# Depression in dementia

Development and testing of a nursing guideline

Renate Verkaik

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http://www.nivel.nl nivel@nivel.nl Telefoon 030 2 729 700 Fax 030 2 729 729

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# Depression in dementia Development and testing of a nursing guideline

Depressie bij dementie Ontwikkeling en evaluatie van een richtlijn voor verzorgenden (met een samenvatting in het Nederlands)

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ter verkrijging van de graad van doctor aan de Universiteit Utrecht, op gezag van de rector magnificus, prof. dr. J.C. Stoof, ingevolge het besluit van het college voor promoties in het openbaar te verdedigen op maandag 20 april 2009 des middags te 4.15 uur

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Renate Verkaik geboren op 30 december 1974 te Rotterdam

#### **Promotoren:**

Prof. dr. J.M.Bensing Prof. dr. M.W. Ribbe

# Co-promotoren:

Dr. A.L. Francke Dr. B.K.G. van Meijel

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# **General introduction**

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# Introduction

It is widely acknowledged that depression in dementia is a burden for patients as well as for their caregivers (e.g. Shin et al., 2005; Kerkstra et al., 1999). On the psychogeriatric wards of Dutch nursing homes most residents suffer from dementia. There are indications that the prevalence of depression in dementia on these wards is high. A pro-active attitude among caregivers is needed to recognize this severe health problem in demented residents and to respond to it.

This thesis firstly seeks to provide greater insight into depression in dementia on psychogeriatric nursing home wards. Secondly, it describes the development of the nursing guideline 'Depression in Dementia', and thirdly it presents the effects of the guideline's introduction on residents and their Certified Nurse Assistants (CNAs). In addition, the factors that may facilitate or hamper the guideline introduction are described. This introductory chapter gives an overview of what is already known about these subjects. Furthermore, the research questions and the structure of the thesis are outlined.

# **Background**

# What is already known about depression in dementia?

Comorbid depression in people with dementia is associated with decreased quality of life (Shin et al., 2005), greater health care utilization (Kunik et al., 2003), higher mortality rates (Suh et al., 2005) and decreased caregiver's wellbeing (Kerkstra et al., 1999; Shin et al., 2005). Little is known about the etiology of depression in dementia. It is thought to be partly caused by neurological changes due to the dementia and partly by psychological reactions to the presence of the dementia (Janzing and Zitman, 2002).

The prevalence rates for significant depressive symptomatology in dementia in previous studies range from 15 percent (Vida et al., 1994) to as high as 50 percent (Migliorelli et al., 1995). Recognition of depression in dementia is a complex task for caregivers and, as a consequence, under-recognition is high (Olin et al., 2002b). This is partly caused by an overlap of some of the symptoms of dementia with prominent symptoms of depression (e.g. apathy). Moreover, people with dementia have severe difficulty in expressing themselves, especially in the latter stages of dementia. In

addition, the assessment of depression in people with dementia is complex, since in this population the syndrome is qualitatively different from depression in non-demented elderly populations as diagnosed with DSM-IV criteria for Major and Minor Depression (DSM-IV: APA, 1994) (Olin et al., 2002b).

In 2002 an expert group from the American National Institute of Mental Health (NIMH) therefore developed specific criteria for depression in Alzheimer Disease, the most frequent type of dementia. These are the 'Provisional Diagnostic Criteria for Depression of Alzheimer Disease' (PDC-dAD) (Olin et al., 2002a). Depression of Alzheimer Disease is assumed to be different from DSM-IV Major Depressive Disorder with respect to the type and intensity of its symptoms. As compared with DMS-IV criteria for Major Depressive Disorder, specific symptoms for depression in Alzheimer Disease are 'irritability' and 'social isolation/withdrawal'. Another important difference compared to DSM-IV criteria is that in Depression of Alzheimer Disease the presence of at least three, instead of five, symptoms is required, and symptoms are not required to be present nearly every day.

Using the PDC-dAD criteria should improve recognition of Depression of Alzheimer Disease. Two recent studies in demented outpatient populations showed that with the Provisional Diagnostic Criteria for Depression of Alzheimer Disease higher rates of depression were indeed identified than with DSM-IV or ICD-10 criteria for Major Depression (Vilalta-Franch et al., 2006; Teng et al., 2008). To our knowledge, the criteria have not been previously applied to a demented inpatient population, such as psychogeriatric nursing home residents.

# What is already known about depression in dementia on psychogeriatric wards?

Psychogeriatric wards in Dutch nursing homes are separate wards or units for psychogeriatric residents, that are specially adapted for these residents. In the Netherlands, the main part of the daily nursing care in nursing homes is delivered by Certified Nurse Assistants (CNAs) who generally have three years of basic nursing training, and who collaborate with other professionals, like nursing home physicians, occupational therapists and psychologists.

About 85% of the residents of psychogeriatric wards in Dutch nursing homes are diagnosed with a dementia syndrome (Schols et al., 2004), mostly moderate to severe (GDS stages 5 to 7) (Zuidema et al., 2007).

To our knowledge there is only one study on the prevalence of depression in the demented residents of Dutch psychogeriatric nursing home wards (Zuidema et al., 2007). In this study a prevalence rate of 20% for depression in dementia was found. This is comparable with published rates from Norway, 21% (Selbaek et al., 2007) and is somewhat lower than in the United States, 27% (Gruber-Baldini et al., 2005). As said, in general, recognition of depression in dementia is difficult. It is often even more difficult in patients on psychogeriatric wards, since most of them are in the latter stages of dementia and cannot express themselves clearly verbally. Teresi et al. (2001) show that nurse assistants only have a sensitivity of 55% in recognizing depression in dementia sufferers. Recognition by other disciplines, such as physicians, is even lower - namely 14% (Bruhl et al., 2007).

# What is already known about evidence based care for people with dementia and depression?

In 2005 the Dutch guideline 'Diagnostics and medicinal interventions for dementia' was published (NVKG, 2005). Although the guideline focuses on medicinal interventions, for depression in dementia the use of non-pharmacological interventions is also recommended. However, the guideline does not recommend the use of a specific type of psychosocial intervention, because this was beyond its scope. The Cochrane Collaboration has conducted some systematic literature reviews of the scientific evidence for a number of psychosocial interventions used relatively often in nursing homes, including Reminiscence (Woods et al., 2005) and Validation (Neal and Barton Wright, 2002). None of the reviews found any proof for their effectiveness, either on depression, or on other outcomes, such as aggression (www.cochrane.org).

However, particularly for depression in dementia, a promising method has been developed in the USA, the so-called BehaviorTherapy-PleasantEvents. Teri et al. (1997) showed that by inducing individualized pleasant activities and reducing unpleasant events, depression in home dwelling people with dementia can be significantly reduced. Specifically for people with dementia, the method is appropriate because hardly any demand is made on their cognitive abilities. Close relatives perform an important coordinating and supporting role in BehaviorTherapy-PleasantEvents. The method also seems promising for psychogeriatric nursing home wards in the Netherlands. The coordinating and supporting role of the relatives could in

this case be assumed by the Certified Nurse Assistants (CNAs) of the demented residents.

# Structure and research questions

This PhD thesis aims to provide greater insight into the characteristics of depression in demented residents of Dutch psychogeriatric nursing home wards. In addition, this thesis will add scientific knowledge about the introduction of a nursing guideline to support residents with dementia and depression on psychogeriatric nursing home wards, and about its effects on residents and Certified Nurse Assistants (CNAs). The thesis is divided into the following four sections with related research questions:

- 1. Understanding depression in dementia:
  - a. Is depression in dementia related to dementia severity?
  - b. What is the prevalence of depression in dementia on psychogeriatric nursing home wards?
  - c. What are the characteristics of comorbid depression in demented psychogeriatric nursing home residents?

#### 2. Guideline development:

- a. How much scientific evidence exists to show that psychosocial care methods reduce depression in dementia?
- b. Which steps need to be taken in developing an evidence based guideline?

# 3. Guideline introduction:

- c. Which factors facilitate or inhibit a successful introduction of the guideline on psychogeriatric nursing home wards?
- d. Which factors facilitate or inhibit a successful application of the guideline on psychogeriatric nursing home wards?

# 4. Effects of the guideline:

- e. What are the effects of introducing the nursing guideline on depression in demented residents of psychogeriatric nursing home wards?
- f. What are the effects of introducing the nursing guideline on the CNAs of psychogeriatric nursing home wards?

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### Content of the thesis

Chapter 2 gives a systematic literature review concerning the relationship between the severity of Alzheimer Disease and the prevalence of comorbid depression.

In *Chapter 3*, the prevalence rate and symptom profile of depression in dementia on psychogeriatric nursing home wards are described. Data come from the diagnostic phase of a clinical trial studying the effects of the nursing guideline 'Depression in Dementia'.

Chapter 4 describes a systematic literature review of the effectiveness of psychosocial methods on depressive, aggressive and apathetic behaviors of people with dementia.

In *Chapter 5* the seven phases in the development of the nursing guideline 'Depression in Dementia' are presented. The systematic literature review of Chapter 4, consultation of an expert group, and conducting a practice test comprise three of these phases.

In *Chapter 6*, factors that facilitate or hamper a successful *introduction* and *application* of the guideline are presented. Using a multiple case study design, qualitative and quantitative data from the clinical trial of the effects of the nursing guideline 'Depression in Dementia' are compared and combined.

Chapter 7 reports the results of the clinical trial of the effects of the guideline introduction on depression in demented residents of the psychogeriatric nursing home wards. It concerns a multicentre controlled clinical trial in nine Dutch nursing homes with randomization at ward level, and with pretest, post-test and follow-up measurements.

*Chapter 8* reports the results of the clinical trial into the effects of the guideline introduction on CNAs working with the depressed and demented residents.

Finally, in *Chapter 9*, the results of our studies are discussed. The general findings are summarized and put into context. Methodological aspects are discussed, as well as the clinical relevance of the results. Recommendations are made for implementation of the guideline and for future research.

# 2

The relationship between severity of Alzheimer's Disease and prevalence of comorbid depressive symptoms and depression

A systematic review

This chapter was published as:

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### **Abstract**

# **Objectives**

To gain more insight into the association between severity of Alzheimer's Disease (AD) and prevalence of comborbid depression.

#### Methods

A systematic literature review based on the Cochrane methodology was performed. PubMed, PsychINFO and EMBASE databases were searched for existing studies that fulfilled predefined inclusion criteria. The studies were divided into: (1) those that analysed the association between severity of AD and prevalence of depressive symptoms ("continuous" approach) and (2) those that investigated the association between severity of AD and diagnosed depression ("categorical" approach). The quality of existing studies was rated and the results were synthesized with a best evidence synthesis.

#### **Results**

Twenty-four studies fulfilled the inclusion criteria. Nineteen reported results for a continuous approach and seven for a categorical approach.

Three of the four high quality studies within the continuous approach did not find a significant association between severity of AD and prevalence of depressive symptoms. None of the three high quality studies using the categorical approach found a significant association between the severity of AD and the prevalence of diagnosed depression.

#### **Conclusions**

There is evidence for a lack of association between the severity of AD and the prevalence of comorbid depressive symptoms or diagnosed depression. Until new studies contradict this conclusion, prevention and intervention strategies for comorbid depression in AD should be aimed at all patients irrespective their disease severity.

# Introduction

According to recent studies up to 50% of patients with Alzheimer's Disease (AD) suffer from depression at least once during their disease course (Starkstein et al., 2005). Comorbid depression in patients with AD has been associated with decreased quality of life (Shin et al., 2005), increased need for institutionalization (Steele et al., 1990), greater health care utilization (Kunik et al., 2003), higher mortality rates (Suh et al., 2005) and decreasing caregiver's well being (Kerkstra et al. 1999; Shin et al., 2005). These serious consequences ask for the development of strategies for prevention, early recognition and intervention for depression in AD. Diagnostic and preventive services should be targeted at those at greatest risk which means that it is important to understand who is most likely to develop depression. In addition, this tells us something about the underlying causes of depression and may help develop preventive and intervention strategies. Within this context, it is important to expand knowledge regarding the relationship between severity of AD and comorbid depression. The results of studies that have examined this relationship are inconsistent (e.g. Harwood et al., 1998; Lopez et al., 2003; Piccininni et al., 2005). Explanations for these diverging results could be multiple, because the studies and study samples differ on many points.

One of the differences between the existing studies is the method used to determine the prevalence of depression: "continuous" or "categorical". Within the continuous method the number of prevalent depressive symptoms is determined without establishing a diagnosis of depression. According to the categorical method, diagnostic criteria for depression are used to determine if a patient suffers from comorbid depression or not. There are various other differences between existing studies that could possibly offer explanations for the diverging results: (1) Many studies group different types of dementia together, (2) Diagnostic procedures for AD differ between studies, (3) The assessment instruments for the severity of AD differ, (4) The instruments used to assess the prevalence of depression are multiple, also within the continuous and categorical approach and (5) Study samples differ in many relevant aspects, such as severity of AD, living situation, history of depression, or use of psychotropic medication.

In order to gain more insight into the relationship between the prevalence of depression and severity of AD we conducted a systematic literature review by systematically analysing the differences, similarities and methodological quality of existing empirical studies. The division into studies that use a continuous or a categorical approach forms the main structure around which the results of the review are presented and discussed.

# Methods

The systematic review was conducted in accordance with a predefined research protocol following the guidelines of the Cochrane Collaboration (Clarke and Oxman (eds.), 2002) that prescribed the following steps: (1) inclusion criteria, (2) search method, (3) selection method, (4) data extraction, (5) assessment of methodological quality, (6) data synthesis. Steps 3 to 6 were performed independently by the first two authors (RV, JN).

#### Inclusion criteria

- 1. *Type of research.* This review included naturalistic studies that conducted cross-sectional analyses on the relationship between severity of AD and prevalence of comorbid depressive symptoms or depression.
- Patients. Studies had to involve patients who had been diagnosed with AD according to established diagnostic methods and criteria (e.g. NINCDS-ADRDA (McKhann et al., 1984), ICD-10 (World Health Organization, 1992), DSM-III-R or DSM-IV criteria (APA, 1987, 1995).
- 3. *Measurement of AD severity*. Only studies using a validated measure for AD severity were included. Scales that just measure degree of cognitive impairment as a measure for the severity of AD (e.g. Minimal Mental State Examination (MMSE); Folstein et al., 1975) as well as scales that also take non-cognitive aspects of AD into account (e.g. Global Deterioration Scale (GDS); Reisberg et al., 1982) were included.
- 4. Measurement of depression. In the case of continuous studies: only studies using an established, validated rating scale for measuring depressive symptomatology were included, regardless of whether the rating scale used was specifically developed to assess depressive symptoms in patients with dementia (e.g. the Cornell Scale for Depression in Dementia (CSDD; Alexopoulos et al., 1988) or not (e.g. the Hamilton Depression Rating Scale (HDRS; Hamilton, 1960).

In the case of categorical studies: those studies were included that either employed established diagnostic criteria for major depressive disorder (MDD) (e.g. DSM-III-R/-IV or ICD-10 criteria) or used an empirically validated cut-off score on a rating scale for depressive symptoms specifically devised for patients with dementia (e.g. CSDD score >12; Lyketsos et al., 1997; Alexopoulos et al., 1988).

5. Statistical analysis. Only studies were included that tested the relationship between severity of AD and prevalence of depressive symptoms or depression for statistical significance.

#### Search method

In March 2006 we searched in three international bibliographical databases, i.e. PubMed, PsychINFO and EMBASE, for all studies that were published in English until that date and potentially fulfilled all five inclusion criteria. The databases were searched using the following strategy that was formulated in PubMed and adapted to the other databases:

Dementia [MESH] AND (Depression [MESH] OR Depressive Disorder [MESH])

All literature lists of possibly relevant studies were also screened for additional references.

#### Selection method

A first selection for inclusion was performed by the first author (RV). On the basis of titles and abstracts all studies that clearly did not meet one of the five inclusion criteria were excluded from the review. If a study appeared to meet the inclusion criteria or if there was any doubt, the full article was read. A second selection was made by two reviewers independently (RV, JN). Based on the full articles both reviewers checked if the studies satisfied all five criteria. Disagreements regarding inclusion status were resolved by discussion. In three cases no consensus could be met and a third reviewer (AF) was consulted.

# **Data extraction**

After the selection procedure, the two reviewers (RV, JN) independently documented the following characteristics of each study:

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- 1. the diagnostic criteria employed to establish presence of AD;
- 2. the characteristics of the study sample of patients with AD (i.e., size, inpatients or outpatients, socio-demographics, and, if reported, other relevant characteristics such as duration of AD, presence of depression prior to the onset of AD);
- the rating scale used to measure severity of AD;
- 4. the rating scale used to measure depressive symptoms OR the diagnostic procedure used to establish presence of depression;
- 5. the dependent and independent variable studied and the statistical technique used to examine their relationship. If a multivariate technique was employed, the included covariates were also documented;
- a short description of the results (i.e., significant or non-significant relationship, and, if reported, descriptive statistics, test statistics, pvalue);
- 7. the direction of the association (in case a significant relationship was found).

The findings of the two researchers were compared and disagreements were resolved by discussion. The extracted data is presented for continuous and categorical studies in two separate tables.

### Assessment of quality

After the data extraction, the quality of each included study was rated independently by the two researchers (RV, JN), using a set of five predefined criteria (figure 2.1). Criteria one to three concerned the internal validity and four and five are statistical criteria. The criteria cover the key domains (1) comparability of subjects (*between studies*) (2) outcome measurement and (3) statistical analyses that are formulated by the U.S. Agency for Healthcare Research and Quality for observational studies (AHRQ, 2002). Studies were considered to be of 'high quality' if at least three quality criteria were met.

# Figure 2.1 Quality criteria

- The diagnosis of AD is established according to the 'golden standard', the NINCDS-ADRDA criteria (McKhann et al., 1984);
- (2) Severity of AD is assessed using a clinical instrument that besides cognitive capabilities also takes account of functional and/or clinical factors: (a) CDR (Hughes et al., 1982) or (b) GDS (Reisberg et al., 1982);
- (3) Regarding studies that use a continuous approach, depressive symptoms are assessed using a rating scale specifically developed for patients with dementia. In studies with a categorical approach this type of rating scale should be used in combination with established diagnostic criteria for major depressive disorder. The following depression rating scales are specifically developed for demented populations: (a) the CSDD (Alexopoulos et al., 1988), (b) the NPI depression subscale (Cumming et al., 1994), (c) the Dementia Mood Assessment Scale (DMAS; Sunderland et al., 1988), (d) the Revised Memory and Behavior Problem Checklist (RMBPC; Teri et al., 1992);
- (4) The statistical analysis controls for the possible influence of at least two of the following confounders known to be associated with comorbid depression: (a) gender, (b) history of depression, (c) history of other psychiatric disorder, (d) current other psychiatric disorder, (e) current use of antidepressant or psychotropic medication, (f) degree of functional impairment;
- (5) The sample size of patients with AD is at least as large as the median sample size of all included studies in the review (n=78).

Several studies examined the relationship between severity of AD and prevalence of depressive symptoms or depression in more than one way either by employing different statistical techniques or by performing the same analytical technique using the scores of different rating scales for measuring depression symptomatology and/or severity of AD. These so-called 'sub-studies' were evaluated independently.

For each of the five quality criteria scoring positively, a (sub-)study received one "quality" point. The methodological quality of a (sub-)study was operationalized simply as the sum of all criteria scoring positively and thus potentially ranged from 0 to 5. There were no disagreements between the two researchers regarding the methodological quality ratings.

# Best evidence synthesis

A "best evidence synthesis" (Slavin, 1995) was conducted to determine the existing evidence for a relationship between severity of AD and prevalence of depressive symptoms and diagnosed depression. Levels of evidence were based on an earlier review of observational studies (Lievense et al., 2002). Figure 2.2 shows the principles of the best evidence synthesis.

Figure 2.2 Principles of Best Evidence Synthesis

#### Evidence:

Provided by consistent outcomes in at least 75% of the studies with a quality score of three or more.

### Insufficient evidence:

If less than 75% of the studies with a quality score of three or more have consistent outcomes.

Or

If no studies received a quality score of three or more.

# **Results**

#### Search results and selection of studies

Figure 2.3 shows the results of each phase in the search method and selection of studies.

Searching the specified databases according to the strategy described above resulted in 5,501 hits. Of these, 208 articles were judged by the first author to be possibly relevant on the basis of titles and abstracts. Based on full articles found, the first two authors agreed that 21 studies met the five inclusion criteria. A screening of reference lists of all 208 articles resulted in the inclusion of three additional studies. Of the total of 24 included studies, 19 reported results of analyses on the relationship between severity of AD and prevalence of depressive symptoms (continuous approach) and seven on the association between severity of AD and prevalence of diagnosed depression (categorical approach). Two studies used both approaches.

Hits: 5,501 studies Source: PubMed (3 March 2006): 3,101 articles PsychINFOo (3 March 2006): +906 articles EMBASE (9 March 2006): +1,494 articles 1st selection based on title/abstract Excluded articles: 5,293 Possibly relevant articles: 208 Excluded articles: 185 2<sup>nd</sup> selection based on full article

Results of database searches and selection methods Figure 2.3

# **Data extraction**

**Included articles: 24** 

The extracted data and quality rating of each included study are presented in table 2.1 (continuous approach) and 2.2 (categorical approach). Studies were ordered by their methodological quality rating. The 19 'continuous' studies included 34 (sub-)studies, and the seven 'categorical' studies included nine (sub-)studies.

