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## Seize the day!

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## Summary

*Seize the day!*

**Chapter 1** is the general introduction to this thesis. There is increasing awareness of the potential influence of daily occupation and activity involvement on the wellbeing of people with dementia living in care homes. However, researchers consistently find a lack of activity involvement in care homes for people with dementia. This thesis addresses this anomaly.

Over the past decades, an immense transformation has taken place in nursing home care for people with dementia. Whereas until the 1970's, nursing home care had a mainly medical focus, seeing residents as patients who needed treatment in a hospital-like setting, it is now recognized that maximizing the residents' psychological wellbeing should be the center focus of the care and guidance that people living with dementia receive. 'Psychological wellbeing' is generally perceived as the most important component of quality of life, and has been described in terms of positive mood, happiness, enjoyment and satisfaction.

With the Healthy Aging model that was published in 2015, the World Health Organization (WHO) has explicitly called upon the care environment to take responsibility for people's wellbeing. The Healthy Aging model states that diseases such as depression, and geriatric syndromes like dementia, comorbidity and other health related factors do not determine the wellbeing of older people, rather the extent to which the reduction in capacities as a result of these diseases are, or are not, compensated by the environment.

In the Netherlands, small-scale group living home care has, for some time, been seen as an important way to influence wellbeing through the environment. With small-scale group living home care, residents live together in groups of 6 to 8, and receive care and guidance in a recognizable, home-like environment. Today, it is estimated that 20 to 30 percent of care homes are arranged in a group living home care manner. However, research has not produced convincing results pointing at a higher quality of life for residents of group living home facilities as compared to residents of traditional nursing home facilities. This anomaly has led to the insight that altering the physical environment does not necessarily generate high quality care as provided by care staff. Care that is focused on the fulfillment of psychological needs might play a more important role in maximizing the residents' wellbeing.

One of these basic human needs is engagement in life in a meaningful way, or meaningful occupation. People with dementia are increasingly less able to fulfill this need themselves, and must rely upon the social environment to involve them in daily activities.

While awareness has increased in the dementia care sector of the need for occupation, care homes generally do not yet seem to have succeeded in providing activities to an accepted level. This is often expressed by people with dementia and their representatives, and also reflected in the research. Activity provision is often perceived as a secondary task for care professionals. And activity programs and interventions as proposed in the literature, generally require a financial investment for implementation in care practice.

With this thesis, we have tried to provide more insight on this matter by studying the relationship between daily activity involvement and wellbeing, as well as the barriers and enabling factors regarding the provision of activities in care home settings. To generate this information, the following research questions were studied: 1) *To what extent are involvement in activities and daily occupation related to the quality of life and wellbeing of people with dementia living in care*



*homes? Is this relationship different for people at varying stages of dementia? And 2) Which characteristics concerning residents, environment and staff influence involvement in activities and daily occupation?*

**Chapter 2** describes the overall design of the Living Arrangements for people with Dementia (LAD-)study. The LAD-study is an ongoing Monitor of developments in Dutch nursing home care for people with dementia, and of the consequences of environmental and organizational characteristics on the wellbeing of residents, family and staff. Data collection takes place every two years. The first measurement cycle of the LAD-study took place in 2008-2009, in which 136 care homes participated -representing different types of Dutch nursing home care. In the second measurement cycle (2010-2011), 144 care homes participated. Some of these homes were the same, and some different, from the first cycle. In the third measurement cycle in 2013-2014, 50 care homes were included. The in-depth study was performed in 2010 among 10 care homes that participated in the first measurement cycle, in order to gain more knowledge on the facilitators and barriers that determine good dementia care. In this study, data from all three measurement cycles were used, as well as data from the in-depth study.

In **chapter 3**, the daily occupation of care home residents with dementia was examined, as well as their levels of wellbeing when involved in different types of occupation. Data from the in-depth study were used (2010). For a period of six hours, Dementia Care Mapping observations were performed on 56 residents representing 10 care homes.

We found that reminiscence, leisure, expression, and vocational occupation seem to be of greater value for residents' wellbeing than other types of occupation. We labeled these types of occupation 'wellbeing-enhancing'. It must be noted that physical exercise, a type of occupation that is frequently found to positively influence wellbeing, did not occur during our observations. We found that the wellbeing-enhancing types of occupation were rarely offered. On average, residents were involved in wellbeing-enhancing occupation for less than 5% of the observed timeframes. There was considerable variation, however, between the participating care homes. Whereas the residents of one care home were engaged in wellbeing-enhancing occupation for 25% of the observed timeframes on average, this was only 1% for the residents of a second care home.

Care homes in which residents were regularly engaged in wellbeing-enhancing occupation more often had a homelike atmosphere, supported social interaction through the environment, and did not have a central activity program.

