimer type, vascular dementia or a combination of these two are admitted. Residents also need to be able to communicate meaningfully on admittance and to get out of

bed by themselves. This mostly corresponds with moderately to moderately-severe dementia. Group living in Sweden is therefore intended for people with dementia between home care and institutional care (Hägström & Norberg, 1996). Lawton's third dimension, the *social environment*, is conceptualized in group living home care by normalizing daily life according to the resident's cultural values and traditions, with common contrasts such as weekday-holiday and day-night. The dimension *physical environment* in Swedish group living home care is designed to be well-known, homelike, small and safe.

Another, more formal way to define a complex concept such as group living home care is the Concept Mapping method (Trochim, 1989). Concept Mapping is a structured conceptualization process in which a group of people create a Concept Map in five consecutive steps: brainstorming, prioritizing, clustering, computation and interpretation. A Concept Map is 'a pictorial representation of the group's thinking which displays all of the ideas of the group relative to the topic at hand, shows how these ideas are related to each other and, optionally, shows which ideas are more relevant, important, or appropriate' (Trochim, 1989). In the Netherlands, the Concept Mapping method was used to define group living home care (Te Boekhorst et al., 2007). The participants were almost all pioneers of Dutch group living home care, such as managers, architects and nursing home physicians. The ten most important statements they generated during the brainstorm are presented in table 1. Clustering, prioritizing and subsequent interpretation led to the Concept Map, shown in figure 1. The six clusters depicted on Concept Map are (ranked according to priority):

1. Residents of group living home care are residents for better or worse
2. In group living home care residents form a normal household
3. In group living home care residents have control over their daily life
4. In group living home care staff is part of the group
5. In group living home care residents form a group
6. A group living home is built as an archetypical house

The outcomes of this Concept Mapping to describe group living home care thus show that group living home care is not so much determined by the physical environment but by the features of the care organization.



**Table 1. The ten most important statements of the Concept Map defining group living home care**

<b>One truly speaks of group living if ...</b>	
1.	... it has a fixed staff
2.	... staff and residents prepare meals themselves
3.	... residents can get out of bed, go to the toilet and go to bed whenever they want
4.	... residents are allowed to stay until death
5.	... the furniture and decoration belongs to the residents
6.	... residents, family and staff together decide the daily course of events
7.	... staff does not wear a uniform
8.	... there is a care vision which originates from the needs of people with dementia
9.	... care planning resembles a household routine
10.	... staff are able to create a homely atmosphere

### ***Ideals or reality?***

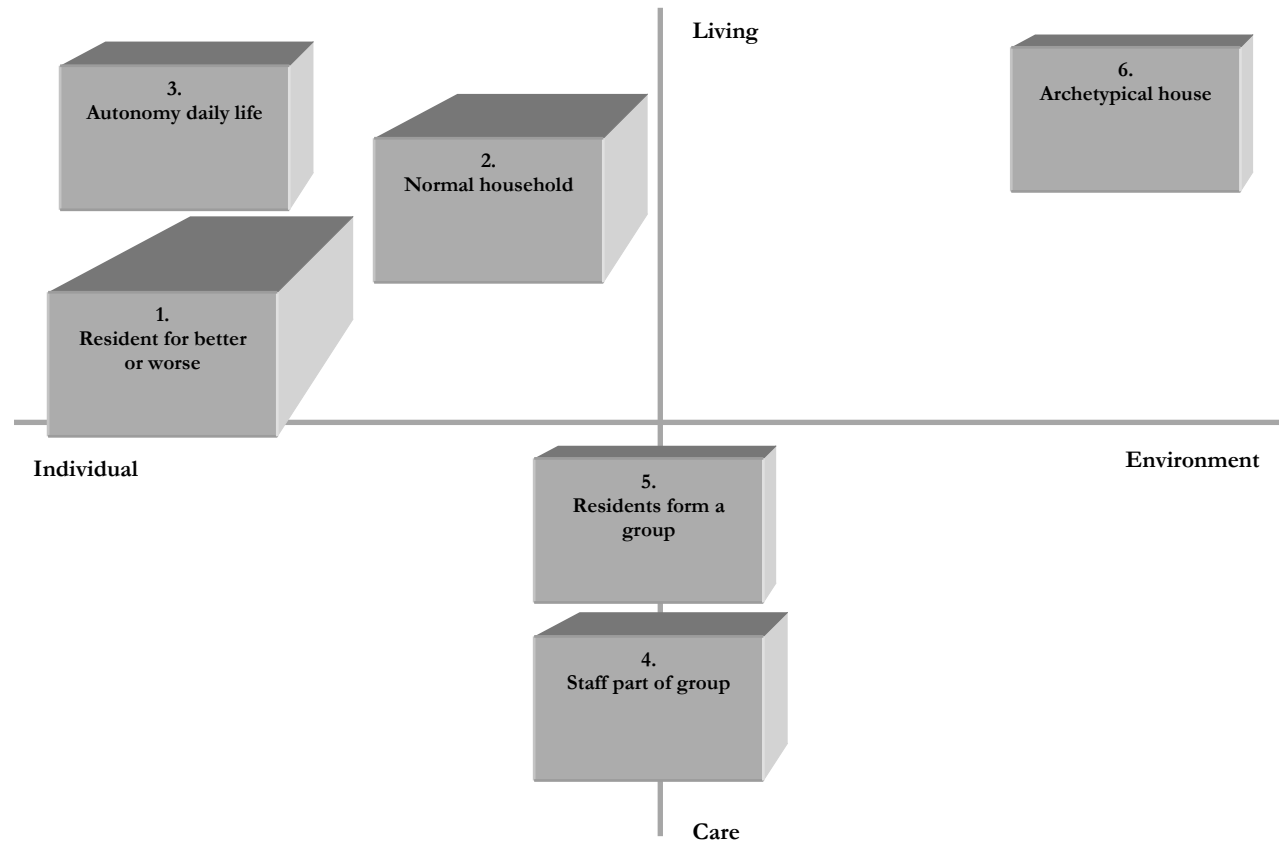
The definition of group living home care made with the Concept Mapping method represents the Dutch ideals of group living home care. However, it is unknown whether group living homes actually follow these ideals. In other words, does group living home care practice what it preaches? The present study therefore wanted to explore whether group living homes practice the ideals depicted on the Concept Map and, by doing so, distinguish themselves from modern traditional nursing home care. To this end, we constructed an exploratory questionnaire based on the statements of the clusters of the Concept Map. Subsequently, we administered it to group living homes and modern traditional nursing homes. The expectation was that, although modern nursing homes also try their best to make their residents feel at home and may therefore use some of the ideals of group living home care, the ideals were practiced to a higher degree in group living homes.

## **METHODS**

### **Sample**

In the Netherlands, nursing homes are publicly funded institutions in which people with psychogeriatric symptoms such as dementia receive separate care from those with somatic symptoms. For this study, only psychogeriatric group living homes and psychogeriatric nursing homes or nursing homes with psychogeriatric units were selected.

Figure 1. Concept Map of Group living home care



Furthermore, group living homes and traditional nursing homes had to meet a number of eligibility criteria to participate in this study. Group living homes were included that (a) had a maximum of six residents, (b) had a maximum of six units, (c) were situated more than 200 meters from the nursing home to which they belonged, (d) prepared their own meals and (e) were built more than two years prior to the start of the study. Criteria (a) and (d) are derived from the Concept Map described above. These criteria are therefore not included in the exploratory questionnaire constructed in this study.

Twenty group living homes met these criteria, of which nineteen group living homes with 56 units with an average of six residents (range 4-6) per unit agreed to participate. These nineteen group living homes employed 305 nurses.

The eligibility criteria for traditional nursing homes were formed to ensure that the group living homes were compared with the best traditional nursing home care the Netherlands had to offer. This meant that traditional nursing homes had to be built according to the Dutch 1997 Building Regulation for Nursing Homes, as these facilities offer, among other structural improvements, only single bedrooms. Furthermore, to ensure the contrast between group living home care and traditional nursing home care, the latter needed to be large-scale as well. Therefore, only traditional nursing homes with more than 20 residents per unit were included in the study.

Fourteen nursing homes met the two criteria, of which seven nursing homes with seventeen units with an average of 28 residents (range 20-30) per unit participated.

All group living homes and nursing homes were recruited previously for participation in other studies by the authors to establish the effects of group living home care on residents, informal caregivers and professional caregivers (Te Boekhorst et al., 2008a; 2008b; 2009).

## **Measures**

### ***Construction questionnaire***

From each of the six clusters of the Concept Map statements were selected that:

- (a) could be transformed into questionnaire items. This excluded items expressing feelings (e.g. '...the residents feels at home'), items expressing principles or ideals (e.g. ....there is a vision which takes the needs of people with dementia into account) and ambiguous items (e.g. ...the doctor looks beyond the ailment).
- (b) could be answered on a five point scale ranging from never (0) to always (5). This excluded items such as 'there is a separate front door for each unit'.
- (c) had a high ranking.

However, if these three criteria could not be met and we did not have at least three items for each cluster, we searched for lower ranked statements that met the first two criteria. The

maximum number of items per subscale was five. After testing each possible item for its usability, the selection process ultimately provided us with a questionnaire of 28 items.

#### ***Reliability questionnaire***

A number of items needed to be recoded before analysis on subscale level. Subscale scores were calculated by adding item scores and dividing them by the number of items in that particular subscale. Cronbach's alpha was computed for each subscale (see also table 2). The alphas ranged from good to acceptable, with the exception of the subscale 'Archetypical house' which had an  $\alpha = 0.18$ . This did not improve by removing one or several items (maximum  $\alpha = 0.31$ ). The subscale 'Archetypical House' was therefore excluded from further analysis.

#### **Procedure**

The questionnaire was digitized and presented on a web page. The link of this website was sent to the 19 managers of the participating group living homes and the 20 ward managers of the participating modern traditional nursing homes. After they completed the questionnaire, it was automatically forwarded to the researchers. When a questionnaire was not completed within a week of sending the link, the researcher contacted the managers to remind them of filling in the questionnaire. This was repeated when there was no completed questionnaire within another week. After reminding, 16 of the 17 traditional nursing home wards and 17 of the 19 group living homes completed the questionnaire, a response of 94% and 90% respectively.

#### **Data analysis**

Units of analysis were group living homes and wards of modern traditional nursing homes, as the number of residents and staff in these units of analysis were roughly the same. Student's T-tests were used to establish whether there were significant differences between group living homes and modern traditional nursing homes. All analyses were conducted with SPSS version 15.0.

## **RESULTS**

The results of the t-tests are presented in table 2, which shows that group living homes scored significantly higher on all but one subscale. This subscale represented the cluster 'Residents for better or worse', on which modern traditional nursing homes scored significantly higher. The means of this subscale indicated that residents of group living homes were seldom 'residents for better or worse', while this was often the case for residents in modern traditional nursing homes. Analysis on item level showed that this significant difference was caused by the scores on the items 'Residents are transferred if their care needs become too extensive' and 'Residents are transferred if there are severe behavioural problems', with residents in group living home care being transferred sometimes to often, while this almost never happened in modern traditional nursing homes.

As shown by the significantly different scores on the subscale 'Normal household' in table 2, residents of group living homes often to always lived in a normal household, while this was seldom to sometimes the case for residents in modern traditional nursing homes. Analysis on item level showed that group living homes had significantly higher scores on indeed all but one item of this subscale. The item 'Residents receive their family in their own bedroom' did not differ significantly between the two groups.

The significantly different scores on the subscale 'Autonomy in daily life' indicate that residents in group living homes often were autonomous in daily life, while residents in modern traditional nursing homes only sometimes did. Analysis on item level showed that group living homes score significantly better on all but one item. Only the item 'Residents eat snacks besides regular meals' did not differ significantly between the two groups.

The subscale scores on 'Staff part of group' showed that staff of group living homes were often part of the group, while this was seldom to sometimes the case for staff of modern traditional nursing homes. Analysis on item level indicated that group living homes had significantly higher score on three of the five items of this subscale. The means of the items 'Nursing staff works in different units' and 'Nursing staff uses a separate room for staff meetings' did not differ significantly.

As shown in table 2, the significantly different scores on the subscale 'Residents form a group' indicate that residents in group living homes sometimes to often form a group, while residents in modern traditional nursing homes only sometimes do. Analysis on item level showed that this significant difference is mainly caused by the higher scores of group living homes on the item 'Residents help with the housekeeping' and, to a lesser degree, by the item 'If family arrives during dinnertime, they eat with the residents'. The other two items did not show significant differences.

Although not central to the research question, it is nevertheless interesting to investigate whether there were individual modern traditional nursing homes whose scores on the subscales were comparable to the average of the group living homes and vice versa. On the subscale 'Resident for better or worse' there were three group living homes who scored within the 95%-CI of 2.54 – 3.04 of the mean for modern traditional nursing homes, which indicates that of the 17 group living homes there were three who did not transfer residents on a regular basis. There were no modern traditional nursing homes who scored within the 95%-CI of 0.68 – 1.79 of the mean for group living homes. On the subscale of the cluster 'Normal household' there was one group living home who scored within the 95%-CI of 1.05 – 1.88. There were no nursing homes who scored within the 95%- CI of 3.10 – 3.60 of the mean for group living homes. On the subscale 'Autonomy in daily life' there was one group living home who scored within the 95%-CI of 2.02 – 2.39 of the mean for modern traditional nursing homes. There

were no nursing homes whose score fell within the 95%-CI of 2.91 – 3.12 of the group living homes' mean. On the subscale 'Staff part of household' there was one group living home who scored within the 95%-CI of 1.22 – 1.97 of the mean of modern traditional nursing homes. On the other hand, there were two modern traditional nursing homes whose score fell within the 95%-CI of 2.51 – 2.91 of the mean of the group living homes. On the last subscale, 'Residents form a group' there were two group living homes who scored within the 95%-CI of 1.41 – 1.97 of the mean for modern traditional nursing homes. There were also two modern traditional nursing homes whose score fell within the 95%-CI of 2.15 – 2.59 for the mean of group living homes.

In conclusion, the cluster 'Resident for better or worse' showed the largest number of group living homes who scored high on this ideal in spite of the reversed mean results, while the clusters 'Staff part of the group' and 'Residents form a group' saw the largest portion of modern traditional nursing homes who scored high on this ideal contrary to their fellows. However, these reversed results were relatively small, never rising above 17% of the total number of participants in each group.

## **DISCUSSION**

This study wanted to explore whether group living homes practice the ideals described by a Concept Map to define group living home care. To this end, a questionnaire based on the items of six clusters of the Concept Map was constructed and administered to both group living homes and modern traditional nursing homes. The hypothesis was that group living homes had incorporated the ideals of group living home care to a higher degree than modern traditional nursing homes.

The study hypothesis was largely confirmed. Items of five of the six clusters could be reliably transferred into a questionnaire. The ideals of four of these five clusters proved to be better implemented in group living homes. Residents in group living homes lived more often in a normal household, had more autonomy in their daily lives and more often formed a group. Furthermore, staff was more often part of this group in group living homes than in modern traditional nursing homes. There are a number of possible limitations to this study. First and foremost, the questionnaire was not filled in by independent observers but by managers who were directly involved in either group living homes or modern traditional nursing homes. This could very well have led to positively biased answers, in particular in group living homes as their managers may have felt the need to conform to the ideals of group living home care. Consequently, the differences between the two research groups could have been exaggerated.