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Table 2.1 Studies on the association between severity of dementia and prevalence of depressive symptoms in patients with Alzheimer's Disease (AD)

Study	Quality	Diagnostic criteria for AD	Characteristics of AD patients <sup>a</sup>	Severity of AD	Severity of depressive symptoms <sup>b</sup>	Statistical analysis	Results	Direction of association
Piccininni et al., 2005	3	NINCDS- ADRDA criteria for probable AD	n = 50 Outpatients Female gender: 76% Age: M(SD)= 69.3(7.5), Range= 53-84 Education: M(SD)= 6.5(3.9) Duration AD (months): M(SD)= 57.7(37.3) Exclusion criteria: a past history of alcoholism or psychiatric disturbances prior to the onset of dementia; drug abuse or dependence	(1) GDS: Mild (score: 2-3): 28%; Moderate (score: 4-5): 54%; Severe (score: >5): 18% (2) MMSE: M(SD)= 16.8(5.6)	NPI depression subscale: M(SD)= 3.3(3.7)	ANOVA: Comparison between mildly, moderately and severely impaired groups regarding NPI- depression score	Mildly impaired group: M(SD)= 3.7(4.0); Moderately impaired group: M(SD)=2.7(3.1); Severely impaired group: M(SD)=4.7(5.0); Overall comparison: <i>p</i> = 0.35	No significant association

- table 2.1 continued -

Study	Quality	Diagnostic criteria for AD	Characteristics of AD patients <sup>a</sup>	Severity of AD	Severity of depressive symptoms <sup>b</sup>	Statistical analysis	Results	Direction of association
Harwood et al., 2000a	3	NINCDS- ADRDA criteria for possible or probable AD	n = 114 Outpatients Female gender: 63% Age: M(SD)= 78.8(6.5), Range= 59-92 Education: M(SD)=11.9(3.5); Range= 2-20 Hispanic: 44% Duration AD: M(SD)= 3.4(2.5); Range= 1-11	MMSE: M(SD)= 17.8(7.2)	RMBPC 9-item depression scale: M(SD)= 8.4(7.8)	Pearson correlation between RMBPC and MMSE scores	r= 0.02, n.s.	No significant association
Harwood et al., 1998	3	NINCDS- ADRDA criteria for probable AD	n = 137 Outpatients Female gender: 70% Age: M= 78.2, Range= 63-95 Education: M= 10.4, Range= 0- 20 Hispanic: 50.4% Duration AD: M= 4.1; Range= 0-14	MMSE: M=15.6, Range= 0-29	CSDD: M= 5.2, Range= 0-25; Mild (score: 8- 12): 9.5%; Moderate (score: >12): 11.7%	Pearson correlation between CSDD and MMSE scores	r= -0.25, p < 0.01	More severe depressive symptoms in more severe AD

- table 2.1 continued -

Study	Quality	Diagnostic criteria for AD	Characteristics of AD patients <sup>a</sup>	Severity of AD	Severity of depressive symptoms <sup>b</sup>	Statistical analysis	Results	Direction of association
Brodaty and Luscombe, 1996	3 & 2°	NINCDS- ADRDA criteria for AD	n = 208 Outpatients Total sample of patients with dementia (n = 288) <sup>d</sup> : Female gender: 55% Age: M(SD)=71.4(7.7) Education: M(SD)=9.7(3.4)	Total sample of patients with dementia d: (1) MMSE: M(SD)= 18.2(7.2); Mild (score: >22); Moderate (score: <22) (2) CDR: score 0.5: 30.0%; score 1: 48.3%; score 2: 15.7%; score 3: 6.0%	HDRS (21-item version): M(SD)= 6.7(5.3)e  Total sample of patients with dementiad: MDD (DSM-IV criteria): 6.3%	(1) Spearman correlations with Bonferroni correction between (a) HDRS and MMSE scores; (b) HDRS and CDR scores  (2) t test: comparison between mildly and moderately impaired groups (based on MMSE) regarding HDRS scores	(1a) significant negative correlation; (1b) n.s. (2) mildly impaired group had a significantly lower HDRS score	(1a&2) More severe depressive symptoms in more severe AD  (1b) No significant association
Müller- Thomsen et al., 2005	2	NINCDS- ADRDA criteria for probable AD	$n = 316^{\circ}$ Outpatients Patients with MMSE ≥18 ( $n = 157$ ): Female gender: 65% Age: M(SD)= 72.7(8.7) Patients with MMSE<18 ( $n = 159$ ):	MMSE: Mild (score: ≥18): 49.7%; Moderate- severe (score: <18): 50.3% Mild: M(SD)= 22.3(2.8); Moderate- severe: M(SD)= 11.6(4.4)	(1) GDS (15- item version) (2) MADRS (3) CSDD	ANOVAs: Comparison between mildly and moderately- severely impaired groups (based on MMSE) regarding: (1) GDS score (2) MADRS score	A: Mildly impaired group B: Moderately-severely impaired group (1) A(n = 140): M(SD)= 4.5(3.3); B(n = 101): M(SD)= 4.6(2.6), n.s.	(1-3) No significant association

# - table 2.1 continued -

Study	Quality	Diagnostic criteria for AD	Characteristics of AD patients <sup>a</sup>	Severity of AD	Severity of depressive symptoms <sup>b</sup>	Statistical analysis	Results	Direction of association
			Female gender: 74% Age: M(SD)= 72.6(9.0)			(3) CSDD score	(2) A(n = 120): M(SD)= 10.1(6.7); B(n = 76): M(SD)= 12.8(8.8), p < 0.10  (3) A(n = 31): M(SD)= 6.7(5.0); B(n = 16): M(SD)= 8.1(5.1), n.s.	
Levy et al., 1998	2	NINCDS- ADRDA criteria for probable AD	n = 30 Outpatients Female gender: 63% Age: M=74, Range= 54-85	MMSE: M(SD)= 17.5(7.0)	NPI depression subscale: M(SD)= 1.2(1.6)	Spearman correlation between NPI-depression and MMSE scores	Nonsignificant trend toward a negative correlation	No significant association

- table 2.1 continued -

Study	Quality	Diagnostic criteria for AD	Characteristics of AD patients <sup>a</sup>	Severity of AD	Severity of depressive symptoms <sup>b</sup>	Statistical analysis	Results	Direction of association
Bungener et al., 1996	2	NINCDS- ADRDA criteria for possible or probable AD	n = 118 Outpatients Female gender: 64% Age: M(SD)= 70.1(7.8), Range= $52-86$ Education: <6: n = 49, 7-11: $n = 38, \ge 12: n =$ 29 Early-onset AD: n = 61, Late-onset AD: n = 55	(1) MMSE: M(SD)=19.1(5.8); Range= 3-29 (2) DRS: M(SD)= 104.8(20.5)	(1) HDRS (17- item version): M(SD)= 8.1(4.6), Range= 0-22 (2) RRS: M(SD)= 9.3(4.0), Range= 3-29  MDD (DSM-III- R criteria): 0% Dysthymia (DSM-III-R criteria): 8.5%	Pearson correlations between (1) HDRS and MMSE scores (2) HDRS and DRS scores (3) RRS and MMSE scores (4) RRS and DRS scores	(1) n.s. (2) n.s. (3) r = -0.27, p = 0.003 (4) r = -0.31, p < 0.001	(1&2) No significant association (3&4) More severe depressive symptoms in more severe AD
Haupt et al., 1995	2	ICD-10 draft criteria for mild to moderate dementia in AD	n = 78 Outpatients Female gender: 73% Age: M(SD)= 74.3(7.5), Range= 57-90 Age at symptom onset: M(SD)= 69.4(7.3) Past history of depression: 0% Antidepressant medication within the 2- year study	(1) MMSE (2) CAMCOG: M(SD)= 36.2(24.4) (3) GDS: score 5: 54%; score 6: 35%; score 7: 11%	DMAS mood subscale: M(SD)= 14(6.6), Range= 2-31	Correlations betweens: (1) DMAS and MMSE scores (2) DMAS and CAMCOG scores	(1) 0.02, n.s. (2) 0.04, n.s.	(1&2) No significant association

# - table 2.1 continued -

Study	Quality	Diagnostic criteria for AD	Characteristics of AD patients <sup>a</sup>	Severity of AD	Severity of depressive symptoms <sup>b</sup>	Statistical analysis	Results	Direction of association
			period: 32%; no patient had to stay on antidepressant medication for >3 weeks					
Verhey et al., 1995	2	NINCDS- ADRDA criteria for possible or probable AD	n = 48 Outpatients Female gender: 65% Age: M(SD)= 72.9(7.6) Education [1(primary school) – 7(university grade)]: 3.6(1.3) Duration AD: M(SD)= 3.28(2.4)	GDS: M(SD)= 4.8(0.9); Very mild (score: 3): 8.3%; Mild (score: 4): 25.0%; Moderate (score: 5): 45.8%; Severe (score: 6): 20.8%; Very severe (score: 7): 0%	HDRS (17-item version): M(SD)= 9.4(9.4) MDD (DSM-III-R criteria): 6.3%	Spearman correlation between HDRS and GDS scores	r = 0.04, n.s.	No significant association

- table 2.1 continued -

Study	Quality	Diagnostic criteria for AD	Characteristics of AD patients <sup>a</sup>	Severity of AD	Severity of depressive symptoms <sup>b</sup>	Statistical analysis	Results	Direction of association
Feher et al., 1992	2	NINCDS- ADRDA criteria for probable AD		MMSE: M(SD)= 19.4(2.9), Range= 12-23	(1) HDRS (17- item version): M(SD)= 4.0(3.1) (2) GDS (30- item version): M(SD)= 7.8(5.4)	Correlations between: (1) HDRS and MMSE scores; (2) GDS and MMSE scores (3) multivariate linear regression: Dependent: GDS score; (a) hierarchical: HDRS scores were entered first; followed by MMSE, memory test and self-awareness scores (b) simultaneous entry	(1) -0.15, n.s. (2) -0.15, n.s. (3a&b) MMSE score was not a significant predictor of GDS score, p > 0.10	(1-3) No significant association

- table 2.1 continued -

Study	Quality	Diagnostic criteria for AD	Characteristics of AD patients <sup>a</sup>	Severity of AD	Severity of depressive symptoms <sup>b</sup>	Statistical analysis	Results	Direction of association
Gottlieb et al., 1988	2	NINCDS- ADRDA criteria for probable AD		GDS: Low (score: 3-4): 55.8% High (score: ≥5): 44.2%	(1) HDRS (17-item version) (2) SDS	t tests: Comparison between low- and high- impaired groups (based on GDS) regarding (1) HDRS score and (2) SDS score	A: High- impaired group B: Low- impaired group (1) A: M(SD)= 2.2(3.0), Range=0-10; B: M(SD)= 3.3(6.1), Range=0-28, t < 1, n.s. (2) A: M(SD)=39.0(8.6), Range=21-54; B: M(SD)= 36.6(8.1), Range=23-55, t < 1, n.s.	(1&2) No significant association

- table 2.1 continued -

Study	Quality	Diagnostic criteria for AD	Characteristics of AD patients <sup>a</sup>	Severity of AD	Severity of depressive symptoms <sup>b</sup>	Statistical analysis	Results	Direction of association
Weiner et al., 1997	1	NINCDS- ADRDA criteria for AD	n=30 Outpatients Age: M(SD)=72.5(6.4), Range= 6-28 Education: M(SD)=12.6(4.0), Range= 3-20	MMSEh: M(SD)=17.3(6.4), Range= 6-28	HDRS (21-item version): (a) Patient's report: M(SD)= 5.7(3.6), Range= 1-12; (b) Caregiver's report: M(SD)= 9.3(5.2), Range= 0-21	Correlations between (1) patient's report HDRS and MMSE scores; (2) caregiver's report HDRS and MMSE scores	(1) n.s. (2) n.s.	(1&2) No significant association
Fitz and Teri, 1994	1	DSM-III-R criteria for AD	n=91 Outpatients Female gender: 55% Age: Range= 46- 90	DRS: M(SD)=102(18.8) , Range= 56-139; Mild (score: <102): 50.5%; Moderate (score: >103): 49.5%	HDRS (17-item version) MDD (DSM-III- R criteria): 50.5%	(1) Pearson correlation between HDRS and DRS scores (2) Comparison between mildly and moderately impaired groups (based on DRS) regarding HDRS score	(1&2) n.s.	(1&2) No significant association

- table 2.1 continued -

Study	Quality	Diagnostic criteria for AD	Characteristics of AD patients <sup>a</sup>	Severity of AD	Severity of depressive symptoms <sup>b</sup>	Statistical analysis	Results	Direction of association
Troisi et al., 1993	1	NINCDS- ADRDA criteria for probable AD	n = 26 Outpatients Female gender: 54% Age: M(SD)= 74.0(5.5), Range= 65-84 Education: M(SD)=7.15(5.0), Range= 0-19	(1) MMSE: mild-moderate (score: 16-23): 50%; severe (score: ≤15): 50%  (2) DSM-III-R: Mild: 26.9%; Moderate: 42.3%; Severe: 30.8%	HDRS (17-item version): Mild-moderate (score: 10-16): 30.8%; Marked (score: ≥17): 7.7%  MDD (DSM-III-R criteria): 23.1%	ANOVA and PLSD posthoc tests: (1) comparison between mildly-moderately and severely impaired groups (based on MMSE) regarding HDRS score  (2) comparison between mildly, moderately and severely impaired groups (based on DSM-III-R) regarding HDRS score	(1) Overall comparison: $p < 0.05$ Posthoc comparison: severely impaired group had significantly higher HDRS score than mildly-moderately impaired group ( $p < 0.05$ )  2) Overall comparison: $p = 0.01$ Posthoc comparisons: severely impaired group had significantly higher HDRS score than mildly ( $p < 0.01$ ) and moderately impaired ( $p < 0.01$ ) and moderately impaired ( $p < 0.01$ ) and moderately impaired ( $p < 0.01$ ) groups	(1&2) More severe depressive symptoms in more severe AD

- table 2.1 continued -

Study	Quality	Diagnostic criteria for AD	Characteristics of AD patients <sup>a</sup>	Severity of AD	Severity of depressive symptoms <sup>b</sup>	Statistical analysis	Results	Direction of association
Sultzer et al., 1992	1	NINCDS- ADRDA criteria for probable AD	n = 61 Outpatients (majority) and inpatients Female gender: 5% Age: M(SD)=73.0(7.8), Range= 53-88 Education: M(SD)= 13.0(3.2), Range= 7-20 Duration: M(SD)= 5.8(3.7), Range= 1-20 Exclusion criteria: history of psychotic disorder prior to onset of dementia; evidence of psychoactive substance use	MMSE: M(SD)= 10.0(8.5), Range= 0-28	HDRS (17-item version): M= 10.3, Range= 1-22	Pearson correlation between HDRS and MMSE scores	r = -0.38, p = 0.003	More severe depressive symptoms in more severe AD

- table 2.1 continued -

Study	Quality	Diagnostic criteria for AD	Characteristics of AD patients <sup>a</sup>	Severity of AD	Severity of depressive symptoms <sup>b</sup>	Statistical analysis	Results	Direction of association
Fischer et al., 1990	1	NINCDS- ADRDA criteria for probable AD	n = 55 Inpatients Female gender: 87% Age: M(SD)=79.4(8.8), Range= 58-93 No patient received antidepressants at the time of investigation or for 2 weeks previously	MMSE: M(SD)= 11.5(9.1), Range= 0-23; Mild (score: 16- 23): 41.8%; Moderate (score: 6-15): 23.6%; Severe (score: <6): 34.5%	HDRS (17-item version): M(SD)= 12.4(5.8), Range= 2-27	(1) Kruskal-Wallis rank test: comparison between mildly, moderately and severely impaired groups (based on MMSE) regarding HDRS score  (2) Spearman correlation between HDRS and MMSE scores	(1) Mildly impaired group: M(SD)= 13.1(6.5); Moderately impaired group: M(SD)= 14.3(5.2); Severely impaired group: M(SD) = 9.9(3.9) Overall comparison: <i>p</i> < 0.05  (2) r = 0.27, <i>p</i> < 0.05	(1&2) Less severe depressive symptoms in more severe AD
Shuttleworth et al., 1987	1	NINCDS- ADRDA criteria for AD	n = 22 Outpatients Female gender: 59% Age: M= 67.1 Education: M= 14.5	MMSE: Mild (score: 20- 25): 31.8%; Moderate (score: 15-19): 36.4%; Severe (score: 5- 14): 31.8%	SDS: M= 41.2 MDD (DSM-III criteria): 41%	ANOVA: comparison between mildly, moderately and severely impaired groups (based on MMSE) regarding SDS score	Mildly impaired group: M= 41.4; Moderately impaired group: M= 41.6; Severely impaired group: M= 40.6; Overall comparison: F= 0.98, d.f. = 2 and 19, n.s.	No significant association

- table 2.1 continued -

Study	Quality	Diagnostic criteria for AD	Characteristics of AD patients <sup>a</sup>	Severity of AD	Severity of depressive symptoms <sup>b</sup>	Statistical analysis	Results	Direction of association
Galynker et al., 1995	0	DSM-III-R criteria for AD	n = 26 Outpatients Female gender: 58% Age: M(SD)=78.8(6.45), Range 63-89 Antipsychotic medication: 26.9% Benzodiazepine s: 23.1% Antidepressants: 15.4%	MMSE: M(SD)=16.8 (7.52), Range= 1- 28	HDRS (17-item version): M(SD)= 10.5(5.73), Range= 2-24	Pearson correlation with Bonferroni correction between HDRS and MMSE scores	r = -0.33, n.s.	No significant association
Teri and Wagner, 1991	0	DSM-III-R criteria for AD	n = 75 Outpatients Female gender: 68% Age: M(SD)=74.0(7.4), Range= 46-89 Education: ≤12th grade: 72%, >12th grade: 28%	(1)MMSE: M(SD)= 18.1(5.7), Range= 4-27; Mild (score: >21): 30.7%; Moderate (score: 21-16): 37.3%; Severe (score: <16): 32.0% (2) GDS: M(SD)=4.6(1.0), Range= 2-6	HDRS (17-item version): (a) patient's report: M(SD)= 5.0(5.2), Range= 0-26; (b) caregiver's report: M(SD)= 7.6(6.9), Range= 0-30; (c) clinician's evaluation: M(SD)= 8.2(6.9), Range= 0-30 MDD (DSM-III-R criteria): 29%	3(source) x 3(severity of AD) repeated measures MANOVA: Dependent: HDRS score; Severity of AD: mild, moderate, severe (based on MMSE); Source: patient, caregiver or clinician	No significant effect of severity of AD	No significant association

Note: NINCDS-ADRDA= National Institute of Neurological and Communicative Diseases and Stroke-Alzheimer's Disease and Related Disorders Association (McKhann et al., 1984); GDS= Global Deterioration Scale (Reisberg et al., 1982); MMSE= Mini-Mental State Examination (Folstein et al., 1975); NPI= Neuropsychiatric Inventory (Cummings et al., 1994); RMBPC= Revised Memory and Behavior Problem Checklist (Teri et al., 1992); n.s.= not significant; CSDD= Cornell Scale for Depression in Dementia (Alexopolous et al., 1988); CDR= Clinical Dementia Rating Scale (Morris, 1993); HDRS= Hamilton Depression Rating Scale (Hamilton, 1960; Williams, 1988); MDD= major depressive disorder; DSM= Diagnostic and Statistical Manual of Mental Disorders, third revised (DSM-III-R) or fourth (DSM-IV) edition (American Psychiatric Association, 1987, 1994); GDS= Geriatric Depression Scale (Yesavage et al., 1983; Sheikh & Yesavage, 1986); MADRS= Montgomery and Åsperg Depression Scale (Montgomery & Åsberg, 1979); DRS= Mattis Dementia Rating Scale (Mattis, 1976); RRS= Retardation Rating Scale (Widlöcher, 1983); ICD-10= International Classification of Diseases, tenth edition (World Health Organization, 1987); CAMCOG= Cambridge Cognitive Examination (Roth et al., 1986); DMAS= Dementia Mood Assessment Scale (Sunderland et al., 1988); SDS= Zung Self-Rating Depression Scale (Zung, 1965); PLSD= Fisher's Protected Least Significant Difference; d.f.= degrees of freedom.

- <sup>a</sup> Data concerning education and duration of AD are presented in years, unless stated otherwise. Only psychiatric exclusion criteria are presented.
- <sup>b</sup> If available data on prevalence of major depression or dysthymia are also presented.
- <sup>c</sup> This study had two different quality scores because separate analyses were performed using scores on different scales to assess severity of AD.
- <sup>d</sup> No (further) data concerning the sample of patients with AD were reported.
- <sup>e</sup> Missing data for 6 patients, n = 202.
- <sup>f</sup>Depression scales were not performed in every patient with AD for various reasons.
- g Results concern those at baseline.
- <sup>h</sup> Missing data for 2 patients, n = 28.

Table 2.2 Studies on the association between severity of dementia and prevalence of diagnosed depression in patients with Alzheimer's Disease (AD)

Study	Quality	Diagnostic criteria for AD	Characteristics of AD patients <sup>a</sup>	Severity of AD	Prevalence of depression <sup>b</sup>	Statistical analysis	Results	Direction of association
Harwood et al., 2000b	3	NINCDS- ADRDA criteria for possible or probable AD	n = 96 Outpatients Female gender: 70% Age: M(SD)= 74.9(6.8) Education: M(SD)= 9.9(5.2) Cuban American: 100% Functional status (BDS): M(SD)= 5.8(4.2) Presence of delusions/hal- lucinations: 32.3%	MMSE: M(SD)= 15.9(6.5)	Depression (CSDD score: ≥7): 39.6% CSDD (all AD patients): M(SD)= 7.4(6.9), Range= 0-28	Multivariate logistic regression: Dependent: depression (0/1); Independent: MMSE score; Covariates: age, education, gender, marital status, functional status and psychosis	OR(95% CI)= 0.9 (0.9-1.0), p = 0.25	No significant association

- table 2.2 continued -

Study	Quality	Diagnostic criteria for AD	Characteristics of AD patients <sup>a</sup>	Severity of AD	Prevalence of depression <sup>b</sup>	Statistical analysis	Results	Direction of association
Lyketsos et al., 1997	3	NINCDS- ADRDA criteria for probable AD	n = 109 Outpatients Female gender: 79% Age: M(SD)= 74.4(7.9) History of depressive disorder: 17.4%.	(1) CDR: Early (score: 0.5): 9.8%; Mild (score: 1): 38.2%; Moderate (score: 2): 29.4%; Severe (score: 3): 21.6%  (2) MMSE: M(SD)= 15.0(6.5), Range= 0-28	(a) MDD (DSM-IV criteria): 22%; (b) Minor depression (depressed mood, crying spells, or anhedonia according to CSDD and CSDD score: >6): 27%; (c) remaining patients: 51%  CSDD (all AD patients): M(SD)= 8.0(7.2), Range= 0-28	Chi-square test: Distribution of the 3 depression groups across CDR scores	χ2= 5.86, d.f.= 4, p = 0.21	No significant association

- table 2.2 continued -

Study	Quality	Diagnostic criteria for AD	Characteristics of AD patients <sup>a</sup>	Severity of AD	Prevalence of depression <sup>b</sup>	Statistical analysis	Results	Direction of association
Ballard et al., 1996	3	NINCDS- ADRDA criteria for possible or probable AD	n = 88 Outpatients  Total sample of patients with dementia (n = 124)s: Female gender: 73% Age: M= 79.6 Exclusion criteria: fulfilment of the CAMDEX criteria for severe dementia	CAMCOG: Total sample of patients with dementias: M= 43.9	MDD (depressive symptoms were rated using the CSDD; next, diagnosis was made according to the RDC criteria): 17.0% CSDD (all AD patients): M= 9.2	Bivariate logistic regression: Dependent: depression (0/1); Independent: CAMCOG score	Wald chi-square test= 0.63, p = 0.43	No significant association
Lopez et al., 2003	2	NINCDS- ADRDA criteria for probable AD	n = 1,155 Outpatients Female gender: 70% Education: M(SD)= 12.0(3.0) Duration AD: M(SD)= 4.0(2.7) African Americans: 6.3% BDS: M(SD)= 6.1(4.2)	(1) MMSE: M(SD)=16.9 (6.1); Mild (score: ≥20): 37.9%; Moderate (score: 10-19): 48.7%; Severe (score: ≤9): 13.3% (2) DRS: M(SD)= 107.4(22.9)	MDD (depressive symptomatolo- gy was rated using the BRSD, HDRS and BDS; next, diagnosis was made according to DSM-III/-III-R/- IV criteria): 17.0%	Chi-square test: Comparison between mildly, moderately and severely impaired groups (based on MMSE) regarding frequency of MDD	MDD: Mildly impaired group: 11.5%; Moderately impaired group: 10.0%; Severely impaired group: 4.5%; $\chi$ 2= 6.03, d.f.= 2, $p$ = 0.04	Lower likelihood of depression in more severe AD

#### - table 2.2 continued -

Study	Quality	Diagnostic criteria for AD	Characteristics of AD patients <sup>a</sup>	Severity of AD	Prevalence of depression <sup>b</sup>	Statistical analysis	Results	Direction of association
			Antidepressants: 19.0% Sedatives, hypnotics and anxiolytics: 6.3% Antipsychotics: 7.7%	(3) CDR: M(SD)= 1.3(6.8)	HDRS (all AD patients; 17-item version): M(SD)= 6.4(4.4)			
Payne et al., 1998	2	NINCDS- ADRDA criteria for possible or probable AD	n = 151 Outpatients Female gender: 81% Age: M(SD)=78.1 (7.9) Caucasian: 80.7% Functional status (PGDRS-P): M(SD)= 7.5(7.5)	MMSE: M(SD)=14.7 (7.3)	Depression (CSDD score: >12): 17% CSDD (all AD patients): M(SD)= 6.6(6.1), Range= 0-25	(1) bivariate logistic regression: Dependent: depression (0/1); Independent: MMSE score (2) multivariate logistic regression: Covariate: functional status	(1) OR(95% CI)= 1.03 (0.97-1.09) (2) OR(95% CI)= 1.09 (1.01-1.19)	(1) No significant association (2) Lower likelihood of depression in more severe AD

- table 2.2 continued -

Study	Quality	Diagnostic criteria for AD	Characteristics of AD patients <sup>a</sup>	Severity of AD	Prevalence of depression <sup>b</sup>	Statistical analysis	Results	Direction of association
Fitz and Teri, 1994	1	DSM-III-R criteria for AD	n = 91 Outpatients Female gender: 55% Age: Range: 46-90	DRS: M(SD)= 102(18.8), Range= 56-139; Mild (score: <102): 49.5%; Moderate (score: >103): 50.5%	MDD (DSM-III-R criteria): 50.5%	Comparison between mildly and moderately impaired groups (based on DRS) regarding frequency of MDD	MDD: Mildly impaired group: 56.5%; Moderately impaired group: 44.4%; n.s.	No significant association
Troisi et al., 1993	1	NINCDS- ADRDA criteria for probable AD	n = 26 Outpatients Female gender: 54% Age: M(SD)= 74.0(5.53), Range= 65-84 Education: M(SD)=7.15 (5.03), Range= 0-19	(1) MMSE: mild-moderate (score: 16-23): 50%; severe (score: ≤15): 50% (2) DSM-III-R: Mild: 26.9% Moderate: 42.3% Severe: 30.8%	MDD (DSM-III-R criteria): 23.1%	Chi-square tests: (1) comparison between control, mildly-moderately and severely impaired groups (based on MMSE) regarding frequency of MDD (2) comparison between control, mildly, moderately and severely impaired	(1) MDD: mildly-moderately impaired group: 7.7%; severely impaired group: 38.5%; control group: 11.5%; $\chi$ 2= 5.51, d.f.= 2, $p$ = 0.06  (2) MDD: Mildly impaired group: 0%; Moderately impaired group: 11.5%; Severely	(1&2) No significant association

#### - table 2.2 continued -

Study	Quality	Diagnostic criteria for AD	Characteristics of AD patients <sup>a</sup>	Severity of AD	Prevalence of depression <sup>b</sup>	Statistical analysis	Results	Direction of association
						groups (based on DSM-III-R criteria) regarding frequency of MDD	impaired group: 11.5%; Control group: 11.5%; \( \chi 2 = 5.11,	

Note: NINCDS-ADRDA= National Institute of Neurological and Communicative Diseases and Stroke-Alzheimer's Disease and Related Disorders Association (McKhann et al., 1984); BDS= Blessed Dementia Scale (Blessed et al., 1968); CSDD= Cornell Scale for Depression in Dementia (Alexopolous et al., 1988); MMSE= Mini-Mental State Examination (Folstein et al., 1975); OR= odds ratio; CI= confidence interval; MDD= major depressive disorder; DSM= Diagnostic and Statistical Manual of Mental Disorders, third (DSM-III), third revised (DSM-III-R) or fourth (DSM-IV) edition (American Psychiatric Association, 1980, 1987, 1994); CDR= Clinical Dementia Rating Scale (Morris, 1993); d.f.= degrees of freedom; PGDRS-P= Psychogeriatric Dependency Rating Scale- Physical dependency scale (Wilkinson and Graham-White, 1980); CAMDEX= Cambridge Mental Disorders in the Elderly Examination (Roth et al., 1986); RDC= Research Diagnostic Criteria (Spitzer et al., 1978); CAMCOG= Cambridge Cognitive Examination (Roth et al., 1986); BRSD= Behavioral Rating Scale for Dementia of the Consortium to Establish a Registry for Alzheimer's Disease (CERAD) (Tariot et al., 1995); HDRS= Hamilton Depression Rating Scale (Hamilton, 1960); DRS= Mattis Dementia Rating Scale (Mattis, 1976); n.s.= not significant.

