Chapter 7

Summary and General Discussion
Summary

The primary objective of this thesis was to study the effects of living in small-scale SCUs, as compared to living in large-scale SCUs on the cognitive function, rest/activity rhythm, behavioural problems, the use of psychotropic medication, and quality of life of residents in the moderate to severe stages of dementia.

We started by reviewing all studies that have compared the effects of different types of care facilities on behavioural problems, cognitive function, functional status and QoL (Chapter 2) [Kok, 2013]. Cross-sectional comparisons of non-SCUs to large-scale SCUs have generally indicated that residents in large-scale SCUs tend to exhibit more challenging or deviant behaviour, in addition to more agitation/aggression, depressive symptoms and, possibly, anxiety, as well as better psychosocial interaction, more severe cognitive global impairment and better communication. Little evidence has been found that SCUs have a beneficial effect on QoL, as compared to non-SCUs.

In general, SCUs have been developed to improve the management of care for residents with BPSD. Our results reveal few, if any differences with respect to behavioural problems or QoL when comparing large-scale SCUs with small-scale SCUs. They do provide some evidence of improvements in global cognitive performance in small-scale SCUs, although these findings are potentially subject to bias in the facility's allocation process. With regard to functional status or activities of daily living (ADL), outcomes in more specialized care facilities tend to be better than those of non-SCUs.

The longitudinal studies, with follow-up durations varying from 6 to 18 months, did not reveal any differences between non-SCUs and either large-scale or small-scale SCUs with regard to global behavioural problems or mood over time. When comparing non-SCUs to large-scale SCUs, people with dementia in large-scale SCUs demonstrated more neuropsychiatric problems, behavioural deterioration and resistance to care. In addition, more agitation was observed in large-scale SCUs than in small-scale SCUs. The results provide no evidence of differences in cognitive function or rate of cognitive decline, functional status and QoL over time. Some of the residents who were observed exhibited more positive affect and more social relations in small-scale SCUs than was the case in large-scale SCUs.

In the present thesis, we investigated longitudinal differences between large-scale SCUs and small-scale SCUs over a period of 8-9 months. Based on our review of the literature (Chapter 2), most of the differences in the variables reviewed could probably be attributed to the allocation of residents to specific types of facilities (non-SCU, SCU,
small-scale SCU), as people with dementia and severe BPSD are highly likely to be placed in SCUs [Te Boekhorst, 2009; Nobili, 2008; Morgan, 2005]. It is interesting to note that such allocation processes may be beneficial for patients with BPSD, as there is some evidence that SCUs have positive effects on BPSD [Richards, 2015; Zuidema, 2010]. It could be that a specific environment (e.g. a SCU) can contribute to best practices in the care for people with dementia [Richards, 2015], in addition to other benefits (e.g. lower apathy levels) [Jao, 2015]. In our study (presented in Chapter 3), residents in the small-scale SCUs exhibited significantly better recognition of pictures three months after transfer, as compared to those remaining in large-scale SCUs (control group). As indicated by the effect sizes, residents in small-scale SCUs performed better on tests of face recognition. They also exhibited less cognitive decline (as observed by legal representatives) and better global cognitive functioning (clustered variables). Six months after the transfer, however, we no longer observed any significant differences between residents in large-scale SCUs and those in small-scale SCUs with regard to cognitive functions [Kok, 2016]. Effect sizes show better recognition of pictures and figure recognition and less global cognitive decline (representatives). For the post and follow up measures residents showed better episodic memory (large effect size) and global cognitive functioning (moderate effect size) in favour of the small scale SCUs.

Quality of life is a highly relevant but rarely investigated outcome of the care provided to residents with dementia [Moyle 2015; Crellin 2014; Clare 2014]. Although other scholars have found no differences between large-scale and small-scale SCUs with regard to QoL (see Chapter 2), we did observe a significant difference in scores on the ‘anxiety’ subscale of the general QoL concept over time (8 months; see Chapter 6). Residents of small-scale SCUs exhibited significantly less anxious behaviour than did those in large-scale SCUs [Kok, 2018].