**Table 2. Results on subscale and item level of the questionnaire ‘Characteristics of group living home care’**

	Nursing homes (n=16)	Group living homes (n=17)		
	<i>Mean</i>	<i>Mean</i>	<i>T</i>	<i>P</i>
<b>Resident for better or worse (<math>\alpha = 0.63</math>)</b>	<b>2.79</b>	<b>1.23</b>	<b>5.43</b>	<b>0.000</b>
Residents are transferred if their care needs grow too extensive <sup>a</sup>	0.13	2.59	-6.581	0.000
Residents are transferred if there are severe behavioural problems <sup>a</sup>	0.25	2.71	-8.112	0.000
After passing away, residents lie in state in their own bedroom	0.75	1.00	-0.529	0.600
<b>Normal household (<math>\alpha = 0.80</math>)</b>	<b>1.46</b>	<b>3.35</b>	<b>-8.36</b>	<b>0.000</b>
Dinner is prepared in the kitchen of the living rooms	1.00	3.88	-7.979	0.000
Meals are served out on the table	1.81	3.88	-4.373	0.000
(Part of) the laundry is done in the unit	1.50	3.59	-4.878	0.000
Residents use their own linen	0.94	3.18	-5.198	0.000
Residents receive their family in their own bedroom	2.06	2.24	-0.599	0.555
<b>Autonomy in daily life (<math>\alpha = 0.69</math>)</b>	<b>2.20</b>	<b>3.11</b>	<b>-7.06</b>	<b>0.000</b>
Residents' bedrooms are locked by day <sup>a</sup>	3.00	0.71	6.748	0.000
Residents get out of bed when they want to	2.81	3.41	-2.703	0.011
Residents go to bed when they want to	3.00	3.76	-4.601	0.000
Residents are helped on the toilet on fixed times <sup>a</sup>	1.75	0.41	4.892	0.000
Residents eat snacks besides regular meals	2.94	2.76	0.618	0.541
Residents get these snacks themselves	1.25	1.88	-2.829	0.008
<b>Staff part of group (<math>\alpha = 0.60</math>)</b>	<b>1.60</b>	<b>2.72</b>	<b>-5.56</b>	<b>0.000</b>
Nursing staff works in different units <sup>a</sup>	2.44	2.24	0.436	0.666
Nursing staff wears a uniform <sup>a</sup>	2.19	0.12	5.128	0.000
Nursing staff does housekeeping	2.38	3.65	-5.507	0.000
Nursing staff eats together with the residents	1.25	3.71	-6.280	0.000
Nursing staff uses a separate room for staff meetings <sup>a</sup>	3.00	3.35	-1.109	0.276
<b>Residents form a group (<math>\alpha = 0.58</math>)</b>	<b>1.69</b>	<b>2.37</b>	<b>-4.09</b>	<b>0.000</b>
Residents help with the housekeeping	1.75	2.82	-4.676	0.000
If family arrives during dinnertime, they eat with the residents	1.06	1.88	-2.225	0.034
Family helps with housekeeping	1.25	1.71	-1.608	0.118
Family feels involved in the ups and downs of the unit	2.69	3.06	-1.687	0.102

Range: 0 (never) – 1 (seldom) - 2 (sometimes) – 3 (often) - 4 (always) <sup>a</sup> Original scores are shown, but items were recoded to compute scale scores

Second, the number of participants was small, which limits the statistical power of this study. However, while the response rate in modern traditional nursing homes was admittedly lower, the response rate of 96% in group living homes shows that all but one of the eligible group living homes participated in the study. Since the differences found between both groups were large, lack of statistical power is not an issue in this study. The third limitation is that the questionnaire constructed in this study was not validated or standardized in any way. We only tested its usability before administering it to our study groups. Furthermore, Cronbach's alphas of some subscales were merely acceptable, indicating at best a modest reliability. The subscale 'Archetypical house' was even removed from analysis because its alpha was too low. However, as this was also the least important cluster on the Concept Map, we estimated that this would not greatly influence our results.

Despite its limitations, this study unequivocally shows that group living homes have incorporated the ideals of group living home care depicted on the Concept Map to a reasonably high degree. However, there are two notable exceptions. First, almost all but three group living homes scored far worse on the cluster 'Resident for better or worse', which indicates that they transfer residents on a regular basis when there are too severe behavioural problems or too extensive care needs. This is a remarkable finding, in particular because this cluster was ranked highest on the Concept Map. Thus, the most central ideal of group living home care, that residents can stay 'home' until they die, seems not to be practiced in group living homes. However, this ideal may be difficult to follow. What can one do with a resident whose extensive care needs leave nursing staff no time to spend with other members of the group or whose behavioural problems severely disrupt the lives of the other members of the group? Group living homes are often small and therefore offer residents little possibility of escaping one another. Many would consider transferring this resident to another facility the obvious choice. However, in light of the crucial importance of the ideal 'residents for better or worse', we urge group living homes to choose this option only when all other possibilities are exhausted.

Another remarkable result is that staff of group living homes often work in different units, while the most important statement of the Concept Map is that group living home care should have fixed teams (see table 1). The idea behind this statement is that residents in group living home care should be familiar with their professional caregivers and not see (too many) unknown faces. The opposite might even be more important: within fixed, small teams professional caregivers are able to thoroughly acquaint themselves with their residents' personality, their life's history and their likes and dislikes. This can only benefit the quality of care. Group living homes should therefore pay far more attention to this ideal of group living home care and adjust their staff policy accordingly.



A third remarkable study finding is that there seems to be little or no difference in the amount of family involvement between group living homes and modern traditional nursing homes, although statements on family involvement are abundant in the cluster 'Residents form a group'. Moreover, group living homes often actually expect family to help with the care for the residents and as a consequence might experience difficulties. What can explain this relative lack of involvement? Research on the effects of group living home care on informal caregivers shows that, while there were no differences between informal caregivers of group living homes and modern traditional nursing homes, both groups exhibited a high amount of psychopathology six months after admittance of their relative (Te Boekhorst et al., 2008b). Other studies also indicate that informal caregivers keep experiencing elements of psychological distress such as depression and anger even after admittance (Gaugler et al., 2007). This could very well explain their lack of involvement: some or maybe even most informal caregivers may simply not feel up to it. Interestingly, involvement of family in group living home care has its potential pitfalls as well. Data from an observational qualitative study (not yet published) show that the daily presence of family in such a small group can influence the dynamics to an unpleasant degree, e.g. because they criticize staff overmuch or interfere with the care for residents other than their own family members.

These and the other examples described above show that it can be very difficult to put the ideals of group living home care into practice. We may therefore have to conclude that for the moment, the ideals of group living home care are as real as they can reasonably get. However, in order to truly fulfil the ideals of group living home care, group living homes need to offer their residents a permanent home and only familiar faces to care for them.

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*Practice of group living home care*

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# 4

## **GROUP LIVING HOMES FOR OLDER PEOPLE WITH DEMENTIA:**

### **THE EFFECTS ON QUALITY OF LIFE AND FUNCTIONING OF RESIDENTS**

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## **ABSTRACT**

### **Objectives**

The aim of this study was to investigate the effects of group living homes on quality of life and functioning of people with dementia.

### **Methods**

The study had a quasi-experimental design with a baseline measurement on admission and an effect measurement six months later. Participants were 67 residents in 19 group living homes and 97 residents in seven traditional nursing homes. DQOL and QUALIDEM measured quality of life, functional status was examined with MMSE, IDDD, RMBPC, NPI-Q and RISE from RAI. Use of psychotropic drugs and physical restraints was also assessed. Linear and logistic regression analyses analyzed the data.

### **Results**

After adjustment for differences in baseline characteristics, residents of group living homes needed less help with ADL and were more socially engaged. There were no differences in behavioral problems or cognitive status. Also after adjusting, two of the twelve quality of life subscales differed between the groups. Residents of group living homes had more sense of aesthetics and had more to do. While there were no differences in prescription of psychotropic drugs, residents of group living homes had less physical restraints.

### **Conclusions**

Group living homes had some beneficial effects on its residents, but traditional nursing homes performed well as well. Possible study limitations included the baseline differences between the study groups and the use of different informants on T0 and T1.

Future nursing home care may very well be a combination of the best group living care and traditional nursing home care have to offer.

## **INTRODUCTION**

Dementia is a progressive syndrome with often severe consequences for the quality of life of the sufferer and his or her environment. The prevalence of dementia is increasing, especially in developed countries where populations are older and life expectancy continues to grow. For example, the Netherlands already have 200,000 people with dementia on a population of 16 million (1.3%), and this number will more than double in the next three decades (National Health Council, 2002).

The majority of people with dementia is initially cared for at home, but a combination of factors such as severe behavioral problems and exhaustion of the primary caregiver almost always leads to a transition to a nursing home facility (Yaffe et al., 2002). In the Netherlands as well as in other countries, nursing home care traditionally resembled hospital care, with large wards and bedrooms for multiple residents. However, in the last decades awareness has increased that this type of facility does not meet the unique needs of people with dementia (Hammer, 1999). A number of initiatives have been taken to improve this situation. One such development is group living care. The ideals of group living care state that a group living home is located in an archetypical house, in which residents can stay until they die. Furthermore, the organization of daily life is analogue to that of a normal household, which means that a small staff determines the daily routine together with the residents and informal caregivers (Te Boekhorst et al., 2007). Group living homes are built in countries such as Sweden and Japan, and to an ever increasing extent in the Netherlands.

A number of, mainly Swedish, studies researched various aspects of group living care for people with dementia. Some of them describe the background, development and consequences of group living homes (Annerstedt, 1993; Malmberg & Zarit, 1993; Häggström & Norberg, 1996; Annerstedt, 1997). Other research examined resident's life in group living care. One such study showed that group living care might raise the quality of life in its residents for a period of no longer than 2-2.5 years in comparison to traditional nursing home care (Annerstedt, 1994). Other research indicated that the quality of life of residents had risen three months after admission and that this increase was influenced by the acquisition of roles within the group living home (Funaki et al., 2005). However, polypharmacy seemed to increase in the two years after admission. Depressive symptoms in particular were present in about 80% of residents, while only 12% received medication for this (Elmståhl et al., 1998).

It is not clear from the literature described above if group living homes do indeed offer a better living environment for people with dementia. This can be at least partly attributed to the fact that just one study compared residents of group living homes with residents in traditional nursing homes. Therefore, our study aimed to examine functional status, quality of life and use

of psychotropic drugs and physical restraints in residents of group living homes compared to residents in traditional nursing homes.

## **METHODS**

### **Design**

This study had a quasi-experimental design. The experimental group consisted of newly admitted residents in group living homes. The control group included newly admitted residents of traditional nursing homes. There were two measurements, one upon admission and one six months later.

The study was approved by the Medical Ethics Committee of the National Institute of Mental Health and Addiction.

### **Setting**

In the Netherlands, nursing homes are publicly funded institutions in which people with psychogeriatric complaints such as dementia receive separate care from those with somatic complaints. For this study, only psychogeriatric group living homes and psychogeriatric nursing homes or nursing homes with psychogeriatric units were selected.

Furthermore, group living homes and traditional nursing homes had to meet a number of eligibility criteria. The criteria for group living homes were formulated on the basis of a Concept Map (Trochim, 1989), that defined group living care (Te Boekhorst et al., 2007). Group living homes were included that (a) had a maximum of six residents, (b) had a maximum of six units, (c) were situated more than 200 meters from the nursing home to which they belonged, (d) prepared their own meals and (e) were built more than two years prior to the start of the study.

Twenty group living homes met these criteria, of which nineteen group living homes with 56 units with an average of six residents (range 4-6) per unit agreed to participate. These nineteen group living homes employed 305 nurses.

The eligibility criteria for traditional nursing homes were formed to ensure that group living care was compared with the best traditional nursing home care the Netherlands already had to offer. This meant that traditional nursing homes had to be built according to the Dutch 1997 Building Regulation for Nursing Homes, as these facilities offer, among other structural improvements, only single bedrooms. Furthermore, to ensure the contrast between group living home care and traditional nursing home care, the latter needed to be large-scale as well. Therefore, only traditional nursing homes with more than 20 residents per unit were included in the study.



Fourteen nursing homes met the two criteria, of which seven nursing homes with seventeen units with an average of 28 residents (range 20-30) per unit participated. These seven nursing homes employed 437 nurses.

### **Sample**

Newly admitted residents in both group living homes and traditional nursing homes were eligible for the study if they had a primary informal caregiver who could provide the necessary information about their relative. Response rates varied from 42% to 100% per unit with an average of approximately 68% in traditional nursing homes and 85% in group living homes. The main reason for not participating in the study was that it would be too stressful for residents and/or informal caregivers.

During the two-year study period, 132 residents in traditional nursing homes participated in the study upon admission, of which 97 (73.5%) survived to participate in the second measurement. In group living homes 79 residents participated in the study upon admission, of which 67 (84.8%) survived to participate in the second measurement. Multilevel survival rates after six months did not differ significantly between the two groups, but there was a trend towards a higher survival rate in group living homes ( $X^2 = 3.92, p = .059$ ).

### **Measures**

#### ***Functional status***

Cognitive functioning was measured with the Standardized Mini-Mental State Examination (Folstein et al., 1975; Molloy et al., 1991). The S-MMSE contains 19 questions with a maximum score of 30 points. A score over 27 is considered normal, 20-26 indicates mild dementia, 10-19 moderate dementia and below 10 severe dementia.

Assistance needed with Activities of Daily Life was assessed with The Interview for the Deterioration of Daily Living activities in Dementia (IDDD) (Teunisse & Derix, 1997). This scale has good construct validity and test-retest reliability, as well as good responsiveness to deterioration over six months. It consists of eleven items on a five point scale (alpha .79). A higher score on the IDDD means more assistance is needed.

Behavioural problems were measured with the Revised Memory and Behavior Problems Checklist (RMBPC) and the Neuropsychiatric Inventory-Questionnaire (NPI-Q). The RMBPC is considered a reliable and valid tool for the empirical assessment of behavioural problems (Teri et al., 1992). It consists of three subscales: memory-related behavioural problems (seven items, alpha .78), depression (ten items, alpha .84) and disruptive behaviour (eight items, alpha .70). All items are measured on a five point scale, with a higher score indicating more problems. The second scale used to assess behavioural problems was the NPI-Q. This is an abridged pen-and-pencil version of the Neuropsychiatric Inventory, which is a well validated instrument for examining psychopathology in dementia (Cummings et al., 1994). Test-retest

reliability of the NPI-Q is acceptable (Kaufer et al., 2000). The twelve items of this scale each measure a psychiatric symptom on a four point scale (alpha .70). A higher score indicates greater symptom severity.

Social engagement was measured with the Revised Index of Social Engagement (RISE) from the Resident Assessment Instrument (RAI) (Gerritsen, 2004; Morris et al., 1990). Compared to the original Index of Social Engagement it has higher content validity, higher internal consistency and better inter-rater reliability. It consists of six items with a dichotomous scale (alpha .72). A higher score indicates higher social engagement.

### ***Quality of life***

Quality of life was examined with two instruments. The first, the Dementia Quality of Life instrument (DQoL), gives a valid and reliable assessment of six dimensions of quality of life in dementia (Brod, 1990). Although this instrument was originally developed as a direct interview with people with dementia, it was used as a proxy measure in this study. Five of the six dimensions of the DQoL were measured on a five point scale: Sense of Aesthetics (five items, alpha .87), Self-esteem (four items, alpha .77), Positive Affect (six items, alpha .87), Negative Affect (eleven items, alpha .89) and Feelings of Belonging (three items, alpha .73). The sixth dimension, Overall Quality of Life, was assessed with one item. A higher score indicated a higher outcome on each particular dimension.

The second quality of life instrument used in this study was the QUALIDEM. This scale measures quality of life of residents with dementia in nursing home facilities. Therefore, it was only administered at the second measurement six months after admission. The instrument has sufficient validity and reliability (Ettema et al., 2007a, b). This scale assesses nine dimensions of quality of life in dementia, each on a four point scale: Care Relationship (seven items, alpha .81), Positive Affect (six items, alpha .86), Negative Affect (three items, alpha .77), Restless Tense Behaviour (three items, alpha .76), Social Relations (six items, alpha .80) and Having Something to Do (two items, alpha .63). Because the three subscales Positive Self Image, Social Isolation and Feeling at Home proved to be not normally distributed even after transformation, they were not further analyzed here.

### ***Use of psychotropic drugs and physical restraints***

Information about the use of psychotropic drugs and physical restraints was given at the second measurement by nursing home physician or psychologist. We asked whether residents were prescribed one or more psychotropic drugs and/or one or more physical restraints.

### **Procedure**

There were two measurements, one upon admission and one six months later. At the first measurement, newly admitted residents' informal caregivers who agreed to participate in the study filled in an informed consent form and a questionnaire about their relative's functional

status and quality of life two weeks prior to admission. This measurement thus provided a baseline for the second measurement six months later. At this measurement the Certified Nursing Assistant (CNA) who was responsible for the resident filled in the same questionnaire that was used at admission.

At both measurements the MMSE was administered by a nursing home physician or psychologist. At the first measurement it was administered as soon as possible after admission, because administration before admission proved to be logistically impossible. At the second measurement six months later, nursing home physician or psychologist also provided information about the use of psychotropic drugs and physical restraints.

#### **Data analysis**

Chi-square tests and multilevel univariate and multivariate linear and logistic regression analyses were used to analyze the data. Model assumptions for regression were verified. Because a number of variables were not normally distributed, they were ln-transformed prior to regression analysis. These variables were duration of memory problems and RMBPC Behaviour subscale at baseline (table 1), RMBPC depression and behaviour subscales and NPI-Q scale six months after admission (table 2) and all QUALIDEM subscales except Having Something to Do (table 3).

The coefficients of the multivariate regression models in table 2 and 3 were all adjusted for the results of that particular variable at the baseline measurement shown in table 1. The QUALIDEM was an exception as it was not measured at baseline. The coefficients in the multivariate regression models in tables 2, 3 and 4 were also adjusted for age and sex. Other demographic variables from table 1 did not prove to be confounders, which was considered present when addition of these variables led to a change of ten percent or more in the coefficient of the predictor variable. MMSE-score at baseline also proved to be a confounder for all outcome variables, except IDDD-score. Thus, all multivariate regression coefficients in tables 2 (except IDDD-score), 3 and 4 were adjusted for baseline MMSE-score as well.

## **RESULTS**

### **Participants**

Table 1 shows that residents in group living homes were more often single females who lived at home prior to admission. Univariate regression analysis showed that, while there were no differences in behavioral problems or social engagement, residents of group living homes had a better cognitive status and needed less assistance with ADL.

