Chapter 1

General Introduction

“All real living is meeting.” Martin Buber (1958)
Dementia (major neurocognitive disorder)
In the 5th edition of the Diagnostic Manual of Mental Disorders (DSM) (2013) ‘dementia’ has been described as a ‘major neurocognitive disorder (NCD)’ with different etiological subtypes, such as Alzheimer’s disease, vascular NCD, NCD with Lewy-Body dementia, NCD due to Parkinson’s disease and frontotemporal NCD. According to DSM-5, a major NCD is present when:
1. Significant cognitive decline from a previous level of performance in one or more cognitive domains (complex attention, executive function, learning and memory, language, perceptual-motor, or social cognition) is visible, based on:
   • Concern of the individual, a knowledgeable informant, or the clinician that there has been a significant decline in cognitive function; and
   • A substantial impairment in cognitive performance, as a result from standardized neuropsychological testing or another quantified clinical assessment.
2. The cognitive deficits interfere with independence in occupational or daily functioning.
3. The cognitive deficits do not occur exclusively in the context of a delirium.
4. The cognitive deficits are not explained by another mental disorder (e.g. depression, schizophrenia).
Although we realise that the overall term dementia syndrome as a diagnostic category may disappear in the nearby future, in this thesis, we decided to continue to use the term dementia, as it is still generally the term used in clinical practice and dementia care research.

Prevalence of Dementia
The World Alzheimer Report (2015) shows that 46.8 million people worldwide are living with dementia, and this number will almost double every 20 years, to 75.6 million in 2030 and 135.5 million people in 2050 (Prince et al., 2015). In the Netherlands, in 2017, there are around 270,000 people with dementia. Old age is the most important risk factor for the development of dementia, and with the increased life expectancy of the world population, longevity is the main cause for the growing prevalence of dementia. The second factor affecting the prevalence of dementia is the improvement of healthcare, contributing to the higher life expectancy for persons with one or more chronic conditions, including dementia. A third factor, with a protective effect on the incidence of dementia, is a healthy lifestyle pursued by a growing number of people (www.Alzheimernederland.nl). Of the 270,000 people with dementia in the Netherlands, an estimated 50,000 live in long-term care settings, such as care homes and nursing homes (www.volksgezondheidenzorg.info/onderwerp/dementie/cijfers-context/incidentie-en-prevalentie#node-aantal-mensen-met-dementie). This thesis focuses on people with dementia living in a nursing home and the communication with their professional caregivers.

Needs of people with dementia
Personal and meaningful contact with other human beings is an essential need of each person, and this also applies to people with dementia (Dröes et al., 2006; Hancock et al., 2006). Other needs reported are, pleasant daytime activities, company, adequate support
when feeling distressed, and preservation of self-esteem (e.g. being accepted for whom you are, feeling attached and being understood). People with dementia consider these needs as being very relevant to their quality of life (Dröes et al., 2006). In the first stages of dementia, people are still able to take initiative in contact and communication with other people, but in the later stages, due to the progressive cognitive dysfunctions, they become more dependent on other people with this regard. Van Haeften-Van Dijk & Boersma (2015) described this deterioration of the ability to communicate for the different stages of dementia, following the stages distinguished by Van der Kooij (2003) and the BUPA Foundation (www.bupa.co.uk/individuals/health-information/directory/d/hi-dementia).

<table>
<thead>
<tr>
<th>Stage of dementia according to Feil (1992) and in Dutch according to Van der Kooij (2003)</th>
<th>Stage of dementia according to BUPA Foundation</th>
<th>Capabilities to communicate</th>
</tr>
</thead>
<tbody>
<tr>
<td>Mal Orientation (Bedreigde-ik-beleving)</td>
<td>Loss of memory and confusion</td>
<td>The person with dementia still takes the initiative and there is reciprocity in the contact.</td>
</tr>
<tr>
<td>Time confusion (Verdwaalde-ik-beleving)</td>
<td>Behavioural changes</td>
<td>The person with dementia still takes the initiative and there is reciprocity in the contact.</td>
</tr>
<tr>
<td>Repetitive motion (Verborgen-ik-beleving)</td>
<td>Losing control of the present</td>
<td>It is still possible to have contact, there can also be reciprocity. However the initiative is not taken by the person with dementia.</td>
</tr>
<tr>
<td>Vegetation (Verzonken-ik-beleving)</td>
<td>Physical vulnerability and dependency</td>
<td>Initiating contact is not taken by the person with dementia and there is little or no reciprocity.</td>
</tr>
</tbody>
</table>