<sup>&</sup>lt;sup>a</sup> Data concerning education and duration of AD are presented in years, unless stated otherwise. Only psychiatric exclusion criteria are presented.

<sup>&</sup>lt;sup>b</sup> If available scores on depression rating scales for the sample of patients with AD are also presented.

<sup>&</sup>lt;sup>c</sup>No (further) data concerning the sample of patients with AD were reported.

The last column of table 2.1 and 2.2 indicates whether or not a significant association was found between the severity of AD and the prevalence of comorbid depressive symptoms or diagnosed depression and, if so, the direction of the association. In studies with a continuous approach eight times a positive association was found, two times a negative association and 24 times no association. In studies with a categorical approach two times a negative association was found and seven times no association.

#### **Best Evidence Synthesis**

Only four studies within the continuous approach and three studies within the categorical approach were rated as being of high methodological quality. Three of these four "continuous" studies found no association between severity of AD and depressive symptoms and all three "categorical" studies demonstrated no relationship between severity of AD and prevalence of diagnosed depression.

Following the principles of the best evidence synthesis within both approaches we found scientific evidence for a lack of association between the severity of AD and the prevalence of depressive symptoms or diagnosed depression.

#### Conclusion and discussion

The main conclusion of this systematic review is that, based on current knowledge, evidence exists for a lack of association between the severity of AD and the prevalence of comorbid depressive symptoms or depression.

Earlier non-systematic literature reviews (e.g. Olin et al., 2002b) often stated that no conclusions about the relationship between the severity of AD and the prevalence of comorbid depression could be drawn due to large differences between existing studies. In this review we used various methods to overcome this problem: in the first place selection criteria were formulated that make sure that (1) all study samples consisted of people with AD and, (2) valid assessment methods for depression and severity of AD were used. Secondly, selected studies were categorized into two groups: those that focused on the prevalence of depressive symptoms (continuous approach) and those that examined the prevalence of diagnosed depression

(categorical approach). In addition the quality of all selected studies was rated, in order to select the studies with the highest validity.

Limitations of this review are that only studies published in English were included and studies that did not have depression or depressive disorder as a keyword were not identified. We do however not consider it very likely that high quality studies were missed because of this.

The finding that comorbid depressive symptomatology or diagnosed depression is not more prevalent in early, mild or severe AD contrasts with what is often theorized in physiological and psychological theories. These theories hypothesize that the prevalence of depression either decreases (psychological theories) or increases (physiological and psychological theories) with the increasing severity of AD. Interactive theories (Alexopoulos, 2003) do however offer a possible explanation for the current findings. According to these theories the neurological and psychosocial factors can reinforce or diminish each other, depending on the specific situation of a patient. Only a longitudinal study could give more insight into the mechanisms underlying the etiology of depression in AD.

Following the systematic approach of this review and using current knowledge, such a longitudinal study should ideally meet the following criteria: (a) establishing diagnosis of AD according to NINCDS-ADRDA criteria (McKhann et al., 1984); (b) assessing severity of AD with a clinical instrument (e.g. CDR; Hughes et al., 1982 or GDS; Reisberg et al, 1982); (c) assessing symptoms of depression with an instrument specifically developed for people with dementia or specifically AD (e.g. CSDD; Alexopoulos et al., 1988 or NPI\_depression subscale; Cummings et al., 1994); (d) establishing diagnosis of depression according to criteria specifically developed for people with AD, such as the Provisional Diagnostic Criteria for Depression of Alzheimer Disease (Olin et al., 2002a); (e) using multivariate analytic techniques to control for known potentially important confounders (e.g. gender, history of depression, current use of antidepressant or psychotropic medication).

For clinical practice the conclusion of the review shows that the development of specific interventions for signalling, preventing and treating comorbid depression in the different severities of AD should continue.

## 3

# Comorbid depression in dementia on psychogeriatric nursing home wards

Which symptoms are prominent?

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#### **Abstract**

#### Objective

To provide insight into the prevalence and clinically relevant symptoms of comorbid depression among dementia patients in psychogeriatric nursing home wards, in order to enhance depression recognition.

#### Design

Cross-sectional analyses of multi-centre diagnostic data.

#### Setting

Psychogeriatric wards of Dutch nursing homes.

#### **Participants**

518 residents with dementia.

#### Measurements

- 1. diagnosis of depression in dementia (PDC-dAD),
- 2. dementia (DSM-IV-PC),
- 3. stage of dementia (GDS).

#### Results

The point prevalence of comorbid depression in dementia (stages 2 to 6) on psychogeriatric nursing home wards was 19%. 'Depressed mood', 'irritability' and 'fatigue' were the most prevalent depressive symptoms. Residents taking antidepressants at the time of the PDC-dAD depression diagnosis showed more depressive symptoms than residents who were not. The mean number of depressive symptoms was 5.6 (SD 1.84), which did not differ between the dementia stages. Also, no differences were found in the point prevalence of the shown symptoms between dementia stages.

#### Conclusion

'Irritability' was put forward by the developers of the Provisional Diagnostic Criteria for Depression of Alzheimer Disease (Olin et al., 2002a), as one of the specific symptoms of depression in Alzheimer Disease. This study shows that 'irritability' is one of the most prevalent depressive symptoms in psychogeriatric nursing home residents diagnosed with comorbid depression. 'Irritability' should therefore alert caregivers to the presence of depression and could help early recognition. The high prevalence rate of comorbid depression in dementia in this setting justifies attention to early recognition and intervention.

## Introduction

Comorbid depression in people with dementia has been associated with decreased quality of life (Shin et al., 2005), greater health care utilization (Kunik et al., 2005), higher mortality rates (Suh et al., 2005) and decreased caregiver's wellbeing (Kerkstra et al., 1999; Shin et al., 2005). These serious consequences ask for early recognition and intervention. However, recognition of depression in dementia is not easy. This is especially the case on psychogeriatric wards in nursing homes where people are in the middle and last stages of dementia and where most patients have significant problems expressing themselves. On these psychogeriatric wards, nurses and nurse assistants may be in the best position to recognize (symptoms of) depression. Yet Teresi et al. (2001) show that nurses and nurse assistants only recognize depression in dementia sufferers with a sensitivity of 49% to 55% respectively. Recognition by other disciplines is often no better. A literature review by Brühl et al. (2007) shows recognition to be as low as 44% for psychiatrists, 37% for social workers and 14% for nursing home physicians.

Recognition of depression in dementia is not only hindered by communication problems, but also by the overlapping of symptoms of depression and dementia. A final major reason why caregivers have difficulty in recognizing depression is that depression in dementia is different from the traditional Major Depressive Disorder as described in DSM-IV (American Psychiatric Association, 1994). Many clinicians and researchers have argued that subclinical levels of depression are also relevant in dementia (Lyketsos et al., 1997; Janzing et al., 2002; Starkstein et al., 2005). In 2002 an expert group initiated by the American National Institute of Mental Health formulated specific diagnostic criteria for people with Alzheimer Disease (Olin et al., 2002a) - the type of dementia that 60% to 80% of the people with dementia suffer from (Knopman et al., 2001). The socalled Provisional Diagnostic Criteria for Depression of Alzheimer Disease (PDC-dAD) differ from the criteria for Major Depressive Disorder regarding nature and intensity of the symptoms. The symptoms 'irritability' and 'social isolation/withdrawal' were added; the symptom 'loss of interest or pleasure' has been reformulated, while the symptom 'diminished ability to think or concentrate' was deleted, as being intrinsically inherent to the dementia syndrome. Also, only three of the ten symptoms need be present for a diagnosis instead of five, and symptoms do not need to be present every day

(Olin et al., 2002b). Table 3.1 shows the criteria and symptoms of the PDC-dAD.

Tabel 3.1 Provisional Diagnostic Criteria for Depression of Alzheimer Disease

#### Diagnostic criteria PDC-dAD

A. Three (or more) of the following symptoms have been present during the same 2-week period and represent a change from previous functioning: at least one of the symptoms is either 1) depressed mood or 2) decreased positive affect or pleasure.

Note: Do not include symptoms that, in your judgement, are clearly due to a medical condition other than Alzheimer Disease, or a direct result of non-mood-related dementia symptoms (e.g. loss of weight due to difficulties with food intake).

- Clinically significant depressed mood (e.g., depressed, sad, hopeless, discouraged, tearful)
- Decreased positive affect or pleasure in response to social contacts and usual activities
- (3) Social isolation or withdrawal
- (4) Disruption in appetite
- (5) Disruption in sleep
- (6) Psychomotor changes (e.g., agitation or retardation)
- (7) Irritability
- (8) Fatigue or loss of energy
- (9) Feelings of worthlessness, hopelessness, or excessive or inappropriate guilt
- (10) Recurrent thoughts of death, suicidal ideation, plan or attempt
- B. All criteria are met for dementia of the Alzheimer Type (DSM-IV-TR)
- C. The symptoms cause clinically significant distress or disruption in functioning.
- D. The symptoms do not occur exclusively during the course of a delirium.
- E. The symptoms are not due to the direct physiological effects of a substance (e.g, drug abuse or medication).
- F. The symptoms are not better accounted for by other conditions such as major depressive disorder, bipolar disorder, bereavement, schizophrenia, schizoaffective disorder, psychosis of Alzheimer Disease, anxiety disorders, or substance-related disorder.

In order to improve recognition by caregivers, information is also required about the prevalence of comorbid depression in dementia using the PDC-dAD, the frequencies of PDC-dAD depressive symptoms and the possible differences between the dementia stages. This study gives this information for residents with dementia stages from "age-related memory impairment"

to "moderately severe dementia" (Global Deterioration Scale stages 2 to 6, see table 3.2 (Reisberg et al., 1982)). Attention is also paid to possible differences between residents who are already taking antidepressants and those who are not, in order to be able to separate 'pure' depressive symptoms from symptoms that are possibly mediated by the antidepressants.

Table 3.2 Stages of dementia as defined by Global Deterioration Scale (Reisberg, 1982)

(======================================	~ <del>-</del> /
Dementia stage	Description
1	No cognitive decline
2	Age Associated Memory Impairment
3	Mild Cognitive Impairment
4	Mild Dementia
5	Moderate Dementia
6	Moderately Severe Dementia
7	Severe Dementia

The research questions addressed are:

- 1. 'What is the point prevalence of comorbid depression in dementia (stages 2 to 6) in residents of Dutch psychogeriatric nursing home wards as assessed with the PDC-dAD?'
- 2. 'What are the characteristics of comorbid depression in dementia (stages 2 to 6), regarding:
  - a) The mean number of depressive symptoms in users and non-users of antidepressants?
  - b) The point prevalence of specific depressive symptoms in users and non-users of antidepressants?
  - c) The mean number of depressive symptoms and the prevalence of specific depressive symptoms in relation to the dementia stages?'

This study was conducted on Dutch psychogeriatric nursing home wards. In the Netherlands there are about 27 nursing home beds per 1000 inhabitants of 65 years of age and over. Of these beds 55% are in psychogeriatric wards for patients with dementia and 45% in somatic wards, primarily for patients with somatic (ie, physical) problems (Data from RIVM, 2003). Most of the

Dutch nursing homes (73%) have psychogeriatric wards as well as somatic wards (Schols et al., 2004). Psychogeriatric wards are separate wards or units in nursing homes for psychogeriatric residents, characterized by corridors, colors, and closed-door systems, that are adapted for these residents. They are comparable with specialized Alzheimer units in the United States. Of the residents 85% is diagnosed with a dementia syndrome, mostly moderate to severe (GDS stages 5 to 7) (Zuidema et al., 2007). Much of the daily nursing care is delivered by Certified Nurse Assistants (CNAs) who in the Netherlands generally have three years of basic nursing training, and who are -regarding educational level and skills- rather comparable with Licensed Practical Nurses in the United States. First responsible for medical care and directions of the total care is the nursing home physician. In the Netherlands the nursing home physician is a formally recognized medical specialization, with two years of postgraduate university training in nursing home medicine. CNAs and nursing home physicians are supported by a team of psychologists, occupational therapists, social workers, and others who are specifically educated for working in the nursing home context (Schols et al., 2004).

## Methods

#### Sample

Data come from the pre-intervention phase of a psychosocial intervention study for dementia sufferers with depression on 16 psychogeriatric wards of Dutch nursing homes (Francke et al., 2004).

The nursing homes in the intervention study had applied in response to an invitation letter from NIVEL and VU University Medical Centre. Nine nursing homes participated each with two comparable psychogeriatric wards. In eight homes all residents from the 16 participating wards were systematically screened and diagnosed with depression in dementia using the PDC-dAD-criteria. In the ninth nursing home not all residents could be screened, owing to personnel problems. Therefore the data from this nursing home were not processed in the analyses for our paper. Background characteristics of the residents diagnosed with comorbid depression in dementia were collected in the baseline measurement of the intervention study.

## Assessment of comorbid depression in dementia

On each of the wards, a two-step process was used to identify residents with depression in dementia, as advised by Logsdon and Teri (1995).

As a first step in the diagnostic process the team manager and/or certified nurse assistants screened all residents of the participating wards for possible depression with the Geriatric Depression Scale-15-caregiver. This scale is a Dutch translation of the Geriatric Depression Scale-15 (Yesavage et al., 1982-1983; D'Ath et al., 1994) that is adapted to a scale suitable for completion by caregivers of people with dementia. The internal consistency (alpha) of this scale tested by Logsdon and Teri was .91 and the sensitivity to diagnose major and minor depression in them was 90% (1995). In our study team managers and CNAs who conducted the screening received verbal and written instructions from the first author (psychologist). An instruction specific for this proxy version of the Geriatric Depression Scale was that the team manager and CNAs should score the presence of a symptom irrespective of its possible cause (e.g. depression or dementia). They were informed that the physician and psychologist would consider the cause in the next step of the diagnostic process. All residents with a score of 4 or higher were selected as possibly depressed (D'Ath et al., 1994).

As a *second step*, either nursing home physicians or psychologists determined whether the positively screened residents met the following three criteria by studying medical status, interviewing and/or observing the resident and consulting with other caregivers:

- 1. Demented (DSM-IV-PC Dutch version (American Psychiatric Association, 1996)).
- 2. Stage of dementia from "age associated memory impairment" to "moderately severe dementia" (Global Deterioration Scale stages 2 to 6). Residents with severe dementia (Global Deterioration Scale stage 7) were excluded from the study because the intervention was aimed at residents who were still able to communicate verbally. For a description of the dementia stages according to the Global Deterioration Scale, see table 3.2 (Reisberg et al., 1982).
- 3. Diagnosed with depression in dementia according to the PDC-dAD (Olin et al., 2002a) (table 3.1). Because the diagnosis of dementia was established but not the specific type, criterion B of the PDC-dAD "All criteria are met for dementia of the Alzheimer type" was not considered.

The second step of the diagnostic process generally took place within a timeframe of two successive weeks, in the first nursing home in October 2005, and in the last nursing home in October 2006.

Physicians and psychologists received the three sets of diagnostic criteria as well as written and verbal instructions on how these should be applied from the first author. The written instructions for the PDC-dAD-criteria include a translation of the operationalizations and case descriptions of the criteria as developed by Rosenberg et al. (2005).

#### Statistical analyses

The first research question ("What is the point prevalence of comorbid depression in dementia (stages 2 to 6) in residents of Dutch psychogeriatric nursing home wards as assessed with the PDC-dAD?") was answered by calculating the percentage of residents diagnosed with comorbid depression in dementia, stages 2 to 6, of the screened sample.

To answer research question 2a ("What is the number of depressive symptoms in users and non-users of antidepressants?"), the group of residents was split into those who received antidepressants and those who did not. The mean number of depressive symptoms was calculated for each group, and differences were tested for significance (p $\leq$ .05) with an ANOVA test, with gender as covariate. Gender was entered as covariate because analyses showed a significant relationship between gender and the prevalence of symptom 2 'decreased positive affect or pleasure in response to social contacts and usual activities' (Wald's  $\chi^2$  (1)= 4.13, p=.03), women showing this symptom significantly more often. Other background characteristics and use of psychoactive medications (table 3.3) did not show relationships and were therefore not entered as covariates into the model.

The prevalence rates of the ten depressive symptoms and differences between antidepressant users and non-users (research questions 2b) were determined by calculating prevalence rates firstly for the total group of residents and secondly for the separate groups. Differences between the groups were tested for significance (p≤.05) using logistic regression analyses. The dependent variable was the presence of each of the ten depressive symptoms (yes/no); the independent variable was antidepressant use (yes/no); gender was a covariate. Again only gender was entered as a covariate because analyses showed a significant relationship, while other background characteristics and psychoactive medication use (table 3.3) did not show a relationship to the dependent variable.

To answer the first part of question 2c ("What is the number of depressive symptoms and is it related to the stage of dementia?) three dementia stage groups were formed: (1) age associated memory impairment (stage 2) to mild dementia (stage 4), (2) moderate dementia (stage 5), and (3) moderately severe dementia (stage 6). The mean number of depressive symptoms was calculated for each group. Differences between the groups were tested for significance (p≤05) using a between-subjects test (ANOVA) with gender as covariate.

To answer the second part of question 2c ("Does the prevalence of specific depressive symptoms relate to the dementia stages?) we calculated prevalence rates of the ten depressive symptoms for the three dementia stage groups. Differences between the groups were tested for significance (p≤.05) using logistic regression analysis with gender as a covariate. The dependent variable was the presence of each of the ten depressive symptoms (yes/no); independent variables were the stages of dementia (stage 2 to 4 yes/no; stage 5 yes/no; stage 6 yes/no). The statistical software used was SPSS 14.0 for WINDOWS.

## Results

#### Prevalence of comorbid depression and dementia

To gain insight into the point prevalence of comorbid depression in demented residents (stages 2 to 6) of Dutch psychogeriatric nursing home wards, we performed two steps: screening for possible depression of all residents in the participating wards (step 1) and diagnosis of depression, dementia and dementia stage (step 2). Figure 3.1 shows a flow-chart with the results of these steps. In total, 518 residents were in the participating wards at the time the screening for possible depression took place (step 1). During the process 20 residents died and a further two dropped out due to transfer. Of the remaining 496 residents 252 had a score of less than 4 on the Geriatric-Depression-Scale-15-caregiver, indicating no possible depression, and were therefore excluded from the further diagnostic procedure. 244 residents had a score of 4 or higher on the Geriatric-Depression-Scale-15caregiver (indicating possible depression) and entered step 2 of the diagnostic process. Of these 244 possibly depressed residents 148 residents did not fulfill the diagnostic criteria for dementia, stage of dementia (residents with severe dementia were excluded) or depression, and 96 did.

The point prevalence of comorbid depression and dementia (stages 2 to 6) is therefore calculated at 19% (all 96 depressed and demented residents within dementia stages 2 to 6 divided by all 496 residents of the psychogeriatric wards).

For two of the 96 residents no informed consent for study participation was given, which results in data of 94 cases to be analyzed. Table 3.3 presents the characteristics of these 94 residents.

Figure 3.1 Steps and results of the diagnostic process

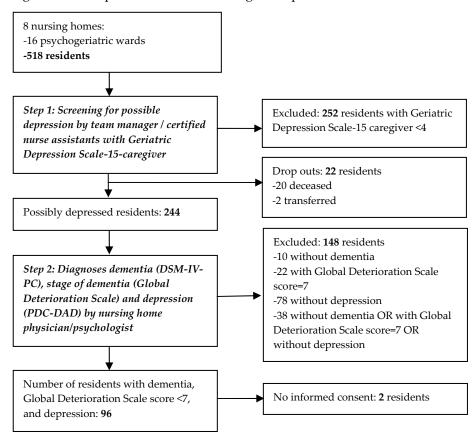


Table 3.3 Characteristics of the 94 residents diagnosed with depression and dementia

Age, years			
Mean ± Standard Deviation	$83.5 \pm 7.1$		
Range	62-99		
Gender, male	19 (20)		
Marital status			
Married	23 (24)		
Widow/widower	66 (70)		
Divorced	3 (4)		
Unmarried	2 (2)		
Duration of institutionalization			
<3 months	4 (4)		
3 months – 1 year	23 (24)		
1 – 3 years	41 (44)		
> 3 years	26 (28)		
Dementia severity (Global Deterioration Scale)			
Age associated memory impairment	2 (2)		
Mild cognitive impairment	3 (3)		
Mild dementia	8 (9)		
Moderate dementia	32 (34)		
Moderately severe dementia	38 (40)		
Missing	11 (11)		
Psychoactive medication use			
Antidepressant drugs	33 (35)		
Antipsychotic drugs	47 (50)		
Benzodiazepines	36 (38)		
ACE-inhibitors/Beta-blockers	8 (9)		
77 . 70			

*Note*: Figures in parentheses indicate percentages. All percentage values are percentages of the total group

## Differences between antidepressant users and non-users

## Mean number of depressive symptoms

For eight residents, explicit data about their symptoms of depression were missing and could therefore not be used in the analyses of the mean number of symptoms.

Information about medication use was missing for eight other residents. Data of these residents could therefore not be used in the analyses of the differences between users and non-users of antidepressants.

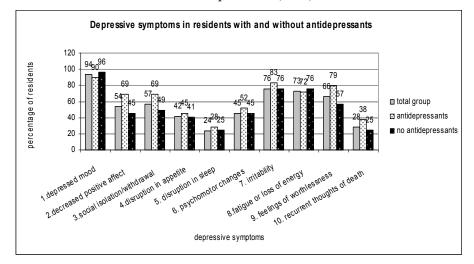
The mean number of depressive symptoms in the total group of residents (n=86) with comorbid depression in dementia on a scale from 0 to 10 was 5.6 (SD 1.84).

In the residents who received antidepressants at the time of the PDC-dAD diagnosis (n=29) the mean number of depressive symptoms was 6.2 (SD 2.1), and in residents without antidepressants (n=49) it was 5.3 (SD 1.7). The difference in mean number of depressive symptoms proved statistically significant – the residents with antidepressants showing significantly more symptoms (F(1,76)=4.42, p=.04) than the non-antidepressant group.

## Prevalence of specific depressive symptoms

Figure 3.2 shows the point prevalence of each of the ten depressive symptoms of the PDC-dAD for the total group of residents (n=86), and for the group that received antidepressants (n=29) and the group that did not (n=49) separately. In the total group 'depressed mood', 'irritability' and 'fatigue' were highly prevalent – each shown by at least 73% of the residents. 'Disruption in sleep' and 'recurrent thoughts of death' were the least prevalent symptoms, shown by 24% and 28% of the residents respectively. In the group of residents that took antidepressants at the time of the PDC-dAD diagnosis one symptom was significantly shown more often than in the group that did not, namely 'decreased positive affect' (Wald's  $\chi^2(2)=4.36$ , p=.04).