**Table 1. Characteristics of residents upon admission**

	Nursing homes (N=97)		Group living homes (N=67)		$\chi^2$	
	N	%	N	%		
<b>Gender</b>					7.74 *	
Male	26	26.8	6	9.0		
Female	71	73.2	61	91.0		
<b>Education level</b>					0.26	
Low	48	49.5	33	50.0		
Medium	38	39.2	28	42.4		
High	11	11.3	5	7.6		
<b>Living situation prior to admission</b>					5.99 *	
At home	41	47.1	30	71.4	4.51 *	
Other institution	46	52.9	12	28.6		
<b>Marital status</b>						
Married	21	21.9	5	7.5		
Single	75	78.1	62	92.5		
<b>Number of children</b>					1.02	
0	12	12.4	6	8.9		
1-3	54	55.7	44	65.7		
>3	31	31.9	17	25.4		
	<i>M</i>	<i>95% CI</i>	<i>M</i>	<i>95% CI</i>	<i>B</i>	<i>95%-CI</i>
<b>Age</b>	83.6	81.1 - 86.1	81.2	79.7 - 82.7	-2.43	-5.31 - .46
<b>Duration memory problems<sup>a</sup></b>	5.6	4.7 - 6.4	4.9	4.1 - 5.9	-0.09	-0.27 - 0.08
<b>MMSE</b>	10.3	8.3 - 12.3	15.4	13.5 - 17.3	5.09**	2.33 - 7.84
<b>IDDD</b>	33.0	30.5 - 35.6	25.9	22.9 - 28.8	-7.18**	-11.09 - 3.26
<b>RMBPC Memory</b>	21.6	21.0 - 22.3	20.8	19.9 - 21.7	-0.85	-1.93 - 0.24
<b>RMBPC Depression</b>	13.1	12.3 - 13.8	14.9	12.8 - 17.0	1.83	-0.37 - 4.03
<b>RMBPC Behavior<sup>a</sup></b>	6.7	6.0 - 7.4	6.1	4.9 - 7.3	-0.03	-0.11 - 0.06
<b>NPI-Q</b>	11.7	10.9 - 12.8	12.1	10.5 - 13.8	0.28	-1.65 - 2.21
<b>RISE from RAI</b>	2.9	2.5 - 3.2	3.2	2.7 - 3.7	0.32	-0.26 - 0.91

\* P < .05

\*\* P < .01

<sup>a</sup>Ln-transformed in regression model

### ***Functional status***

The results of both univariate and multivariate regression analysis in table 2 show that residents of group living homes needed less assistance with Activities of Daily Living (IDDD) on the second measurement. However, the mean IDDD scores in table 2 indicate that both groups still needed a large amount of assistance with ADL. Furthermore, a comparison between mean IDDD scores on admission and six months later (table 1 and 2) seem to indicate a decline in this element of functional status for both groups. The significance of the adjusted regression coefficient in table 2 shows however that this deterioration was less pronounced in residents of group living homes.

Univariate regression analysis in table 2 shows that residents of group living homes were significantly more socially engaged on the second measurement than their counterparts in traditional nursing homes (RISE from RAI). This difference, although smaller, remained significant after adjustment for baseline RISE score, baseline MMSE score, age and sex in the multivariate model. A comparison between mean RISE scores in table 1 and 2 seems to indicate that both groups were more socially engaged on the second measurement than at admission. However, the significant adjusted regression coefficient shows that this improvement was greater in residents of group living homes.

The other measures of functional status, cognitive status (MMSE) and behavioral problems (RMBPC subscales and NPI-Q), did not differ between the two groups on the second measurement. Univariate regression analysis in table 2 shows that residents of group living homes had a higher MMSE score on the second measurement, but this difference was not significant in multivariate regression as it was already present at admission (table 1). When comparing mean RMBPC and NPI-Q scores in table 1 and 2, they seem to indicate an improvement in behavioral problems in both groups, which were not very severe even at admission. This improvement was not significantly greater in either group.

### ***Quality of life***

As shown in table 3, one of the six subscales of the DQoL differed significantly between the two groups. On the second measurement, residents of group living homes had a greater sense of aesthetics than residents of traditional nursing homes: the former enjoyed their surroundings sometimes to often, while the latter only seldom to sometimes did. There were no differences in the other subscales. Mean scores on these subscales indicated a reasonable quality of life for both groups.

Results of both univariate and multivariate regression analysis in table 3 show that the QUALIDEM subscale Having Something to Do differed significantly between the two groups on the second measurement. Residents of group living homes sometimes had something to do, while residents of traditional nursing homes only seldom had something to do. Univariate regression

analysis indicated that residents of group living had better social relations, but after adjustment for age, sex and baseline MMSE-score, this difference was no longer significant. There were no differences in the other subscales. Mean scores on these subscales again indicated a reasonable quality of life for both groups.

***Use of psychotropic drugs and physical restraints***

Table 4 indicates no significant difference in the use of psychotropic drugs in both groups: approximately 65% of residents in both group living homes and traditional nursing homes was prescribed one or more psychotropic drug. However, there was a significant difference in use of physical restraints. In group living homes 10% of residents was prescribed one or more physical restraint, while this was the case for 50% of residents in traditional nursing homes. Multivariate regression analysis showed that this difference remained significant after adjustment for age, sex and baseline MMSE-score.

*Effects on residents*

**Table 2. Functional status of residents six months after admission**

	Nursing homes (N = 97)		Group living homes (N = 67)		Nursing homes vs. group living homes			
	<i>M</i>	<i>95%-CI</i>	<i>M</i>	<i>95%-CI</i>	<i>B unadj.</i>	<i>95%-CI</i>	<i>B adj.<sup>b</sup></i>	<i>95%-CI</i>
<b>MMSE</b>	8.9	6.2 - 11.6	13.0	10.4 - 15.6	4.11*	0.38 - 7.85	0.54	-1.43 - 2.50
<b>IDDD</b>	34.6	31.9 - 37.2	28.3	26.3 - 30.3	-6.30**	-9.60 - 3.00	-4.37**	-7.06 - -1.69
<b>RMBPC Memory</b>	17.2	14.8 - 19.7	15.8	14.3 - 17.3	-1.40	-4.26 - 1.46	-0.30	-3.21 - 2.61
<b>RMBPC Depression<sup>a</sup></b>	8.0	7.4 - 8.6	8.9	7.4 - 10.5	0.01	-0.04 - 0.15	0.01	-0.12 - 0.14
<b>RMBPC Behavior<sup>a</sup></b>	5.4	4.7 - 6.0	4.5	3.5 - 5.4	-0.05	-0.13 - 0.03	0.02	-0.09 - 0.14
<b>NPI-Q ¶</b>	8.8	7.5 - 10.1	7.5	6.2 - 8.7	-0.07	-0.17 - 0.02	-0.04	-0.13 - 0.04
<b>RISE from RAI</b>	3.2	2.6 - 3.7	4.5	4.0 - 5.0	1.32***	0.58 - 2.10	0.79*	0.11 - 1.50

\* P < .05

\*\* P < .01

\*\*\*P < .001

<sup>a</sup>Ln-transformed in regression model

<sup>b</sup>All outcome variables are adjusted for age, sex, MMSE-score on T0 and scale-score on T0, except MMSE and IDDD which are adjusted for age, sex and scale-score on T0.

Group living homes for older people with dementia

Table 3. Quality of life of residents six months after admission

	Nursing homes (N = 97)		Group living homes (N = 67)		Nursing homes vs. group living homes			
	M	95%-CI	M	95%-CI	B unadj.	95%-CI	B adj. <sup>c</sup>	95%-CI
<b>DQoL</b>								
Sense of Aesthetics	7.1	5.2 - 8.9	10.8	9.5 - 12.2	3.78**	1.49 - 6.10	3.01*	0.54 - 5.48
Self-Esteem	6.6	5.0 - 8.1	7.8	6.8 - 8.8	1.24	-0.62 - 3.10	-0.18	-1.66 - 1.31
Positive Affect	12.1	11.2 - 13.0	13.7	12.3 - 15.1	1.55	-0.12 - 3.22	0.93	-0.96 - 2.82
Negative Affect	16.9	14.3 - 19.6	18.6	16.6 - 20.5	1.62	-1.64 - 4.87	0.79	-3.10 - 4.68
Feelings of Belonging	5.5	4.7 - 6.3	6.6	5.8 - 7.4	1.14	0.02 - 2.30	0.13	-0.85 - 1.12
Overall Quality of Life	2.0	1.8 - 2.2	2.3	2.0 - 2.6	0.30	-0.10 - 0.71	0.04	-0.38 - 0.47
<b>QUALIDEM</b>								
Care Relationship <sup>a</sup>	6.1	5.6 - 6.6	5.3	4.2 - 6.4	-0.04	-0.12 - 0.04	-0.01	-0.11 - 0.10
Positive Affect <sup>a</sup>	4.7	4.0 - 5.4	4.0	3.1 - 4.8	-0.05	-0.13 - 0.02	-0.01	-0.08 - 0.07
Negative Affect <sup>b</sup>	3.4	2.7 - 4.2	3.5	3.0 - 4.0	0.00	-0.05 - 0.07	0.02	-0.04 - 0.08
Restless Tense Behavior <sup>b</sup>	3.5	2.1 - 4.7	3.4	2.4 - 4.2	-0.01	-0.12 - 0.11	0.04	-0.04 - 0.12
Social Relations <sup>a</sup>	7.3	5.7 - 8.9	4.8	3.4 - 6.1	-0.16*	-0.29 - -0.03	-0.00	-0.13 - 0.09
Having Something to Do	1.9	1.3 - 2.7	4.3	3.8 - 4.8	2.36***	1.50 - 3.22	1.58**	0.61 - 2.55

\* p < .05

\*\* p < .01

\*\*\* p < .001

<sup>a</sup>Ln-transformed in regression model, lower score means better outcome

<sup>b</sup>Ln-transformed in regression model

<sup>c</sup>All outcome variables are adjusted for age, sex, MMSE-score on T0 and scale-score on T0, except MMSE and IDDD which are adjusted for age, sex and scale-score on T0



*Effects on residents*

**Table 4. Use of psychotropic drugs and physical restraints six months after admission**

	Nursing homes (N = 97)		Group living homes (N = 67)		Nursing homes vs. group living homes			
	<i>Number</i>	<i>%</i>	<i>Number</i>	<i>%</i>	<i>OR unadj</i>	<i>95% CI</i>	<i>OR adj<sup>a</sup></i>	<i>95% CI</i>
<b>Psychotropic drugs</b>					-0.05	-1.06 - 0.97	0.01	-0.97 - 0.99
No	29	34.9	18	36				
Yes	54	65.1	32	64				
<b>Physical restraints</b>					-2.15**	-3.40 - -0.90	-1.66*	-2.94 - -0.37
No	42	50.6	44	89.8				
Yes	41	49.4	5	10.2				

\* P < .05

\*\* P < .01

<sup>a</sup>Adjusted for age, sex and MMSE-score

## **DISCUSSION**

This study aimed to examine the effects of group living homes for people with dementia. To this end, we compared functional status, quality of life and the use of psychotropic drugs and physical restraints in residents of group living homes and traditional nursing homes. The results show that group living homes do have some beneficial effects on residents. They needed less help with Activities of Daily Living and were more socially engaged. Moreover, residents of group living homes had more sense of aesthetics and had more to do. They were also prescribed less physical restraints. However, we could not find differences in cognitive status and behavioral problems, such as depression and psychiatric symptoms. Furthermore, there were no differences in the large majority of quality of life scales and in the prescription of psychotropic drugs.

There were a number of possible limitations to this study. First of all, residents in both facilities were followed for only six months, while a longer follow-up period may have yielded valuable additional information. However, as with all research with frail elderly, the high mortality rate makes this very difficult.

A second possible limitation is that information about residents was given by two different observers. Informal caregivers of residents filled in the questionnaire on admission of their relative, while six months later the same questionnaire was filled in by a Certified Nursing Assistant. This might have influenced the comparability of both measurements. However, we deemed that informal caregivers of residents, while being well acquainted with the situation before admission, were not sufficiently aware of the functional status and quality of life of the resident in the nursing home facility to provide reliable information about it. Conversely, CNA's cannot provide reliable information about functional status and quality of life of the resident prior to admission. Therefore, two different informants on both measurements were indicated. To increase comparability of both measurements, we encouraged both informal caregivers and CNA's to consult others when uncertain about items on the questionnaire. However, as we did not check that this advice was followed, it remains unclear whether, and if so to what extent, the differences between the two measurements were actually caused by the two different informants.

Another limitation could be that the Dementia Quality of Life (DQoL) was used as a proxy measure in this study, while it was originally intended as a direct interview with the person with dementia. The reason for this decision was that quality of life needed to be assessed *retrospectively* at baseline, as participants were selected for the study after admission. We felt people with dementia would not be able to do this reliably. However, although caregiver and patient ratings on quality of life can differ substantially, it is not yet known which report is most accurate (Ready et al., 2004). Also, research shows that patient and caregiver ratings at

least agree on the factor structure of the DQoL (Ready et al., 2007). Still, although the study design necessitated the decision, the use of the DQoL as a proxy instrument remains questionable. Moreover, we do not know how the use of these proxy ratings influenced the quality of life scores.

A fourth possible limitation is that cognitive status of residents was not assessed prior to admission, but shortly after. However, numerous studies indicate that cognitive status is not significantly influenced by transition to a nursing home facility (Engle, 1985; Walker et al., 2007). Therefore, we considered the MMSE score at the first measurement to be indicative of cognitive status shortly before admission.

Last but certainly not least, the most important limitation of this study is that it was not a Randomized Clinical Trial (RCT), but had a quasi-experimental design. The reason for this was that it was logistically, but above all ethically impossible to randomly assign new residents to either group living homes or traditional nursing homes. However, this decision had obvious consequences. Baseline results indicate that new residents in group living homes differed from those in traditional nursing homes. Specifically, they seemed to have a better cognitive and functional status at admission. We adjusted the results after six months for these differences at baseline, so the analyses are statistically correct. However, if the two study groups really were dissimilar, their rate of decline might have differed as well, independent of the type of nursing home care they received. We do not know to what extent this phenomenon has influenced the results.

The differences in resident characteristics also reveal a major clinical dilemma of group living care: is it suitable for all people for dementia? The results of our study do not provide an answer, but the baseline results suggest that the group living homes participating in this study only admit a certain type of resident. But what about residents who do not fit this profile? Group living care may lose a great deal of its initial appeal if only a small group profits from it, especially since the number of people with dementia is rising so rapidly. However, Dutch policy is already focusing on integrating group living care and traditional nursing home care. As a consequence, future nursing homes will most likely consist of small scale group living care within large scale nursing homes. Although its effectiveness needs to be studied, this approach may very well give people with dementia the best of both ways: the expertise of large nursing homes within the intimate environment of group living homes.

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# 5

## GROUP LIVING HOMES FOR OLDER PEOPLE WITH DEMENTIA: THE EFFECTS ON PSYCHOLOGICAL DISTRESS OF INFORMAL CAREGIVERS

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## **ABSTRACT**

### **Objectives**

The aim of this study was to investigate the effects of group living care on the psychological distress of informal caregivers, compared to regular nursing home care.

### **Method**

This study had a quasi-experimental design with two measurements. 67 primary informal caregivers in 19 group living homes and 99 primary informal caregivers in 7 regular nursing homes filled in a questionnaire upon admission (baseline measurement) of their relative and six months later (effect measurement). Linear and logistic regression analyses were performed on three outcomes of psychological distress: psychopathology, caregiving competence and caregiver burden.

### **Results**

There were no significant differences in caregiver competence and caregiver burden between informal caregivers of residents in group living homes and those in regular nursing homes, although there was a trend towards less psychopathology in group living homes after adjustment for confounding.

### **Conclusion**

Informal caregivers of residents in group living homes do not have less psychological distress than informal caregivers of residents in regular nursing homes. Although there was a trend towards less psychopathology in informal caregivers of group living homes, the amount of symptoms remained very high in both caregiver groups. This means that the psychological well-being of caregivers deserves the continuing attention of health care providers, also after admittance of their relative in a nursing home facility.



## **INTRODUCTION**

Informal caregivers of people with dementia often experience a high amount of psychological distress from their caregiving role (Burns & Rabins, 2000). They are more vulnerable to depression and other psychopathology than non-caregivers (Cuijpers, 2005; Pot et al., 1997). Caregiver distress has multiple contributing factors, such as caregiver's coping style and health deterioration and behavioural problems of the person with dementia (Burns, 2000; Donaldson et al., 1998; Gaugler et al., 2005; Pot et al., 1998).

Caregiver distress often persists after admission of the relative in a nursing home facility (Grant et al., 2002; Lieberman & Fisher, 2001; Pot et al., 1997; Stephens et al., 1991). Although caregivers are relieved from some difficult care tasks, new elements of psychological distress relating to the nursing home and the caregiver's changing caregiving role arise (Skaff et al., 1996). Caregivers can experience feelings of depression, guilt, anger and loss of self up to several years after admission of their relative (Gaugler et al., 2007; Zarit & Whitlach, 1992), although the former authors also found decreases in role overload and anxiety following placement in a nursing home facility.

In the Netherlands, nursing home care was traditionally based on a hospital model, with large wards and bedrooms for multiple residents. However, in the last decades awareness has increased that this type of facility does not meet the unique needs of people with dementia (Hammer, 1999). Following countries like Sweden (Annerstedt, 1993) and Japan (Funaki et al., 2005), nursing home care in the Netherlands is increasingly directed toward group living care. The ideals of group living care state that a group living home is located in an archetypical house, in which residents can stay until they die. Furthermore, the organization of daily life is analogue to that of a normal household, which means that a small staff determines the daily routine *together* with the residents and informal caregivers (Te Boekhorst et al., 2007; Te Boekhorst et al., 2008).

