## Group living homes for older people with dementia

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# SUMMARY

## 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 20th 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 20th 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

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

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.