Figure 3.2 Prevalence of the 10 depressive symptoms in the total group of residents (n=86), residents with antidepressants (n=29) and without antidepressants (n=49)



## Relationship with dementia stage

#### Mean number of depressive symptoms

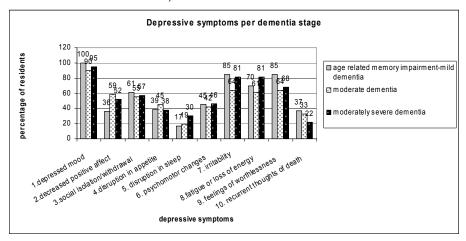
Subsequently we analyzed whether there is a relationship between the number of depressive symptoms and the stage of dementia (n=81). Data for five residents could not be used because information about their dementia stage was missing.

In the group of residents with age-related memory impairment to mild dementia (n=13) the mean number of symptoms is 5.8 (SD 1.83), in moderate dementia (n=31) it is 5.3 (SD 2.0), and in moderately severe dementia (n=37) it is 5.7 (SD 1.6). Using ANOVA with gender as covariate no differences between dementia stages were found (F(2, 78)=.40, p=.67).

## Prevalence of specific depressive symptoms

Finally, analyses were performed on the prevalence of the ten specific depressive symptoms in the three dementia stage groups, and the possible differences between the groups were studied. Figure 3.3 shows the prevalence rates of symptoms in the three groups. Logistic regression with gender as covariate showed no significant differences in this respect between the dementia stages. Wald's Chi-square was highest for symptom 8 'fatigue/loss of energy' (Wald's  $\chi^2(2)=1.6$ , p=.20) and lowest for symptoms 3 'social isolation/withdrawal' and 6 'psychomotor changes' (Wald's  $\chi^2(2)=.02$ , p=.89).

Figure 3.3 Prevalence of the 10 depressive symptoms in the three dementia stage groups (age-related memory impairment-mild dementia n=13; moderate dementia n=31; moderately severe dementia n=37)



## Discussion

## Reflections on the main findings

Using the Provisional Diagnostic Criteria for Depression of Alzheimer Disease (PDC-dAD) we found a point prevalence of 19% comorbid depression in dementia among residents with dementia severities 2 to 6 in Dutch psychogeriatric nursing home wards. This rate is comparable with the depression rate of 22% in residents of Dutch somatic nursing home wards using DSM-IV criteria for major and minor depression (Smalbrugge et al., 2006) and the rate of 20% comorbid depression and dementia found by Zuidema et al. (Francke et al., 2004) in Dutch psychogeriatric nursing home wards using the NPI-NH-depression subscale. One of the few researchers who have published about prevalence rates using the PDC-dAD are Vilalta-Franch et al. (2006). They found a somewhat higher rate of comorbid depression and dementia of 27% in people still living at home in Spain. The prevalence rate of 19% that we found and the known serious consequences of comorbid depression in dementia (e.g. higher mortality rates, lower quality of life) justifies considerable attention being paid to early recognition and intervention of depression on psychogeriatric nursing home wards.

Teaching nurses, nurse assistants and other caregivers about the most frequent symptoms could help them in recognizing possible depression. After recognition, nurses or nurse assistants could ask a physician or psychologist to make a formal depression diagnosis using the PDC-dAD and as a next step possible treatments could be discussed.

We found that the most frequently shown depressive symptoms are 'depressed mood', 'irritability' and 'fatigue/loss of energy'. The fact that 'irritability' – one of the symptoms added as being specific for depression in AD is one of the most prevalent symptoms, is an important finding for depression recognition. The study by Vilalta-Franch et al. showed that irritability is also highly prevalent in a depressed and demented outpatient population. Starkstein et al. (2005) likewise found that outpatients with major or minor depression and Alzheimer's Disease had significantly higher scores for irritability than non-depressed patients.

The mean number of depressive symptoms was 5.6 (SD 1.84). Interestingly, residents already taking antidepressants showed more different symptoms on average than residents without antidepressants. Residents using antidepressants also showed one specific symptom more often, namely 'decreased positive affect or pleasure in response to social contacts and usual activities'. We did not check if residents receiving antidepressants already had had an earlier diagnosis of depression. It is possible that antidepressants were given for other medical problems, e.g. urinary incontinence, and/or that doses were too low to be therapeutic. We therefore have analysed the types of prescribed antidepressants and the doses. In 90% of the cases nontryciclic antidepressants were prescribed. In only one case the dose was much lower than the advised dose for the elderly (Dutch Health Care Insurance Board (CVZ), Pharmaceutical therapeutic guide 2008). There was also no administration of duloxetine, which is sometimes prescribed for female urinary incontinence. We therefore consider it plausible that the antidepressants were indeed prescribed for depression, and that residents receiving antidepressants were still depressed at the time of the current diagnosis. The more different symptoms in antidepressant users might indicate that they are more severely depressed than non-users.

Unfortunately, we could not relate the Geriatric-Depression-Scale-15-caregiver scores to the individual residents, because these scores were anonymised by the team managers. Pre-intervention data from the clinical trial, however, suggest that antidepressant-users were not more severely

depressed: scores on the MDS-Depression Rating Scale and the Cornell Scale for Depression in dementia taken about two to four weeks after the depression diagnosis did not differ significantly between the groups (ANOVA, gender as covariate,  $p \le .05$ ). The more different types of symptoms seem to suggest that antidepressant users show another profile of depressive symptoms. Different explanations are again possible. The higher frequency of some symptoms could be related to adverse effects of the antidepressants, but it is also possible that residents with more different depressive symptoms have a higher chance of receiving medication. Future research is needed to test these hypotheses. Still, it remains remarkable that residents already receiving antidepressants did not show less symptoms or were less severely depressed than non-receivers. The antidepressants were obviously not sufficiently effective. For clinical practice this again emphasizes the importance of monitoring reactions to antidepressants very closely. If not effective, another dose or type of medication could be used. Besides, psychosocial interventions should always be considered (Verkaik et al., 2005).

There were no large differences between the dementia stages for the mean number of depressive symptoms or the prevalence of specific symptoms. In a recent systematic review we also found that there is no relationship between dementia severity and the prevalence of comorbid depression and dementia (Verkaik et al., 2007). The finding that there are no significant differences contradicts the suggestion that the profile of depression changes with increasing severity of dementia (Starkstein et al., 2005), but this finding could make depression recognition easier.

The background characteristics of our study sample (age, sex and marital status) as well as the point prevalence of depression are comparable to those found in the recent cross-sectional study by Zuidema et al. (2007) among 1322 residents from 59 Dutch psychogeriatric wards. This forms an indication for the generalizability of the results to all Dutch psychogeriatric wards.

## Limitations of the study

The study described in this article has a few limitations. In the first place the conclusions are limited to residents with dementia severity ranging from "age-related memory impairment" to "moderately severe dementia" (stages

2 to 6). Residents with "severe dementia" were excluded. Although the included group forms about 72% of the Dutch psychogeriatric nursing home population (Zuidema et al., 2007), the group with severe dementia (stage 7) is not negligible (28%). Because depression recognition in residents with severe dementia is even harder than in the earlier stages (Evers et al., 2002), it is important that future research aims at improving recognition of depression in this group as well.

Another limitation of the current study is that the type of dementia in the sample is unknown, while the PDC-dAD were developed specifically for people with Alzheimer Disease. It could be that in, for example, vascular dementia the depression type is different from that in Alzheimer Disease (Kim et al., 2003; Park et al., 2007). However, in 60% to 80% of people with dementia, the dementia is that of the Alzheimer type (Knopman et al., 2001). Also, the type of dementia is mostly unknown in any case, among residents of psychogeriatric nursing home wards, which enhances the applicability of the current results.

## 4

The effects of psychosocial methods on depressed, aggressive and apathetic behaviors of people with dementia

A systematic review

This chapter has been published as:

Verkaik R, Van Weert JCM, Francke AL. The effects of psychosocial methods on depressed, aggressive and apathetic behaviours of people with dementia: a systematic review. *Int J Geriatr Psychiatry* 2005;20:301-14.

#### **Abstract**

## **Objectives**

This systematic review seeks to establish the extent of scientific evidence for the effectiveness of 13 psychosocial methods for reducing depressed, aggressive or apathetic behaviors in people with dementia.

#### Methods

The guidelines of the Cochrane Collaboration were followed. Using a predefined protocol, 11 electronic databases were searched, studies selected, relevant data extracted and the methodological quality of the studies assessed. With a Best Evidence Synthesis the results of the included studies were synthesized and conclusions about the level of evidence for the effectiveness of each psychosocial method were drawn.

#### Results

There is some evidence that Multi Sensory Stimulation / Snoezelen in a Multi Sensory Room reduces apathy in people in the latter phases of dementia. Furthermore there is scientific evidence, although limited, that BehaviorTherapy-PleasantEvents and BehaviorTherapy-ProblemSolving reduce depression in people with probable Alzheimer Disease who are living at home with their primary caregiver. There is also limited evidence that Psychomotor Therapy Groups reduce aggression in a specific group of nursing home residents diagnosed with probable Alzheimer Disease. For the other 10 psychosocial methods there are no or insufficient indications that they reduce depressive, aggressive or apathetic behaviors in people with dementia.

#### **Conclusions**

Although the evidence for the effectiveness of some psychosocial methods is stronger than for others, overall the evidence remains quite modest and further research needs to be done.

#### Introduction

Dementia is often accompanied by behavioral and psychological disturbances that can be highly problematic to patients, their informal and formal caregivers. The International Psychogeriatric Association has assigned the term Behavioral and Psychological Symptoms of Dementia (BPSD) to these disturbances. They define BPSD as 'signs and symptoms of disturbed perception, thought content, mood or behavior that frequently occur in patients with dementia'. BPSD can be clustered into one of five syndromes: psychosis, aggression, psychomotor agitation, depression and apathy (Finkel and Costa e Silva, 1996). Various studies have been conducted into the prevalence of BPSD and describe figures between 58% and 100% of patients with at least one of the five syndromes (Zuidema and Koopmans, 2002).

Earlier research shows that most serious problems experienced by nurses caring for patients with dementia concern depression, aggression and apathy (Ekman et al., 1991; Halberg and Norberg, 1993; Kerkstra et al., 1999). One way to support nurses who are often confronted with these problems is through the development of guidelines. The guidelines should be based on psychosocial methods that are scientifically proven to reduce the BPSD. A systematic review of the existing research literature can help to determine the effectiveness of psychosocial methods in reducing BPSD. In recent years some systematic literature reviews have already been conducted. Following the review method of the Cochrane Collaboration these literature reviews explored the effects of Validation, Reminiscence, Reality Orientation, Multi Sensory Stimulation/Snoezelen (Neal and Briggs, 2002; Spector et al., 2002; Spector et al., 2002; Chung et al., 2002). These reviews did not result in solid conclusions, because of, among others, the limited number of studies that could be included. For this reason and because of the lack of systematic reviews of some other psychosocial methods (e.g. Psychomotor Therapy, Behavior Therapy, Gentle care) a new, large-scale systematic review has been conducted as a first phase in a research project aimed at the development of evidence based guidelines for nurses (including nursing assistants) working with clients suffering from dementia. In this review the amount of evidence for the effectiveness of 13 psychosocial methods to reduce depression, aggression and apathy in people with dementia is established. Not only methods employed by nurses were studied but also

methods utilized by other disciplines, such as by occupational therapists, psychologists and psychotherapists. If these methods should prove to be effective they could be adapted to nursing practice. Previous reviews included only randomized clinical trials (RCTs). In order to increase the chances that more solid conclusions could be drawn, non-randomized controlled clinical trials (CCTs) were also included in the review. The possible selection biases produced by the inclusion of CCTs are controlled for in the data synthesis of the review. In this article the methods, results and conclusions of the review are presented and discussed.

## **Methods**

The review has been conducted following the guidelines of the Cochrane Collaboration. This entails that (1) most steps in the review are performed by two researchers independently, (2) the researchers work in accordance with a predefined protocol and (3) the methodological quality of the studies is taken into account during the data synthesis. The method is described in detail in the Cochrane Reviewers' Handbook (Clarke et al., 2002).

#### Inclusion criteria

Types of studies. Randomized clinical trials (RCTs) and controlled clinical trials (CCTs), also including cross-over trials with a sufficient wash-out period (depending on the specific psychosocial method), were included in the review when there was a full article or description of the study obtainable.

Types of participants. People were included who have been diagnosed as having a type of dementia according to DSM-III-R, DSM-IV, ICD-10 or other comparable instruments. Both inpatients and outpatients and all severities of dementia were included.

Types of psychosocial methods. The 10 psychosocial methods distinguished by the American Psychiatric Association were included, their names sometimes adjusted to current practice (APA, 1997), supplemented with three methods (in table 4.1 with an asterisk) that are well known to be used in the Netherlands.

*Types of outcome measures.* Only studies using depression, aggression or apathy as an outcome measure were included.

Table 4.1 Included methods

Behavior oriented	Emotion oriented	Cognition oriented	Stimulation oriented
- Behavior Therapy	<ul> <li>Supportive Psychotherapy</li> <li>Validation / Integrated Emotion- Oriented Care</li> <li>Multi Sensory Stimulation/Snoezele</li> <li>Simulated Presence Therapy</li> <li>Reminiscence</li> <li>Gentle Care*</li> <li>Passivities of Daily Living (PDL)*</li> </ul>	- Reality Orientation - Skills Training	<ul> <li>Activity/Recreational Therapy</li> <li>Art Therapy</li> <li>Psychomotor Therapy*</li> </ul>

#### Search method

From September 2002 to February 2003 we searched in various international and national bibliographical databases for intervention studies that fulfilled all four inclusion criteria. Eleven databases were searched: PubMed, Cochrane CENTRAL/CCTR, Cochrane Database of Systematic Reviews, PsychInfo, EMBASE, CINAHL, INVERT, NIVEL, Cochrane Specialized Register CDCIG, SIGLE, Cochrane Database of Abstracts of Reviews of Effectiveness.

The databases were searched using the following strategy that was formulated in PubMed and adapted to the other databases:

dementia [MESH] AND (psychotherapy OR complementary therapies OR psychosocial treatments OR psychosocial\* OR emotion-oriented care OR emotion-oriented\* OR validation therapy OR validation-therapy OR multi-sensory stimulation OR sensory stimulation OR sensory integration OR snoezelen OR simulated presence therapy OR simulated presence\* OR reminiscence therapy OR reminiscence\* OR warm care OR gentle care OR passivities of daily living OR PDL OR behavioral therapy OR behavior\* therapy OR cognitive therapy OR reality orientation OR ROT OR skills training OR recreational therapy OR psychomotor therapy OR psychomotor\* OR psychomotor-therapy)

Limits: Clinical Trial

All identified systematic reviews were screened for additional references.

#### Selection method

A first selection for inclusion was performed by the first author (RV). On the basis of titles and abstracts all studies that clearly did not meet one of the four inclusion criteria were excluded from the review. If the studies seemed to meet the inclusion criteria or if there was any doubt, the full article was ordered by library services, obtained by contacting authors or by contacting the Cochrane Dementia and Cognitive Improvement Group. A second selection was made by two reviewers independently (RV, JvW). On the basis of the full articles the two reviewers checked if the studies satisfied all four criteria. Disagreements regarding inclusion status were resolved by discussion. If no consensus could be met, a third reviewer (AF) was consulted.

#### Assessment of methodological quality

The methodological quality of the selected RCTs and CCTs was rated by a list developed by Van Tulder (1997). This list, containing specified criteria proposed by Jadad (1996) and Verhagen et al. (1998) consists of 11 criteria for internal validity, six descriptive criteria and two statistical criteria. The list was developed in close contact with the Dutch Cochrane Center. All criteria were scored as yes, no, or unclear. Equal weight was applied to all items. Studies were considered to be of 'high quality' if at least six criteria for internal validity, three descriptive criteria and two statistical criteria were scored positively. Otherwise, studies were considered of 'low quality'. The methodological quality of the included trials was independently assessed by two reviewers (RV, JvW). The assessments were compared and disagreements were resolved by discussion.

## **Data extraction**

Two reviewers (RV, JvW) independently documented the following characteristics of each included study:

- 1. Study design.
- Participants: inclusion and exclusion criteria; number of patients; sex; age; type of dementia and diagnostic instruments used; severity of the dementia and diagnostic instruments used; duration of the dementia; inpatients/outpatients; duration of institutionalization.
- Psychosocial method: type of psychosocial support method in the experimental condition(s); type of psychosocial support in the control condition(s), features of methods (duration, frequency, setting).

- 4. Outcome measures/instruments (aggression, depression or apathy): instrument(s) used; timing of measurements; number of participants who completed the study in the experimental and control conditions; mean scores for experimental and control conditions; standard deviations in experimental and control conditions.
- 5. A short description of the results.

The documentations of the two researchers were compared and disagreements were resolved by discussion.

#### Data synthesis

Owing to diversity in the features of the psychosocial methods and in outcome measures, it was not possible to pool the data for each type of method. Therefore a 'Best Evidence Synthesis' was conducted (see table 4.2) based upon criteria developed by Van Tulder et al. (2002) and adapted by Steultjens et al. (2002). The Best Evidence Synthesis is conducted by attributing various levels of evidence to the effectiveness of the psychosocial methods. The synthesis takes into account the design, the methodological quality and the outcomes of the studies. Table 4.2 shows that that at least one high quality RCT or two high quality CCTs were necessary to establish some evidence for an intervention.

#### Sensitivity analysis

A sensitivity analysis was performed in order to identify how sensitive the results of the Best Evidence Synthesis are to changes in the way it was conducted. The Best Evidence Synthesis was repeated in two different ways, using the following principles:

- 1. Low quality studies were excluded.
- 2. Studies were rated 'high-quality' if they at least met four criteria of internal validity (instead of six).

The results of the altered syntheses were then compared with those of the Best Evidence Synthesis and the sensitivity of the method was described.

#### Table 4.2 Principles of Best Evidence Synthesis

#### **Evidence:**

Provided by consistent, statistically significant findings in outcome measures in at least two high quality RCTs.

#### Moderate evidence:

Provided by consistent, statistically significant findings in outcome measures in at least one high quality RCT and at least one low quality RCT or high quality CCT.

#### Limited evidence:

Provided by statistically significant findings in outcome measures in at least one high quality RCT

Or

Provided by consistent, statistically significant findings in outcome measures in at least two high quality CCTs (in the absence of high quality RCTs).

#### Indicative findings:

Provided by statistically significant findings in outcome measures in at least one high quality CCT or low quality RCT (in the absence of high quality RCTs)

#### No/Insufficient evidence:

If the number of studies that have significant findings is less than 50% of the total number of studies found within the same category of methodological quality and study design

Or

In case the results of eligible studies do not meet the criteria for one of the above stated levels of evidence

Or

In case of conflicting (statistically significantly positive and statistically significantly negative) results among RCTs and CCTs

Or

In case of no eligible studies.

#### Results

#### Selection of studies

Application of the search strategy to the specified databases resulted in 3.977 hits. Based on titles and abstracts, the first author selected 189 studies which possibly met the four inclusion criteria.

A total of 177 studies were tracked down, 12 studies could not be retrieved. Four of these studies investigated the effects of Validation (Buxton, 1996; Esperanza, 1987; Pretczynski et al., 2002; Snow, 1990), two studied the effects of Psychotherapy (Burns, 2000; Marino-Francis, 2001), two the effects of Multi Sensory Stimulation (Creany, 2000; Sansom, 2002), one the effects of Reminiscence (McKiernan et al., 1990) and one the effects of Behavior Therapy (Howard, 1999). Of the interventions in the other two studies

(North of England Evidence Based Guideline Development Project, 1998; Sharp, 1993) it was not clear which psychosocial method they concerned.

The 177 studies were independently assessed on the four inclusion criteria by the first two authors. The evaluations of the two authors were compared for all four inclusion criteria which showed a consensus on 79% of the evaluations. After discussion all disagreements were resolved. Twenty-three of the 177 articles fulfilled all four inclusion criteria. Of these articles eight described the same four studies; these were combined. This left us with a total of 19 studies to be included in the review. Of the 154 excluded studies, 89 were excluded because they did not meet one of the four selection criteria: 33 did not use a control group or a cross-over design, 21 studies did not use the formulated outcome measures, 17 did also include subjects that were not demented and 18 studies evaluated other methods than the 13 that were selected. Of the other 65 excluded studies, two were excluded because the articles did not contain a complete description (Brack, 1997; Ermini-Fünfschilling et al, 1995). Sixty-three studies did not meet more than two of the selection criteria.

#### Data-extraction and quality assessment

This section describes the features of each study and the rating of their methodological quality. The description includes the items mentioned in the Methods section about data-extraction as far as they were described in the articles. Table 4.3 contains an overview of the main methodological characteristics and results of the included studies. The text following table 4.3 describes the more precise content of the psychosocial methods and the control groups(s) that were used in each study.

Table 4.3 Characteristics of included studies (E=Experimental group, C=Control group)

Treatment type and first author	Quality	Design	Treatment intensity (E&C)/ careprovider	Participants (N; sex; age)	Participants (Type and severity dementia)	Outcome measures	Results 1)
Validation, Finnema et al., 1998; 2000, Dröes, 1999	High	RCT	24-h care during 7 months / nursing assistants	N completers=146 (67 exp; 79 contr.) Female n=118 Male n=28 Age exp M=83,8 SD 5,3 Age contr M=83,6 SD 5,8	107 Alzheimer's Disease 29 Dementia Syndrome 8 Alzheimer's and Vascular 2 Amnestic Syndrome  Severity dementia (GDS-score) Mild n=7 Moderate-Severe n=69  Severe-Very severe n=70	Apathy: - Behavioral Assessment Scale for Intramural Psychogeriatrics (BIP)_Subscale apathy - Dutch Assessment Scale for Elderly Patients (ASEP)_Subscale inactivity Depression: - Cornell Scale for Depression in dementia Aggression: - Cohen-Mansfield Agitation Inventory (CMAI)_Subscales verbally and physically aggressive behaviors - Dutch Assessment Scale for Elderly Patients (ASEP)_Subscale aggression	Apathy: No significant changes. Depression: No significant changes. Aggression: No significant changes.

-table 4.3 continued -

Treatment type and first author	Quality	Design	Treatment intensity (E&C)/ careprovider	Participants (N; sex; age)	Participants (Type and severity dementia)	Outcome measures	Results 1)
Validation, Toseland et al., 1997	High	RCT	Group sessions, 30 minutes, 4 times a week, during 1 year / trainers with bachelor's degrees and experience with nursing home residents	N (baseline)=88 Female n=66 Male n=22 Age exp M=87.8 SD 6.0 Age contr.1 M=87.3 SD 6.12 Age contr.2 M=87.8 SD 7.6	At least moderate level of dementia (MDS)  Cognitive functioning (errors SPMSQ): Errors exp. M=7.4 SD=2.1 Errors contr.1 M=7.5 SD=2.8 Errors contr.2 M=7.2 SD=3.0	Apathy: - Multidimensional Observation Scale for Elderly Subjects (MOSES)_Subscale withdrawn behavior Depression: - Multidimensional Observation Scale for Elderly Subjects (MOSES)_Subscale depression Aggression: - Cohen-Mansfield Agitation Inventory (CMAI)_Subscales verbally aggressive behavior (VAB) and physically aggressive behavior (PAB)	Depression: Sign. difference after 1- year between validation therapy group (VT) and social contact group (SC), caused by increased depression scores of SC. No sign. differences between VT and usual care group (UC). Aggression: According to nursing staff assessment: Sign. changes in PAB after 3 months and 1 year. Sign. lower VAB-scores after 1 year for both VT and SC. According to nonparticipant observers: No sign. changes in PAB. Sign. lower VAB scores for SC.

-table 4.3 continued -

Treatment type and first author	Quality	Design	Treatment intensity (E&C)/ careprovider	Participants (N; sex; age)	Participants (Type and severity dementia)	Outcome measures	Results 1)
Validation, Schrijnemaekers, 2002	Low	CCT	24-h care during 8 months / professional caregivers	N (baseline)=151 Female=136 Male=15 Age exp. M=84.3 SD=5.5 Age contr. M=85.9 SD=5.6	Moderate to severe cognitive impairment (MMSE score) score exp. M=10.8 SD=5.1 score contr. M=11.3 SD=5.1	Apathy: - Dutch Behavior Observation Scale for Psychogeriatric Inpatients (GIP)_Subscale apathetic behavior Aggression: - Cohen-Mansfield Agitation Inventory (CMAI)_Subscales verbally and physically aggressive behaviors	Apathy: No significant changes. Aggression: No significant changes.
Validation/ Reality Orientation, Scanland et al., 1993	Low	CCT	Group sessions, 30 minutes, 5 times a week, during 4 months / registered nurse with a background in psychotherapy	N (completers)=34 Age M=76.8 (≥60)	Presence of confusion (MMSE≤24)	Depression: - Modified Beck Depression Inventory	Depression: No significant changes.