These ideals seem to correspond to what is described as beneficial for informal caregivers. Port et al. (2005) pointed out that the family of residents with dementia wish to communicate more and better with the nursing home staff. Also, a larger involvement in the care of residents is positively associated with the well-being of caregivers (Gaugler et al., 2004; Tornatore & Grant, 2002). Moreover, Reggentin (2005) reported a greater acceptance of group living care by informal caregivers because they felt comfortable with the familiar environment compared with regular nursing homes.

Despite these positive implications, research done on the impact of group living care on caregiver distress is relatively scarce. An international comparison of several nursing home facilities revealed that group living care was the most effective and efficient way to decrease the burden of informal caregivers (Colvez et al., 2002). A Swedish study also found that care

burden experienced by informal caregivers had decreased twelve months after admission of the relative with dementia. However, disappointment of informal caregivers had increased in those twelve months (Elmståhl et al., 1998). Moreover, this study did not include a control group to which these results could be compared.

These few studies with somewhat mixed results give rise to the question whether informal caregivers indeed experience less psychological distress when their relative lives in group living care, in particular when compared to modern regular nursing home care, where high quality standards such as single bedrooms and larger living spaces are compulsory. This study therefore examined psychological distress of informal caregivers of residents with dementia living in group living homes for six months compared with residents with dementia living in modern regular nursing homes for six months. Because of the assumed beneficial effects of group living care on informal caregivers described above, the hypothesis was that informal caregivers in group living care would have less psychological distress than informal caregivers in regular nursing home care.

## **METHODS**

### **Design**

This study had a quasi-experimental pretest posttest control group design. The experimental group consisted of primary informal caregivers of newly admitted residents in group living homes. The control group included primary informal caregivers of newly admitted residents of regular nursing homes. There were two measurements, a baseline measurement upon admission and one six months later.

The study was approved by the Institutional Review Board of the National Institute of Mental Health and Addiction.

### **Setting**

In the Netherlands, nursing homes are publicly funded institutions in which people with psychogeriatric complaints such as dementia receive separate care from those with somatic complaints. For this study, only psychogeriatric group living homes and psychogeriatric nursing homes or nursing homes with psychogeriatric wards were selected.

Furthermore, group living homes and regular nursing homes had to meet a number of eligibility criteria. The criteria for group living homes were formulated on the basis of a Concept Map (Trochim, 1989), that defined group living care (Te Boekhorst et al., 2007). Group living homes were included that (a) had a maximum of six residents per unit, (b) had a maximum of six units, (c) were situated more than 200 meters from the nursing home to which they belonged, (d) prepared their own meals and (e) were built more than two years prior to the start of the study.

Twenty group living homes met these criteria, of which nineteen group living homes with 56 units agreed to participate. Almost all group living homes had six residents per unit, save three group living homes which had four (1) or five (2) residents per unit.

The eligibility criteria for regular nursing homes were formed to ensure that group living care was compared with the best regular nursing home care the Netherlands already had to offer. This meant that regular nursing homes had to be built according to the Dutch 1997 Building Regulation for Nursing Homes, as these facilities offer, among other structural improvements, only single bedrooms. Furthermore, to ensure the contrast between group living home care and regular nursing home care, the latter needed to be large-scale as well. Therefore, only regular nursing homes with more than 20 residents per ward were included in the study.

Fourteen nursing homes met these two criteria, of which seven nursing homes with seventeen wards agreed to participate. These wards had an average of 28 residents (range 20-30).

Both group living homes and nursing homes were located in similar geographic areas. There were participating facilities in urban areas in the West of the Netherlands as well as rural areas in the North, East and Southwest. Because group living home care was practically non-existent in the Southeast of the Netherlands at the start of the study, regular nursing homes from this region were excluded.

### **Sample**

During the two-year study period, all informal caregivers of new residents in both nursing home facilities were asked to participate in the study. Initial response rates varied from 42% to 100% per unit/ward with an average of approximately 85% in group living homes and 68% in nursing homes. The most frequently given reason for not participating was that it would be too stressful.

The baseline measurement on admission was completed by 79 informal caregivers in group living homes and 131 informal caregivers in regular nursing homes. Due to resident mortality and transfer, 67 (84.8%) informal caregivers in group living homes and 97 (73.5%) informal caregivers in regular nursing homes participated in the second measurement six months later.

### **Measures**

#### ***Outcome measures***

##### *Psychological distress informal caregivers*

Psychological distress was conceptualized with three separate outcome variables: psychopathology, caregiver burden and feelings of caregiving competence.

Psychopathology was measured with the 12-item version of the General Health Questionnaire (Goldberg & Williams, 1988), of which the Dutch translation has good

psychometric properties (Koeter & Ormel, 1991). Because informal caregivers in the study were exposed to the care situation for a longer period, ranking was done according to the alternative scaling for chronic psychopathology (Goodchild & Duncan-Jones, 1985). A score of two or more on this scale indicates psychopathology (range 0-12, Cronbach's alpha 0.84 in this study).

Feelings of caregiving competence were measured with the Caregiving Competence Scale (Pearlin et al., 1990). It consists of ten items on a four point scale. A higher score implies a higher feeling of competence (range 0-30, Cronbach's alpha 0.79 in this study).

Caregiver burden was measured with the Self-Perceived Pressure from Informal Care Questionnaire (SPPIC). The pressure refers to the demands of the caregiving situation as opposed to the personal interests of the caregiver. The SPICC is a hierarchical scale: at first, pressure manifests itself in the caregiver's mind and then in the interaction with his or her surroundings. The SPICC has good psychometric properties (Pot et al., 1995; Pot et al., 1998). It consists of nine items on a five point scale, which are subsequently dichotomized in positive and negative answers. The higher the score the more stress is experienced (range 0-9, Cronbach's alpha 0.85 in this study).

### ***Potential confounders***

#### *Baseline psychological distress*

Baseline levels of psychopathology, feelings of caregiving competence and caregiver burden were measured with the three scales described above.

#### *Sociodemographic characteristics informal caregivers*

Caregiver's sex, age, education level (high, middle, low), marital status (not single, single) and relationship with the resident (spouse, child/other) were measured.

#### *Characteristics residents*

Residents' sex and age and baseline cognitive status, assistance needed with Activities of Daily Life and behavioural problems were assessed.

Cognitive status was examined with the Standardized Mini-Mental State Examination (Folstein et al., 1975; Molloy et al., 1991).

Assistance needed with Activities of Daily Life was assessed with the Interview for Deterioration in Daily living activities in Dementia (IDDD) (Teunisse & Derix, 1997). This scale has good construct validity and test-retest reliability, as well as good responsiveness to deterioration over six months. It consists of eleven items on a five point scale (range 0-44, Cronbach's alpha .79 in this study). A higher score on the IDDD means more assistance is needed.

Behavioural problems were measured with the NPI-Q. This is an abridged pen-and-pencil version of the Neuropsychiatric Inventory, which is a well validated instrument for examining

psychopathology in dementia (Cummings et al., 1994). Test-retest reliability of the NPI-Q is acceptable (Kaufers et al., 2000). The twelve items of this scale each measure a psychiatric symptom on a four point scale (range 0-36, Cronbach's alpha .70 in this study). A higher score indicates greater symptom severity.

### **Procedure**

At first acquaintance with the nursing home facility, informal caregivers were asked to participate by the social worker or professional caregiver involved. Caregivers who agreed received an informed consent form and a questionnaire (T0). This questionnaire assessed psychological distress experienced prior to admission and thus served as a baseline measurement. It also measured residents' behavioral problems and assistance needed with ADL prior to admission. Residents' cognitive status was assessed by a nursing home physician or psychologist as soon after admission as possible.

Six months later (T1), a second questionnaire was sent to those informal caregivers whose relatives were still living in the same unit/ward of the same nursing home facility. This questionnaire only assessed psychological distress of informal caregivers.

### **Data analysis**

Survey chi-square tests and t-tests were used to compare informal caregivers' sociodemographic characteristics, their baseline psychological distress, and the residents' characteristics upon admission (T0).

Survey univariate linear and logistic regression analyses were performed to compare the three outcomes of psychological distress between informal caregivers in group living homes and regular nursing homes six months after admission (T1). Model assumptions for regression analysis were verified. In all regression analyses, the total SPICC score was dichotomized on the median because the data remained skewed after log transformation.

To control for confounding survey multivariate linear and logistic regression analyses were performed. All variables measured at T0 were considered potential confounders, which was considered to be present when addition of a variable to the regression model led to a change of ten percent or more in the coefficient of the predictor variable. To clarify the influence of the baseline levels of psychological distress, two separate multivariate regression models were performed. In the first model the regression coefficient was adjusted for baseline score on the three outcomes of psychological distress, as all these three baseline scores proved to be confounders. In the second model the regression coefficient was also adjusted for sociodemographic characteristics of the informal caregiver and sociodemographic and baseline characteristics of the resident, whenever these proved to be confounders.

## **RESULTS**

### **Caregiver and resident characteristics**

Informal caregivers of residents in group living homes were younger and more often female than informal caregivers in regular nursing homes (table 1). Other sociodemographic characteristics did not differ between the two groups.

Furthermore, there were significant differences in baseline scores on all three variables that conceptualized psychological distress. As can be seen in table 1, informal caregiver of group living homes had more psychopathology, felt less competent in caring for their relative and had a higher sense of caregiver burden. This indicates more baseline psychological distress in informal caregivers of residents in group living homes.

Table 1 shows that upon admission, residents of group living homes were younger and more often female. They also had a better cognitive status and needed less assistance with ADL. There were no differences in behavioural problems between the two groups.

### **Psychological distress**

Table 2 presents the results of the regression analyses. Both the unadjusted and two adjusted regression coefficients are given.

#### ***Psychopathology***

Although the unadjusted coefficient showed no significant differences in psychopathology, there was a trend towards less psychopathology in informal caregivers in group living homes after adjustment for baseline levels of psychopathology ( $p = .069$ ). This trend proved to be robust after further adjustment for informal caregivers age and residents' baseline cognitive status and assistance needed with ADL ( $p = .091$ ).

#### ***Caregiving Competence***

As can be seen in table 2, there were no significant differences in experienced caregiving competence between informal caregivers of residents in group living homes and regular nursing homes, even after adjustment for all confounders. The means on the Caregiving Competence Scale presented in table 2 indicate that both caregiver groups felt reasonably competent in caring for their relative.

#### ***Caregiver Burden***

Both unadjusted and adjusted OR's showed no significant differences in caregiver burden experienced by informal caregivers in group living homes and those in regular nursing homes. The mean SPICC scores suggests that both caregiver groups felt only slightly pressured by the care for their relative.

**Table 1. Characteristics of informal caregivers and their relatives upon admission**

	Nursing homes (N = 97)		Group living homes (N = 67)		X <sup>2</sup>
	N	%	N	%	
<b>Informal caregivers</b>					
<b>Sex</b>					4.54*
Male	36	36.4	14	20.9	
Female	63	63.6	53	79.1	
<b>Education level</b>					2.50
Low	4	4.0	1	1.5	
Middle	64	64.7	38	56.7	
High	31	31.3	28	41.8	
<b>Marital status</b>					1.87
Not single	81	81.8	60	89.6	
Single	18	18.2	7	10.4	
<b>Relationship with relative</b>					0.65
Spouse					
Child or other	12	12.2	3	4.5	
	86	87.8	64	95.5	
	<i>M</i>	<i>95% CI</i>	<i>M</i>	<i>95% CI</i>	<i>T</i>
<b>Age</b>	57.6	55.9 - 59.2	52.9	51.1 - 54.6	3.16**
<b>Psychopathology</b>	4.7	4.2 - 5.1	6.3	5.3 - 7.2	-3.40***
<b>Caregiving competence</b>	21.4	20.9 - 21.9	19.6	18.1 - 21.0	2.27*
<b>Caregiver Burden</b>	4.5	4.2 - 4.8	5.7	4.9 - 6.6	-3.12*
	N	%	N	%	X <sup>2</sup>
<b>Residents</b>					
<b>Sex</b>					8.42*
Male	26	26.8	6	9.0	
Female	71	73.2	61	91.0	
	<i>M</i>	<i>95% CI</i>	<i>M</i>	<i>95% CI</i>	<i>T</i>
<b>Age</b>	83.8	81.6 - 86.1	81.0	79.6 - 82.5	2.53**
<b>Cognitive status</b>	10.8	9.7 - 12.0	16.4	14.9 - 17.9	-5.65***
<b>Help needed with ADL</b>	33.1	30.5 - 35.8	25.7	23.0 - 28.4	4.97***
<b>Behavioural problems</b>	12.0	11.0 - 13.0	12.2	10.6 - 13.8	-0.16

\* p < .05

\*\* p < .01

\*\*\* p < .001

**Table 2. Psychological distress of informal caregivers six months after admission**

	Nursing homes (N = 97)		Group living homes (N = 67)		Nursing homes vs. group living homes					
	<i>M</i>	<i>95% CI</i>	<i>M</i>	<i>95% CI</i>	<i>b unadj.</i>	<i>95% CI</i>	<i>b adj.<sup>a</sup></i>	<i>95% CI</i>	<i>b adj.</i>	<i>95% CI</i>
<b>Psychopathology</b>	3.6	3.1 - 4.2	3.7	3.0 - 4.5	0.10	-0.87 - 1.10	-0.81‡	-1.69 - 0.07	-0.75 <sup>b</sup> ‡	-1.63 - 0.13
<b>Caregiving Competence</b>	22.3	21.9 - 22.8	21.9	20.3 - 23.4	-0.47	-2.10 - 1.16	-0.42	-0.99 - 1.83	0.24 <sup>c</sup>	-0.97 - 1.45
<b>Caregiver Burden</b>	2.9	2.6 - 3.2	3.0	2.4 - 3.6	0.91	0.43 - 1.91	0.69	0.29 - 1.65	1.05 <sup>d</sup>	0.31 - 3.53

‡  $p < .10$

<sup>a</sup> Adjusted for baseline scale score

<sup>b</sup> Adjusted for baseline scale score, caregiver age, resident baseline cognitive status and assistance needed with ADL.

<sup>c</sup> adjusted for baseline scale score, caregiver sex, age, education level, marital status, resident baseline cognitive status and assistance needed with ADL.

<sup>d</sup> Adjusted for baseline scale score, caregiver age, resident baseline cognitive status



## **DISCUSSION**

The hypothesis of this study was that informal caregivers of residents with dementia living in group living homes for six months experienced less psychological distress than informal caregivers of residents with dementia living in regular modern nursing homes for six months. This expectation was not confirmed. Both caregiver groups experienced an equal amount of caregiving competence and caregiver burden six months after admission, although there was a trend towards less psychopathology in informal caregivers of group living homes. It can therefore be concluded that informal caregivers in group living care do not have, or maybe only very slightly, less psychological distress than informal caregivers in regular modern nursing home care.

A somewhat different but legitimate interpretation of these findings also allows for the conclusion that there were no differences in decrease in psychological distress between the two caregiver groups. It can therefore also be stated that group living care does not seem to be more effective in relieving psychological distress in informal caregivers than modern regular nursing home care. Although different methodology always complicates comparisons between studies, this seems to be inconsistent with the existing literature on the effects of group living care on psychological distress of informal caregivers. The results of this study indicate a decrease in caregiver burden in group living homes as described by Elmstahl et al. (1998), but we found this decrease to be present in regular nursing homes as well. Therefore, our findings do not support the results of the study of Colvez et al. (2002), who found group living care to be more effective and efficient in reducing caregiver burden than other forms of nursing home care. However, it is important to emphasize that we did not compare group living homes with the average Dutch nursing home, but only with modern ones. Just fourteen of the approximately 350 nursing homes in the Netherlands met the criteria for comparability with group living homes, which were formulated to ensure group living care would be compared with regular nursing home care of the highest quality. It is possible that psychological distress of informal caregivers of residents with dementia in group living homes is significantly less when compared to *average* Dutch nursing homes. However, our self-imposed selection bias prevented us from examining this hypothesis.

The analyses in this study were all statistically controlled for the possibility that the variation in the studied variables between the different facilities within the experimental and control groups could be larger than the variation between the experimental and control groups as a whole. However, a full multilevel analysis could not be conducted due to the relatively small number of participants. Moreover, other characteristics of the facilities unrelated to the conceptual differences between group living care and regular care could of course have influenced caregiver distress as well. This may also have contributed to the lack of clear

findings in favour of group living care. Further research needs to examine which other characteristics of nursing home facilities influence caregiver distress.

Although not explicitly studied, an alternative explanation of our finding that group living care is not more effective in reducing caregiver distress may be that there seemed to be a large improvement in psychopathology and caregiver burden present in *both* caregiver groups. This overall effect could have masked any additional effect of group living homes may have had, a well known statistical phenomenon. A longer follow-up period may have yielded additional information, but the high mortality rate of nursing home residents (approximately 45% per year in the Netherlands) makes research with long follow-up periods very difficult.