The findings express the need to evaluate the use of time in daily care practice. With the right types of occupation, one might reach higher levels of wellbeing among residents with dementia than is currently the case. An example would be to focus on reminiscence instead of the usual small talk.

In this study, staff ratio was not found to be clearly related to time spent in wellbeing enhancing occupation. This suggests that the occupation of residents depends on how care workers use the available time and how staff are equipped to engage residents in wellbeing-enhancing activities. Training on involving residents in occupation by using the stimuli that are (or should be) present in the residents' living environment might be a key answer to improving their wellbeing.

In **chapter 4**, our large-scale study on the relationship between duration of involvement in activities and different outcomes of quality of life is described. Data were obtained by structured observational questionnaires that were filled in by care staff in the period 2010-2011. For 1,144 residents representing 144 care homes, data on involvement in a wide range of activities and

quality of life were available.

It was found that, on average, residents were involved in activities for less than three hours during a three day period. For reliability reasons, listening to music, watching television and having a conversation were not included. There was much variation between individuals in duration of activity involvement: 38.8% of the residents were involved for less than one hour over three days (defined as low activity involvement); 30.2% were involved for one to three hours (medium activity involvement); and 31% for more than three hours (high activity involvement).

More activity involvement was related to higher outcomes of quality of life in terms of a better care relationship, higher positive affect, less restless behavior, better social relations, and more often having something to do. These results likewise applied to people with severe dementia.

Activity involvement also had negative outcomes. More activity involvement was related to lower positive self-image as compared with medium and low activity involvement. Furthermore, high activity involvement was related to more social isolation as compared with low activity involvement. This shows that activity provision is a complex task, and should be carefully adjusted to a resident's preferences and capabilities.

The sole contribution of activity involvement to residents' quality of life appeared to be relatively minor in this study - it explained a small amount of the difference in quality of life found between residents of the low, medium and high activity involvement groups. Nonetheless, our findings are promising, since overall, residents were involved in activities to only a limited extent. The 'involvement for over one hour a day' was defined as 'higher activity involvement'. It can be expected that if low activity involvement were compared with truly high activity involvement (for example involvement for four hours a day), the relative impact on quality of life would be much greater. The fact that activity involvement was related to several domains of quality of life, as proposed in several quality of life theories, illustrates the diverse impact and meaning it may have for someone's wellbeing.

The measurement instrument used in this study, the *Activity Pursuit Patterns*, proved to be difficult in practice, presumably because of its retrospective character. Owing to incomplete data, 17% of the resident sample could not be studied. In addition, care staff found it hard to discriminate passive from active activity involvement, with consequences for the validity and reliability of our study results.

In **chapter 5**, the level of occupation among care home residents with dementia and its relationship with wellbeing for these residents was studied once more, while taking their stage of dementia into account. Based on our experiences with the measurement instruments that were used in previous studies, a new observational method was applied as a potentially feasible alternative instrument for monitoring occupation in this study population. With this method, care staff members observed the occupation and wellbeing of two residents, during three work shifts. In total, 171 residents representing 50 care homes were observed in 2013-2014.

We found that various types of occupation were related to higher wellbeing. In the overall sample, the occupation types 'having visitors, playing games, physical exercise or sports, activity related to the past, and conversation' had the strongest relationship with wellbeing. Performing domestic tasks, creative activities and occupying the mind were also related to wellbeing but at a somewhat lower level.



Eating or drinking, and listening to music or watching TV only had a small positive correlation with wellbeing.

The relationship between types of occupation and wellbeing was found to vary amongst people at different stages of dementia. In those with very severe dementia, eating or drinking seemed to be more important for their wellbeing than in other groups. Activities related to the past were also of great importance in this resident group. Additionally, this group benefitted from looking around with attention, in other words, being passively involved. Having visitors was less important for this resident group in terms of wellbeing.

Our findings reveal the need for residents to stay in touch with their network, or with other persons who specifically come to visit them and give them personal attention, at least for those with mild to moderately-severe dementia. Our study also shows that active stimulation of residents with dementia is desirable. However, consistent with our previous research, the observed residents mainly spent their time in types of occupation that were not significantly linked to better wellbeing, which implies there is room for improvement.

The findings also show that different types of occupation are important for residents, depending on their stage of dementia, which underlines the importance of identifying the resident's functioning level. When the disease progresses, care staff and family must re-discover what types of occupation are suitable for the person with dementia and discuss how to organize these activities.

This study suggests that regular care staff seem able to observe their residents' occupation and wellbeing. Although there is a need to study its validity and reliability in more detail and to further fine-tune the different types of occupation, the instrument seems promising.