Table 1. Stages of dementia and opportunities for communication

**Person-centered care interventions and the influence on the person with dementia and their caregivers**

By the end of the previous century researchers realised a different vision on dementia was needed (Dröes, 1991; Feil, 1992; Miesen, 1990). Kitwood (1997) elaborated on this different vision on dementia and dementia care by focusing on people with dementia as ‘being a person’. Instead of devaluing the person with dementia, he recognised them in their full humanity as unique persons being welcomed, embraced and heard. He explained the change of focus very clearly:

“Our frame of reference should no longer be person-with DEMENTIA, but PERSON-with-dementia.”
Kitwood’s paradigm shift comprised that not the disease dementia solely causes their problematic behaviours, but also the fact that the social environment surrounding the person has difficulty understanding their behaviours. According to Kitwood, people with dementia try to communicate via their so-called ‘problematic’ behaviours, in other words, by their behaviour they give us messages about their needs. Caregivers should try to understand these messages and engage with the perceptions of the people with dementia when their individual needs are not being met. In this way, formal and informal caregivers can have a significantly positive influence on the behaviour and well-being of people with dementia. Brooker (2004) built on the pillars Kitwood had placed and developed the VIPS model. The VIPS definition, an acronym, consists of four essential elements (Brooker & Latham, 2015):

- **Valuing** people with dementia and those who care for them: promoting their citizenship rights and entitlements regardless of age or cognitive impairment.
- Treating people as **Individuals**: appreciating that all people with dementia have a unique history, identity, personality and physical, psychological, social and economic resources, and that these will affect their response to cognitive impairment.
- Looking at the world from the **Perspective** of the person with dementia: recognising that each person’s experience has its own psychological validity, that people with dementia act from this perspective and that empathy with this perspective has its own therapeutic potential.
- Recognising that all human life, including that of people with dementia, is grounded in relationships, and that people with dementia need an enriched **Social environment** that both compensates for their impairment and fosters opportunities for personal growth.

When care is provided with emphasis on these elements, people with dementia will feel acknowledged in their personhood and can maintain a sense of well-being (Brooker & Latham, 2015). During the past decades, many person-centred care methods (e.g. multisensory stimulation, movement activity, validation and reminiscence) have been developed for the use in psychogeriatric care, with the aim to respond better to the needs of people with dementia and thus positively influencing their well-being (Brooker & Duce, 2000; Dröes, 1991; Feil, 1992; Van Weert et al., 2005). Although, these methods have shown small to moderate positive effects on the behaviour (e.g. less disruptive behaviour, agitation and aggressiveness), mood (less depression) and / or quality of life of the people with dementia, there seems room for improvement. Reviews show that more effort is needed to optimise interventions, in order to confer more consistent benefits (Olarazán et al., 2010; Testad et al., 2014; Van Mierlo et al., 2010). Most likely people with dementia will benefit more from person-centred care when methods are combined.

Besides the fact that that people with dementia benefit from person-centred care, also their formal and informal caregivers may profit from providing person-centred care. Different studies report on positive outcomes related to how caregivers carry out and experience their work. For example, caregivers who were trained in providing person-centred care showed more autonomy in planning specific interventions in care plans of the residents
(Chenoweth et al., 2009), and were better able to handle difficult behaviour of clients with dementia by using psycho-social interventions (Deudon et al., 2009). Edvardsson et al. (2011) found a positive relation between providing person-centred care and job satisfaction of the caregivers. Though recent studies have shown that caregivers are able to provide person-centred care, thus positively influencing the behaviour and well-being of people with dementia as well as the working experience of themselves as caregivers, it also appears from these studies that providing good-quality person-centred care in daily nursing home care remains a challenge. Challenging factors are for example: the clinging to traditions, the low priority status of the dementia care, the driving forces of the medical profession and medicalisation of dementia. Last but not least: person-centred care requires a staff - resident ration of one to four and a continued investment in developing the caregivers’ skills of interaction (Brooker & Latham, 2015).