An interesting study result is the significantly higher level of baseline psychological distress of informal caregivers of group living home residents. We have adjusted the results for these differences, so statistically they are of no importance. But the question remains why these informal caregivers experience more psychological distress prior to admission. A possible explanation is that they are more vulnerable to the stress which arises from the situation of their relative with dementia. This larger (or maybe even over-) emotional involvement might lead them to admit their relative into a group living home, as this is largely considered to be the most innovative form of nursing home care currently available in the Netherlands. Such emotional involvement in informal caregivers might also lead to more exhaustion, which could explain the fact that new residents of group living homes are in an earlier stage of dementia, indicated by their better cognitive and functional status and by their younger age. Thus, certain personality aspects of informal caregivers may play a role in their choice for both type of nursing home facility and timing of admittance of their relative with dementia. However, further research needs to examine these speculative explanations.

Last but not least, it is important to underscore that while psychopathology seemed less pronounced in informal caregivers of group living homes, still approximately 70% of *all* caregivers experienced psychopathology six months after admission of their relative. This is consistent with results of earlier studies (Grant et al., 2002; Lieberman & Fisher, 2001, Pot et al., 1997; Stephens et al., 1991). The psychological well-being of informal caregivers therefore deserves the continuing attention of health care providers after admittance of their relative with dementia into a nursing home facility, whether this is a regular nursing home or a group living home.

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# 6

## GROUP LIVING HOMES FOR OLDER PEOPLE WITH DEMENTIA:

### THE EFFECTS ON JOB SATISFACTION AND BURNOUT OF PROFESSIONAL CAREGIVERS AND THE ROLE OF JOB CHARACTERISTICS

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## **ABSTRACT**

### **Background**

Group living homes are a fast growing form of nursing home care for older people with dementia. This study seeks to determine the differences in job characteristics of nursing staff in group living homes and their influence on well-being.

### **Methods**

We examined the Job Demand Control Support (JDCS) model in 183 professional caregivers in group living homes and 197 professional caregivers in traditional nursing homes. Multilevel linear regression analysis was used to study the mediator effect of the three job characteristics of the JDCS-model (demands, control and social support) on job satisfaction and three components of burnout (emotional exhaustion, depersonalisation and decreased personal accomplishment).

### **Results**

Results showed that demands were lower in group living homes, while control and social support from co-workers were higher in this setting. Likewise, job satisfaction was higher and burnout was lower in group living homes. Analysis of the mediator effects showed that job satisfaction was fully mediated by all three psychosocial job characteristics, as was emotional exhaustion. Depersonalisation was also fully mediated, but only by control and social support. Decreased personal accomplishment was partially mediated, again only by job characteristics control and support.

### **Conclusion**

This study indicates that working in a group living home instead of a traditional nursing home has a beneficial effect on the wellbeing of nursing staff, largely because of a positive difference in psychosocial job characteristics.



## **INTRODUCTION**

The Netherlands already has 200,000 people with dementia on a population of 16 million (1.3%), and this number will more than double in the next three decades (Gezondheidsraad, 2002). The majority of people with dementia is cared for at home, but nursing home placement usually follows as the disease continues and the family caregiver becomes exhausted.

Traditionally, nursing homes in the Netherlands were based on a hospital model. However, in recent years there has been an increasing awareness that living in a large-scale institute cannot meet the unique needs of people with dementia (Hammer, 1999). Following the example of other countries such as Sweden (Malmberg & Zarit, 1993) en Japan (Onishi et al., 2006), an ever increasing number of group living homes is being built across the Netherlands.

In group living homes a small group of older people with dementia lives together in a homelike environment. In order to keep daily life for the residents as normal as possible, the required personal care is integrated in the everyday-routine. This means that nursing staff in group living homes perform care tasks as well as domestic tasks, such as cooking and cleaning. In traditional nursing homes, nursing staff generally does not perform domestic services. Furthermore, the concept of group living care entails that residents lead a normalized family life and is therefore to be managed by just one or two nurses a day. This is also a major distinction from traditional nursing homes, where usually more staff is present.

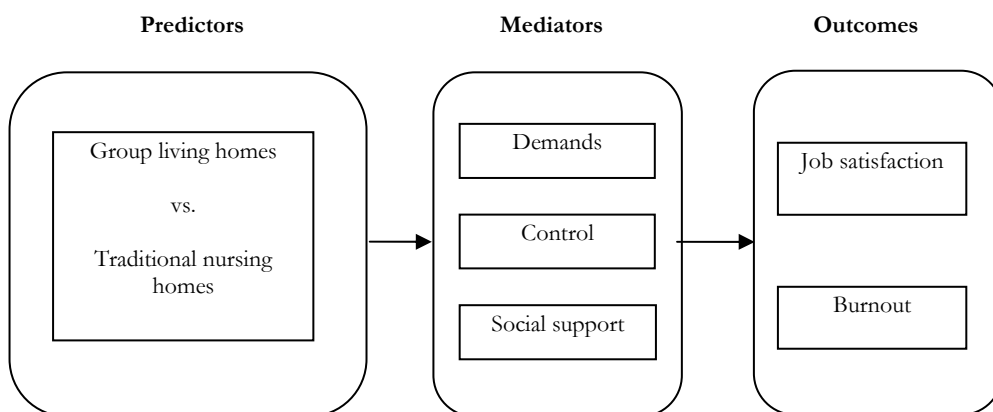
These and other differences in the job characteristics of nursing staff in group living homes may have an impact on their well-being. Till now, the wellbeing of nursing staff in group living homes has hardly been studied. An exception is the study of Alfredson & Annerstedt (1994), which showed that nursing staff of group living homes experienced heightened motivation, job satisfaction and quality of work after they received a training in group living care. It is important to establish whether and if so *why* working in group living increases well-being of staff, because personnel shortage in dementia care is growing almost as fast as the number of people with this syndrome. If group living homes prove to be an attractive work environment, it could motivate more people to work in nursing home care.

A widely used model of occupational stress, the Job-Demand-Control Model, states that two structural psychosocial job characteristics, demands and control, influence job appraisal and well-being (Karasek, 1979). This model was later expanded with a third psychosocial characteristic, social support, which can be divided in social support from a supervisor and social support from co-workers. This resulted in the Job-Demand-Control-Support Model (Johnson & Hall, 1988). The interactions between the three characteristics of the JDCS model are shown in the tension hypothesis and activation hypothesis (De Lange, 2005). The tension hypothesis states that a high level of demands, a low level of control and a low level of social support will lead to negative outcomes (Karasek, 1979), such as reduced job satisfaction and

burnout (Van der Doef & Maes, 1999). An opposite effect can be seen in the activation hypothesis, which states that a high level of control can still lead to positive outcomes such as an increased intrinsic job motivation, even with high demands and low social support (Karasek & Thorell, 1990).

Working in a group living home instead of a traditional nursing home may lead to different levels of the three psychosocial job characteristics of the JDCA-model. For example, working alone or with just one colleague could well increase control, but could also increase demands. Level of social support may be low in group living homes, simply because there are not many colleagues to support each other. According to the activation and tension hypotheses, these differences in work conditions will lead to different levels of well-being, such as job satisfaction and burnout. This study is therefore based on the model shown in figure 1. We investigated job satisfaction and burnout in group living homes and traditional nursing homes as well as the three job characteristics of the JDCA-model (demands, control and social support). We then examined whether these three characteristics explained the relationship between type of home and job satisfaction and burnout in nursing staff. It was hypothesized that in group living homes, a higher level of job satisfaction and a lower level of burnout in group living would be found, because of a higher level of control among nursing staff. Although one may expect that demands in group living homes would be higher as well while the level of social support would be lower than in traditional nursing homes, the higher level of control in group living homes would nevertheless still increase wellbeing.

**Figure 1. Study model**



## **METHODS**

### **Sample**

#### ***Locations***

In the Netherlands, nursing homes are publicly funded institutions in which people with psychogeriatric complaints such as dementia receive separate care from those with somatic complaints. For this study, only psychogeriatric group living homes and psychogeriatric nursing homes or nursing homes with psychogeriatric units were selected.

Furthermore, group living homes and traditional nursing homes had to meet a number of criteria to participate in the study. The eligibility criteria for group living homes were formulated on the basis of a Concept Map (Trochim, 1980), that defined the concept of group living care (Te Boekhorst et al., 2007). Group living homes were included that (a) had a maximum of six residents, (b) had a maximum of six units, (c) were situated more than 200 meters from the nursing home to which they belonged, (d) prepared their own meals and (e) were built more than two years prior to the start of the study.

Twenty group living homes met these criteria, of which nineteen group living homes with 56 units with an average of six residents (range 4-6) per unit agreed to participate. These nineteen group living homes had 336 residents and employed 305 nurses.

The eligibility criteria for traditional nursing homes were formed to ensure that group living homes were to be compared with the best traditional nursing home care the Netherlands already had to offer. This meant that traditional nursing homes had to be built according to the Dutch 1997 Building Regulation for Nursing Homes, as these facilities offer, among other structural improvements, only single bedrooms. Furthermore, to ensure the contrast between group living home care and traditional nursing home care, the latter needed to be large-scale facilities as well. Therefore, only traditional nursing homes with more than 20 residents per unit were included in the study.

Fourteen nursing homes met the two eligibility criteria, of which seven nursing homes with seventeen units with an average of 28 residents (range 20-30) per unit participated. These seven nursing homes had 476 residents and employed 437 nurses.

Both group living homes and nursing homes were located in similar geographic areas. There were participating facilities in urban areas such as Amsterdam and Rotterdam in the West of the Netherlands as well as rural areas in the North and East. Because group living home care is practically non-existent in the South of the Netherlands, traditional nursing homes from this region were excluded from the study.

### **Participants**

Nursing staff were eligible for the study if they performed all care tasks (washing, dressing, bathroom visits, transfers, eating and drinking). 183 nurses in group living and 197 nurses in nursing homes participated, resulting in a response of 60% and 45% respectively.

### **Measures**

The mediators from the JDACS model (demands, control and social support) and one of the outcome variables (job satisfaction) were measured with the Leiden Quality of Work Questionnaire (Van der Doef & Maes, 1999). This questionnaire is based on the JDACS model and the Michigan model (Caplan et al., 1975) and measures eleven job characteristics on a four point scale. Four of these subscales were used in this study. The Work and Time Pressure subscale (Cronbach's  $\alpha = .78$ ) measured demands, with a higher score suggesting lower demands. The Decision Authority subscale ( $\alpha = .72$ ) measured control, in which a higher score indicated a higher level of control. The Social Support Supervisor subscale ( $\alpha = .90$ ) and the Social Support Co-workers subscale ( $\alpha = .82$ ) measured social support, with higher scores again indicating higher levels of social support. A higher score on the four point Job Satisfaction subscale ( $\alpha = .86$ ) indicated a higher level of job satisfaction.

The outcome variable burnout was measured with the Dutch version of the Maslach Burnout Inventory (Maslach & Jackson, 1986), the Utrecht Burnout Scale - C (Schaufeli & Dierendonck, 2000). This scale measures three components of burnout: emotional exhaustion (Cronbach's  $\alpha = .87$ ), depersonalisation ( $\alpha = .50$ ) and decreased personal accomplishment ( $\alpha = .76$ ). Higher scores on a six point scale suggested higher burnout.

### **Procedure**

The outcomes and mediators were assessed using a self-report questionnaire. Managers in the participating group living homes and nursing home wards handed out the questionnaires to nursing staff who met the criterion described above. Because anonymity is of the utmost importance in this kind of research, the nursing staff returned the questionnaires directly to the researchers. To further ensure anonymity the questionnaires could not be traced back to individual units in the group living homes or to individual wards in the traditional nursing homes.

The study was approved by the Metigg, the Medical Ethics Committee of the National Institute of Mental Health and Addiction.

### **Analysis**

Multilevel linear regression analysis was used to study the mediator effect of the three job characteristics of the JDACS-model, demands, control and social support, on job satisfaction and burnout with the widely used method described by Baron & Kenny (1986). A mediation model seeks to identify the mechanism which underlies an observed relationship between a

predictor and an outcome variable through the inclusion of a third variable, the mediator. It is hypothesized that the predictor variables causes the mediator variable, which then causes the outcome variable. In order to assess mediation in this study, multilevel linear regression analysis was performed to study the relationship between the predictor variable institution type, group living homes vs. nursing homes, and the mediators, the three characteristics of the JDCA model demands, control and social support. Next, multilevel linear regression analysis was done to assess the relationship between the predictor variable institution type and the outcome variables job satisfaction and burnout. In the final step, the relationship between institution type and job satisfaction and burnout was studied while the three mediators were added to those regression models. Mediation was present if (a) there was a relationship between institution type and each of the three mediators, if (b) there was a relationship between institution type and the two outcome variables and if (c) the latter relationship weakened or disappeared when the mediators were added.

Model assumptions for regression were verified. Because the outcome variable emotional exhaustion, a component of burnout, was not normally distributed, it was subsequently log-transformed before addition to the regression model.

The demographic variables in table 1 were used to check for confounding in linear regression models (a) and (b). Confounding was considered present when addition of the potential confounder led to a change of ten percent or more in the coefficient of the predictor variable (institution type). Confounders for models (a) and (b) were also added to the relevant linear regression models (c).

## **RESULTS**

### **Characteristics of participants**

Table 1 shows that nursing staff in group living homes were older and had a different education level. There were no differences in sex (almost all participants were female), marital status, number of years employed in institution type and number of contract hours per week.

**Table 1. Characteristics of participants**

	Nursing homes (n = 197)		Group living homes (n = 183)		$\chi^2$
	N	%	N	%	
<b>Sex</b>					0.66
Male	11	5.6	14	7.7	
Female	186	94.4	169	92.3	
<b>Marital Status</b>					5.39
Married	114	57.9	107	58.8	
Living together	40	20.3	24	13.2	
Single	43	21.8	51	28.0	
<b>Education level<sup>a</sup></b>					16.22*
Level 1	0		0		
Level 2	6	3.5	18	11.4	
Level 3	150	86.7	125	79.1	
Level 4	12	6.9	1	0.6	
Level 5	5	2.9	14	8.9	
<b>Employment in institution type</b>					0.63
< 5 years	136	69.0	128	69.9	
5 - 10 years	38	19.3	38	20.8	
> 10 years	23	11.7	17	9.3	
<b>Contract hours per week</b>					13.94
< 22 hours	66	33.5	57	31.2	
22 -29 hours	37	18.8	64	35.0	
> 29 hours	94	47.7	62	33.8	
	<i>M</i>	<i>95%-CI</i>	<i>M</i>	<i>95%-CI</i>	<i>F</i>
<b>Age</b>	37	35 - 40	43	41 - 45	10.79(1, 22)**

\* p < .05

\*\* p < .01

<sup>a</sup> Dutch education levels: level 2 is equivalent to nursing assistant (NA), level 3 to certified nursing assistant (CNA), and level 4 to registered nurse (RN).

### Mediators

As shown in Table 2, linear regression analysis identified significantly different levels of the mediators between the two institution types. Demands were significantly lower in group living homes, while control and social support from co-workers were significantly higher. The mediator social support from the supervisor did not reach significance. Therefore three of the four mediators met the first criterion of mediation stated by Baron & Kenny (1968) mentioned above and were analyzed further.

### Outcome variables

Table 3 indicates that nursing staff in group living experienced significantly more job satisfaction than their colleagues in nursing homes. The three components of burnout differed significantly between the two institution types as well. Emotional exhaustion, depersonalisation

and decreased personal accomplishment were all lower in group living, indicating that there was less burnout in this setting.

**Mediator effect**

When comparing the coefficients in table 3 and 4, one can see that the previously highly significant relationship between institution type and job satisfaction dropped below significance after the mediators were added. This indicates a full mediation. The higher level of job satisfaction in group living could therefore be fully ascribed to the significantly lower level of demands, the significantly higher level of control and the significantly higher level of social support from co-workers in group living homes. Table 3 and 4 also show an increase in the amount of explained variance for job satisfaction after the mediators were added, from 10% to 35%.

Addition of the mediators lead to different effects for each component of burnout. Emotional exhaustion lost significance, indicating a full mediation of the significantly lower level of demands and the significantly higher level of control and social support from co-workers in group living homes. The amount of explained variance for emotional exhaustion increased as well, from 9% to 31%. The relationship between institution type and depersonalisation also dropped below significance after adding the mediators, again indicating a full mediation. However, only the mediators control and social support from co-workers contributed to this mediation effect while the mediator demands was not significant. The relationship between institution type and decreased personal accomplishment weakened but still remained significant after the mediators were added, indicating a partial mediation. Table 4 shows again that while the mediators control and social support from co-workers contributed to this mediation effect, the mediator demands did not. The amount of explained variances for these last two dimensions of burnout increased in these partial mediation models (from 6% to 12% and 6% to 15% respectively), but less than in the full mediation models for job satisfaction and emotional exhaustion.