In addition to the cognitive aspects of dementia and QoL, we studied differences between large-scale and small-scale SCUs with regard to the rest/activity rhythms and medication use of people with dementia. Disturbance in the rest/activity rhythm tend to become more severe as dementia progresses [Musiek, 2015; Peter-Derex, 2015, Ju, 2013]. We argue that an enriched environment that offers more privacy (as is the case in small-scale SCUs) may have a positive effect on the rest/activity rhythms of residents. In Chapter 4, we discuss our examination of the rest/activity rhythms of the residents in both groups, based on actigraphy and observation scales. The results were mixed with regard to the identified differences between groups and their effect sizes. The only significant findings were that intra-daily stability was higher for the small-scale group, with the control group exhibiting more inter-daily stability. All differences identified on the various observational measures were non-significant, and their effect sizes were small.
The use of psychotropic medication is another clinically relevant topic, in addition to being of primary concern in the care provided to people with dementia [McGrattan, 2017]. For this reason, we examined the use of psychotropic medication, assuming that moving to a small-scale SCU would result in a reduction in the use of psychotropic medication (see Chapter 5). No significant differences were found between the two groups. The effect sizes show an increase of drug use over time for the small-scale SCUs for hypnotics & sedatives (large), analgesics, anti-Parkinson, anxiolitics and total psycholeptics (moderate). The large-scale SCUs showed an increase in the use of anti-epileptics, anti-depressants (large) and total use of psychoanaleptics (moderate).

Taken all of the results together, with the exception of a positive effect on anxiety, we found no statistically significant differences between people with dementia living in small-scale SCUs and those living in large-scale SCUs with regard to cognitive functions, rest/activity rhythms, psychotropic medication use or QoL over a period of 8-9 months. This raises questions concerning whether small-scale SCUs actually enhance the care provided to people with dementia.

**Limitations**

The results reported in this thesis suggest several recommendations for further research and clinical practice. Before addressing these implications, it is important to address several limitations of the studies.

The research reported in this thesis is based on a longitudinal quasi-experimental field design involving an intervention group and a control group. Such a design assumes that participants are not randomly assigned to the two groups. Because randomization is not possible in this type of research, however, our design was the best feasible option. Another limitation to the present research has to do with its reduced explanatory power due to attrition and the associated missing data. Although this was to be expected, it does complicate the interpretation of the data. The most important reasons for this reduction in power of the study were death, serious illness and the restricted nature of the research population.

A third limitation of the present research has to do with the fact that no records were kept of the comorbidities of the residents. The number of chronic conditions (e.g. hypertension, connective tissue disease, diabetes and depression) is associated with QoL [Nelis, 2018]. Comorbid somatic diseases (e.g. diabetes type 2) have been associated with cognitive and behavioural disturbances [Ho, 2013]. Possible differences between
residents in small-scale and large-scale SCUs with regard to comorbid diseases could have therefore affected our outcome measures. For future research, therefore, we recommend the registration of comorbidities (e.g. based on the Cumulative Illness Rating Scale, or CIRS-G).

Furthermore, we observed floor effects on several measures (e.g. cognitive tests and proxy instruments), due to the severe cognitive deficits in the patients with dementia. The sensitivity of the instruments to detect changes over time is therefore low [de Jong, 2005]. More specifically, we observed floor effects on the assessment of cognitive function and mood based on the Mini-Mental State Examination (MMSE, global cognitive functioning), the Eight-Word Verbal Memory Test (8-WT, verbal memory), the Rivermead Behavioural Memory Test (RBMT, visual memory), the Fluency, Boston Naming Test (BNT, language), the Van Heugten apraxia test, the Trail-Making Test (TMT, executive functioning), the CLOX instrument (visuoconstruction), the Incomplete Drawings task (visual perception) and the Geriatric Depression Scale (GDS, depression).

In addition to the direct measurements, we used several indirect measures to examine possible differences between the two groups. These measurements offer a more reliable way of assessing the functioning of residents than do performance measures that must be administered to the patients [Lima-Silva, 2015; Curyto, 2008]. We asked legal representatives and professional caregivers (nurses) to complete various observation lists; the Behavioural Observation Scale for Intramural Psychogeriatrics (abbreviated in Dutch to GIP), the Information Questionnaire on Cognitive Decline in the Elderly (IQCODE) and the QUALIDEM.