-table 4.3 continued -

Treatment type and first author	Quality	Design	Treatment intensity (E&C)/ careprovider	Participants (N; sex; age)	Participants (Type and severity dementia)	Outcome measures	Results 1)
Reality Orientation, Spector et al., 2001	Low	RCT	Groups sessions, 45 minutes, 15 times / member of the research team & staff member from the nursing home	N (baseline)=35 Age M=85.7 SD=6.7	Dementia according to DSM-IV criteria Ability to communicate and understand communication (CAPE score 1 or 0 on questions 12 and 13)	Depression: - Cornell Scale for Depression in Dementia (CSDD)	Depression: Significant differences in pre-/post change scores.
Reality Orientation, Hanley et al, 1981	Low	RCT	Groups sessions, 30 minutes, 4 times a week, during 12 weeks / therapist	N (completers)=57 Hospital residents of long-stay psychogeriatric unit (n=41) Residents old peoples home (n=16) Female n=53 Male n=4	Senile dementia n=39 Arteriosclerotic dementia or Cerebral arteriosclerosis n=9 Alcohol related dementia n=2 Korsakoff n=1 No diagnosis n=6 Severity of dementia (Koskela test) Hospital	Apathy: - Geriatric Rating Scale (GRS)_Subscale withdrawn/apathy	Apathy: No significant changes.

-table 4.3 continued -

Treatment type and first author	Quality	Design	Treatment intensity (E&C)/ careprovider	Participants (N; sex; age)	Participants (Type and severity dementia)	Outcome measures	Results 1)
					residents psychogeriatric unit Mild=7% Moderate=27% Grave=25% Nursing home residents Mild=20% Moderate= 55% Grave=25%		
Reality Orientation, Baldelli et al., 1993	Low	CCT	Group sessions, 60 minutes, 3 times a week, during 3 months /-	N (baseline)=23 Female n=23 Male n=0 Age M=84.5 SD=6.4	Senile Alzheimer's Disease n=23 MMSE ≥10 and ≤24	Depression: - Geriatric Depression Scale (GDS)	Depression: No significant changes.

-table 4.3 continued -

Treatment type and first author	Quality	Design	Treatment intensity (E&C)/ careprovider	Participants (N; sex; age)	Participants (Type and severity dementia)	Outcome measures	Results 1)
Reality Orientation, Ferrario et al., 1991	Low	CCT	Group sessions, 60 minutes, 5 times a week, during 24 weeks / therapist	N (completers)=19 Female n=11 Male n=8	MMSE >18 and <24	Apathy: - Multidimensional Observation Scale for Elderly Subjects (MOSES)_Subscale withdrawn behavior Depression: - Multidimensional Observation Scale for Elderly Subjects (MOSES)_ Subscale depression	Apathy: Significant lower apathy scores than at pretest.  Depression: No significant changes in depression scores.
Multi Sensory Stimulation/ Snoezelen Baker et al., 2001	High	RCT	1:1 sessions, 30 minutes, 2 times a week, during 4 weeks / staff member day hospital & occupational therapist or psychology assistant	N (baseline) =50 Female n=25 Male n=25 Age M=78 (≥60)	Alzheimer's Disease n=33 Vascular Dementia n=7 Mixed n=10 (psychiatrist & CAMDEX)  MMSE Score exp. M=11.0 SD=6.5 Score contr. M=6.1 SD=5.1	Apathy: - INTERACT_Short (differences in the amount of interaction at 10 minutes before each session and at 10 minutes after each session).	Apathy: Significant interaction effect on 'attentiveness to tto the environment'.

-table 4.3 continued -

Treatment type and first author	Quality	Design	Treatment intensity (E&C)/ careprovider	Participants (N; sex; age)	Participants (Type and severity dementia)	Outcome measures	Results 1)
Multi Sensory Stimulation/ Snoezelen, Kragt et al., 1997, Holtkamp et al., 1997	High	Rcross- Over	1:1 sessions, 30- 60 minutes, 3 successive days / activity therapist	N (baseline)=16 Female n=15 Male n=1 Age M=86 <78,97>	Diagnosis dementia (MMSE)	Apathy: - Dutch Behavior Observation Scale for Psychogeriatric Inpatients (GIP)_Subscale apathetic behavior	Apathy: Significant effect on apathy.
Multi Sensory Stimulation/ Snoezelen, Robichaud et al., 1993	High	RCT	Group sessions, 30-45 minutes, 3 times a week, during 10 weeks / doctoral student gerontology and geriatrics	N (completers)=40 Age M=78.4 <66,88>	Dementia according to DSM-III-R Modified MMSE score≤75 Physically able to attend the sessions	Depression: - Revised Memory and Behavior Problems Checklist (RMBPC)_Subscale depression	Depression: No significant effect.

-table 4.3 continued -

Treatment type and first author	Quality	Design	Treatment intensity (E&C)/ careprovider	Participants (N; sex; age)	Participants (Type and severity dementia)	Outcome measures	Results 1)
Reminiscence, Goldwasser et al., 1987	Low	RCT	Group sessions, 30 minutes, 2 times a week, during 5 weeks / graduate student clinical psychology & a social worker	N (completers)=27 Female n=20 Male n=7 Age M=82.3 <70,97>	Clinical diagnosis of dementia: Alzheimer's Disease n=6 Multi-infarct n=11 Dementia secondary to a medical disorder n=10 MMSE score M=10.4 <1,22>	Depression: - Beck Depression Inventory	Depression: Significant lower self-reported depression score at posttest. Note: Reminiscence group participants had higher depression scores at baseline than the 2 control groups.
Reminiscence, Namazi et al., 1994	Low	CCT	Group sessions, 30 minutes, 3 times a week, during 4 weeks / trained instructor	N (completers)=15 Female n=15 Male n=0 Age M=81.5 SD 3.6	Alzheimer's disease n=15 MMSE Score exp. M=13.4 SD=4.9 Score contr.1 M=12.6 SD=3.9	Apathy: Verbal responses during session_'Related responses <5 or >5 words' and 'Unrelated responses <5 or >5 words'	Apathy: No significant changes.

-table 4.3 continued -

Treatment type and first author	Quality	Design	Treatment intensity (E&C)/ careprovider	Participants (N; sex; age)	Participants (Type and severity dementia)	Outcome measures	Results 1)
Psychomotor Therapy, Hopman-Rock et al., 1999	High	RCT	Group sessions, 2 times a week, during 6 months / activity therapist	N (baseline)=92 Female n=87 Male n=5 Age exp. M=83.8 SD=5.8 Age contr. M=84.2 SD=5.6	Cognitive impairment (CST-14 maximum score=14) Score exp. M=11.5 SD=3.3 Score contr. M=11.5 SD=5.7	Apathy: - Dutch Behavioral Observation Scale for Intramural Psychogeriatry (BIP)_Subscale apathetic behavior Depression: - Dutch Behavioral Observation Scale for Intramural Psychogeriatry (BIP)_Subscale depression	Apathy: No significant changes.  Depression: No significant changes.
Psychomotor Therapy, Dröes, 1991	High	RCT	Groups sessions, 45 minutes, 3 times a week, during 11 months / a graduate and a doctoral student Human Movement Sciences	N (baseline)=43 Female n=36 Male n=7 Age M=84.2 SD=5.39	Diagnosis probable dementia of Alzheimer type (DSM-III-R) MMSE score M=12.7 SD=4.16	Apathy: - Dutch Behavior Observation Scale for psychogeriatric Inpatients GIP_Subscale apathetic behavior Depression: - Dutch Depression list Aggression: - Dutch Beoordelingsschaal voor Oudere Patiënten [Assessment Scale for Elderly Patients] (BOP)_ Subscale aggression	Apathy: No significant changes. Depression: No significant changes. Aggression: Significantly lower aggression scores in subgroup of patients with more functional disorders than in this type of patients in the control group.

-table 4.3 continued -

Treatment type and first author	Quality	Design	Treatment intensity (E&C)/ careprovider	Participants (N; sex; age)	Participants (Type and severity dementia)	Outcome measures	Results 1)
Skills Training, Meier et al.,1996	Low	CCT	Group sessions, 60 minutes, 1 time a week, 4 quarters / -	N (completers)=53 Female=34 Male=19 Age exp. M=74.7 SD=8.7 Age contr. M=75.6 SD=7.2	Alzheimer's Disease (NINCDS- ADRDA) n=28 Vascular Dementia (NINDS-AIREN) n=25 MMSE score Score exp. M=24.7 SD=2.9 Score contr. M=24.6 SD=3.2	Depression: - Geriatric Depression Scale	Depression: No significant changes.
Behavior Therapy, Teri et al., 1997	High	RCT	1:1 sessions, 60 minutes, 1 time a week, during 9 weeks / geriatrician	N (completers)=72 Female n=34 Male n=38 Age M=76.4 SD=8.2	Probable Alzheimer's Disease (NINCDS- ADRDA criteria) MMSE score M=16.5 SD=7.4	Depression: - Hamilton depression Scale - Cornell Scale for Depression in Dementia - Beck Depression Inventory	Depression: Significantly lower depression scores in both experimental groups after 9 weeks intervention period and after 6 months follow- up.

-table 4.3 continued -

Treatment type and first author	Quality	Design	Treatment intensity (E&C)/ careprovider	Participants (N; sex; age)	Participants (Type and severity dementia)	Outcome measures	Results 1)
Art Therapy, Wilkinson et al., 1998	Low	CCT	Group sessions, 45 minutes, 1 time a week, during 12 weeks / -	N (completers)=15 Female n=10 Male n=5 Age exp. M=79.6 Age contr. M=80	Consultant diagnosis of dementia (DSM-IV)	Depression: - Cornell Scale for Depression in Dementia	Depression: No significant changes.
Gentle Care, Bråne et al., 1989	Low	ССТ	24-hour, during 3 months / nursing staff	N (baseline)=26 Age exp. M=83.5 SD=5.3 Age contr. M=81.5 SD=5.3	Patients in the experimental group were demented according to their MMSE-score (Folstein et al., 1975)	Apathy: - Depression in Dementia Scale_Subscale withdrawal Depression: - Depression in Dementia Scale_Subscale depressed mood	Apathy: Significant changes in withdrawal change scores. Depression: No significant changes.

<sup>1)</sup> Significant results are in favor of the experimental group, unless otherwise stated. Only results concerning apathetic, depressive or aggressive behavior are mentioned.

#### Validation/Integrated Emotion-Oriented Care:

Four studies into the effects of Validation/Integrated Emotion-Oriented Care were included in the review. Validation aims to restore self-worth and reduce stress by validating emotional ties to the past (APA, 1997). Integrated Emotion-Oriented Care is a combination of methods and techniques from emotion-oriented approaches, based on the needs of the resident in question. The method mainly consists of Validation, supplemented by other emotion-oriented methods (see table 4.1) and is integrated into the 24-hour care given by nurses.

The first included study, reported by Finnema et al. (1998, 2000) and Dröes et al. (1999), investigated the effects of 24-h Integrated Emotion-Oriented Care on depression, aggression and apathy on nursing home residents in the Netherlands. Participants in the experimental group received 24-h Integrated Emotion-Oriented Care. Participants in the control group received usual nursing home care.

The second study measured the effects of Validation and was conducted by Toseland et al. (1997). It investigated the effects of structured Validation Therapy group sessions on depression, aggression and apathy of nursing home residents in the United States. Participants in the experimental group received structured Validation Therapy group sessions. The first control group received Social Contact group sessions. The second control group continued to participate in regular social and recreational programs.

The third included study, reported by Schrijnemaekers (2002), investigated the effects of Integrated Emotion-Oriented Care on aggression and apathy of residents in homes for the aged in the Netherlands. The experimental group received 24-hour Integrated Emotion-Oriented Care, while the control group received regular nursing care.

#### *Validation/Reality orientation:*

The fourth study on Validation/Integrated Emotion-Oriented Care is also the first included study on the effects of Reality Orientation, and was performed by Scanland et al. (1993) among nursing home residents in the United States. The aim of Reality Orientation is to redress cognitive deficits (APA, 1997). In classroom Reality Orientation, a prepared instructor reviews facets of reality with a small group of confused people.

The first experimental group received Validation Therapy group sessions. The second experimental group received Reality Orientation group sessions. A third group formed the control group and received no formal therapy. Scanland et al. measured the effects on depression.

The second included Reality Orientation study, reported by Spector et al. (2001), investigated the effects of Reality Orientation on depression among nursing home residents in the United Kingdom. The experimental group received Structured Reality Orientation Group Therapy. The control group received usual care.

The third study on the effects of Reality Orientation was performed by Hanley et al. (1981) to establish the effects on apathy among residents of a long-stay psychogeriatric unit of a hospital, and residents of an old peoples home in the United Kingdom. The experimental groups received Classroom Reality Orientation. The control groups received usual care.

The fourth study on the effects of Reality Orientation was conducted by Baldelli et al. (1993) among institutionalized people with Alzheimer Disease in Italy. The experimental group received formal Classroom Reality Orientation Therapy. The control group received usual care. Baldelli et al. measured the effects on depression.

The fifth included study on the effects of Reality Orientation, reported by Ferrario et al. (1991), investigated the effects on depression and apathy among institutionalized psychogeriatric patients in Italy. The experimental group received formal Classroom Reality Orientation Therapy. The control group received usual care.

#### Multi Sensory Stimulation/Snoezelen:

The aim of Multi Sensory Stimulation/Snoezelen is to maintain or improve contact with demented people and to improve their well-being by positive stimulation of their senses (visual, auditory, tactile, olfactory and gustatory stimulation).

The first included study on the effects of Multi Sensory Stimulation/ Snoezelen was conducted by Baker et al. (2001) among people living at home with their primary caregiver and attending a hospital day center in the

United Kingdom. People in the experimental group received 1:1 Multi Sensory Stimulation sessions in a Multi Sensory Stimulation room. The control group attended 1:1 Activity Therapy sessions.

The second study into Multi Sensory Stimulation/Snoezelen is a cross-over study, reported by Kragt et al. (1997) and Holtkamp et al. (1997), into the effects on apathy among nursing home residents in the Netherlands. The experimental method consisted of 1:1 Snoezel sessions in a Snoezel room. The control method consisted of staying in the living room and receiving usual care.

The third included study on the effects of Multi Sensory Stimulation/ Snoezelen was conducted by Robichaud et al. (1994) and measured the effects on depression of nursing home residents and residents of a hospital for long-term care in Canada. The experimental group followed a so called Sensory Integration Group program. The Sensory Integration sessions also contained Reality Orientation and cognitive stimulation. The control group took part in the usual leisure activities of their institution.

#### Reminiscence:

Two studies that were included in the review investigated the effects of Reminiscence. The aim of Reminiscence is to stimulate memory and mood in the context of the patient's life history (APA, 1997).

The first study, reported by Goldwasser et al. (1987), measured the effects of Reminiscence Therapy Group sessions on depression among nursing home residents in the United States. The experimental group received Reminiscence Group Therapy sessions. There were two control groups. The first control group attended Support Group sessions that focused on present and future events and problems. The second control group received usual care.

The second study on Reminiscence was conducted by Namazi and Haynes (1994) and investigated the effects of so called Sensory Reminiscence on apathy among nursing home residents in the United States. The experimental group attended Sensory Reminiscence Group sessions. The Sensory Stimulation part consisted of colored photographs of objects and sounds related to the objects. Participants in the control group attended

discussion sessions in which the events of the day and future times were discussed, without the aid of sensory stimuli.

#### Psychomotor Therapy:

Two studies into the effects of Psychomotor Therapy were included. The aim of Psychomotor Therapy is to help people with dementia to cope with the changes they encounter as a consequence of their disease. Sporting activities and games are used to stimulate cognitive and psychosocial functions (Dröes, 1991).

The first study was performed by Hopman-Rock et al. (1999) and measured the effects of Psychomotor Therapy on apathy and depression among cognitive impaired residents of homes for the elderly in the Netherlands. The experimental group attended Psychomotor Activation Program Group sessions. The control group participated in usual activities.

The second study on the effects of Psychomotor Therapy, reported by Dröes (1991), investigated the effects of Psychomotor Therapy on depression, aggression and apathy among nursing home residents in the Netherlands. The experimental group attended Psychomotor Therapy group sessions. The participants in the control group attended Activity Group sessions with the same intensity.

#### Skills Training:

One included study researched the effects of Skills Training on people with dementia. The aim of (Cognitive) Skills Training is to redress cognitive deficits (APA, 1997), by activating remaining cognitive functions. It is often conducted in a classroom setting.

This Swiss study performed by Meier et al. (1996) measured the effect of Cognitive Skills Training on depression. The participants were living at home with their primary caregiver and were attending a memory clinic. The experimental group received Cognitive Skills Training in groups of eight to nine persons. The people in the control group received no treatment and were on a waiting list for receiving Cognitive Skills Training or lived too faraway to attend the sessions.

#### Behavior Therapy:

One study on the effects of Behavior Therapy was included. The aim of Behavior Therapy is to reduce or improve behavior by analyzing the situations in which the behavior occurs and anticipate these situations.

This study was conducted by Teri et al. (1997) and investigated the effects of BehaviorTherapy-PleasantEvents and BehaviorTherapy-ProblemSolving on depressed Alzheimer patients, living at home with their primary caregivers in the United States. Two experimental groups and two control groups participated in the study. In the first part of BehaviorTherapy-PleasantEvents patients and their primary caregivers learned how to reduce depression by increasing pleasant events. In the second part they learned how to identify and confront behavioral disturbances that interfered with pleasant events. In BehaviorTherapy-ProblemSolving the focus was on problem-solving patient depression behaviors that were of specific concern to the caregiver. The control groups received either Typical Care Control (patients and caregivers received advice without specific problem solving or behavioral strategies) or were on a waiting List.

#### Art Therapy:

One study on the effects of Art Therapy was included in the review. Art Therapy (e.g. music, dance, drama) provides stimulation and enrichment, and in this way can mobilize the patient's available cognitive resources (APA, 1997).

The study, reported by Wilkinson et al. (1998), investigated the effects of Drama and Movement Therapy on depression in the United Kingdom. Participants were living at home and attending a psychiatric day hospital for the elderly. The experimental group attended Drama and Movement Therapy group sessions. The control group received the usual care of the day hospital.

#### Gentle Care:

One included study measured the effects of Gentle Care, sometimes called Integrity Promoting Care, on people with dementia. The aim of Gentle Care is to create an atmosphere in which people with dementia feel safe, and in this way reduce feelings of fear and insecurity. Closeness, recognition and liberty are central concepts of gentle care (Buijssen, 1991).

Bråne et al. (1989) measured the effects of Integrity Promoting Care on apathy and depression of nursing home residents in Sweden. Residents in the experimental group received 24-h Integrity Promoting Care from trained nursing staff. The control group received usual 24-h care.

#### Data synthesis

Using the principles of the Best Evidence Synthesis (see table 4.2), taking into account the design, methodological quality and outcomes of the studies, the following conclusions can be drawn.

#### Apathy:

There is some scientific evidence that people with moderate to severe dementia (MMSE 0-17) and high care dependency, are less apathetic when remaining in a Multi Sensory Stimulation/Snoezel room than when receiving Activity Therapy or staying in the living room. The evidence comes from two studies with apathy as outcome measure, both with the same significant positive findings. The studies were two high quality RCTs conducted by Baker et al. (2001) and Kragt et al. (1997)/Holtkamp et al. (1997).

#### Depression:

There is limited scientific evidence that people with probable Alzheimer Disease (NINCDS-ADRDA), meeting DSM-III-R criteria for major or minor depressive disorder, and living with their caregivers at home, are less depressed when their informal caregivers are trained in using Behavior Therapy-PleasantEvents or BehaviorTherapy-ProblemSolving than when a) their informal caregiver receives standard information from a therapist or when b) the informal caregiver does not receive any special training or information. The evidence comes from one study, conducted by Teri et al. (1997), with depression as outcome measure. This study was an RCT that was rated as being of high methodological quality.

#### Aggression:

There is limited scientific evidence that people living in nursing homes who meet DSM-III-R criteria for probable Alzheimer Disease, who are mobile (including wheelchair), who are support-dependent or slightly care-dependent (BOP 0-6) but are relatively highly functionally disordered (PADL<44) are less aggressive when following Psychomotor Therapy groups than when following Activity Groups. The evidence comes from one

study with aggression as an outcome measure that shows significantly positive results. This study, conducted by Dröes (1991), was a RCT that was rated as being of high methodological quality.

There is no evidence that Multi Sensory Stimulation/Snoezelen, BehaviorTherapy-PleasantEvents, BehaviorTherapy-ProblemSolving or Psychomotor Therapy also have positive effects on the other outcome measures that were subject of this review. For Validation/Integrated Emotion-Oriented Care, Reality Orientation, Activity/Recreational Therapy, Reminiscence, Skills Training, Art Therapy, Gentle Care, Passivities of Daily Living, Supportive Psychotherapy and Simulated Presence Therapy, there is no or too limited evidence that they have positive effects on either apathetic, depressed or aggressive behaviors of people with dementia.

# Sensitivity analysis

The results of the data synthesis appeared not to be sensitive to the principles used in the Best Evidence Synthesis. The results remained the same when the analysis was repeated with low quality studies excluded and when studies were rated to be of 'high-quality' if four or more criteria of internal validity were met.

#### Conclusion and discussion

The main results of this review are that: (1) there is some evidence that Multi Sensory Stimulation / Snoezelen in a Multi Sensory Room reduces apathy in people in the latter phases of dementia, (2) there is scientific evidence, although limited, that BehaviorTherapy-PleasantEvents and BehaviorTherapy-ProblemSolving reduce depression in people with probable Alzheimer Disease who are living at home with their primary caregiver, (3) there is also limited evidence that Psychomotor Therapy Groups reduce aggression in a specific group of nursing home residents diagnosed with probable Alzheimer Disease. The evidence comes from a maximum of two high quality RCTs that arrive at the same positive results.

The systematic review as described has some limitations. In the first place it was not possible to track down complete descriptions of 12 studies (see section 'Selection of studies'). If some of these studies should meet all four

inclusion criteria the results of the review could be different. If, for example, the omitted studies on Multi Sensory Stimulation/Snoezelen were also to measure the effects on apathy, and these studies were not to find the same positive results as the included studies, there would be no scientific evidence left for Multi Sensory Stimulation/Snoezelen. Also, if one of the excluded studies were a randomized controlled trial of high methodological quality on a psychosocial method for which no studies were yet included, and with positive effects, there would also be limited scientific evidence for the effectiveness of this method. However, the odds that the results of the review would be different if the 12 studies had been included are small. Of the 12 not-included studies four measured the effects of Validation/ Integrated Emotion-Oriented Care. Looking at the method of Best Evidence Synthesis, these studies can no longer influence the results of the review, because of the lack of significant findings in the studies already included. The other eight studies were on: Supportive Psychotherapy, Multi Sensory Stimulation/Snoezelen, Reminiscence, Behavior Therapy and two as yet unclear psychosocial methods. If the percentage of the studies that meet all four inclusion criteria is comparable with that of the studies already included (14%), only one of these eight studies would be included.

Another limitation of the review is that the included studies were classified into one of 13 psychosocial approaches according to their main principles. While the main principles of the methods are similar, the specific content and intensity of the methods classified into one approach could sometimes be quite different. In the Validation/Integrated Emotion-Oriented Care group, for example, studies were included that measured the effects of 24-h Integrated Emotion-Oriented Care and studies that measured the effects of Validation Therapy Group sessions. The more specific content and intensity of the methods in some cases might play a larger role than the main principles. Moreover, the measurement instruments used to measure the effects of a psychosocial approach on, for example, apathy could differ between specific methods. If the Best Evidence Synthesis is repeated with some subdivisions of methods that belong to an approach, this however does not change the results. And when looking more closely at the measurement instruments used for apathy in the Multi Sensory Stimulation/ Snoezelen studies, these are comparable.

Another point related to the focus on 13 types of psychosocial interventions, is that studies into other (possibly effective) interventions are not being described. The reason to limit the study to these interventions was however

the possibility to combine their results. Inclusion of all psychosocial methods would have made this impossible.

A substantial limitation of the review would be if not all existing studies into the effectiveness of the 13 psychosocial methods on reducing depressive, aggressive and apathetic behaviors of people with dementia would have been considered for inclusion. The search in eleven different databases in combination with screening relevant other reviews (n=22) gives us confidence that the search strategy has been robust.