**Table 2. The effects of institution type on psychosocial job characteristics**

	Nursing homes (n=197)		Group living homes (n=183)		Nursing homes vs. group living homes	
	<i>M</i>	<i>95%-CI</i>	<i>M</i>	<i>95%-CI</i>	<i>B</i>	<i>95%-CI</i>
<b>Demands</b>	2.5	2.4 - 2.6	3.0	3.0 - 3.1	0.55***	0.40 - 0.70
<b>Control</b>	2.9	2.8 - 2.9	3.1	3.1 - 3.2	0.29***	0.20 - 0.38
<b>Social support co-workers</b>	3.0	3.0 - 3.2	3.2	3.2 - 3.3	0.16 <sup>a</sup> **	0.05 - 0.27
<b>Social support supervisor</b>	3.1	2.9 - 3.2	3.1	3.0 - 3.2	0.08	-0.09 - 0.26

\*\*  $p < .01$

\*\*\*  $p < .001$

<sup>a</sup> adjusted for education level

**Table 3. The effects of institution type on job satisfaction and the three components of burnout**

	Nursing homes (n=197)		Group living homes (n=183)		Nursing homes vs. group living homes		
	<i>M</i>	<i>95%-CI</i>	<i>M</i>	<i>95%-CI</i>	<i>B</i>	<i>95%-CI</i>	<i>R<sup>2</sup></i>
<b>Job satisfaction</b>	3.0	2.9 - 3.1	3.3	3.2 - 3.4	0.29 <sup>b</sup> ***	0.18 - 0.46	0.10
<b>Burnout</b>							
Emotional exhaustion	1.7	1.4 - 2.0	1.1	0.9 - 1.2	-0.23 <sup>c</sup> **	-0.34 - -0.11	0.09
Depersonalization	0.8	0.6 - 1.0	0.5	0.4 - 0.6	0.29**	-0.47 - -0.10	0.06
Decreased personal accomplishment	1.6	1.5 - 1.8	1.2	1.1 - 1.3	-0.38***	-0.56 - -0.19	0.06

\*\*  $p < .01$

\*\*\*  $p < .001$

<sup>b</sup> adjusted for age

<sup>c</sup> ln transformed



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**Table 4. Regression models for the mediator effect of the three psychosocial job characteristics on institution type and the three components of burnout**

	Job satisfaction <sup>a, b</sup>			Burnout								
	<i>B</i>	<i>95%-CI</i>	<i>R</i> <sup>2</sup>	Emotional Exhaustion <sup>a, c</sup>			Depersonalization <sup>a</sup>			Decreased personal accomplishment <sup>a</sup>		
	<i>B</i>	<i>95%-CI</i>	<i>R</i> <sup>2</sup>	<i>B</i>	<i>95%-CI</i>	<i>R</i> <sup>2</sup>	<i>B</i>	<i>95%-CI</i>	<i>R</i> <sup>2</sup>	<i>B</i>	<i>95%-CI</i>	<i>R</i> <sup>2</sup>
<b>Nursing homes vs. Group living homes</b>	0.07	-0.07 - 0.21	0.35	-0.00	-0.10 - 0.09	0.31	-0.16	-0.39 - 0.07	0.12	-0.18*	-0.36 - -0.01	0.15
<b>Demands</b>	0.16*	0.02 - 0.30		-0.32***	-0.40 - 0.23		-0.10	-0.31 - 0.12		-0.04	-0.25 - 0.17	
<b>Control</b>	0.33***	0.18 - 0.47		-0.13**	-0.22 - 0.04		-0.19*	-0.35 - 0.02		-0.43***	-0.64 - -0.21	
<b>Social support co-workers</b>	0.36***	0.19 - 0.05		-0.11*	-0.20 - -0.03		-0.21**	-0.36 - -0.07		-0.25*	-0.49 - 0.02	

\*  $p < .05$

\*\*  $p < .01$

\*\*\*  $p < .001$

<sup>a</sup> adjusted for education level

<sup>b</sup> adjusted for age

<sup>c</sup> ln transformed

## **DISCUSSION**

In order to assess the wellbeing of nursing staff in group living homes for older people with dementia, this study examined the Job-Demand-Control-Support model (Karasek, 1979; Johnson & Hall, 1988) in both group living homes and traditional nursing homes. The results indicate that nursing staff in group living homes have a higher job satisfaction and a less burnout than their colleagues in traditional nursing homes, because they have more control, less demands and more social support from their co-workers.

Although the results largely confirm our expectations, the higher level of social support from co-workers in group living homes was surprising. One explanation for this finding may be that social support from co-workers is not so much determined by the sheer quantity of social interactions, but by its quality. High levels of control mean sharing responsibility for the residents with just a few colleagues. Consequently, it seems likely that interactions with these colleagues will revolve around the residents and thus increase social support. Recent research supports this suggestion. Sundin et al. (2006) showed that the organizational characteristic job control has the largest impact on perceived social support. Another explanation may be that working in this relatively innovative form of dementia care increases team spirit, thereby increasing the amount of experienced social support.

The second unexpected result concerning the job characteristics of the JDACS model, is the lower level of demands in group living homes. One explanation for this finding may be that group living homes are not organizations with strict rules and regulations. They focus on the wishes and needs of the individual resident rather than on the tasks that need to be performed. Furthermore, it follows the routine of normal daily life. As a consequence, the staff may perceive less demands.

Another possible explanation for the lower level of demands in group living homes also forms a major limitation of this study. The majority of group living homes in this study have selection criteria for residents. These criteria are diverse, but they often state that a resident cannot be admitted if he or she has severe behavioural problems or needs major assistance in the activities of daily life. Traditional nursing homes never refuse a resident. This may very well lead to a difference in resident population between the two settings, with residents in group living homes generally being in a better physical and cognitive condition. As a consequence, levels of demands in group living homes could be lower. We have not adjusted for the differences in functioning between residents in group living homes and traditional nursing homes, thereby ignoring a possibly powerful confounder. However, the job characteristic demands contributes least to the mediation effect, which would lessen the influence of this potential confounder. Nonetheless, not adjusting for this difference in resident population is a

major limitation of this study, especially because we cannot estimate its direct effects on the variables job satisfaction and burnout.

Another limitation of this study is that we did not measure psychological characteristics of the nursing staff, such as coping style or mastery. It seems likely that these kinds of variables are confounders as well, especially because anecdotal as well as scientific evidence indicates that a specific personality style is needed to work in group living homes (Häggström & Norberg, 1996). Our finding that nursing staff of group living homes were older and somewhat better educated could support this view. On the other hand, a study by Waldenstrom et al. (2003) showed that psychological characteristics do not significantly influence the appraisal of the characteristics of the Job Demand Control Support model. Furthermore, another study showed that individual factors do not have a significant effect on job satisfaction and burnout in psychiatric nurses, a population similar to the participants in this study (Thomsen et al., 1999). This would minimize the effect of these possible confounders on the outcome variables as well. Nevertheless, not all variance in job satisfaction and burnout could be explained by the mediators control, demands and social support. Other variables must therefore also contribute to the higher level of job satisfaction and the lower level of burnout in group living homes. Future research should examine whether these variables are other characteristics of group living homes or indeed personal characteristics of caregivers.

In conclusion, the results of this study suggest that group living homes provide a more attractive psychosocial working environment, resulting in a higher level of well-being of the nursing staff in comparison to traditional nursing homes. However, our data also suggest that a higher level of control in traditional nursing homes could significantly improve well-being of staff in these facilities as well. Although the organisation of a traditional nursing home described earlier might make this more difficult to achieve, it would nevertheless be very important to do so and study its effectiveness. If the results are positive, both group living homes and traditional nursing homes would offer an attractive working environment, which could motivate more people to start a career in dementia care.

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**7**

**GENERAL DISCUSSION**

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## **INTRODUCTION**

Group living home care is an innovative form of nursing home care, created as a reaction on the hospital like setting of traditional nursing homes. In a group living home a small group of people with dementia lives together in a homelike environment leading a life as close to normal as possible. Group living home care was created in the early eighties and gained enormous popularity in the mid and late nineties. Currently, in the Netherlands it is considered the standard for nursing home care. However, prior to the studies of this thesis much uncertainty existed on the concept of group living home care. Moreover, there was no solid scientific evidence that group living home care was actually more beneficial for those involved than traditional nursing home care. This thesis therefore focused on both concept and effects of group living home care.

The purpose of this chapter is fourfold. First, it summarizes the main findings of the studies. Second, several general methodological issues are discussed. Third, implications of the outcomes of this thesis for clinical practice and health policy are discussed. Last, it gives recommendations for further research into group living home care.

## **SUMMARY OF FINDINGS**

The results of the studies presented in this thesis provide answers to two research questions: what is group living home care and what are its effects?

### **What is group living home care?**

Two studies assessed both ideals and reality of group living home care. The ideals of group living home care were conceptualized with the Concept Mapping method (Trochim, 1988), which led to six clusters describing group living home care (ranked according to priority):

1. Residents of group living home care are residents for better or worse
2. In group living home care residents form a normal household
3. In group living home care residents have control over their daily life
4. In group living home care staff is part of the group
5. In group living home care residents form a group
6. A group living home is built as an archetypical house

In the second study, an exploratory questionnaire based on the statements of these clusters was used to assess whether group living homes actually followed their own ideals and by doing so distinguished themselves from modern traditional nursing homes. Results showed that group living homes scored significantly higher on the clusters 'normal household', 'control over daily life', 'staff part of group' and 'residents form a group'. However, group living homes scored significantly lower on the most important cluster of the Concept Map: 'resident for better or

worse'. This could be wholly attributed to the fact that group living homes transfer residents on a regular basis when behavioural problems or care needs grow too extensive while residents of modern traditional nursing home rarely if ever get transferred. The most important statement of the Concept Map – 'one truly speaks of group living home care if it has a fixed staff' – was also not incorporated in group living homes. Staff of group living homes work as often on different units as staff of modern traditional nursing homes do. It can therefore be concluded that group living homes follow the ideals of the Concept Map to a reasonable degree, but in order to fulfil the core ideals of group living home care, they need to offer residents a permanent home and only familiar faces to care for them.

### **What are the effects of group living home care?**

Three studies on the effects of group living home care were presented in this thesis. The first study focused on the effects of group living home care on functioning quality of life and use of psychotropic drugs and physical restraints of residents. After adjustment for differences in baseline characteristics, results showed that residents of group living homes needed less help with ADL and were more socially engaged than residents of modern traditional nursing homes. There were no differences in behavioral problems or cognitive status. Again after adjusting for baseline characteristics, two of the twelve quality of life subscales differed between the groups. Residents of group living homes had more sense of aesthetics and had more to do. While there were no differences in prescription of psychotropic drugs, residents of group living homes had less physical restraints. From these results it can be concluded that group living home care had some beneficial effects on its residents compared to residents of modern traditional nursing homes.

The second study assessed the effects of group living home care on of informal caregivers' psychological distress, conceptualized as caregiver competence, caregiver burden and psychopathology. There were no significant differences between caregiver competence and caregiver burden of informal caregivers of group living homes and modern traditional nursing homes, although there was a trend towards less psychopathology in group living homes after adjustment for confounding. The conclusion therefore is that informal caregivers of residents in group living homes do not have less psychological distress than informal caregivers of residents in regular nursing homes.

The last study focused on the effects of group living home care on job satisfaction and burnout of professional caregivers. Results showed that job satisfaction was higher and burnout was lower in professional caregivers of group living homes than in professional caregivers of modern traditional nursing homes. Furthermore, the psychosocial job characteristics control and social support from co-workers were higher in group living homes,

while demands were lower. Subsequent analyses showed that job satisfaction was fully explained by the difference in these three job characteristics. The three components of burnout were largely explained by these three factors as well, with control and social support having the biggest influence. These results indicate that working in a group living home instead of a modern traditional nursing home has a beneficial effect on the wellbeing of nursing staff, because of a positive difference in psychosocial job characteristics.

## **METHODOLOGICAL CONSIDERATIONS**

The section addresses the following methodological issues: the quasi-experimental design of the studies on residents and informal caregivers, the cross-sectional design of professional caregivers study and the differences in response and attrition rate. Also, a number of limitations of the measurement instruments used in the studies are discussed.

### **Quasi-experimental design**

The studies on the effects of group living home care on residents and their informal caregivers had a quasi-experimental design which lacked randomization. We did not randomize because we felt that family of residents would refuse to participate if they had no choice in type of nursing home care their relative received. Also, admission policy and waiting list administration for nursing home care differs for each region in the Netherlands, making random placement very complex to organize. Finally, group living home care was not as widespread at the start of the studies as it is now, which meant that new residents would have been placed too far from their preferred area.

The decision not to randomize was not without consequences. The three studies on the effects of group living home care revealed differences in baseline characteristics between residents, informal caregivers and professional caregivers of group living homes and modern traditional nursing homes. Residents of group living homes were more often single females who lived at home prior to admission. Moreover, they had a better cognitive status and needed less assistance with ADL. Informal caregivers of residents in group living homes were younger and more often female than informal caregivers in regular nursing homes. Moreover, they had more psychopathology, felt less competent in caring for their relative and had a higher sense of caregiver burden, indicating more psychological distress.

However, in all studies on the effects of group living home care outcome variables were adjusted for confounding baseline differences. Therefore, the reported results are statistically correct. Moreover, distinguished authors such as Zarit & Femia (2008) point out that an Randomized Controlled Trial design, which lessens the influence of confounding variables, is often a suboptimal design for intervention studies on care for people with dementia, or indeed

on care in general. The strict rules of an RCT are not applicable to such real-life, multi-factorial situations and therefore limit the outcomes. In sum, the quasi-experimental design of the effect studies has its faults, but may have merits as well.

### **Cross-sectional design**

The studies on residents and their informal caregivers had a longitudinal design with a baseline measurement to assess the influence of possible confounding variables. The study on professional caregivers was cross-sectional, which meant that the results could only be adjusted for certain confounding demographic variables. Considering the finding that professional caregivers in group living homes were older and had a different education level, it would have been better to have baseline measurements of the outcome variables job satisfaction and burnout as well. However, practical necessity forced us to use a cross-sectional design, as recruiting a sufficient number of new nursing staff and following them for a period of time would have taken much too long.

### **Response rate**

All studies showed a lower response rate in modern traditional nursing homes. This effect was already seen with the selection of research locations, with group living homes having a response of 96%, while 50% of the suitable modern traditional nursing homes agreed to participate. Somewhat smaller differences in response rate were seen in the studies themselves on residents, informal caregivers and professional caregivers. This is not an unusual phenomenon since participating in a control group is less desirable as it often means being compared to what is considered to be new and innovative. It is unclear what kind of bias this difference in response rate has caused, but it could have made the differences between the two groups smaller than they actually were. Traditional nursing homes who participated may have done so because they felt they offered excellent care themselves and thus were up to the challenge.

### **Attrition rate**

As in any kind of research with frail elderly, the attrition rate in our study on residents was high, approximately 21% in six months. This concurs with the yearly survival rate of residents in Dutch nursing homes of 45-50%, which means that on average residents of nursing home care die within two years after admission. The high mortality rate makes longitudinal research into any aspect of nursing home care very difficult.

What is more, there was a trend toward a higher mortality rate in residents of modern traditional nursing homes. Our finding that on admission, residents of modern traditional

nursing homes were older, needed more help in ADL and were in a more advanced stage of dementia as indicated by a lower MMSE-score, may explain this trend. Another, entirely speculative, explanation could be that the beneficial effects of group living home care found in our studies caused its residents to live longer. However, this seems unlikely especially since these effects were modest at best.

### **Measurement instruments**

In the study on the effects of group living home care on residents, cognitive functioning was measured with the Standardized Mini-Mental State Examination, the S-MMSE (Folstein et al., 1975; Molloy et al., 1991). Although we needed an indication of cognitive functioning of residents pre admission, MMSE was administered within two weeks after admission. However, numerous studies indicate that cognitive status is not significantly influenced by transition to a nursing home facility (Engle, 1985; Walker et al., 2007). Therefore, we considered MMSE score shortly after admission to be indicative of cognitive status shortly before admission.

Quality of life was examined with two instruments. The first, the Dementia Quality of Life instrument (DQoL), gives a valid and reliable assessment of six dimensions of quality of life in dementia (Brod, 1990). Although this instrument was originally developed as a direct interview with people with dementia, it was used as a proxy measure in this study. The reason for this was that quality of life needed to be assessed *retrospectively* at baseline, as participants were selected for the study after admission. We felt people with dementia would not be able to do this reliably. However, although caregiver and patient ratings on quality of life can differ substantially, it is not yet known which report is most accurate (Ready et al., 2004). Also, research shows that patient and caregiver ratings at least agree on the factor structure of the DQoL (Ready et al., 2007).

The second quality of life instrument used in this study was the QUALIDEM, a relatively new scale which measures quality of life of residents with dementia in nursing home facilities (Ettema et al., 2007a, b). This scale assesses nine dimensions of quality of life in dementia. However, the three subscales Positive Self Image, Social Isolation and Feeling at Home proved to be not normally distributed even after ln-transformation and were therefore not further analyzed. As a consequence, these aspects of quality of life may have been insufficiently addressed.

### **IMPLICATIONS FOR CLINICAL PRACTICE AND POLICY**

Our studies into the effects of group living home care show that group living homes have a beneficial effect on professional caregivers and, to a somewhat lesser extent, on residents. It is thus a reasonably good alternative for traditional nursing home care.