**Chapter 6** contains a description of the relationship between small-scale group living home characteristics and involvement in activities in general, and activities that are specifically preferred by the resident. The study used a sample of 1,327 care home residents with dementia. These residents lived in 136 care homes that represented different types of nursing home care in the Netherlands and their data were collected in the first measurement cycle of the LAD-study (2009-2010).

A first indicator of small-scale group living home care was the care home's score on the Group living home care characteristics questionnaire, reflecting the implementation of typical features of group living home care (e.g.: living rooms have a homelike atmosphere, dinner is prepared in the kitchen of the living rooms, nursing staff do housekeeping, and residents can get out of bed whenever they want). Secondly, the number of residents at the total facility site was used as an indicator of small-scale care.

Residents of facilities with more group living home care characteristics were involved in more general as well as preferred activities. Furthermore, they were more often involved in task related activities, outdoor activities, leisure pursuits, physical exercise, and interaction with others. For the other types of activities (religion, creative activities, intellectual activities and activities involving the senses) no differences were found as compared to residents with fewer characteristics of group living home care.

The number of residents at the total facility site was not related to involvement in activities, except for the finding that residents of larger facilities were less involved in intellectual pursuits. The results appear to contradict the concerns that a strong focus on a normalized life, and the absence of a central activity program or specialized activity workers, lead to low activity levels among residents within small-scale care homes.

As a secondary finding, we discovered that neuropsychiatric problems and ADL dependency (needing more help with physical care, transferring, toileting and eating and drinking), as well as

the age and sex of residents were stronger predictors of activity involvement than the indicators of small-scale care. These findings indicate that older residents, male residents, residents with more challenging behavior and more ADL dependency should receive specific attention when it comes to activity involvement.

**Chapter 7** explored the predictive value for activity involvement of several resident characteristics, resources in terms of finances and staff, care culture, staff experiences, the environment and activity offer. A sample of 1,218 residents representing 139 care homes was used, derived from the second measurement cycle (2010-2011) of the LAD-study.

Out of 40 factors that were studied, seven were identified as having the strongest relationship with higher activity involvement (defined as involvement for more than one hour a day). Higher activity involvement was predicted by: less agitated behavior, less ADL dependency and cognitive impairment, a higher educational level of staff, fewer perceived job demands and less social supervisor support, and a smaller number of residents in the facility. Factors that were also related to higher activity involvement, but proved to be of secondary importance, were: more involvement of family caregivers in the decisions and procedures in the care for their relative, greater unity in care philosophy among staff, more group living home care characteristics, and more help from volunteers at the facility, less transformational leadership, a higher staff ratio and not offering activities in the form of clubs.

The results imply that in order to increase the activity involvement of care home residents with dementia, it seems vital to 1. Reduce staff's experienced job demands, 2. Elevate their overall educational level, 3. Train staff to provide suitable activities considering the behavior and preserved capabilities of residents and 4. Foster transition towards small-scale care. In order to do so, care organizations might need to evaluate the use of their financial means.

Further research is needed to study the role of the supervisor in activity involvement of residents.

**Chapter 8** contains the overall discussion of this thesis. In this chapter, the main findings are summarized and discussed. Furthermore, several implications for care practice, health policy and future research are described.

#### Main study outcomes

In our study, we consistently found that activity involvement is beneficial for the overall quality of life of care home residents with dementia. Residents who were more involved in activities had higher scores on several quality of life subscales, and their involvement in several types of daily occupation was related to higher wellbeing scores.

This conclusion can be drawn for people in all stages of dementia, although the correlation with activity involvement and quality of life was somewhat weaker for residents with very severe dementia, and somewhat different types of occupation were related to their wellbeing compared to residents with less advanced dementia. Our observation of the types of daily occupation that residents were involved in revealed that certain types of daily occupation were related to higher wellbeing, and others were not. Having visitors, playing games and engaging in leisure activities, physical exercise, reminiscence activities, conversation and domestic tasks had the





largest impact on wellbeing. However, these 'wellbeing enhancing types of occupation' were not often observed.

Although there is much variation between and within care homes, overall it can be said that there is only occasional involvement of dementia care home residents in activities or wellbeing-enhancing types of occupation. This implies that there is much room for improvement in care homes.

Several factors were found to enhance or limit activity involvement or daily occupation. These facilitating and impeding factors should be referred to when attempting to improve activity involvement in care homes for people with dementia. First, disease-related characteristics of residents are strongly related to their level of activity involvement: residents who are more physically and cognitively impaired are generally less involved in activities. Second, a stimulating environment seems to increase the residents' involvement in activities and daily occupation. Characteristics of small-scale group living home care as well as fewer residents living in the care facility predicted higher activity involvement and were also related to more involvement in activities of preference of the resident. A home-like atmosphere and an environment that supports social interaction might contribute to more involvement in wellbeing-enhancing types of occupation. Third, factors relating to the manpower that is needed to provide activities for residents with dementia (a higher percentage of staff with educational level 3 or higher, less perceived job demands by staff, a higher staff ratio, more assistance from volunteers) are related to higher activity involvement. And finally, more involvement of relatives in decision making, a well implemented care philosophy, and less supervisor support and less transformational leadership were associated with higher activity involvement.