We also used actiwatches (Cambridge Neurotechnology Ltd, Cambridge UK) to provide a direct measure of the rest/activity rhythms of the residents without having to rely on their compliance. We assessed six variables in this manner: intra-daily variability, inter-daily stability, amplitude of movement, relative amplitude of movement, the 5 sequential least active hours (L5) and the 10 sequential most active hours (M10) in a 24-hour period (Chapter 4). At the time of writing, newer actiwatches with more refined parameters had become available, which could be used to obtain more detailed information about differences in rest/activity rhythms in relation to small-scale or large-scale SCUs. Polysomnography, which records several biophysical changes that occur during sleep, is not a feasible method to use within this frail population.
Recommendations

In our study population, we found no significant differences between residents in small-scale SCUS and those in large-scale SCUs with regard to cognitive function, rest/activity rhythm or medication use. Because of the single bedrooms and higher number of social activities offered in the small-scale SCUs, we expected the smaller units to have positive effects on the rest/activity rhythms of their residents. Our results nevertheless provide no evidence in favour of smaller SCUs. It could be that the residents participating in this study were cognitively and socially unable to respond positively to the new environment due to the severity of the dementia [Kumfor, 2014; James 2011; Shany-ur, 2011]. Moreover, the differences between the two conditions with regard to the range of social activities offered might have been too small, as the number of staff members in the facilities addressed in our study remained the same.

We found no evidence that the scale of the facility had any effect on the actigraphy variables. One possible explanation is that the progression of dementia led disturbances in the sleep/wake rhythm to become so severe that it was impossible to measure any effect [Musiek, 2015; Ju, 2013; Peter-Derex, 2015; Zwijsen, 2016]. Positive effects could possibly be enhanced by combining small-scale care with more nursing staff and activities, thereby resulting in more personalized attention.

We found no differences between the residents of small-scale SCUs and those in large-scale SCUs with regard to either behavioural problems or medication use. The duration of the study (8 months) might have been too short to reveal any significant changes in medication regimes [Ozaki, 2018; Törmälehto, 2017]. For future studies, we recommend the continuous registration of medication and non-pharmacological interventions during residential care, in addition to the registration of dose-response relationships for off-label psychotropic medication.

The environment within which care is provided to residents with dementia can have an influence on BPSD. The type of environmental intervention or activities offered might be more relevant than the scale of residential care is with regard to the QoL and well-being of residents (as manifested in behavioural problems). For example, reductions in behavioural symptoms and enhanced QoL have been reported for dementia patients who had been exposed to Japanese gardens [Goto, 2014], aquariums [Edwards, 2013], animals [Nordgren, 2014] or Green Farms [de Boer, 2017]. Furthermore, an environmental design that is more natural than formal (e.g. with a garden room with plants and furniture) has been reported to be associated with lower pulse rates on the part of residents, thus reflecting a reduction in stress [Goto, 2014]. Another study [Jao,
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2015] suggests that an uncomplicated and age-adapted environmental design (e.g. better lighting) could help to reduce apathy levels amongst residents [Richards, 2011], while increasing social interaction and engagement [Lee, 2016]. Although visually complex environments should be avoided [Padilla, 2011], care facilities should have good lighting and visual contrast [Douglas, 2015]. In addition to environmental interventions, studies have demonstrated that music therapy, aromatherapy and ‘snoezelen’ can be effective in temporarily reducing agitation [Sé, 2014; Padilla, 2011; Ball, 2005].

From our perspective, the subjective experiences of people with dementia (as manifested in disturbances in neuropsychological functions) constitute an important starting point for the organization of care facilities [Zwijsen, 2016; Cadieux, 2016]. For example, the ways in which people with dementia interpret meaningful activities [Moyle, 2012] might differ from the interpretations of those who do not have dementia [Jing, 2016]. Future studies should address the relationship between the stage of dementia and specific meaningful activities.

In general, people with dementia can react positively to environmental interventions. In the present study, however, we found no differences. Most previous studies on this topic have been based on cross-sectional research designs, which are not superior to our design. One possible explanation is that publication bias might have resulted in the publication of only studies with positive outcomes. In addition, the lack of standardization complicates the comparability of the existing studies. To enhance comparability and identify the specific characteristics that influence the BPSD in order to optimize treatment, future studies should pursue standardization with regard to the type of psychosocial treatment, activities, aspects of the environment (e.g. colour use, plants, furniture, interior of the rooms) used in SCUs for people with dementia.

