Chapter 1

General introduction
Background

Worldwide, nearly 50 million people have dementia, and this number is expected to double every 20 years. Every three seconds, someone will be diagnosed with dementia. The economic and societal burdens are enormous [www.alz.co.uk, 2019]. In the Netherlands, the prevalence of people with dementia parallels worldwide figures, with 260,000 people with dementia living at home and about 50,000 others living in residential care facilities [www.volksgezondheidenzorg.info, 2019]. The number of patients with dementia in the Netherlands is estimated to increase to 620,000 by 2050 [www.alzheimer-nederland.nl, 2019]. In recent decades, residential care for people with dementia in the Netherlands has been transformed from large-scale traditional facilities based on a medical model to small-scale facilities with a more psychosocial orientation [Ballard, 2018; Boekhorst, 2007]. Although the current political credo calls for ensuring that people with dementia are able ‘to stay at home as long as possible’, most people with moderate to severe dementia will eventually need a safe residential-care environment [Meerveld, 2013].

This thesis is intended to examine whether people with dementia benefit from living in small-scale care facilities (as compared to large-scale facilities) with respect to cognitive function, rest/activity rhythms, quality of life and the use of psychotropic medication. Although small-scale dementia care has become the standard in the Netherlands, evidence of its benefits for the residents is limited [Kok, 2013].

Dementia

The process of dementia is characterized by a profound decrease in cognitive and behavioural functions over time [Weintraub, 2012; Cerejeira, 2012], with age being a major risk factor [Hussenoeder, 2018]. A wide range of cognitive dysfunctions (e.g. executive dysfunction, memory impairment, aphasia, apraxia) and visuospatial impairments may occur [Hugo, 2014]. These functions are assessed according to neuropsychological tests [Di Pucchio, 2018].

In addition to neurocognitive dysfunction, many patients with dementia exhibit behavioural and psychological dysfunctions (BPSD), including agitation and depression, particularly in the later stages [van der Linde, 2014; Perri, 2014; Poletti, 2013]. These symptoms together may influence the rest/activity rhythm (i.e. the sleep/wake rhythm) [Musiek, 2015; Bombois, 2010]. In the absence of interventions that can successfully treat the actual decline in cognitive functions, most existing interventions
focus primarily on reducing the severity of BPSD [de Oliveira, 2015; Cankurtaran, 2014]. The treatment of BPSD frequently involves the use of psychotropic medication [Tampi, 2014], although the potentially positive effects are not observed in all patients [Lee, 2004]. It is therefore important to investigate the effects of non-pharmacological interventions that could have a positive influence on BPSD.

Quality of Life (QoL) is perhaps the most relevant aspect in life for any human being. The measurement of QoL in residents with dementia is challenging, given that the residents themselves are no longer capable of responding in a valid manner [Yang, 2018]. For this reason, most of the few existing studies use proxy measurements for QoL [Beerens, 2013].

Although the type of care unit, the segregation of care units or similar factors can also influence QoL for caregivers and nursing-home residents [Palm, 2018], research on such factors is quite scarce [Kok, 2013].

**Dementia care facilities**

In the Western world, institutionalized care for people with dementia was historically organized in large nursing homes with large dormitory rooms for elderly people with a variety of somatic diseases or psychiatric disorders. The first specialized nursing homes for people with dementia were created in the mid-1970s. In recent decades, large-scale nursing homes have been remodelled or transformed into small-scale facilities, within which a homelike environment is created for residents with dementia. Meals are often prepared together, groups are relatively small, activities are decentralized and residents have their own bedrooms [Ausserhofer, 2016; Day, 2000]. Another innovation in dementia care in the Netherlands involves ‘Green Houses’ or farms [Buist, 2018; Rabig, 2006], which are characterized by a variety of homelike aspects, domestic activities and access to outdoor environments [Buist, 2018; de Boer, 2017].

**Small-scale homelike care facilities**

Care facilities for people with dementia have transformed over time from being rooted in a more traditional medical perspective [Finnema, 2000; Wills, 1998] (non-Special Care Units) to Special Care Units (SCUs). The development of SCUs is in line with a general trend towards non-pharmacological treatment for BPSD [Cerejeira, 2012]. Although there is no general definition of SCUs, those in the Netherlands could be
characterized as small-scale living facilities for people with dementia [Verbeek, 2009]. Evidence that such facilities are beneficial to residents is nevertheless limited. According to some findings, small-scale facilities apparently have some positive effects for family caregivers, who experience less emotional burden and are more satisfied with the nursing personnel [Rooij, 2012-1; Verbeek, 2010] than are those whose loved ones are in large-scale facilities. Members of the nursing staff in small-scale facilities report higher job satisfaction and motivation [Verbeek, 2010], in addition to experiencing less time and work pressure [Willemse, 2014] than do their counterparts working in large-scale facilities.