In conclusion, it seems noteworthy that until now (1) the number of studies of sufficient scientific quality on the effectiveness of psychosocial methods in dementia care is rather limited, though there are some convincing examples of high quality research and (2) treatments based on a non-cognition oriented theory seem to produce the most promising results. Multi Sensory Stimulation/Snoezelen, BehaviorTherapy-PleasantEvents and Behavior-Therapy-ProblemSolving are all methods that aim to improve the patients' well-being and to fit the individual needs of demented patients. However, other psychosocial methods, such as Validation/Integrated Emotion-Oriented Care or Gentle Care, do have comparable goals. There might be several reasons why there is, until now, no or insufficient evidence (Toseland et al, 1997; Bråne et al, 1987) for the effectiveness of these methods for as far as reduction of depression, apathy and aggression are concerned: lack of sufficient high quality scientific research (e.g. in the case of Gentle Care), the heterogeneity of the study population, the measurements used and the specific content of the method or the duration of the implementation period (Finnema, 2000). New scientific research is needed to get more insight into the effectiveness of psychosocial methods used in the care for demented elderly with BPSD.

# 5

# Supporting people with dementia who are depressed or apathetic

The development and evaluation of two evidence-based nursing guidelines

This article was published in Dutch:

Verkaik R, Francke A. Begeleiding van mensen met dementie die depressief of apathisch zijn: de ontwikkeling en evaluatie van twee evidence based richtlijnen voor verzorgenden. *Verpleegkunde. Nederlands-Vlaams Wetenschappelijk Tijdschrift voor Verpleegkundigen* 2006;21:53-61.

# Summary

Recently, two evidence-based nursing guidelines were drawn up for CNAs in respect of helping people with dementia who are depressed or apathetic. The guidelines were developed in seven stages: 1 assembling existing guidelines; 2 systematic literature review; 3 assessing existing guidelines; 4 developing draft guidelines; 5 evaluation of draft guidelines by a group of experts and the steering committee; 6 testing the guidelines in a practice trial; 7 final adaptations to the guidelines.

This article describes the approach taken to the project. This approach is characterized by the fact that not only ample attention has been paid to the scientific basis of the guideline, but also to the experiences of care professionals. The latter was achieved by asking Certified Nurse Assistants (CNAs) specifically for their opinions and experiences, within the framework of a group of experts, as well as in a practice trial.

# Introduction

An estimated 200.000 people with dementia are currently living in the Netherlands. Alzheimer Disease, vascular dementia or a combination of these diseases, are the most frequent types of dementia. The number of people with dementia is expected to grow in the next decades from 207.000 in 2010 to 412.000 in 2050 (Gezondheidsraad [Health Council], 2000).

Depression and apathy are frequently occurring symptoms in people who are suffering from some kind of dementia. Recent research suggests that, in every stage of dementia, 50% of sufferers also have depressive symptoms (Janzing et al., 2002). Apathy, i.e. not being able to make contact with other people, with words or in other ways, occurs in the last stage of dementia in all dementia sufferers (Janzing and Zitman, 2002). Depression and apathy in people with dementia are partly caused in a direct way by changes in the brain; they are also partly caused by the way people experience changes in their cognition and mobility and the way they, as well as the people around them, cope with these changes.

Helping people with dementia is often a difficult task for CNAs and other caregivers. This task becomes even more difficult if the person with dementia is also depressed or apathetic. Depression can cause the CNA to feel powerless, while the person with dementia becomes more gloomy and does not want to do anything at all. Apathy also often causes feelings of powerlessness (Kerkstra et al., 1999), partly because people with apathy hardly show any emotions or reactions.

Two guidelines were drawn up in order to help CNAs in supporting residents with dementia: "Supporting people with depression in dementia", in short 'Depression in Dementia', and "Supporting people with apathy in dementia" (NIVEL/Verpleeghuis Waerthove, 2004, a,b,c). The guidelines are primarily aimed at CNAs, because theirs is the discipline most frequently involved with dementia sufferers. The development and evaluation of the guidelines have been made possible by a grant from the first round of the program "Verpleegkundige en Verzorgende Beroepsgroepen. Tussen Weten en Doen" (Nursing professions. In between knowing and acting) of ZonMw [The Netherlands Organisation for Health Research and Development].

The project was carried out between June 2002 and December 2003, by the two authors, in cooperation with Daan van Delden, a psychiatric nurse, who

was employed during the project in Nursing Home *Waerthove* at Sliedrecht in the Netherlands.

In the next paragraph, we will outline the various project stages.

#### Outline of the project

This project consisted of seven stages:

## Stage 1: Assembling existing guidelines

Before developing the guidelines, we first assembled existing guidelines (i.e. written instructions on how to act) in the Netherlands, on supervising people with dementia who had psychological or behavioral problems, such as apathy and depression.

We contacted a total of 170 institutions (nursing homes, homes for residential care and home care institutions); we published notices in nursing journals and on websites, and we searched data banks for guidelines or research on this matter. We did not search specifically for guidelines used exclusively by CNAs – our search included multidisciplinary guidelines and guidelines from other disciplines.

#### Stage 2: Systematic review

A systematic literature review was conducted to find out whether there is any scientific evidence for the effectiveness of psychosocial care methods in the existing guidelines. We searched eleven Dutch and international electronic data bases, such as PUBMED, CINAHL, PSYCHLIT and the NIVEL catalogue, for scientific studies on the effects of psychosocial care methods for supporting people with dementia who are depressed or apathetic.

# Stage 3: Evaluation of guidelines based on the systematic literature review

We re-examined the existing guidelines, using the knowledge acquired in the systematic literature review. Our basic premise was that we would not have to develop completely new guidelines if the existing guidelines corresponded sufficiently well with the effective methods found, and if they already had a reasonably workable format for CNAs in practice.

Stage 4: Developing draft guidelines

Subsequently, a first draft of the guidelines was written.

Stage 5: Evaluation of draft guidelines by a group of experts and the steering committee

During this stage, the draft guidelines were evaluated by a group of experts and by the steering committee; they were subsequently adapted where needed.

## Stage 6: Practice trial

The adapted versions of the two guidelines were tested by a nursing team in a nursing home and in a residential care home.<sup>1</sup>

#### Stage 7: Final adaptations to the guidelines

The guidelines were adapted, where needed, using the lessons learned from the practice trial. Then they were evaluated for the last time by the members of the steering committee.

#### Results

# Results of stage 1 (assembling existing guidelines)

We contacted a total of 170 institutions, placed notices in specialized journals and on websites and searched data bases; this resulted in 59 guidelines that were related to our subject. Table 5.1 sums up the collected guidelines, divided into categories of type, discipline(s) for which the guideline was created, and the specific subject the guideline focuses on.

The second author studied all 59 guidelines, starting with the prevailing psycho-social care methods.

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The guidelines were introduced within a nursing team in home care. Because this nursing team did not have sufficient clients to whom they could apply the guidelines, the practice trial in home care was not included in the further description of our study.

Table 5.1 Characteristics of the collected guidelines (n=59) (the number of guidelines satisfying the criteria is between brackets)

Type of guideline	Disciplines	Subject*
<ul> <li>Book with instructions on how to act (22)</li> <li>Guideline/protocol/ approach developed by a care institution (21)</li> <li>Article in journal (8)</li> <li>Course developed outside a care institution (5)</li> <li>Guideline/protocol/ approach developed outside a care institution (3)</li> </ul>	<ul> <li>Caregivers of elderly people with dementia in general (23)</li> <li>Nurses and/or CNAs (19)</li> <li>Psychologists (7)</li> <li>Relatives of people with dementia (3)</li> <li>Other (7)</li> </ul>	<ul> <li>Supporting people with dementia in general (21)</li> <li>Problematic behavior in general in people with dementia (13)</li> <li>Depression in dementia (8)</li> <li>Apathy in dementia (1)</li> <li>Aggression in dementia (22)</li> </ul>

<sup>\*</sup> some guidelines focused on more than one subject

#### Results of stage 2 (the systematic literature review)

The studies included in the literature review discussed one of the following psychosocial care methods that are used in Dutch nursing care: Validation/Integrated Emotion-Oriented Care, Reality Orientation, Multi Sensory Stimulation/"Snoezelen", Activity/Recreational Therapy, Reminiscence, Psychomotor Therapy, Skills Training, Behavior Therapy, Art Therapy, Gentle Care, Passivities of Daily Living (PDL), Supportive Psychotherapy, Simulated Presence Therapy (Verkaik et al., 2005).

We evaluated the scientific quality of these studies and described the methodological characteristics, including the exact content of the psychosocial care methods examined and the effects of these on depression and/or apathy. We included all these aspects in our final assessment of the scientific evidence for the effectiveness of the various psychosocial methods. We found some scientific evidence that Multi Sensory Stimulation/Snoezelen helps reduce people's apathy in the last stages of dementia (Verkaik et al., 2005). The main principle of Multi Sensory Stimulation, or "Snoezelen", is that people in the last stage of dementia can still have contact with their environment and can experience positive sensations. This can be realized by stimulating the senses in a positive way, for example with music, light, taste, fragrance or by feeling materials.

We also found scientific proof, although still limited, that the so-called BehaviorTherapy-PleasantEvents reduces depression in people with dementia who are living at home with their primary caregiver. The evidence is limited, because BehaviorTherapy-PleasantEvents had been examined so

far in only one study (Teri et al., 1997). However, this concerned a (randomized) study of good scientific quality, with convincing methods and results. The main principle of the 'Pleasant-Events-Method' is that the "depression-spiral" in a person with dementia can be broken when he is supported in undertaking hobbies or other activities that give him pleasure. The negative depression-spiral starts when a person with dementia undertakes less and less, because he is confronted with his limitations when engaging in activities. By doing less and less he starts worrying. This makes him even more depressed, he does even less, etc. When caregivers stimulate and support the person with dementia in undertaking activities again that he really enjoys, the spiral can be broken.

We did not find convincing scientific proof that the other psychosocial methods mentioned can reduce depression or apathy in people with dementia. This lack of proof can be explained as follows. Certain methods, such as Supportive Psychotherapy and Simulated Presence, have not yet been studied adequately with regard to the effects on depression or apathy in people with dementia. Other methods, like Validation or Reality Orientation, may have been studied, but the required effects on apathy or depression have, so far, not been shown or they were not unequivocal.

# Results of stage 3 (review of guidelines)

We examined all the guidelines found to establish whether they met two requirements. The guidelines had to be: (1) evidence-based as much as possible and (2) meet the needs of people with dementia and their CNAs. For the first requirement we took the psychosocial methods that had proved effective in our literature review. The literature review had shown that Multi Sensory Stimulation/Snoezelen is effective in reducing apathy and that the Pleasant-Events-Method is effective in reducing depression. The only existing guideline we found on supporting people with dementia and apathy did indeed describe Multi Sensory Stimulation/Snoezelen. The problem was, however, that this guideline was contained in a rather large book which was cumbersome for CNAs to use in daily practice. The same was the case for a guideline on supporting people with dementia and depression. Just one of the 59 guidelines we found described a method that had links with the Pleasant-Events-Method. This too concerned a guideline in book format which was not very practical for CNAs to use. We, therefore, decided to develop a new, short, clear guideline for apathy and depression, based on Multi Sensory Stimulation/Snoezelen and the Pleasant-Events-Method.

We tried to fulfill the second requirement "meeting the needs of people with dementia and their CNAs", in several different ways. We searched the literature for what is known about these needs and used this information for developing the guidelines. Existing literature showed that CNAs believe a client centered attitude is particularly important, i.e. identifying oneself with a person with dementia and his world (Boeije, 1994). This attitude is, obviously, also appreciated by dementia sufferers and their relatives. Multi Sensory Stimulation/Snoezelen and the Pleasant-Events-Method are already basically client centered and therefore fit in very well with these needs.

# Results of stages 4 and 5 (writing and evaluating draft guidelines)

Once a first version of the draft guidelines was finished, we submitted it to a group of "experts". During a five-hour meeting with 13 experts we discussed the design, content, basis and the practical usability of the draft guidelines. Five other experts, who could not be present for different reasons, commented on the draft outside the meeting. The experts were practicing CNAs, specialized nurses, psychologists, a nursing home physician, a guideline developer and representatives of patient organizations, informal care organizations, professional and inter-sector associations.

We also submitted the draft guidelines to the six members of the steering committee, represented by various groups from politics, practice and science. This steering committee advised us at various intervals on aspects of the project, one of the most important of these occasions being the discussion of the draft guidelines.

We adapted the first versions of the two guidelines, following discussion with and the recommendations of the experts and the steering committee. For example, the experts indicated that, in their view, the way the guidelines were written did not adequately reflect the jargon used generally by CNAs. We took this comment into account in our next version, resulting in three separate booklets: two with guidelines specifically aimed at the CNAs themselves and a separate booklet containing background information and scientific explanation. CNAs do not have to read the latter; it is aimed specifically at managers or experts who happen to be interested in the scientific basis of the guidelines.

The experts as well as the steering committee members also pointed out that it is important for CNAs to adopt an emotion-oriented care vision and that more emphasis should be placed on this aspect in the guidelines. After all, each person with dementia is unique and has his own emotions, preferences and possibilities. We also adhered to this recommendation. The experts and the steering committee agreed to structure the guidelines in line with the care cycle, because this would promote a systematic approach to Multi Sensory Stimulation/Snoezelen and the Pleasant-Events-Method.

# Results of stage 6 (practice trial)

Fifteen CNAs in the nursing home and nine in the residential home received the guidelines and were trained during a short period by a psychiatric nurse who had broad experience with this target group of CNAs and residents. In the residential home, two occupational therapists completed the training. The training took 2.5 hours and consisted of an explanation of the guidelines and assignments. After the training, residents were selected with whom the first group of CNAs could test the guidelines during a six week period. After the six weeks, all CNAs who had taken part in the training received a questionnaire about the benefit of guidelines and the training. Additionally, CNAs, occupational therapists and team managers who had been involved in the introduction and application of the guidelines were interviewed in a group meeting. In general, the results were positive. The CNAs were pleased to have the Multi Sensory Stimulation/Snoezelen method and the Pleasant-Events-Method on paper, even though some indicated that certain elements of these methods, for example "using pleasant stimuli", were not new to them. The guidelines helped them to use the methods more systematically. The CNAs said that the reactions of the residents were also positive.

#### Results of stage 7 (final adaptations)

In this last stage, only a few marginal textual adaptations were needed, because the CNAs were positive about the previous versions in the trial. However, these CNAs did give suggestions on how to improve the layout and the content of the so-called Pleasant-Activities-Plan and the Multi Sensory Stimulation-Plan. These suggestions were taken on board for the final versions.

The guidelines have been written down in two booklets titled "Supporting people with dementia who are depressed", in short 'Depression in

Dementia, and "Supporting people with dementia who are apathetic" (NIVEL/Verpleeghuis Waerthove, 2004b and c). Additionally, a booklet containing background information and scientific explanation of the guidelines was published (NIVEL/Verpleeghuis Waerthove, 2004a), as mentioned before. Box 5.1 gives more information on the structure and content of the guidelines.

#### Box 5.1 Description of the two guidelines

Introductory paragraphs

The two guideline booklets first describe the relationship between dementia and depressive complaints, and between dementia and apathy respectively.

Then both guideline booklets discuss the importance of an *emotion oriented care vision*. The booklets explain that an *emotion oriented care vision* means that CNAs or others providing care try to feel and think as a resident with dementia does. When you, as a CNA, know more about the background of the person with dementia and identify as much as possible with how it must be for that person to suffer from dementia, you will understand that person better and be able to provide resident oriented care.

Both guideline booklets also briefly discuss the *care cycle*. Broadly speaking, the care cycle consists of four stages – mapping needs, planning, applying and evaluating care – that one must go through when implementing the Pleasant-Events-Method, as well as the Multi Sensory Stimulation/Snoezelen-method.

Core aspect of the guideline for depression. The guideline "Supporting people with dementia and depression" provides information about the Pleasant-Events-Method. The main premise of this method is outlined, i.e. that the client's depression is expected to decrease if he undertakes pleasant activities and is worrying less. Then, along with the four stages of the care cycle, an explanation is given of how the Pleasant-Events-Method can be used with a resident suffering from dementia and how one can seek out –together with the resident where possible – enjoyable activities and opportunities to engage in these activities.

Core aspect of the guideline for apathy. Here, Multi Sensory Stimulation/Snoezelen is discussed. Sensory Stimulation in this respect means stimulating the senses of a resident in a positive way. To be able to do this, the CNA needs to collect information about which sensory stimulation the resident finds pleasant – certain smells and flavors, soft materials, certain music or others sounds, visual stimulation. The CNA collects this information in two ways. First, by talking with colleagues who are involved with the resident and with the relatives of the resident. Second, by observing the resident's reactions to sensory stimulation.

Forms. The guidelines also include forms that CNAs can use to set up a Pleasant-Activities-Plan or a Multi Sensory Stimulation/Snoezelen Plan.

# From research to practice

Developing evidence-based guidelines is not an aim in itself. Ultimately, the aim is that caregivers will base their actions on methods that have proven to be effective, which, in turn, will benefit the quality of care and the quality of life of certain patient groups. Moreover, the process of developing guidelines takes a lot of time, effort and money. The dissemination and implementation of the guidelines should, therefore, not stop at the small-scale practice trial that was part of their development process. In this paragraph, we discuss the conditions for a successful implementation.

First of all, it is important that the implementation of the guideline is supported by the various levels within the hierarchy of an institution. We know, from experience with the practice trial, that it is crucial to prepare the implementation thoroughly. For example: everyone who wishes to implement guidelines first of all has to inform management on the objective and the content of the guidelines. Not before senior management supports it, is it useful to inform direct staff and executive CNAs about it and make them enthusiastic. The more parties agree with the approach and the implementation of the guidelines, the greater the chance that implementation will succeed.

Once the decision is taken to implement the guidelines in an institution, the CNAs need to be trained. Two points are extremely important at this stage: First of all, the training must be of good quality. But even more important is to find a suitable trainer. In this case, the ideal trainer is a person with teaching qualifications and he/she must be familiar with the target group of CNAs and people with dementia. Also, he needs to be in touch with the culture and organization of the institutions that will implement the guidelines. In the practice trial of this project, for example, the CNAs were trained by a psychiatric nurse who regularly advises and coaches CNAs in their daily work for people with dementia and behavioral and psychological problems.

The practice trial showed that, among other things, support and coaching by the direct team managers is vital for the guidelines to be actually put into practice. Each team or unit must agree separately on how the guidelines will be positioned in the care process: for example, how and when CNAs can propose a resident for application of a guideline and how members of the team and other disciplines can consult each other on how to use the methods of this guideline.

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Additionally, it can be a good idea to create a promotion group to promote the implementation and application of the guidelines in practice – also in the long term. Such a group can consist of one or two CNAs, one team manager and an occupational therapist. Although our guidelines are primarily focused on CNAs, an occupational therapist can certainly play a facilitating and stimulating role in the implementation of the Pleasant-Events-Method and Multi Sensory Stimulation/Snoezelen.

## Box 5.2 Core findings

- The systematic literature review shows that some scientific evidence exists that Multi Sensory Stimulation /Snoezelen positively influences apathetic behavior among people in the last stage of dementia.
- Furthermore, the existing research shows that there is scientific evidence, although limited, that the Pleasant-Events-Method positively influences depressive complaints in people with dementia in the community.
- According to CNAs, the guidelines developed in this project were clear and accessible.
- The effects of implementing the guideline about supporting people with dementia who
  are depressed is currently being further investigated in a project financed by ZonMW.

## Discussion

When we started this project in 2002, no clear instructions existed on how to develop guidelines for CNAs or nurses. In the meantime, the "Landelijk Expertisecentrum Verpleging en Verzorging" (LEVV, the National Nursing and Caring Expertise Centre) has developed a stepwise approach, in cooperation with NIVEL, to perfect existing guidelines (Poot et al., 2003). Although we have developed completely new guidelines, the stages in the stepwise approach largely correspond with the seven development stages that we describe in this article.

After this project we submitted both guidelines to the national Dutch Nurses' Association V&VN for evaluation. A review committee judged these guidelines to be a good step towards national approved guidelines. The Committee said that the systematic review had been well substantiated and the care process was clearly described in the guidelines. However, the guidelines did not fully satisfy their criteria: according to the committee, our practice trial of six weeks had been too short. We will be able to address this point in future, as far as it concerns the guideline on supporting people with

dementia and depression: at the moment, this guideline is being tested intensively and on a long term basis – see next paragraph. We are now working on several textual adaptations, proposed by the V&VN; our next step will be to submit the adapted guidelines once again for evaluation.

This project has resulted in two guidelines for CNAs that were tested and proved to be usable. However, this certainly does not mean that we have sufficient insight into the effects of the guidelines. "Evidence-based" in this case only means that the psychosocial care methods given in the guidelines have proven to be effective - and not the guidelines. We also have to take into account that in previous scientific studies the methods – the Pleasant-Events-Method and Multi Sensory Stimulation/Snoezelen – were, in most cases, used by other caregivers than CNAs. A follow-up study will have to show whether the translation to CNAs, in these guidelines, produces the effects we aim at. Additionally, a follow-up study is important to gain more insight into the factors of success and failure for the implementation of the guidelines to be used by CNAs.

We have, therefore, developed a proposal for a follow-up study which we submitted during the second round in 2004 of the program "Verpleegkundige en Verzorgende Beroepsgroepen. Tussen Weten en Doen" (Nursing professions. In between knowing and acting). This proposal was accepted and in spring 2005 we started a multiannual, multicenter study in nursing homes into the effects of the introduction of the guideline for supporting people with dementia and depression – which concerns mainly the Pleasant-Events-Method. In two to four years' time, a thesis will be published by the second author – that is, if all goes according to plan – describing the effects of the introduction of the guideline on depressive complaints of nursing home residents with dementia and depression, as well as the effects on CNAs' professional experience. This study will also provide deeper insight into the conditions for introducing this guideline successfully.

The guideline for supervising people with apathy has, so far, not been evaluated on a large scale. However, other research is increasingly providing evidence that activating the senses, which involves this guideline to a considerable extent, has a favorable influence on apathy and other behavioral problems in residents, as well as on how CNAs experience their work (Van Weert, 2005a).

# 6

# Introducing a nursing guideline on depression in dementia

A multiple case study on influencing factors

This article was submitted as:

Verkaik R, Francke AL, Van Meijel B, Ouwerkerk J, Ribbe MW, Bensing JM. Introducing a nursing guideline on depression in dementia: a multiple case study on influencing factors.

#### **Abstract**

## **Background**

Successfully introducing care innovations depends on the type of care setting, the intervention and specific circumstances. In this study the factors influencing the introduction of an evidence based nursing guideline on depression in psychogeriatric nursing home residents were studied.

#### Methods

A qualitative multiple case study design was used. The cases consisted of nine psychogeriatric wards participating in the intervention group of a controlled clinical trial. Eight types of data source (qualitative and quantitative) were used in the analyses. Triangulation of researchers, data and methods took place. Factors were categorized according to their organizational level: nursing home management (level 1), nursing team (level 2), CNAs (level 3), and residents (level 4).

#### **Results**

Factors influencing guideline introduction were mainly found at the levels of the nursing home management and the nursing team. Most factors concern stability of the organization and team (e.g. the inhibiting effects of reorganizations and other innovations), motivation (e.g. the facilitating presence of an opinion leader) and compatibility with current practice and vision (e.g. a facilitating emotion-oriented care vision). Factors influencing a successful application of the guideline are mainly found at CNA and resident level. At CNA level most factors relate to an emotion-oriented care vision (e.g. having a warm and creative personality). At resident level inhibiting factors mainly concern the residents' health status (e.g. feeling sick and/or having much pain). Important facilitating factors are positive attitudes of relatives and observing a reduction of depression severity.

#### Conclusions

Special facilitating factors for the guideline introduction and application seem to be the presence of a local opinion leader and the positive attitudes of relatives. Together they can motivate a nursing team in using the guideline. After a successful introduction of the guideline it's important to focus on its consolidation in daily practice.

# **Background**

Depression in psychogeriatric nursing home residents is highly prevalent (Zuidema et al., 2007) and has serious consequences, such as reduced quality of life (Shin et al., 2005), greater health care utilization (Kunik et al., 2003) and higher mortality rates (Suh et al., 2005). From previous research it is known that Certified Nurse Assistants (CNAs) who provide much of the care on the psychogeriatric wards, often experience problems in caring for demented elderly with comorbid depression (Kerkstra et al., 1999). The lack of effective methods to intervene in the depression themselves may leave them feeling powerless (Kerkstra et al., 1999). Therefore we developed an evidence based nursing guideline to support residents with dementia who suffer from comorbid depression.