The Veder Contact Method (VCM)

The original Veder method was developed in 2009 by Foundation Theatre Veder (www.theaterveder.nl/nl/). This person-centred method has two variants: the Veder method as a ‘living-room theatre performance’ (carried out by professional actors or trained caregivers) and ‘the Veder Contact Method (VCM)’ as delivered by caregivers in 24-hour care. Both variants aim to improve the communication with people with dementia in order to achieve reciprocity in the contact with them and to promote feelings of well-being, identity and self-esteem. Both variants also combine core elements of existing psychosocial methods, such as reminiscence, validation, integrated emotion-oriented care and neuro-linguistic programming, with theatrical elements (like characters, music, costumes, props and poetry), on the assumption that combining the different psychosocial methods more positively influences the person with dementia.

First, the Veder method as a ‘living-room theatre performance’ was developed, interactive theatre plays performed by professional actors at nursing home wards. Subsequently, also professional caregivers in nursing homes were trained to apply the theatre performance. Research by Van Dijk et al. (2012) showed that the ‘living-room theatre performances’ by professional actors had significantly more positive effects on the behaviour (laughing, confusing, alertness), mood (happy) and quality of life (social isolation, feeling at home) of people with dementia than a regular reminiscence activity or the living-room theatre performed by professional caregivers. Although the trained caregivers experienced pleasure in executing the Veder method as a group activity, it appeared also difficult for them to perform the theatre play with the same quality and intensity as professional actors (Van Dijk et al., 2011; Van Haeften-Van Dijk et al., 2015). When the trained caregivers discussed the Veder method as ‘living-room theatre performance’ in focus groups, they suggested the method could possibly have (more) added value by offering the key-elements, such as the use of theatrical elements and a more explicit use of the voice (e.g. intonation), timing and presentation (e.g. ‘acte de présence’), in one-on-one contact during the daily care (Van Dijk et al., 2011; 2012). In 2012, therefore Foundation Theatre Veder developed the
Veder Contact Method (VCM). VCM teaches caregivers to combine different psychosocial methods with theatrical, poetic and musical communication, pursuing a focused interaction and reciprocity in the contact with the person with dementia in daily 24-hour care (www.theaterveder.nl/nl). An example is the use of reminiscence (the retrieval of memories) in combination with music, theatre and/or poetry. VCM is specifically developed for use during daily care tasks, e.g. during washing, going to bed, having meals, during coffee/tea breaks, and other activities in the living-room of the nursing home. The theatrical stimuli are applied to the (often apathetic) people with dementia, sometimes literally to wake them up, and tempt them into interaction. VCM follows, like the Veder method as group activity, a fixed procedure sequence. The consecutive steps are (1) greeting by one-on-one contact, (2) appealing to long-term memory, (3) communication about the present time (connection to short-term memory), and (4) saying goodbye. The relation between the procedural steps, the key elements of VCM, and the used communication strategies are described in Table 2. Central in this thesis is the Veder Contact Method (VCM), applied in daily nursing home care.

<table>
<thead>
<tr>
<th>Procedural steps of VCM</th>
<th>Key elements of VCM</th>
<th>Examples of the communication strategies</th>
</tr>
</thead>
<tbody>
<tr>
<td>Greeting by one-on-one contact</td>
<td>Theatrical communication</td>
<td>Presentation/act de présence, timing and intonation/tone</td>
</tr>
<tr>
<td>Appealing to long-term memory</td>
<td>Poetic communication</td>
<td>Rhythm, associating, intonation/sound</td>
</tr>
<tr>
<td>Communication about the present time</td>
<td>Musical communication</td>
<td>Recognizable songs of the past, humming, intentional use of music</td>
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</tbody>
</table>

Table 2. Relation between the procedural steps, key elements and communication strategies of the Veder Contact Method (VCM) in daily care.