#### Implications for care practice and health policy

Based on our study findings, we have several recommendations for care practice and health policy.

- To increase the provision of activities in care homes, a change in perception of the content of nursing home care is needed. ***It should be recognized that involving residents in activities is just as vital for resident wellbeing as providing physical care.***
- Since activities should match the physical and cognitive abilities of a resident and also his or her interests, ***knowing the residents is a precondition for activity involvement that is aligned with the person's need.***
- Providing activities to residents with dementia during the day is not an easy task. Therefore, ***care staff must be taught what meaningful occupation entails, and how to integrate activity provision within their daily work.***
- Our findings show that the physical environment can contribute to activity involvement. ***Care homes should become a stimulating environment that lowers the threshold for staff to provide activities. Providing small-scale group living home care is a good starting point.***
- Having visitors is important for residents; family involvement in decision making is related to more activity involvement and family can provide information on a resident's life history, preferences and social network. Therefore, ***cooperation with family members is essential for residents to get the most out of their lives in the care home.***

- Care homes should embrace the potential of volunteers in activity provision. ***Since finding as well as keeping volunteers is challenging, care homes must discover their needs and motivation in order to get and keep them on board.***
- Today, people often move into care homes when they have complex care needs. To be able to offer these people activities besides providing physical care, ***care staff must receive training on the most recent care guidelines and evidence on dementia care. Furthermore, care managers should embrace their staff's aspirations, creativity and ideas for a better life for residents.***
- ***Proper staffing levels in care homes are essential for activity provision in the care home and need to be ensured.*** The large differences in staff ratio and educational levels between care homes, indicate that care organizations must evaluate their use of the available means.
- If more money becomes available for dementia care homes for the purpose of attracting more staff, ***the care sector must repair the negative image of long term dementia care.*** Showing society that working in nursing home care also includes fulfilling the residents' need for activity involvement and thereby making time for making true contact and contributing to the happiness and wellbeing of residents, will help in this process.

#### Suggestions for future research

The outcomes of this research, as well as our experiences with the data material and study design, led us to make the following suggestions for future research.

- In our study, we found that activity involvement and resident wellbeing were related, as measured at a single point in time. Our study does not provide evidence that activity involvement or daily occupation also affects wellbeing or quality of life in the long run. ***The maximum potential of activity involvement can best be studied with longitudinal research.***
- In order to further improve nursing home care in the Netherlands for people with dementia, ***we recommend that the Dutch government puts more emphasis on monitoring research and making optimal use of the knowledge that has already been generated by several research institutes.***
- As one of the instruments to measure daily occupation and wellbeing of residents with dementia, we used staff observations. ***Further development of this instrument may lead to a feasible alternative to collecting data, but also to increased awareness among care staff on this area.***
- ***The role of activity involvement as part of the impact of small-scale group living home on resident wellbeing should be further investigated.*** Based on our research, we hypothesize that the effect of group living home care on quality of life might be determined by the extent to which the environmental stimuli and compensations for which the concept was intended, are actually used.



- **Additional research on the role of family in enabling care home residents to keep living a meaningful life is needed.** This study points at the importance of family involvement. Despite the availability of tools and shared experiences between care organizations, care homes still have difficulties with regard to increasing the involvement of and cooperation with family members. More in-depth research might contribute to solving this problem.
- **The determinants of job demands (or work pressure) among care staff need further exploration.** Experienced job demands are not the sole result of staffing levels. Given the important impact on activity involvement of residents, it is vital to further explore what contributes to job demands, in order to combat this negative experience of care staff.
- Inconsistent with the literature, the supervisor support perceived by care staff was found to be negatively, yet strongly, related to higher activity involvement. **Further research is needed to clarify the relationship between the role of leadership and activity involvement by residents.**

To conclude, activity provision should be recognized as a core element of the care for people with dementia living in care homes, even for those with severe dementia. When care homes succeed in finding ways to ensure proper staffing levels and equip their entire care staff with skills to integrate activity provision in their daily work, the wellbeing of residents at all stages of dementia can be improved. It is often thought that this is a matter of having enough financial resources. Best practices show us, however, that attention for activities is possible, even within the budgets that are currently available. Therefore, to make a real change, it is essential for care homes to recognize that money is not the sole cause of the problem, and that they must take responsibility for the activation of their residents.