In a multi-centre controlled clinical trial the guideline was introduced to nine psychogeriatric wards in nine nursing homes. The guideline proved to be effective in reducing depression (Verkaik et al., submitted). As part of the clinical trial the facilitating and inhibiting factors for successful introduction and application of the guideline were studied. Knowledge of these factors is important for (1) better interpretation of the effects measured in the clinical trial, (2) refining the guideline introduction, (3) advising nursing homes about implementation issues for this (and other) guideline(s).

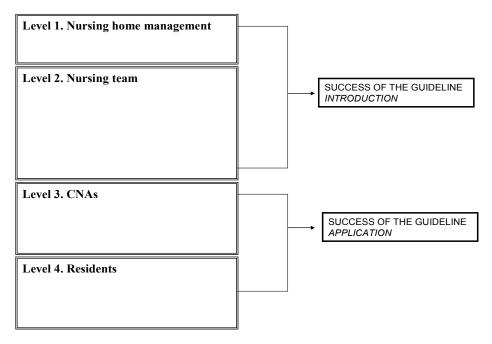
It is widely known that introducing new guidelines or other care innovations into practice is no guarantee for success. Reviews of successful dissemination and implementation strategies conclude that success seems to depend on the type of care setting, type of intervention and specific circumstances (Grinmshaw et al., 1998).

Successful introduction seems to be most difficult in chronic care (Grinmshaw et al., 1998). A review by Cabana et al. (1999) of 76 studies showed that obstacles to use guidelines often arise at different levels of the health care system: at the level of the patients, the individual professional, the health-care team, the health-care organization or the wider environment. To study the facilitating and inhibiting factors for the introduction and application of the nursing guideline 'Depression in Dementia' on psychogeriatric nursing home wards we used a comparable multi-level approach.

In this case the organizational level is related to the nursing home and its management (level 1). The team level concerns the nursing team consisting of the team manager, CNAs and non-certified assistants (level 2); the

professional level concerns the individual CNAs (level 3); and the patient level concerns residents of psychogeriatric nursing home wards that suffer from comorbid depression in dementia (level 4) (see figure 6.1).

Figure 6.1 Levels of factors influencing successful guideline introduction and application



The research questions that are addressed in this paper are:

- 1. Which factors facilitate or inhibit the successful *introduction* of the guideline in psychogeriatric nursing home wards?
- 2. Which factors facilitate or inhibit the successful *application* of the guideline by CNAs in their support of residents with comorbid depression?

# Methods

# Intervention

The guideline was based on the principles of the BehaviorTherapy-PleasantEvents method as developed by Teri et al. (1997), which was shown to be effective in reducing depression in people with dementia still living in

the community. Key elements of the newly developed guideline are (1) inducing individualized pleasant events, and (2) reducing unpleasant events. The guideline was developed according to the internationally validated AGREE criteria (AGREE Collaboration, 2003).

The strategies to introduce the guideline on each ward were multifaceted, consisting of (1) printed educational materials (guideline booklet, forms and training program), (2) interactive team training consisting of two training sessions and one follow-up session, (3) setting up of a promotion group. During the training sessions CNAs learned how to apply the guideline to their own residents by developing so-called individualized Pleasant-Activities-Plans. The training sessions were primarily aimed at CNAs, although the team manager, occupational therapists and psychologists working on the wards were also invited to participate. Non-certified nurse assistants were to be instructed by the trained CNAs themselves in between and after the training sessions. In this way the guideline was introduced to the complete nursing team.

A promotion group (in general a team manager, occupational therapist and two CNAs) was initiated on each participating ward in the experimental condition to facilitate and promote the application of the guideline. This group had the task of meeting every two weeks during the intervention period to discuss promotion and facilitation activities. The members of the promotion group were encouraged to consult the trainer during the introduction period, if they had any questions on the introduction or application of the guideline.

#### **Participants**

#### CNAs

All 109 CNAs that worked at least 20 hours per week on one of the nine participating wards in the experimental condition of the clinical trial were invited to participate in the training. In the Netherlands, CNAs provide much of the care on psychogeriatric wards and generally have three years of basic nursing training. They are more or less comparable - regarding educational level and skills - to Licensed Practical Nurses in the United States. Non-certified nurse assistants (helpers) were not invited because they were not previously educated in developing care plans.

Of the 109 invited CNAs 98 participated in the training. Reasons for not attending were pregnancy leave (n=1), illness (n=1), vacation (n=1), only working night shifts (n=3), arguments with the team manager (n=1) and

changing jobs (n=4). The mean age of the trained CNAs was 37.6 years (SD 9.9) and 6% were male. Mean working hours per week were 28.1 (SD 6.7), mean years in psychogeriatric care, 8.5 (SD 6.7) and number of working years on the ward, 5.6 (SD 5.5).

On every ward the CNAs that were the most and the least positive about the training were asked for an interview about the guideline introduction and application. It was decided to interview CNAs with extreme opinions because these were expected to provide the most insight into the facilitating and inhibiting factors. Depending on availability in every home, at least one most positive and one least positive CNA was interviewed. In total 20 interviews took place (ten most positive; ten least positive). There were no significant differences between the background characteristics of CNAs who were interviewed and those who were not (p≥.05).

#### Residents

The guideline was used for 62 residents on the nine wards who were diagnosed by the nursing home physician and/or psychologist as being demented (DSM-IV-PC: APA, 1994) and depressed (PDC-dAD: Olin et al., 2002a). Residents with severe dementia (Global Deterioration Scale stage 7: Reisberg et al., 1982) were excluded from the study because the intervention was aimed at residents who were still able to verbally communicate. Residents who were supported with the guideline had a mean age of 83.4 (SD 7.2); 73% had moderate or moderately severe dementia; 50% had resided between one and three years on the ward and 26% longer than three years.

#### Data collection

Data were collected using a multiple case study design in which the cases consisted of the nine wards on which the guideline was introduced. Characteristics of a multiple case study are that (a) data are collected and analyzed at different levels (e.g. nursing home management, nursing team, CNAs and residents), (b) several types of data collection are used (e.g. interviews, observation), and (c) a phenomenon is analyzed within its original context (Strauss and Corbin, 1998). This design allows data and methodological triangulation (Dezin, 1978; Teunissen, 1985) and the combining of qualitative and quantitative data. Data collection took place via eight data sources (see figure 6.2).

Figure 6.2 Data sources per research question

Pigure 6.2 Data sources per research	Data sources
Research question 1: Which factors facilitate or inhibit the successful introduction of the guideline in psychogeriatric nursing home wards?	<ul> <li>interviews with promotion groups</li> <li>interviews with individual CNAs</li> <li>memos of first meetings with nursing home management</li> <li>training evaluation forms filled out by CNAs</li> <li>presence of Pleasant-Activities-Plans in care files</li> <li>training reports from researcher/coresearcher</li> <li>observations of residents</li> <li>background characteristics of CNAs</li> </ul>
Research question 2: Which factors facilitate or inhibit the successful application of the guideline by CNAs in their support of residents with comorbid depression?	<ul> <li>interviews with promotion groups</li> <li>interviews with individual CNAs</li> <li>presence of Pleasant-Activities-Plans in care files</li> <li>training reports from researcher/coresearcher</li> <li>observations of residents</li> <li>background characteristics of CNAs</li> </ul>

The interviews with the promotion groups and with individual CNAs were semi-structured and focused on (1) the success or failure of the introduction and the actual application of the guideline, (2) facilitating and inhibiting factors. Topic lists were used to loosely structure the interviews. The interviews were conducted by the first author (RV: psychologist) and a research assistant (a student of nursing science). All interviews were taperecorded and then transcribed verbatim.

In addition we studied memos by the researcher describing agreements with nursing home management of the participating homes, made in meetings before the study and intervention period started. The memos also described specific situations (e.g. regarding care vision, recent training courses) in the nursing homes.

In addition, evaluation forms were analyzed. At the end of the third training session each participating CNA filled out an evaluation form about his/her experience. Information was gathered about clarity, usefulness,

practicability and motivating aspects of the training. CNAs were also asked to score their level of appreciation of the training on a scale from 0 (very low) to 10 (very high).

Furthermore, the number of Pleasant-Activities-Plans that was present in the residents' care files two weeks after the follow-up training was counted. According to explicit instructions in the guideline and the training program, CNAs had to put the Pleasant-Activities-Plans into the residents' care files after they evaluated them.

Training reports were also analyzed. All training sessions on the nine wards were attended by the first (RV) or the fourth author (JO: research assistant). For every session, a training report was written afterwards.

Reports on observations of residents and their interactions with CNAs and others were analyzed as well. These observations were made by the fourth author (JO) on three occasions: just before the first, after the second, and after the follow-up training. Observations at different times made it possible to record possible changes in residents and their interactions. For practical reasons it was only possible to commence observation on the five wards to which the guideline was introduced last. On each of these wards between two and four residents were observed, depending on the number of residents participating in the clinical trial. In total 16 residents were observed. Different stages of dementia were included in the selection of residents, in order to be able to observe possible differences between stages. Observations focused on mood, behavior and interactions of the residents with CNAs, other residents and relatives. Specific observation times were: morning care, meals, recreation and personnel shifts. An observation protocol with points of interest and observation times was used to structure the observations. The observer took notes during the observations and if necessary made verbal memos on audiotape directly after an observation was finished. Afterwards the memos were transcribed.

Background characteristics of CNAs participating in the training and the interviews were derived from the baseline measure of the intervention study, and were analyzed as well.

#### **Analysis**

In order to answer the two research questions we used the following method of analysis.

First the level of success of the introduction of the guideline on each ward was derived from:

- 1. the average score the CNAs awarded to the training (scores ≥7.5=1 point; 5-7.5=0 points; <5=-1 point);
- 2. the percentage of residents for whom a Pleasant-Activities-Plan was put in their care files after the follow-up training (≥70%=1 point; 50-70%=0 points; <50%=-1 point);
- 3. the number of times the promotion group met (≥1=1 point). A composite score was calculated ranging from -2 to 3. Wards with a score of 2 or 3 were considered successful, with a score of 1 moderately successful, and a score between 0 to -2 not successful.

Second, the texts of the transcribed interviews with the promotion groups, individual CNAs, memos of first meetings with nursing home management, training reports and reports of resident observations were imported into MaxQDA (VERBI Software, 2007). MaxQDA is a software tool specifically developed for qualitative data analysis. In MaxQDA the texts were read through several times, and each text fragment was assigned one or more code words (Strauss and Corbin, 1998). All the code words were based directly on the content of the fragments.

Third, using the coded text fragments, the first author analyzed which facilitating and inhibiting factors differed between the wards that were most successful, moderately successful and not successful. To improve the quality of the analysis, about half of the interviews with promotion groups and individual CNAs were also analyzed by the research assistant (JO) separately (researcher triangulation). Mutual codes and results of the analyses were compared and discussed. There were no disagreements about the most important facilitating and inhibiting factors or their specific nature. Fourth, in order to analyze if background characteristics of CNAs working on a ward were related to the success of the guideline introduction, we performed Chi-square tests and ANOVAs in which the level of success was the dependent variable (none, moderate, high) and the CNA characteristics the independent variables (e.g. level of education, mean age and working hours per week).

#### Medical ethics and informed consent

The intervention and measures of the controlled clinical trial as well as the case study activities were approved by the Dutch Central Committee on Research involving Human Subjects (CCMO). On behalf of all participating residents, legal guardians gave their informed consent for the intervention,

measures and observations. The study took place from March 2005 to May 2007.

# **Results**

# Success of the guideline introduction

Table 6.1 provides the scores of the nine nursing home wards on the variable 'success of the guideline introduction'.

Table 6.1 Success of the guideline introduction

Ward	Average mark for training	Percentage of Pleasant-Activities- Plans in care files	Meetings of promotion group (≥1=1 point)	Success guideline introduction		
	(≥7.5=1 point;	(≥70%=1 point;		(-2 to +3)		
	5-7.5=0 points; <5=-1 point)	50-70%=0 points; <50%=-1 point)				
1	7.9 (1)	100% (1)	2 (1)	3		
2	7.6 (1)	100% (1)	1 (1)	3		
3	7.7 (1)	60% (0)	3 (1)	2		
4	7.4 (0)	100% (1)	0 (0)	1		
5	8.0 (1)	67% (0)	0 (0)	1		
6	7.7 (1)	63% (0)	0 (0)	1		
7	7.5 (1)	67% (0)	0 (0)	1		
8	4.7 (-1)	56% (0)	1 (1)	0		
9	6.9 (0)	0% (-1)	0 (0)	-1		

The last column in table 6.1 shows the division of the nine wards into three groups:

- 1. successful wards (nos.1 to 3);
- 2. moderately successful wards (nos.4 to 7);
- 3. unsuccessful wards (nos.8 and 9).

Box 6.1 describes the guideline introduction on two of the successful wards (nos.1 and 3) and box 6.2 the introduction at the two unsuccessful wards (nos.8 and 9).

# Box 6.1 Case descriptions of two successful wars (nos.1,3)

#### Successful wards

#### Ward no.1

The decision to introduce the guideline came from the ward itself. A **psychologist** connected to the ward played an important role in the introduction. She was very enthusiastic, took part in the training sessions, promotion group meetings and supported the team. She invented the 'buddy-principle' in which two CNAs who knew a resident well were coupled. Together the buddies were responsible for the application of a Pleasant-Activities-Plan. This worked very well. The team of this ward was very **stable** and **cohesive** and had a shared **emotion-oriented attitude**. They were an **enthusiastic union**. One CNA described this as follows: "I think that we all enjoy working here. That you get the hug of a resident, that's the aim of us all. We are a union, yes. We laugh and cry together. This ward feels like a warm blanket." **Family members** of the residents were **very enthusiastic** about the method. They provided the CNAs with life history information and facilitated pleasant activities. One CNA: "I really liked the information and knowledge we got from the family members. We really need that. Also the positive contact. At last you can talk with relatives about something pleasurable."

The CNAs of this ward were still applying the guideline at the time that the interviews took place. The Pleasant-Activities-Plans were in the residents' care files. The CNAs saw an improvement of depression in all residents and thought that this was at least partly due to the use of the guideline.

#### Ward no.3

CNAs of the ward were at first sceptical about the guideline introduction. They perceived it as 'just another training course'. But when they saw that application indeed had a positive effect on the residents they became really enthusiastic. "The reactions of Ms. X were the best". Also the way the training was organised was experienced as very stimulating. "Doing it together, with many practical examples was very encouraging."

The occupational therapist, psychologist and team manager were all highly engaged in the guideline introduction. The promotion group came together every two weeks and the nursing home's policy day was dedicated to the guideline introduction. Now, after the guideline introduction, CNAs ask the psychologist earlier for help, and the occupational therapist reports that she is now more involved with the daily care of the residents. The team manager reports that the nursing home management has plans for introducing the guideline throughout the entire nursing home.

#### Unsuccessful wards

#### Ward no.8

The decision to participate in the guideline introduction was made by a nursing home physician and team manager who at the time of the guideline introduction were no longer connected to the ward. The new team manager did not see the value of the guideline introduction. When some CNAs mentioned positive effects of the introduction at the end of the follow-up training, the team manager denied these. This happened just before the CNAs were asked to give their level of appreciation to the training course (0=very low; 10 =very high). The average appreciation score then given was 4.7!

CNAs had also expected another type of guideline and training. They **expected to receive ready-made solutions** for individual residents and not a guideline that showed them how to develop and apply their own care plans. A CNA exclaims "Now we had to do even more!". They also said that they already applied the method. One CNA states "There was nothing new on it, no new possibilities or methods, we all already did this." This ward developed Pleasant-Activities-Plans, but none of the principles of the guideline were followed.

#### Ward no.9

The management of the nursing home, together with the team manager of the ward, had decided to participate in the study. Despite the fact that the research team had warned the management not to introduce other methods or have other training courses during the guideline introduction, a **new reporting system** was introduced and **another training course** was given. The team manager of the ward tells"...in the same period we were burdened with some other training courses that were appointed by the nursing home management. Three new methods were introduced at the same time!"

The team of this ward had **shortage of staff** during the whole introduction period. The team manager explained the effect on the guideline introduction and application "…because if you are so short of personnel as we were……You can do the work if there are seven CNAs , the quality of care rises with eight. If I tell you that we had to do the work with five, than it is clear that we gave priority to group activities instead of individual…"

Many of the family members did not want to provide the CNAs with life history information of their relatives, probably because of prior negative relationships. According to the CNAs it was therefore very difficult or impossible to develop individualised Pleasant-Activities-Plans

The CNAs of this ward developed a Pleasant-Activities-Plan for every resident during the training (information form training reports), but none of the plans could be found in the care files at the time the interviews were held. Interviewed CNAs stated that they had applied the plans, but did not see effects on depression.

# Factors that relate to a successful guideline introduction and application

Factors that play a role in the guideline introduction appear to exist on two levels: (level 1) nursing home management, and (level 2) nursing team. The factors on these levels interact with those that play a role in the guideline application on level 3 (CNAs), and level 4 (residents). The specific inhibiting or facilitating factors on the different levels are described below.

#### Level 1. Nursing home management

Inhibiting factors

- Reorganizations or other innovations at the time of the guideline introduction.

In the nursing home of ward no.7 a large-scale reorganization had taken place that was not yet finished at the time the guideline introduction started. Before the reorganization the team manager had an office on the ward, whereas the new manager took office in another part of the nursing home, away from residents and caregivers. The team had to become self-steering. The commotion this created in the team left little room for the introduction of the guideline.

On ward no.6 at the same time 'living in small units' was implemented. This overload of new information and methods made it difficult for the teams to focus on the guideline introduction. Despite agreements that were made with the nursing home management, on ward no.9 a new reporting system and another training course were initiated simultaneously with the guideline introduction. This resulted, for example, in no Pleasant-Activities-Plans being put into the residents' care files.

- Top down introduction of the guideline.

CNAs of ward no.7 were critical beforehand regarding the guideline introduction on their wards, because of reorganizations in the nursing home and their team, and a shortage of certified personnel. Despite this, the management of the nursing home decided to participate. The CNAs felt they were not sufficiently involved in the decision making, and this caused much resistance at the beginning of the guideline introduction and slowed down the implementation process.

# Level 2. Nursing team

Facilitating factors

 Presence of an opinion leader: a respected person who is connected to the ward and encourages, motivates and supports the whole team in using the guideline.

In the nursing home of ward no.1, a psychologist working on the ward motivated the entire team in using the guideline and proposed creative solutions for practical problems. According to the promotion group and individual CNAs she was 'super enthusiastic' and a real motivator.

Likewise, on ward no.2 there was a psychiatric nurse who had a very stimulating role. He had the task of introducing 'emotion-oriented care' in the nursing home and considered the guideline introduction to be part of this. He devoted himself to making it a success. For example, he organized a meeting to inform the non-certified nurse assistant and other nursing helpers about the guideline.

On wards no.3 to 9 there were no persons that took the position of opinion leader.

- Having a reporting system that the guideline fits into.

The successful wards (nos. 1 to 3) all mentioned that the Pleasant-Activities-Plans and related reporting fitted in well with their existing reporting system. On the other wards this was mostly not the case. There the introduction of the guideline was thought to incur additional paper work.

# Inhibiting factors

- Team manager does not recognize relevance of guideline introduction. Only a team manager who is convinced of the importance of the guideline will facilitate and motivate his/her team to use it. A team manager who is not convinced, will give priority to other tasks or methods. On ward no.8, one of the two unsuccessful wards, the team manager did not see the relevance of the guideline. This team manager was new in the nursing home and did not work there at the time the nursing home management and team managers made the decision for the guideline introduction. On this ward the introduction was limited: Pleasant-Activities-Plans were made, but were not based on new observations or life history information and were hardly applied.
- High staff turnover.

On ward no.5 five CNAs departed their jobs during the guideline introduction. Some of these CNAs had taken the Pleasant-Events-Plans that they developed with them instead of leaving them in the residents care files or with colleagues. Also their knowledge and (sometimes very special) relationship with the residents were gone.

- Shortage of certified personnel.

Ward no.9 as well as ward no.7 had a very high shortage of CNAs at the time of the guideline introduction. The promotion groups and individual CNAs on these wards indicated that this impeded the guideline introduction significantly.

A calculation was made of the CNA-resident ratio within the team. The results also point in the direction that sufficient certified personnel is needed: the highest CNA-resident ratio was found on the ward where the

guideline introduction was most successful: this ratio was .6. The lowest ratio was found on the ward where the introduction was least successful: here the ratio was .2.

- Not sharing an emotion-oriented care vision.

On ward no.4 the CNAs indicated that there was a division between young CNAs who really wanted to work in an emotion-oriented way and older CNAs who worked in a more task oriented manner and claimed that they did not consider the application of the Pleasant-Activities-Plans to be part of their job. The introduction of an emotion-oriented care method on this ward divided the two groups even more. They blamed each other for spending their time on the wrong tasks.

- The view that depressed residents should not have more privileges than non-depressed residents.

Wards no.8 and 6 shared the opinion that residents with comorbid depression and dementia should not have more privileges than demented residents without depression. On ward no.8 there was a real resistance against the individual activities and support for the depressed and demented residents. On ward no.6 this attitude caused CNAs to try and involve non-depressed residents in the individualized activities of the depressed and demented.

- The expectation that the guideline and training would bring instant solutions for depression in dementia.

Ward no.8 had the expectation that the guideline introduction would bring instant solutions for residents with comorbid depression and dementia and the sometimes related behavioral problems. They also had not expected that they had to develop Pleasant-Activities-Plans themselves. These expectations inhibited the guideline introduction extensively.

#### Inhibiting characteristics

 The fact that non-certified or non-registered nurses or nursing assistants were not trained.

All nine wards had difficulty in informing the untrained members of the team about what was learned and agreed in the training sessions. According to the CNAs this had to do with (a) disappointment and misunderstanding among non-certified team members about not being trained, and (b) difficulties on the part of the CNAs with explaining the content of the guideline to their non-certified colleagues. From the observations of residents and their interactions with CNAs it became very clear that the non-

certified or non-registered nurses or nursing assistants indeed contributed very little to the application of the guideline.

#### Level 3. CNAs

Analysis of the influence of background characteristics

The possible relationship between the success of the guideline introduction and background characteristics of the CNAs from the nine wards was statistically analyzed. Characteristics that were studied were: mean age, gender, educational level, current position, type of contract, working hours, years in psychogeriatrics and years on the ward. No significant relationships were found ( $p \ge .05$ ).

# Facilitating characteristics

- Warm and creative personality.

On all successful and moderately successful wards in the interviews with promotion groups and individual CNAs the names of one or more CNAs were mentioned that were very successful in applying the guideline. These CNAs were always described as warm and creative, enjoying one-to-one contact with residents. Having a sense of humor is also often mentioned as one of their characteristics.

- Sharing interests with resident.

Some CNAs had a very special relationship with one or two residents. This seemed related to sharing a major interest like, for example, religion. One CNA on ward no.5 developed a complete Pleasant-Activities-Plan around religious activities, like psalm singing and bible reading. A difficulty in these cases was that other CNAs could not always help in applying the plans that were (partly) built on the personal interests and relationships.

#### Inhibiting characteristics

- The view that 'a resident has the right to be depressed'. In some interviews CNAs expressed the opinion that in old age, after a long and sometimes difficult life, one has the right to be depressed. In their opinion one should not make much effort to change this.
- Employment: small contracts and alternating shifts.

  When working less than 32 hours a week it seems more difficult for CNAs to really get to know their residents, which is important for proper application of the guideline. Also working in different shifts hampers CNAs from

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keeping themselves informed about changes in residents. With small

contracts and alternating shifts, CNAs largely depend on written reports, which often lack information on non-medical subjects.

#### Level 4. Residents

Facilitating factors

Visible reduction of depression.

According to the CNAs, the factor that had the most motivating effect on guideline application and further introduction of the guideline was perceiving positive effects on depression. Immediate and lasting effects had the most stimulating impact. If no effects on depression were perceived, this had an inhibiting effect on the application of the guideline to the individual resident and sometimes on the further introduction of the guideline. This seemed to be related to the expectations of CNAs and nursing teams about the guideline introduction and its effects. If they expected instant effects and quick solutions for the depression, they were soon disappointed and inhibited in further application and introduction.

- Positive attitudes of relatives.

On ward no.1 there was considerable willingness among relatives to provide life history information. This not only facilitated the development of Pleasant-Activities-Plans, but also worked in a very stimulating way for the CNAs. The same counts for relatives providing photo albums or videos of family events, like weddings. The reactions of relatives to positive results of the guideline application were also perceived to be very motivating. On ward 9 many of the relatives did not want to provide the CNAs with life history information of their family members, probably because of prior negative relationships. According to the CNAs it was therefore very difficult or impossible to develop individualised Pleasant-Activities-Plans.

#### Inhibiting factors

Stage of dementia>6.