Implementation of person-centered methods in nursing home care

Much research has been conducted focusing on the effects of psychosocial and person-centred methods in dementia care, in particular with respect to behaviour and quality of life of people with dementia (Olazarán et al., 2010; Testad et al., 2014; Van Mierlo et al., 2010; Vernooij-Dassen et al., 2010). Far less attention was paid to aspects of implementation of psychosocial and person-centred care methods. One could see this as a limitation, given the fact that the effectiveness of these methods also depend on how well they are implemented in daily care over a longer period of time (Vernooij-Dassen & Moniz-Cook, 2014). In this thesis we are specifically interested in the process of implementation.

What exactly do we mean with implementation? Rabin et al. (2008) defined implementation as follows: ‘Implementation is the process of putting to use or integrating evidence-based
interventions within a setting’. It is well-known that implementation of new methods in the care is generally complex (Glasgow et al., 2003; Grol & Grimshaw, 2003). This also applies to implementation of new methods in nursing home dementia care (Meiland et al., 2004; Van Haeften-van Dijk et al., 2015; Vernooij-Dassen & Moniz-Cook, 2014). It is naive to assume that these methods are always carried out according to plan. The multiple and competing demands of nursing home caregivers within routine care settings impact treatment fidelity to a large extent (Grol & Grimshaw, 2003; Vernooij-Dassen & Moniz-Cook, 2014). Before the year 2000 implementation research focused mainly on the transfer of knowledge and skills to caregivers. Less attention was given to other aspects of the process of implementation of the new method, such as motivation of personnel and organisational factors. From 2000 onwards changes became apparent, but still, only very limited research was carried out to evaluate the implementation of new methods in regular care settings (Burgio et al., 2001).

To contribute to new knowledge in this field, we carried out an implementation study. According to Grol & Grimshaw (2003), implementation studies provide a better understanding in factors that facilitate or impede the implementation process, and give insight into the efficiency of the used implementation strategy. We searched for a model which could support us in our study. Many implementation frameworks with different underlying theories exist (Tabak et al., 2012), for example theories focussing on the impact, the process, cognition, education, motivation, social interaction, organisational context, total quality management, and theories on the political and economic context (Grol et al., 2007). In this thesis we aimed to measure the successfulness of the implementation of VCM using a framework that reflects the process of implementation (e.g. facilitators and barriers), but also provides insight into the implementation outcomes (changes in behaviour of caregivers and residents). Tabak et al. (2012) found in their review 61 existing implementation models (theories and/or frameworks) which enhance dissemination and implementation of existing and/or new interventions. Without devaluing other frameworks, we opted for the RE-AIM framework for monitoring the implementation process and outcomes of VCM. This framework is a basis for socio-ecological thinking and is compatible with evidence-based medicine (Glasgow et al., 1999). The RE-AIM framework focuses on three levels of socio-ecological thinking: the community, the organisation and the individual. The focus on the organisation and the individual are particularly important for our study. Although our study is an implementation study, we also wanted to gain insight in the effect of the intervention (evidence-based medicine) especially on the behaviour and quality of life of the people with dementia and the behaviour of the caregivers. ‘Effectiveness’ is one of the dimensions of the RE-AIM framework.

**RE-AIM framework**

The RE-AIM framework supports program developers, program evaluators, funders and policymakers to consider the different elements of an intervention, including external validity that can improve long-term adoption and implementation of effective, generalizable, evidence-based interventions. The RE-AIM framework was developed to support the planning and evaluation of the implementation of evidence-based health care interventions (Glasgow et al., 1999; About
RE-AIM, www.re-aim.hnfe.vt.edu/about_re-aim/what_is_re-aim/index.html). It consists of five constructs: Reach, Effectiveness, Adoption, Implementation and Maintenance (RE-AIM), and can be used to assess the level of implementation of interventions (Dzewaltowski et al., 2004). The impact of an intervention (I) was earlier described as Reach x Effectiveness (I = R x E) (Abrams et al., 1996). Glasgow et al. (1999) added three more dimensions (Adoption, Implementation, Maintenance - AIM). Effects on these five evaluative dimensions together lead to the ultimate impact of an intervention. Over the past decade the RE-AIM framework has also been used successfully in dementia care (Altpeter et al., 2013; Gitlin et al., 2010), which supports our assumption that this framework is an appropriate model to describe the process of implementation and to assess the implementation-effectiveness of psychosocial interventions in psychogeriatric nursing home care. We define implementation-effectiveness as ‘the degree to which the implementation of the innovation has been successful’ (Van der Kooij et al., 2013). Implementation-effectiveness should be distinguished from innovation-effectiveness, which indicates the (positive) effect of the application of a (successfully) implemented innovation. The definition of the different dimensions of the RE-AIM framework are presented in Table 3.