However, there are a number of caveats to group living home care. First, although the most important ideal of group living home care on the Concept Map is that its residents are there for better or worse, the majority of the group living homes in our studies select and transfer their residents. This evokes the important and much debated question if group living home care is suitable for all people with dementia. Central to this dilemma are two different ideals of group living home care, which are also evident on the Concept Map: autonomy and a sense of control vs. familiarity and hominess. The emphasis on autonomy is also seen in the Swedish model of group living home care for people with dementia (Annerstedt, 1993) and is even more prominent in the Dutch model of group living homes for people with psychiatric disorders and mental disabilities (Wennink, 1989; Otten & Hoekman, 1999). However, when autonomy is the main focus of group living home care for people with dementia, residents may benefit for just a limited period of time. After all, autonomy is intrinsically lost in more advanced stages of the disease. When group living home care uses familiarity and hominess as guiding principles, all residents may benefit, even those in advanced stages of dementia. We would therefore caution group living homes to put too much emphasis on maximizing autonomy for its residents. Rather, it can be integrated into a design where familiarity and hominess are leading. Autonomy can then be offered to those who are able to profit from it, familiarity and hominess are for all.

A second caveat of group living home care is that managers, architects and staff focus too much on the design of the physical environment, while group living home care essentially revolves around the way staff cares for and interact with residents. The outcomes of the Concept Map clearly show that the physical environment is the least important ideal of group living home care, with the lowest ranked cluster on the Concept Map representing it. The five other clusters are about the individual lives of the residents and the collective lives of staff and residents. Having said that, physical design still is an important factor in group living home care: the wrong environment makes practicing group living home care much more difficult for all involved.

As mentioned above, the way professional caregivers care for and interact with residents is critical in group living home care. They have to provide residents with a daily life as normal as possible, in which they have to cook and clean themselves in addition to practicing their nursing skills. They also need to let go of set routines and tailor care to the individual wishes of each resident, which may in fact mean giving person-centered and emotion-oriented care (De Lange, 2004; Finnema et al., 2005). Moreover, group dynamics in group living homes can be difficult at times and nursing staff has to manage these as well. Last but not least, all this has to be done independently, as they often work alone. In sum, working in group living home care may be far from easy. In this context, the low education level of Dutch nursing staff is

alarming, especially since the number of group living homes is still growing. We therefore argue for a better nursing education, in which ample attention is given to caring for people with dementia in general and skills needed in group living home care in particular.

Since the start of these studies in 2003, numerous variations of group living home care have emerged in the Netherlands, forming a continuum from single group living homes with just six residents to as much as 174 residents in 29 group living units within one building (Kenniscentrum Wonen-Zorg, 2010). An advantage of these larger forms of group living home care may be that they are able to offer residents with complex needs more expertise than small group living homes, thereby minimizing the risk of resident transfer when care or behavioural problems grow too extensive. Also, more room to wander and avoid each other in case of altercations might have a positive influence on group dynamics. However, there is a very real danger that the ideals of group living home care will be compromised in such large institutions, where rules and regulations prevail easily. We therefore advise large group living homes to keep the ideals of group living home care in mind with every decision they make. Group living home care was originally designed to deinstitutionalize care for people with dementia and that should remain its ultimate goal.

Finally, our studies did not show a beneficial effect of group living home care on psychological distress of informal caregivers. Rather, informal caregivers of both group living homes and modern traditional nursing homes experienced enormous relief of psychological distress after admission of their relative. This finding does not support federal policy aimed at keeping people with dementia in the care of family members for as long as possible (Ministry of Health, Welfare and Sports, 2010), at least not without ample and expert support. Furthermore, while care burden and perceived care competence of informal caregivers improved after admission of their relative, levels of psychopathology remained high. This is consistent with other findings (Grant et al., 2002; Lieberman & Fisher, 2001; Pot et al., 1997; Stephens et al., 1991) and shows that even after admission of their relative, informal caregivers of people with dementia deserve attention from health care professionals.

## **RECOMMENDATIONS FOR FUTURE RESEARCH**

Considering the enormous rise in popularity and the relatively few studies on its effectiveness, further research into group living home care is urgently needed.

Since residents may live for a (relatively) long time in group living home care, research into its long-term effects is recommended. While our study followed residents and informal caregivers for just six months, a few Swedish studies assessed long(er)-term effects of group living home care. They showed that total burden of caregivers decreased 12 months after admission of their relative in group living home care. However, their degree of isolation was

unchanged and feelings of disappointment even significantly increased (Elmståhl, 1998). Moreover, residents used significantly more medication two years after admission into group living home care (Elmståhl 1998). The author also stresses that residents' depressive symptoms may be underrated and need to be monitored closely. These studies did not compare group living home care with traditional nursing home care and consequently, it is unknown whether these phenomena occur in regular nursing homes as well. However, the negative findings underline the need to further assess the long-term effects of group living home care.

Another aspect of group living home care that urgently needs scientific attention is its cost-effectiveness. Many managers report that group living home care is more expensive than traditional nursing home care, which may hamper its realization. Swedish research into cost-effectiveness of group living home care state that it cost significantly less than traditional nursing home care (Wilmo et al., 1991). However, this study is dated and may be inapplicable in any case as the Dutch health care system probably differs from the Swedish. A thorough cost-effectiveness analysis is therefore indicated.

Group living home care is still becoming increasingly popular internationally. The 'Domus' concept in Great Britain (Lindesay et al., 1992) and the 'Cantou' concept in France (Ritchie et al., 1992) are both forms of group living home care. Japan also has numerous group living homes (Traphagan & Nagasawa, 2008). Recently, research was presented on The Green House, an American small-house nursing home model (Rabig et al., 2006). Results showed that after adjustment for differences in baseline characteristics, residents had a significant better quality of life than regular nursing home care (Kane et al., 2007). Informal caregivers were somewhat less involved with their relative in The Green House, but more satisfied with care (Lum et al., 2008). An international comparison of the concept and effects of these various forms of group living home care would be enlightening and could be beneficial for all involved.

As described above, there now exists a continuum of group living home care in the Netherlands. The studies of this thesis focused on the small form of group living home care, with a maximum of 36 residents in one building. The effects of larger forms of group living home care need to be assessed as well, as these now form the majority of group living homes (Pot & de Lange, 2010). In fact, research on larger forms of group living home care are already underway in the Netherlands (Verbeek et al., 2009). Moreover, studies on the entire continuum of group living home care are ongoing (Pot & de Lange, 2010) and further results are eagerly awaited.



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## **SUMMARY**

*Group living homes for older people with dementia*

## INTRODUCTION

Dementia (literally ‘deprived of mind’) is a generic term for a large number of medical and neurological conditions which come often, but certainly not always, with advancing age. The main features of dementia are loss of function in cognition, emotions and behavior, which has severe consequences for the quality of life for both the sufferer as his or her environment. The number of people with dementia is rising rapidly worldwide. In the Netherlands, on a population of 17 million there are more than 200.000 people with dementia. The expectation is that this number will have risen to over 500.000 in 2050.

The majority of people with dementia are cared for at home. However, due to a combination of factors such as severe behavioral problems or exhaustion of the informal caregiver, admittance into a nursing home is sometimes inevitable. In the Netherlands there are approximately 350 nursing homes for people with somatic as well as psychogeriatric symptoms. It is estimated that six new nursing homes will be have to built each year to house all people with dementia in need of nursing home care in 2050.

In the Netherlands as well as in other countries, nursing home care was traditionally modeled on hospital care. However, in the last decades of the 20<sup>th</sup> century, realization grew that, unlike hospitals, nursing homes needed to serve as *homes* in the literal sense of the word. An institutional setting is particularly unsuited for people with dementia, who have unique needs such a sense of security and easy orientation. As a reaction to this the concept of group living home care arose. In group living home care, a small group of people with dementia live together in a homelike environment leading a life as normal as possible.

Originally developed in Sweden in the late 70s and early 80s, Dutch group living home care followed close behind. The first group living home opened its doors in 1981, after which its popularity increased steadily. However, the real growth did not occur until the last years of the 20<sup>th</sup> century. Nowadays (april 2010), the Netherlands have 432 group living homes with more than 12,000 residents. This corresponds to almost 25% of the nursing home population with psychogeriatric complaints. Moreover, it is an increase of 178% compared to 2005, when there were little over 4,000 people living in group living home care. Indeed, group living home care is now considered to be the preferred type of nursing home care for people with dementia.

Simultaneously with this enormous rise in popularity, uncertainty on the concept of group living home care grew. Perspectives on group living home care differed, with divergent practical consequences. Moreover, there was no solid scientific evidence that group living home care was actually more beneficial for those involved than traditional nursing home care.

The aim of this thesis is therefore twofold. First, it wants to give a full and accurate description of group living home care for people with dementia. Second, the effects of group living home care on residents, informal caregivers and professional caregivers are studied.

## **RESEARCH LOCATIONS**

This thesis consists of five studies. With the exception of the first study, which defined the ideals of group living home care with the Concept Map method, all studies took place in group living homes (experimental group) and traditional nursing homes (control group). Group living homes had to meet five eligibility criteria to participate:

1. A maximum of six residents per unit
2. A maximum of six units
3. Situated more than 200 metres of the nursing home to which they belonged
4. Prepared their own meals
5. Built more than two years prior to the studies

To ensure that group living home care was compared with the best traditional nursing home care the Netherlands already had to offer, participating traditional nursing homes had to meet two eligibility criteria:

1. Built according to the Dutch 1997 Building Regulations for Nursing Homes
2. A minimum of 20 residents per unit

Twenty group living homes and fourteen traditional nursing homes met these criteria, of which nineteen and seven participated in the studies.

## **FINDINGS**

The **second chapter** of this thesis presents a study which defines the ideals concept of group living home care with the Concept Mapping method. Seventeen experts from different backgrounds formulated 91 statements about group living home care. Next, these statements were ranked according to priority (most important statement: group living home care needs a fixed nursing staff) and according to content. This led to a Concept Map with six clusters, spread over two dimensions: care versus living (horizontal axis) and individual versus environment (vertical axis). The six clusters were (ranked according to priority):

1. Residents of group living home care are residents for better or worse
2. In group living home care residents form a normal household
3. In group living home care residents have control over their daily life
4. In group living home care staff is part of the group
5. In group living home care residents form a group
6. A group living home is built as an archetypical house

Five of these clusters centred around the arrangements of the individual lives of the residents and the collective lives of residents and staff, while only one held statements about the physical characteristics of a group living home. Therefore, it can be concluded from this Concept Map



### *Summary*

that group living home care is not so much determined by the physical characteristics but by the organisational features of the care context.

The **third chapter** describes a study investigating whether group living homes practice the ideals of group living home care and by doing so distinguish themselves from modern traditional nursing homes. An exploratory questionnaire was designed based on statements of the Concept Map described above and subsequently filled in by managers of 17 group living homes and 16 units of traditional nursing homes. Results show that group living homes scored significantly higher on the subscales normal household', 'autonomy in daily life', 'staff part of group' and 'residents form a group'. However, group living homes scored significantly lower on the most important subscale of the Concept Map: 'resident for better or worse'. They also scored lower on the most important statement of the Concept Map which states that each unit of a group living home needs to have a fixed staff. Therefore, the conclusion was that group living homes follow the ideals of the Concept Map to a reasonable degree, but in order to fulfil the core ideals of group living home care, they need to offer residents a permanent home and only familiar faces to care for them.

The **fourth chapter** described a study investigating the effects of group living homes on quality of life and functioning of people with dementia. It had a quasi-experimental design with a baseline measurement on admission and an effect measurement six months later. Participants were 67 group living home residents and 97 nursing home residents. DQOL and QUALIDEM measured quality of life, functional status was examined with MMSE, IDDD, RMBPC, NPI-Q and RISE from RAI. Use of psychotropic drugs and physical restraints was also assessed. Linear and logistic regression analyses analyzed the data.

After adjustment for differences in baseline characteristics, residents of group living homes needed less help with ADL and were more socially engaged. There were no differences in behavioral problems or cognitive status. Also after adjusting, two of the twelve quality of life subscales differed between the groups. Residents of group living homes had more sense of aesthetics and had more to do. While there were no differences in prescription of psychotropic drugs, residents of group living homes had less physical restraints. The conclusion is that group living homes had some beneficial effects on its residents, but traditional nursing homes often performed on the same level.

The **fifth chapter** presents a study investigating the effects of group living home care on the psychological distress of informal caregivers. 67 informal caregivers of group living home residents and 99 informal caregivers of nursing home residents filled in a questionnaire upon

admission of their relative (baseline measurement) and six months later (effect measurement). Linear and logistic regression analyses were performed on three outcomes of psychological distress: psychopathology, caregiving competence and caregiver burden.

There were no significant differences in caregiver competence and caregiver burden between informal caregivers of residents in group living homes and those in nursing homes, although there was a trend towards less psychopathology in group living homes after adjustment for confounding. Informal caregivers of residents in group living homes do not have less psychological distress than informal caregivers of residents in traditional nursing homes. Although there was a trend towards less psychopathology in informal caregivers of group living homes, the amount of symptoms remained very high in both caregiver groups. This means that the psychological well-being of caregivers deserves the continuing attention of health care providers, also after admittance of their relative in a nursing home facility.

In the **sixth chapter**, a cross-sectional study is described on the effects of group living home care on professional caregivers. 183 professional caregivers of the participating group living homes and 197 professional caregivers of the participating traditional nursing homes assessed their job satisfaction and symptoms of burnout, as well as three psychosocial job characteristics demands, control and social support. Multilevel linear regression analysis was used to study the influence of these three job characteristics on job satisfaction and burnout.

Results showed that job satisfaction was higher and burnout was lower in professional caregivers of group living homes than in professional caregivers of modern traditional nursing homes. Furthermore, the psychosocial job characteristics control and social support from co-workers were higher in group living homes, while demands were lower. Subsequent analyses showed that job satisfaction was fully explained by the difference in these three job characteristics. Symptoms of burnout were largely explained by these three factors as well, with control and social support having the biggest influence. These results indicate that working in a group living home instead of a modern traditional nursing home has a beneficial effect on the wellbeing of nursing staff, because of a positive difference in psychosocial job characteristics.

## **DISCUSSION**

The **seventh** chapter summarizes the results of the studies in this thesis, discusses several methodological issues and gives recommendations for clinical practice and future research.

The studies on the effects of group living home care had a quasi-experimental design which lacked randomization. As a consequence, there were large differences in baseline characteristics between residents, informal caregivers and professional caregivers of group living homes and

### *Summary*

modern traditional nursing homes. However, because all results were statistically adjusted for confounding baseline differences, the reported outcomes are correct.

The baseline differences between residents of group living home care and traditional nursing home care indicate a clinical issue: is group living home care suitable for all people with dementia? Central to this dilemma are two different ideals of group living home care, also seen on the Concept Map: autonomy and control vs. a sense of familiarity and hominess. When autonomy is the main focus, residents may benefit for just a limited period of time. When group living home care uses familiarity and hominess as guiding principles, all residents may benefit, even those in advanced stages of dementia. Group living homes should therefore integrate autonomy in a design where the latter principles are leading. Autonomy can then be offered to those who are able to profit from it, familiarity and hominess are for all.

The results of the study on the effects of group living home care on professional caregivers show that working in a group living home offers a high level of job satisfaction. However, it may be far from easy. They often work alone. Also, they have to provide residents with a daily life as normal as possible, in which they have to cook and clean themselves in addition to practicing their nursing skills. Moreover, group dynamics in group living homes can be difficult at times and nursing staff has to manage these as well. In this context, the low education level of Dutch nursing staff is alarming, especially since the number of group living homes keeps on growing. A better nursing education is needed, in which ample attention is given to caring for people with dementia in general and skills needed in group living home care in particular.

Since the start of these studies in 2003, numerous variations of group living home care have emerged in the Netherlands, forming a continuum from single group living homes with just six residents to as much as 174 residents in 29 group living units within one building. An advantage of these larger forms of group living home care may be that they are able to offer residents with complex needs more expertise than small group living homes, thereby minimizing the risk of resident transfer when care or behavioural problems grow too extensive. Further research needs to assess this hypothesis, and is in fact already doing so.

However, a real danger of such large settings is that the ideals of group living home care will be compromised. Rules and regulations prevail easily in large institutions. We therefore advise large group living homes to keep the ideals of group living home care in mind with every decision they make. Then group living home care will continue to help improve the quality of life of people with dementia.

*Group living homes for older people with dementia*

## **SAMENVATTING**

*Group living homes for older people with dementia*

## INTRODUCTIE

Dementie is een verzamelnaam voor verschillende hersenziekten, die gekenmerkt worden door stoornissen in cognitie, stemming en gedrag. Dementie heeft daarmee verregaande consequenties voor de kwaliteit van leven van de persoon met dementie en zijn of haar omgeving. Met de toenemende vergrijzing in Nederland groeit ook het aantal mensen met dementie in hoog tempo. Er zijn nu al meer dan 200.000 mensen met dementie en verwacht wordt dat dit aantal in 2050 gestegen is tot 500.000.

De meeste mensen met dementie worden thuis verzorgd. Wanneer dat echter niet meer mogelijk is - meestal vanwege uitputting van de mantelzorger -, volgt een opname in een verpleeghuis. In Nederland zijn momenteel zo'n 350 verpleeghuizen. Dat zijn er bij lange na niet genoeg om de komende decennia alle mensen met dementie een plaats te kunnen bieden. De Gezondheidsraad heeft berekend dat er tot 2050 elk jaar zes verpleeghuizen moeten worden gebouwd om deze toename het hoofd te kunnen bieden.