The bio-psychosocial model has been emphasized for purposes of interpreting the perspectives of residents with dementia (particularly in severe cases) [Zwijsen, 2016]. We propose that clear diversity in private and community spaces [Fleming, 2016] (e.g. a Snoezel room or accessible garden) and a focus on the specific needs and levels [Ball, 2005] of individual residents [Padilla, 2011] could decrease BPSD [Richards, 2015] and enhance QoL. A familiar, household model [Morgan-Brown, 2013] and a calm, age-friendly and person-centred [Edvardsson, 2014] environment [Douglas, 2015; Keating, 2012; Lippa, 2010] is likely to be the best-suited means of addressing disturbances in the brain functions and well-being of residents. Given the severe cognitive deterioration that can occur within this population, the primary focus of efforts targeting various aspects of QoL should probably be on the basic needs and possibilities [Scholzel-Dorenbos, 2010] of residents with dementia.
In the Netherlands, almost all regular SCUs for people with dementia have been transformed into small-scale homelike SCUs. Such facilities are characterized by relatively high costs [Lai, 2009], and there is very little evidence that transferring to such a facility is actually beneficial to the cognitive and behavioural functioning of people with dementia [Kok, 2013]. Professional caregivers and the family members of patients, however, are positive about small-scale living facilities for people with dementia [Zwakhalen, 2018; Verbeek, 2010]. What might be considered an optimal environment from the perspective of a healthy person is likely to differ from what would be optimal from the perspective of a person with dementia. Research on larger groups is needed in order to unravel the factors that contribute to an optimal therapeutic environment for people with dementia.

In the Netherlands, the care provided to people with dementia is focused on helping them to retain individual control and management [Zadelhoff, 2013; te Boekhorst, 2007; Rapport Schuttelaar en Partners, 2016]. This approach stands in contrast to the process of dementia, which obviously leads to the ultimate loss of control over all aspects of a person’s life [Weintraub, 2012; Cerejeira, 2012], due to increasing cognitive impairment. A focus on QoL and coping with disease and dependency is most suitable during the later stages of dementia. The type of care to be provided to residents of small-scale and large-scale SCUs should be based primarily on the outcomes of structural QoL monitoring (routine outcome monitoring) by family caregivers and nursing personnel [Beerens, 2013; Kim, 2018; Choi, 2017; Weber, 2015].

Given the limited availability of tools for monitoring changes in people with moderate to severe dementia for purposes of intervention, there is a need to develop measuring instruments for people with dementia. In our research, we identified differences between the residents of the two types of facilities with regard to anxiety. In general, residents with dementia experience relatively high levels of anxiety [Diefenbach, 2014; Neville, 2011]. Anxiety is a serious problem for such residents, and the reduction of symptoms of anxiety could decrease behavioural problems and enhance their QoL [Seignourel, 2008]. For example, the development of a proxy instrument for detecting symptoms of anxiety could improve the process of monitoring the effects of non-pharmacological interventions in residents with dementia.
**General conclusion**

Our study did not produce any evidence that small-scale SCUs have positive effects (as compared to large-scale SCUs) for residents with moderate to severe dementia with regard to cognitive function, rest/activity rhythm, behaviour and psychotropic medication. In our study, one aspect of QoL, anxious behaviour, was significantly lower in residents living in small-scale SCUs than it was for those in large-scale SCUs. Although no other significant differences were found, the effect sizes suggest a need for further research on the effects of small-scale SCUs for residents with dementia.
References


3. Cerejeira J, Lagarto I & Mukaetova-Ladinska E. Behavioral and psychological symptoms of dementia. Front Neurol Dementia 2012; Article 73.


29. Dichter MN, Schwab CG, Meyer G, Bartholomeyczik S, Dortmann O, Halek M. Measuring the quality of life in mild to very severe dementia: testing the inter-rater and intra-rater reliability of
the German version of the QUALIDEM. Int Psychogeriatr. 2014;26(5):825-36. doi: 10.1017/S1041610214000052.