In a qualitative examination of family caregivers and personnel experiences in small-scale facilities, Verbeek [2012] reports positive experiences that are in line with these findings. In contrast, Rooij [2012-2] reports that professional caregivers in small-scale facilities experience more emotional strain in general, due to a heavier perceived workload.

The existing evidence raises questions concerning what should be taken as the leading perspective for providing care environments for people with dementia [van Dijk, 2018]. The perspective of residents with dementia should obviously take precedence, along with that of family members and professional caregivers.

Higher levels of QoL have been observed amongst residents in small-scale facilities, as manifested by more positive affect, less negative affect and less restless behaviour [Smit, 2012; de Rooij, 2012-3], accompanied by an increase in social engagement and non-aggressive behaviour [Verbeek, 2014], as compared to residents in large-scale SCUs. In addition to higher levels of observed QoL, small-scale facilities have been associated with a decrease in the use of physical restraints and psychotropic drugs [Verbeek, 2014]. In contrast, residents in large-scale settings have reported feeling more at home over time [de Rooij, 2012-3], as compared to those in small-scale homelike settings. The caregiver relationship and observations of negative affect have been reported to be lower in large-scale settings than they are in small-scale settings (lower scores). Mixed results have also been found across different small-scale settings with regard to the number of activities and social relationships [de Rooij, 2012-2].

Taken together, the available evidence suggests that, while professional and family caregivers are generally positive about small-scale settings, the effects of these settings on the QoL of residents with dementia are mixed. Furthermore, it is not clear why people with dementia might feel less at home in homelike settings.
The aforementioned studies are based on longitudinal observation with no intervention. The potentially beneficial QoL effects of a different therapeutic environment for people with dementia could be studied by examining a group of patients during a period in which they were relocated from a large-scale SCU to a small-scale homelike SCU.

**Aim and outline of the current thesis**

The general research objective of this thesis is to examine the effects of transferring to a small-scale SCU on cognitive function, rest/activity patterns, QoL and the use of psychotropic medication in people with dementia. The outcomes are intended to provide advice concerning the role of environmental aspects on the future care of patients with dementia.

The study is designed as a longitudinal quasi-experimental field study, in which patients moving from a large-scale SCU to a small-scale SCU are followed and compared to a control group consisting of patients remaining in a large-scale facility throughout the study period. The data for the studies in this thesis were collected over a period of 8-9 months in two large-scale special care facilities (SCUs).

The thesis opens with a review of the literature (**Chapter 2**). The review focuses particularly on 32 studies on the behavioural symptoms, cognitive functions, functional status and QoL of people with dementia in Special Care Units (SCUs) and non-SCUs.

Dementia affects a wide range of cognitive functions, including global cognitive functioning, verbal and visual memory, language, praxis, executive functioning and visual perception [Hugo, 2014]. In **Chapter 3**, we assess the effects of moving to a small-scale SCU (as compared to remaining a large-scale SCU) on a variety of cognitive functions, hypothesizing improvement or less deterioration.

Disturbances in a person’s rest/activity rhythm could potentially be positively related to the course of dementia [Figueiro, 2017] and the severity of deterioration in cognitive functions. In **Chapter 4**, we discuss a comparison of the effects of living in small-scale care facilities on the rest/activity rhythms of residents to those of residents living in large-scale care facilities, based on actigraphy and observations.

After conducting the comparison described above, we investigated the prescription of psychotropic medication. Given the high level of medication use for nursing-home residents with dementia [McGrattan, 2017], we hypothesized that the prescription of
medication would be reduced in a small-scale care environment, as compared to a large-scale facility (see Chapter 5).

One highly relevant clinical question concerns whether small-scale homelike settings can improve various aspects of QoL. In Chapter 6, we report on a study of the effects of a small-scale care environment on QoL, based on observations made by the nursing staff. Chapter 7 provides a summary of the thesis and a discussion of the implications of the studies, along with the limitations of our research and recommendations for future care and research.
References

1. https://www.alz.co.uk/research/statistics