De Nederlandse verpleeghuiszorg is jarenlang gebaseerd geweest op het ziekenhuismodel, waarin lange gangen, meerpersoonskamers en personeel in witte uniformen het beeld bepaalden. Langzaamaan groeide echter het besef dat verpleeghuizen vooral een *thuis* moeten zijn voor de mensen die er, vaak voor de rest van hun leven, verblijven. Bovendien hebben mensen met dementie zeer specifieke behoeftes, zoals herkenbaarheid en geborgenheid, die door het wonen in een ziekenhuisomgeving niet vervuld worden. Kortom, het werd tijd dat het medische model in de verpleeghuiszorg voor mensen met dementie vervangen werd door een model waarin het wonen centraal stond.

Kleinschalig wonen is een innovatie die voortkomt uit dit model. In een kleinschalige woonvorm leeft een kleine groep mensen met dementie met elkaar samen in een huiselijke omgeving, waar zij een zo normaal mogelijk dagelijks leven leiden. Het is oorspronkelijk ontwikkeld in Zweden, waar eind jaren zeventig en begin jaren tachtig de eerste kleinschalige woonvormen werden opgestart. In Nederland opende de eerste kleinschalige woonvorm eveneens begin jaren tachtig zijn deuren, maar kleinschalig wonen werd pas midden en eind jaren negentig echt populair. Op dit moment (april 2010) zijn er 432 kleinschalige woonvormen in Nederland, waarin ongeveer 12.000 mensen met dementie wonen. Dit correspondeert met ongeveer 25% van het totale aantal verpleeghuisbewoners, een toename van 178% ten opzichte van 2005.

Analoog aan de enorme toename van kleinschalige woonvormen ontstond echter ook steeds meer onduidelijkheid over de inhoud van het concept. Er bleken verschillende opvattingen te bestaan, waarbij het accent dan weer op zelfstandigheid, dan weer op geborgenheid lag. Bovendien was er nog nauwelijks wetenschappelijk bewijs dat kleinschalig

wonen echt beter was voor de betrokkenen dan de traditionele verpleeghuiszorg, een voor de overheid noodzakelijke voorwaarde om kleinschalig wonen te stimuleren.

Het doel van dit proefschrift is dan ook tweeledig. Ten eerste wil het een goede omschrijving van kleinschalig wonen geven. Daarnaast worden de effecten van kleinschalig wonen onderzocht op de mensen die er het meest bij betrokken zijn: de bewoners, hun mantelzorgers en hun professionele verzorgenden.

### **ONDERZOEKSLOCATIES**

In dit proefschrift staan vijf studies beschreven. Met uitzondering van het eerste onderzoek, waarin een groep experts met behulp van de methode Concept Mapping het begrip kleinschalig wonen inhoud gaf, vonden deze alle plaats in kleinschalige woonvormen (de experimentele groep) en moderne traditionele verpleeghuizen (de controlegroep). Om ervoor te zorgen dat de kleinschalige woonvormen ook daadwerkelijk kleinschalig van aard waren, moesten zij aan de volgende vier criteria voldoen:

1. Hoogstens zes bewoners per woning
2. Meer dan 200 meter van het verpleeghuis
3. Clustering van maximaal zes woningen
4. Dagelijks zelf koken

Om de vergelijking met kleinschalig wonen zo correct mogelijk te laten verlopen, moesten de verpleeghuizen modern (d.w.z. evenals de kleinschalige woonvormen met eenpersoonskamers) en grootschalig zijn. Daarom golden voor deze groep de volgende twee criteria:

1. Gebouwd volgens de bouwmaatstaf van het College bouw zorginstellingen uit 1997
2. Afdelingen met minimaal 20 bewoners

Twintig kleinschalige woonvormen en veertien moderne traditionele verpleeghuizen voldeden aan deze voorwaardes. Daarvan waren respectievelijk negentien en zeven bereid om aan de onderzoeken deel te nemen.

### **BEVINDINGEN**

In het **tweede hoofdstuk** van dit proefschrift wordt met behulp van de methode Concept Mapping het begrip kleinschalig wonen nader omschreven. Zeventien experts uit verschillende vakgebieden rondom de verpleeghuiszorg formuleerden 91 uitspraken over kleinschalig wonen. Vervolgens rangschikten zij deze uitspraken op volgorde van belangrijkheid (belangrijkste uitspraak: 'er is pas sprake van kleinschalig wonen als er een vast team medewerkers is') en op inhoudelijke samenhang. Dit leidde tot een landkaart - de Concept Map - met daarop zes clusters, die verdeeld werden over de dimensies individu vs. omgeving (x-as) en wonen vs. zorg (y-as). Deze zes clusters waren, in volgorde van belangrijkheid:



### *Samenvatting*

1. In kleinschalig wonen zijn bewoners in voor- en tegenspoed bewoners,
2. In kleinschalig wonen vormen bewoners een gewoon huishouden,
3. In kleinschalig wonen hebben bewoners zelf de regie over hun dagelijks leven,
4. In kleinschalig wonen zijn de verzorgenden onderdeel van de groep,
5. In kleinschalig wonen vormen bewoners een groep,
6. Een kleinschalige woonvorm is een archetypisch huis.

Op basis van de ligging van de clusters op de x- en y-as kunnen deze clusters in drie thema's worden samengevat die samen kleinschalig wonen bepalen. Het eerste thema beschrijft het gezamenlijke leven van bewoners en verzorgenden in kleinschalig wonen en bevat cluster 2, 4 en 5. Het tweede thema beschrijft het individuele leven van de bewoners in kleinschalig wonen en bevat cluster 1 en 3. Het derde thema beschrijft de fysieke kenmerken van kleinschalig wonen en bestaat uit cluster 6.

De uitkomsten van de Concept Map laten dientengevolge zien dat kleinschalig wonen niet zozeer bepaald wordt door de fysieke omgeving, maar veel meer door de manier waarop de zorg rondom de bewoners georganiseerd wordt.

In het **derde hoofdstuk** wordt een onderzoek beschreven naar de mate waarin de idealen van kleinschalig wonen ook in de dagelijkse praktijk van kleinschalig wonen onderscheidend zijn. Een aantal uitspraken uit de zes clusters van de Concept Map uit hoofdstuk 2 diende als basis voor een exploratieve vragenlijst. Deze vragenlijst werd ingevuld door teamleiders of zorgmanagers van de deelnemende kleinschalige woonvormen en van de deelnemende afdelingen van de moderne traditionele verpleeghuizen.

Vergelijking van de resultaten van de kleinschalige woonvormen en de verpleeghuizen laat zien dat kleinschalige woonvormen significant hoger scoorden op het cluster 'gewoon huishouden', 'regie over het dagelijks leven', 'verzorgenden onderdeel van de groep' en 'bewoners vormen een groep'. Kleinschalige woonvormen scoorden echter significant lager op het cluster 'bewoners in voor- en tegenspoed', nota bene het belangrijkste cluster uit de Concept Map. Dit werd verklaard door het feit dat kleinschalige woonvormen vaak bewoners overplaatsen bij te ernstige gedragsproblemen of te grote zorgbehoefte. Bewoners van traditionele verpleeghuizen worden zelden of nooit overgeplaatst. Een andere opvallende bevinding was dat de belangrijkste uitspraak van de Concept Map – in kleinschalig wonen moet een vast team medewerkers zijn – in de dagelijkse praktijk niet onderscheidend was voor kleinschalig wonen. Verzorgenden van kleinschalige woonvormen werkten net zo vaak op verschillende units als verzorgenden in verpleeghuizen.

De conclusie van dit onderzoek luidt dan ook dat kleinschalige woonvormen de idealen van kleinschalig wonen redelijk goed volgen. Echter, om de kernidealen van kleinschalig

wonen te behouden, moeten zij bewoners een permanent thuis bieden met alleen vertrouwende gezichten om voor hen te zorgen.

Het **vierde hoofdstuk** beschrijft de effecten van kleinschalig wonen op de bewoners. Aan dit onderzoek deden 67 nieuwe bewoners van de hierboven beschreven kleinschalige woonvormen en 97 nieuwe bewoners van de hierboven beschreven moderne traditionele verpleeghuizen mee. Onderzocht werden kwaliteit van leven en functioneren, onderverdeeld naar hulp bij Activiteiten in het Dagelijks Leven (ADL), sociale betrokkenheid en gedragsproblemen. Dit vond plaats door middel van een vragenlijst, die bij opname door de mantelzorger werd ingevuld (basismeting) en zes maanden na opname door de meeste betrokken verzorgende werd ingevuld (effectmeting). Op dit meetmoment werd ook het gebruik van vrijheidsbeperkende maatregelen en psychofarmaca vastgesteld.

Na correctie voor verschillen bij opname bleek dat bewoners van kleinschalig wonen minder hulp bij ADL nodig hadden en meer sociaal betrokken waren. Ook hadden zij een betere score op twee van de twaalf schalen die kwaliteit van leven meten. Bovendien hadden bewoners van kleinschalig wonen, wederom na correctie voor verschillen bij opname, minder vrijheidsbeperkende maatregelen. Er waren geen verschillen in gedragsproblemen of het gebruik van psychofarmaca.

Uit deze resultaten kan worden afgeleid dat kleinschalig wonen wel wat beter is voor mensen met dementie, maar dat traditionele verpleeghuizen op veel uitkomstmaten op hetzelfde niveau presteren. Toekomstige verpleeghuiszorg voor mensen met dementie moet dan ook misschien bestaan uit het beste dat deze beide vormen te bieden hebben.

In het **vijfde hoofdstuk** worden de effecten van kleinschalig wonen op mantelzorgers besproken. Mantelzorgers van nieuwe bewoners van kleinschalige woonvormen en traditionele verpleeghuizen uit het bovenstaande onderzoek werd gevraagd om een vragenlijst in te vullen. Dit gebeurde bij opname van hun familielid (basismeting) en zes maanden na opname (effectmeting). De vragenlijst onderzocht psychische gezondheid, ervaren zorgbelasting en ervaren zorgcompetentie.

Na correctie voor verschillen tussen de mantelzorgers bij opname bleek dat er geen significante verschillen waren tussen de psychische gezondheid, ervaren zorgbelasting en ervaren zorgcompetentie van mantelzorgers van bewoners van kleinschalig wonen en moderne traditionele verpleeghuizen. Wel was er een trend richting een betere psychische gezondheid bij mantelzorgers van bewoners in kleinschalig wonen. Hoewel alle uitkomstmaten in de twee groepen mantelzorgers aanzienlijk verbeterden na opname van hun familielid, bleef de psychische gezondheid in beide groepen zorgwekkend.

### *Samenvatting*

Uit deze resultaten kan worden geconcludeerd dat mantelzorgers van mensen met dementie ook na opname van hun familielid – in welk type verpleeghuiszorg dan ook – de aandacht blijven verdienen van zorgprofessionals.

Het **zesde hoofdstuk** beschrijft de effecten van kleinschalig wonen op verzorgenden. In een cross-sectionele studie werd onderzocht of er verschillen waren in arbeidstevredenheid en de drie symptomen van burnout: emotionele uitputting, depersonalisatie en ervaren verminderde competentie. Tevens werd onderzocht of verschillen in drie psychosociale werkkenmerken - ervaren werkeisen, autonomie en sociale steun - de verschillen in werktevredenheid en burnout symptomen konden verklaren. Het onderzoek vond plaats door middel van een vragenlijst, die door 183 verzorgenden van de kleinschalige woonvormen en 197 verzorgenden van de traditionele verpleeghuizen ingevuld werd.

De resultaten lieten zien dat verzorgenden van kleinschalige woonvormen meer arbeidstevredenheid en minder symptomen van burnout hadden dan hun collega's in moderne traditionele verpleeghuizen. Daarnaast ervoeren verzorgenden van kleinschalige woonvormen lagere werkeisen, meer autonomie en meer sociale steun. Het verschil in arbeidstevredenheid werd volledig verklaard door de verschillen in de deze drie psychosociale werkkenmerken. Hetzelfde gold voor het burnout symptoom emotionele uitputting. Het burnout symptoom depersonalisatie werd ook volledig verklaard, maar alleen door de verschillen in autonomie en sociale steun. Het burnout symptoom ervaren verminderde competentie werd slecht gedeeltelijk verklaard en dan alleen door de werkkenmerken autonomie en sociale steun.

Uit deze resultaten kan worden geconcludeerd dat werken in een kleinschalige woonvorm positieve effecten heeft op het welzijn van verzorgenden. Dat wordt met name verklaard doordat zij in kleinschalig wonen lagere werkeisen, meer autonomie en meer sociale steun ervaren.

### **DISCUSSIE**

Het **zevende hoofdstuk** vat de belangrijkste bevindingen van dit proefschrift nog eens samen, plaatst een aantal methodologische kanttekeningen bij de verschillende onderzoeken en bespreekt aanbevelingen voor de klinische praktijk en toekomstig wetenschappelijk onderzoek.

De drie onderzoeken naar de effecten van kleinschalig wonen hadden een quasi-experimentele opzet, waarin om praktische en ethische redenen geen randomisatie van respondenten heeft plaatsgevonden. Het gevolg daarvan was dat er grote baseline verschillen waren tussen bewoners, mantelzorgers en verzorgenden van kleinschalige woonvormen en moderne

traditionele verpleeghuizen. Omdat hiervoor in de data analyses echter statistisch is gecorrigeerd, zijn de gerapporteerde onderzoeksresultaten accuraat.

De bij opname gevonden verschillen tussen bewoners van kleinschalig wonen en verpleeghuizen werpen echter wel een belangrijk klinisch dilemma op: is kleinschalig wonen geschikt voor alle mensen met dementie? Voor het antwoord op deze vraag moeten we terug naar de twee soms conflicterende idealen van kleinschalig wonen die ook op de Concept Map naar voren komen: autonomie en zelfstandigheid vs. huiselijkheid en geborgenheid. Wanneer in kleinschalig wonen autonomie van de bewoners in op de voorgrond staat, zal een beperkte groep bewoners er voor een beperkte tijd van kunnen profiteren. Huiselijkheid en geborgenheid zijn echter cruciaal voor (bijna) alle mensen met dementie. Wij dringen er dan ook op aan om het streven naar autonomie te integreren in een ontwerp waarin huiselijkheid en geborgenheid leidend zijn. Autonomie kan dan worden aangeboden aan hen die daar profijt van hebben, huiselijkheid en geborgenheid zijn voor iedereen.

Uit de resultaten beschreven in dit proefschrift blijkt dat werken in kleinschalig wonen voor verzorgenden veel arbeidstevredenheid biedt. Dat wil echter niet zeggen dat het een eenvoudige baan is. De grote zelfstandigheid, de verscheidenheid aan taken en het hanteren van de groepsdynamiek vergen veel van verzorgenden. Wij willen daarom aandringen op een structurele betere opleiding voor verzorgenden, met daarin veel meer aandacht voor werken met mensen met dementie in het algemeen en werken in kleinschalig wonen in het bijzonder.

Sinds de start van de studies van dit proefschrift is er in Nederland een grote verscheidenheid aan kleinschalige woonvormen ontstaan, die een continuüm vormen van zes bewoners in een eengezinswoning tot 174 bewoners in 29 groepen in één gebouw. Een voordeel van grotere vormen van kleinschalig wonen kan zijn dat zij bewoners met een ingewikkelde zorgvraag of moeilijk hanteerbare gedragsproblemen meer expertise kunnen bieden dan de kleine vormen. Verder onderzoek, dat momenteel reeds plaatsvindt, moet dit uitwijzen.

Een groot risico is echter dat in zulke grote kleinschalige woonvormen de regels van de organisatie weer de boventoon gaan voeren. We zouden grote voorzieningen waar kleinschalige zorg wordt aangeboden dan ook aanraden om de idealen van kleinschalig wonen zeer ter harte te nemen. Alleen zo zal deze innovatie daadwerkelijk een bijdrage blijven leveren aan de kwaliteit van leven van mensen met dementie.

## **DANKWOORD**

*Group living homes for older people with dementia*

### *Dankwoord*

De totstandkoming van dit proefschrift heeft heel wat voeten in aarde gehad. Daarom wil ik allereerst mijn promotoren, Jan Eefsting en Anne Margriet Pot, en mijn co-promotoren, Marja Depla en Jacomine de Lange, heel erg bedanken voor hun geduld en vertrouwen de afgelopen jaren.

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*Group living homes for older people with dementia*

## **ABOUT THE AUTHOR**



Selma te Boekhorst was born in Veenwouden in Friesland, the Netherlands on the 13th of May 1977. She attended the Stedelijk Gymnasium in Leeuwarden, where she graduated in 1995. From 1995 to 1997 she studied the violin at the Prins Claus Conservatorium in Groningen and the Conservatorium van Amsterdam in Amsterdam, but a chronic tendon injury prevented her from continuing her music studies. After working in Switzerland for a year, she enrolled in the study Psychology at the Utrecht University in 1998, where she specialized in neuropsychology. After graduating in 2003, she started her PhD project resulting in this thesis at the Netherlands Institute for Mental Health and Addiction and the Institute for Extramural Medicine of the VU University Medical Centre. During this time she also completed the Postgraduate Epidemiology Programme of the latter institute.