<table>
<thead>
<tr>
<th>Dimension (level)</th>
<th>Original definition by Glasgow et al. (1999)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Reach (Individual)</td>
<td>Proportion of the target population that participated in the intervention.</td>
</tr>
<tr>
<td>Effectiveness (Individual)</td>
<td>Success rate if implemented as in guidelines; defined as positive outcomes minus negative outcomes.</td>
</tr>
<tr>
<td>Adoption (Organisation)</td>
<td>Proportion of settings, practices, and implementation plans that will adopt this intervention.</td>
</tr>
<tr>
<td>Implementation (Organisation)</td>
<td>Extent to which the intervention is implemented as intended in the real world.</td>
</tr>
<tr>
<td>Maintenance (Individual &amp; Organisation)</td>
<td>Extent to which a program is sustained over time.</td>
</tr>
</tbody>
</table>

Table 3. Definitions of the five dimensions of the RE-AIM framework and definition in this review

**Research questions and outline of the thesis**

The goal of this thesis is to provide more insight in the complex process of implementation of psychosocial and person-centred interventions in daily nursing home care for people with dementia. With a systematic review we first aimed to get insight in the barriers and facilitators which come along with the implementation process of psychosocial interventions in daily nursing home care. Subsequently, we conducted an implementation study: Foundation Theatre Veder implemented VCM in six nursing home wards, taking into account the barriers and facilitators that were detected in earlier research about the Veder ‘living-room theatre’ method (Van Haeften-Van Dijk et al., 2015). During the three-year implementation study, we systematically evaluated, according to the RE-AIM framework,
if and how VCM was implemented effectively in the daily nursing home care for people with dementia.

The research questions of this thesis were:
1. What are, according to the literature, the strategies for successful implementation of psychosocial interventions as offered by professional caregivers in the daily residential dementia care?
2. How is VCM integrated in daily nursing home care, and what are the conditions for successful implementation?
3. How is the implementation of VCM reflected in:
   a) The communicative behaviour and attitudes of professional caregivers?
   b) The content of the care plan?
   c) The behaviour, mood and quality of life of people with dementia?
4. Does implementation of VCM on nursing home wards have a positive impact on the job satisfaction of professional caregivers who were trained in applying the method in daily care?

This thesis is structured as follows:
Chapter two presents the literature review. Here we mapped, following the five constructs of the RE-AIM framework, which psychosocial methods were integrated in daily 24-hour care for people with dementia in the last decades, how these were implemented, what facilitators and barriers were experienced and what the results were of the implementation.
Chapter three describes the study protocol of the implementation of VCM. In this chapter the design, setting and methods are displayed in detail. With a mixed model we researched the facilitators and barriers of the implementation of VCM and we also gathered quantitative data before and after the implementation of VCM on the behaviour of the caregivers and the residents, the care plans of the residents and the attitude of the caregivers.
Chapter four reports on the results of the process analysis, in which we studied to what extent the implementation of VCM was successful according to the five dimensions of the RE-AIM framework. Besides this, we explored the facilitating and hindering factors throughout the implementation of VCM in daily nursing home care.
In chapter five we report on our study into the implementation-effectiveness of VCM with various types of quantitative data (questionnaires, observations and analysis of care plans) which were collected among caregivers and residents in the experimental and control groups.
Chapter six describes the research in which the influence of the implementation of VCM on the job satisfaction of caregivers was studied by quantitative data (a self-report questionnaire) and qualitative data gathered during the process analysis from chapter four. The qualitative data provided understanding of the influence of implementing VCM on caregivers' job satisfaction.
Finally, in chapter seven 'General discussion' the main findings of this study are presented and discussed in relation to the literature. Methodological issues, as well as scientific and clinical relevance, recommendations for future research and implications for practice and policy are discussed.
References