Before the guideline introduction the guideline was already considered unsuitable for people with severe dementia. The analyses confirm this view. It shows that for residents whose cognitive functions declined rapidly during the study period most activities that were developed were no longer applicable. Residents reaching the last stages of dementia could not, for instance, even concentrate on television programs about a favorite subject anymore.

Multiple behavioral and emotional disturbances.

CNAs reported that for residents with aggressive or agitated behaviors and strong mood fluctuations, or with a history of major depression or schizophrenia, it was more difficult to apply the guideline. With these residents it was, for example, more difficult to plan activities for a specific date or time. In these cases CNAs seemed to need more creativity, flexibility and help from psychologists and others.

- Feeling sick / having much pain.

In some cases residents suffered from (new) somatic complaints during the period of the guideline introduction. If a resident felt sick or had much pain, undertaking activities with him/her was not possible. For some residents this meant that they could not be assisted according to the guideline for quite a while, which inhibited its success.

The answers to research questions 1 and 2, about factors related to the successful introduction and application of the guideline on the ward are summarized in figure 6.3.

Figure 6.3 Factors influencing successful guideline introduction and application

# Level 1. Nursing home management

Inhibiting factors

- reorganizations or other innovations at the time of the guideline introduction
- top down introduction of the guideline

#### Level 2. Nursing team

Facilitating factors

- presence of an opinion leader
- a reporting system that the guideline fits into

#### Inhibiting factors

- team manager does not recognize relevance of guideline introduction
- high staff turnover
- shortage of certified personnel
- not sharing an emotion-oriented care vision
- view: 'depressed residents must not have more privileges than non-depressed residents'
- expectation: expecting instant solutions for depression
- not training non-certified or non-registered caregivers

#### Level 3. CNAs

Facilitating factors

- personality: warm and creative
- sharing interests with residents

# Inhibiting factors

- view: 'resident has the right to be depressed'
- employment: small contracts; varying shifts

# Level 4. Residents

Facilitating factors

- visible reduction of depression
- positive attitudes of relatives

# Inhibiting factors

- stage of dementia >6
- multiple behavioral and emotional disturbances
- feeling sick / having much pain

SUCCESS OF THE GUIDELINE INTRODUCTION

SUCCESS OF THE GUIDELINE APPLICATION

# Discussion

# Inhibiting and facilitating factors

Factors directly influencing the *introduction* of the guideline were predominantly found on the level of the nursing home management (level 1) and the nursing team (level 2). The most important inhibiting factors concern the instability of the organization or team, chiefly caused by reorganizations or the introduction of other methods at the time of the guideline introduction. These factors are well known from the literature (e.g. Francke et al., 2008; Van Weert et al., 2004; Schrijnemaekers et al., 2002; Holtkamp et al., 2001). Also the result that insufficient support for and unmet expectations at the level of the team manager and team can seriously inhibit success has been reported in earlier studies (e.g. Grol et al., 2007; Benson and Dundis, 2003). The lack of a shared emotion-oriented care vision may also have an inhibiting effect.

An important facilitating factor for the guideline introduction seems to be the presence of an opinion leader. A respected person within the organization who really understands the guideline and is motivated to make the introduction a success. A psychologist or a psychiatric nurse proved to be successful in this role. The importance of an opinion leader in psychosocial interventions is also emphasized by other researchers (Benson and Dundis, 2003). Another facilitating factor is having a reporting system that the guideline fits into. A compatible reporting system makes the introduction less complex. In their meta-review Francke et al. (2008) described complexity as the most frequently described guideline characteristic adversely influencing implementation.

Factors directly influencing the *application* of the guideline were found on the level of the CNAs (level 3) and the residents (level 4). Facilitating factors with CNAs are having a warm and creative personality and sharing interests with residents.

Inhibiting factors concern small contracts, working in alternating shifts, and, more importantly, the opinion of some that residents with depression and dementia should not have more privileges than residents who are not depressed. This view conflicts with the emotion-oriented care vision of the guideline. Incompatibility of guidelines with existing values is a known inhibiting factor (Grol et al., 1998).

At the level of the resident, inhibiting factors are severe dementia and feeling sick and/or having much pain. These factors seem related to the

specific content of the guideline aimed at undertaking more pleasant activities, which residents with severe dementia and/or feeling sick or having much pain are unable to do. Comorbid behavioral or emotional problems also make application of the guideline more difficult. This is also described by Van Weel and Schellevis (2006).

The enthusiasm of relatives about the guideline can, on the other hand, have a strongly motivating effect on guideline application. According to CNAs, the most important facilitating factor for both the guideline introduction and application seems to be observability of the results: seeing that the guideline has positive effects on the depression of the residents.

The fact that the training program was practical and organized around the residents of the wards was generally experienced very positively. This is consistent with the finding in a review by Grol and Grimshaw (2006) that small group interactive education with active participation shows positive effects on implementation in patient care. There was one aspect of the training that needs adjustment: all team members, including those not certified or registered and working less than 20 hours per week should be trained. Not being trained frustrated caregivers and it proved to be too difficult for trained CNAs to properly transfer what was learned to their untrained colleagues. In another emotion-oriented care intervention in homes for the elderly not training the whole team was also cited as a hampering factor (Schrijnemaekers et al., 2002).

# Strengths and limitations of a multiple case study design

With a multiple case study design it was possible to look at the facilitating and hampering factors for a successful guideline introduction and application from different perspectives. Using data from nine wards in different nursing homes enhanced the completeness and transferability of the results, and made a comparison between successful and not successful wards possible. Using data from multiple sources and methods enhanced the validity of the results. An example of this is the result that sufficient CNAs on a ward are needed. This was a result derived from the qualitative interviews with promotion groups, individual CNAs and was confirmed by the quantitative analysis of the CNA-resident ratio.

A limitation of the current study is the dual role of the first author: she collected most of the data and conducted most of the analyses. The first role

could influence the second. A safeguard for this was the use of the fourth author in analyzing part of the data.

#### **Practical consequences**

In general: For a successful introduction of this or other broad care interventions a team should be sufficiently stable and the managers very well informed and enthusiastic (Benson and Dundis, 2003). Managers should also make sure that caregivers have the right expectations of the training course.

Emotion-oriented care: For the introduction of an emotion-oriented care method a shared emotion-oriented vision is important. If this is not present, it should be established first. In addition, it is advisable to find a opinion leader: a psychologist or psychiatric nurse related to a ward/unit, who is respected, understands the specific content of the intervention and really sees it as his/her job to make the introduction a success. The involvement of family members, if possible, is also highly advisable, because of the positive and stimulating interactions they bring with them.

#### **Conclusions**

By pursuing a multiple case study design it is possible to show which factors facilitate or inhibit a successful introduction and application of the nursing guideline 'Depression in Dementia' on psychogeriatric nursing home wards. Factors influencing a successful *introduction* are mainly found at the first two levels of the nursing home: nursing home management (level 1) and nursing team (level 2). Factors influencing a successful application of the guideline are mainly found on the last two levels: CNAs (level 3) and residents (level 4). Most variables regarding the introduction are well known from the literature, and mainly concern the stability of the organization and team, and compatibility of the guideline with current practice and vision. Other important factors regarding the introduction and application of the guideline seem to be the presence of an opinion leader (a respected caregiver, related to the ward and who perceives it to be his/her personal goal to make the introduction a success) and the positive attitudes of relatives. Together they can really motivate a nursing team to use the guideline.

We studied the introduction of the nursing guideline 'Depression in Dementia'. For a real implementation its use should be consolidated. A local opinion leader could also play an important role in this.

# 7

# The effects of a nursing guideline on depression in psychogeriatric nursing home residents

This article was submitted as:

Verkaik R, Francke AL, Van Meijel B, Spreeuwenberg MM, Ribbe MW, Bensing J. The effects of a nursing guideline on depression in psychogeriatric nursing home residents.

#### **Abstract**

# Objective

To study the effects of introducing a nursing guideline on depression in demented residents of psychogeriatric nursing home wards.

#### Methods

A multi-centre controlled clinical trial with randomization at ward level was used to study the effects of the guideline introduction. Nursing teams were trained in applying the guideline to their own residents diagnosed with depression in dementia. Key elements of the nursing guideline are increasing individualized pleasant activities and decreasing unpleasant events. Participating residents were 97 residents diagnosed with dementia and comorbid depression, from 18 psychogeriatric nursing home wards, in 9 Dutch nursing homes. Measurements took place at pre-test, post-test and follow-up. Primary outcome is severity of depression measured with the MDS/RAI-Depression Rating Scale and the Cornell Scale for Depression in Dementia. Secondary outcome is mood as measured by the FACE-observation scale.

#### Results

Compliance with the nursing guideline was moderate. Despite this, residents on the experimental wards showed a significant reduction in depression on the Depression Rating Scale. With the Cornell scale a reduction of depression was found as well, although not significantly different from that in the control group. No effects on observed mood were found.

# Conclusion

This study shows significant reductions in depression severity by introducing a nursing guideline on psychogeriatric nursing home wards. Better compliance with the guideline could probably enlarge the effects. Some ways to achieve enhanced compliance are: (1) additionally train non-certified nurse assistants, and (2) emphasize necessary conditions for successful introduction of the guideline to nursing team managers.

# Introduction

The prevalence rate of depression in Dutch psychogeriatric nursing home residents with dementia has recently been estimated at 20% (Zuidema et al., 2007). This is comparable to the prevalence rate in the UK (Margallo-Lana et al., 2001) and somewhat lower than the rate of 29% in the United States (Evers et al., 2002). Comorbid depression in patients with dementia has been associated with decreased quality of life (Shin et al., 2005), greater health care utilization (Kunik et al., 2003) and higher mortality rates (Suh et al., 2005). It is not only residents who are burdened by the depression but also indirectly their close relatives and professional caregivers (Shin et al., 2005; Kerkstra et al., 1999). In 2003 we therefore developed a guideline for nurse assistants (NIVEL/Waerthove, 2004a,b; Francke and Verkaik, 2006). In the first phase of the development trajectory a systematic review into the effectiveness of thirteen often used psychosocial methods (like Validation and Reminiscence) was performed (Verkaik et al., 2005). The review concluded that there was evidence, although still limited, BehaviorTherapy-PleasantEvents as developed and studied by Teri et al. (1997) was effective in reducing depression in home-dwelling people with dementia who attended a day care centre of a hospital. BehaviorTherapy-PleasantEvents is based on the Integrative Theory of Depression and the Pleasant Events Schedules developed by Lewinsohn et al. (1985). Figure 7.1 shows the depression cycle described in the Integrative Theory of Depression.

According to this theory an existing depression can be interrupted by breaking into the depression cycle at any point (A to F). The Pleasant Events Schedules aim at breaking into the depression cycle specifically at point C, the point at which depressed individuals experience fewer activities as pleasant, engage in pleasant activities less frequently, and therefore obtain less positive reinforcement than other individuals. The Pleasant Events Schedules aim at increasing pleasant activities and positive interactions with the environment. Besides increasing pleasant events, a second aim of the BehaviorTherapy-PleasantEvents is reducing unpleasant events for people with dementia - the second part of element C of Lewinsohn's model.

Α В С D Disruption of Reduced rate Increased self-Increased Consequences "scripted" or of positive awareness dysphoria/ depression automatic reinforcement (state): depression evoking behavior and/or cognitive events focus on oneself patterns and/or elevated rate - emotional - selfcriticism immediate of aversive emotional experience - somatic negative response expectations - interpersonal G Predisposing characteristics - vulnerabilities - immunities

Figure 7.1 Integrative Theory of Depression (Lewinsohn et al., 1985)

For our nursing guideline we adapted the method of Teri et al. (1997) to the context of residential care provided by Certified Nurse Assistants (CNAs) in collaboration with other caregivers. For the introduction of the guideline into the psychogeriatric nursing home wards a specific training program was developed in which the nursing teams learned how to apply the guideline to their own residents. The objective of this article is to study the effects of the introduction of the nursing guideline on depression in demented nursing home residents of psychogeriatric wards.

# Methods

# Design

The study is a multi-center controlled intervention on 18 psychogeriatric wards of nine nursing homes, with randomization at ward level. Each nursing home provided an experimental and a control ward. On the nine experimental wards the nursing guideline was introduced. On the nine control wards usual care continued. The introduction period lasted 11 weeks per ward. There were three measuring moments:

- 1. pre-test (in the two weeks just before the guideline introduction);
- 2. post-test (in the two weeks after the intervention period);

3. follow-up (10 to 12 weeks after the intervention period). Data-collection took place between November 2005 and May 2007. The study was approved by the Dutch Central Committee on Research involving Human Subjects (CCMO).

#### Setting

The participating nursing homes had applied in reaction to an invitation letter that was sent to 109 nursing homes in the central and western part of the Netherlands. The participating homes were the first nine which applied and met the following eligibility criteria:

- 1. A minimum of two nursing teams working at two different but comparable psychogeriatric wards;
- 2. The nursing teams did not work on each other's wards;
- 3. The nursing teams were not yet applying any systematic methods that are comparable to the guideline;
- 4. No reorganizations or other interventions had been planned for the wards that might interfere with the introduction of the guideline.

# **Participants**

*CNAs* In the current study, in principle, complete nursing teams participate. Exclusion criteria for individual caregivers were: (1) not certified or not registered; (2) employed for less than 20 hours per week.

#### Residents

Initially all residents of the 18 participating wards (n=598) were screened for dementia with comorbid depression in two steps, as advised by Logsdon and Teri (1995). As a *first step* the nursing team manager or another nurse (assistant) were trained and screened all residents of the participating wards for possible depression with the Dutch proxy version of the Geriatric Depression Scale-15 (Yesavage et al., 1982-1983; D'Ath et al., 1994), called Geriatric Depression Scale-15-caregiver. All residents with a score of 4 or higher were selected as possibly depressed (D'Ath et al., 1994), and entered the second step of the screening process. As a *second step* either the nursing home physician or psychologist determined by observing and interviewing the patient, consulting other caregivers and by studying the medical file, whether a resident met the following inclusion criteria:

- 1. Suffering from dementia (all types) (APA, 1996);
- 2. Severity of dementia from "age associated memory impairment" to

- "moderately severe dementia" (Global Deterioration Scale stages 2 to 6: Reisberg et al., 1982). Residents with severe dementia (Global Deterioration Scale stage 7) were excluded from the study because the intervention was aimed at residents who were still able to verbally communicate;
- 3. Diagnosed with depression in dementia according to the Provisional Diagnostic Criteria for Depression of Alzheimer Disease (PDC-dAD: Olin et al., 2002a). Because the diagnosis of dementia was established but not the type (see inclusion criterion 1), criterion B of the PDC-dAD "All criteria are met for dementia of the Alzheimer type" was not considered.

For all residents that met the three inclusion criteria, their legal guardians were asked to give informed consent for study participation.

#### **Conditions**

In each nursing home the two participating wards were randomly assigned to one of two conditions (1) 'usual care' (no intervention), or (2) 'introduction of the guideline' in addition to usual care (intervention). Figure 7.2 describes the content of the guideline introduction. The CNAs of the control wards were kept blind for the content of the guideline. CNAs of the experimental wards signed an agreement that they would not talk to the caregivers of the control wards about the guideline and the content of the training they received. In the same contract they agreed not to work on each other's wards during the period the experiment took place.

Figure 7.2 Content of the guideline introduction

# Content of the introduction of the nursing guideline on the wards (1) Training and home work

At each participating ward the training was provided by one of three trainers of the Centre for Training and Expertise Osira/Bernardus from Amsterdam. Although the training was focused on CNAs, the nursing team manager and occupational therapist were also invited to attend all three training sessions. This was considered important for sufficient support of the CNAs in using the guideline. The training consisted of: three hours of training in week 1 (first training session); home work in week 2 and 3; three hours of training in week 4 (second training session); home work in weeks 5 to 10; a three hour follow-up training in week 11 (follow-up training);

#### First training session

Core elements of the first training session, in line with the key elements of the guideline, were (1) how to increase individualized pleasant activities, and (2) how to decrease unpleasant events. Additionally, attention was paid to recognition of comorbid depression in dementia and the importance of a person centered and systematic way of working. At the end of the first training session CNAs learned which of their current residents were diagnosed by the nursing home physician or psychologist with comorbid depression and dementia. During the training session, groups of three to five CNAs were formed around each diagnosed resident. In the following weeks each group had to develop a Pleasant-Activities-Plan for their resident.

#### Pleasant-Activities-Plans (homework)

As a first step, data about the life history, personality and preferred and disliked activities were collected from the resident and his or her family. Also information was gathered about present depressive symptoms and the contexts in which these occur. Based on the collected information, the Pleasant-Activities-Plans had to contain written information on depression symptoms and the purposes, planning and evaluation of individualized and tailor-made pleasant activities. Activities in the plan could be conducted by CNAs themselves during regular care (e.g. play preferred music or make jokes during morning care) or during additional care (e.g. go outside into the garden). Activities could also be performed by occupational therapists or relatives of the resident (e.g. take the resident to a riding school if he loves horses or to the local pub), but the CNAs are responsible for developing, facilitating and evaluating the activities.

2nd and follow-up training sessions

In the second training session the formulated Pleasant-Activities-Plans were discussed in the group. After the necessary adaptations were made, the plans were integrated into daily care and evaluated as described in the plan. In the follow-up training the experiences of the CNAs were discussed for each participating resident and plans were made for further introduction of the guideline onto the ward.

#### (2) Promotion group

A "promotion group" consisting of the nursing team manager, occupational therapist and two CNAs was installed, with a view to encouraging and supporting the team in following the guideline. This group could consult the trainer between weeks 1 and 11.

#### **Outcome measures**

#### Primary outcome

The primary outcome is depression severity. Instruments used to assess depression severity are the Cornell Scale for Depression in Dementia (Alexopoulos et al., 1988) (Dutch version) and the Depression Rating Scale (DRS) of the Minimum Data Set (MDS) of the Resident Assessment Instrument (Burrows et al., 2000) (Dutch version). The Cornell Scale contains nineteen depressive symptoms in five domains (Mood-related signs, Behavioral Disturbance, Physical Signs, Cyclic Functions, Ideational Disturbance). Each item is rated on a scale from 'absent', 'mild' to 'severe'. The Cornell scale has a high inter-rater reliability (weighted Kappa=.67) and internal consistency (Cronbach's  $\alpha$ =.84) and was specifically developed to assess depression in people with dementia (Alexopoulos et al., 1988).

The Depression Rating Scale (DRS) is an observational scale, based on seven items (Negative statements, Persistent anger, Expressions of what seem to be unrealistic fears, Repetitive health complaints, Repetitive anxious complaints/concerns, Sad/pained/worried facial expressions, Crying/tearfulness) which are rated on a scale from 'indicator not exhibited in last 30 days', 'indicator of this type exhibited up to five days a week', to 'indicator of this type exhibited daily or almost daily'. The internal consistency of the DRS has been established at .71 (Cronbach's  $\alpha$ ) and the sensitivity against a formal diagnosis of depression at 91%. The scale was specifically developed to assess depression in the frail nursing home population based on CNA observations (Burrows et al., 2000).

#### Secondary outcome

As secondary outcome to the severity of depression, the variable 'mood' is assessed. Observed mood concerns the emotional consequences of depression (see part F of Lewinsohn's Integrative Theory of Depression), and is assessed with the instrument FACE that was proved to be reliable in a severely demented and institutionalized population (Volicer et al., 1999). FACE consists of three face diagrams with different mouth shapes. Mood is rated as © if smile pre-dominates; © if the expression is neutral; © if frown predominates. Scores range from 1 (happy) to 3 (sad).

# Control measures

Control measures (covariates) are gender, marital status, duration of residence in the nursing home, care dependency as measured with the Care

Dependency Scale (Dijkstra et al., 1996 and 1999), cognitive impairment as measured with the Cognitive Performance Scale of the Resident Assessment Instrument (Morris et al., 1994), and medication use (antidepressants, antipsychotics, benzodiazepines and ACE-inhibitors/β-blockers) during the study period as reported by the nursing homes' pharmacists. In the literature these variables are mentioned as (possible) confounders for the occurrence of depression in people with dementia and/or nursing home residents (Grünblatt et al., 2008; Van Beek et al., submitted; Smalbrugge et al., 2006; Holtzer et al., 2005; Gruber-Baldini et al., 2005; Dhondt et al., 2002).

#### Data collection

There were four different ways of collecting data:

- an interview with the primary CNA of the resident, during which the Cornell, DRS, CPS, CDS were rated;
- 2. observation of morning care (FACE);
- 3. observation during residence in the living room (FACE);
- collection of medical data from nursing home pharmacies.

During the interview with the primary CNA of the resident background information of the resident was also collected.

# Blinding

The interviews and observations were carried out by blinded trained research assistants, who were not informed about the research questions and conditions. In total 15 different research assistants conducted the interviews and observations. The inter-rater reliability for the observations during morning care was established during the training of the assistants using three videotaped sessions of morning care for demented nursing home residents. The Intraclass Correlation Coefficient (ICC) for the average FACE measures was .88 (CI95% .53-.99) based on the observations of eight research assistants.

# Sample size

A two-sided alpha of 5% and 80% power was used to calculate the sample size of nursing home residents. Based on the study of Teri et al. (1997) the effect size for measuring differences in depression severity was cautiously estimated as 0.7 on the Cornell Scale. This means that with 80% power a sample of 33 nursing home residents in both groups would be needed (Cohen et al., 1988).

#### Statistical methods

Multilevel Repeated Measures Analysis was used for analyzing the data, using MLwiN-software (Rasbash et al., 2000). Four different levels of analysis were distinguished in the model: (1) measurement; (2) resident; (3) ward; (4) nursing home. The multilevel model takes into account all available data yielding outcome measures in an adequate way: the paired samples of residents that have all three or two of the tests (pre-test and posttest) as well as the unpaired pre-measurement data of those residents that only have pre-test data. The correlated paired measurements are controlled for by modeling the covariance between the measurements at the residents' level (Bryk and Raudenbusch, 1992; Goldstein, 1995). The multilevel model cannot be applied to residents for whom not all covariate data are complete. These cases (n=3) were excluded from the analyses. Data of the residents with complete covariate data (n=97) were analyzed using the intention-totreat principle: all participants were analyzed according to group assignment. For all outcome measures on pre-test, post-test and follow-up adjusted estimated means and standard errors were calculated for the experimental and control group. Adjusted estimated means are the average scores corrected for the scores on the baseline measurement and other covariates. To compare differences in trends from pre-test to follow-up (linear or quadratic) between the experimental and the control group Chi squares (df=1) were calculated. Trends were considered to differ significantly if Chi-square ≥3.84 (p≤.05). Linear and quadratic differences were both calculated because it is possible that the effects of the guideline introduction are larger immediately after the intervention (post-test) than at follow-up.

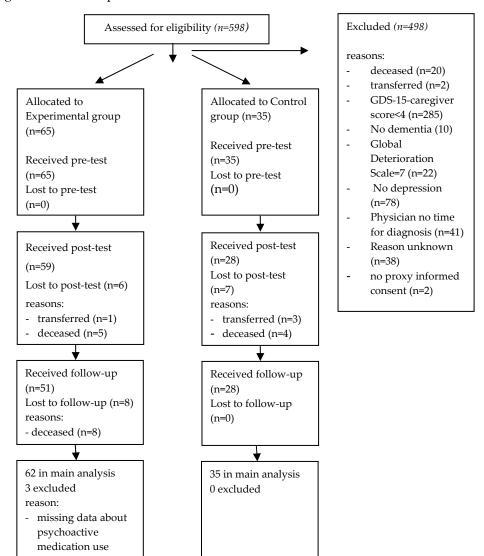
#### Results

#### Selection of participants

As described, the selection of participants took place in two steps. Figure 7.3 presents the study flow diagram. As a first step all residents (n=598) of the 18 participating wards were screened by the team manager or certified nurse (assistant) for possible depression with the Geriatric-Depression-Scale-15-caregiver (302 residents on the experimental wards and 296 on the control wards). Analyses show that the percentage of residents with possible depression (GDS-15-caregiver score<4) did not significantly differ between the experimental and control group. During the second step the pre-selected

291 possibly depressed residents were diagnosed by the nursing home physician or psychologist for presence of dementia, dementia severity and depression. In the experimental group 65 residents were diagnosed for depression and dementia (Global Deterioration Scale <7), in the control group 35. Analyses show that the mean number of PDC-dAD depression symptoms did not significantly differ between the experimental and control group at time of the diagnosis.

Figure 7.3 Participant flow



The analysis of this article includes data of 62 residents in the experimental group and 35 residents in the control group (n=97). Data of 3 residents in the experimental group could not be used because of missing data about their psychoactive medication use. Background characteristics of the 97 residents are presented in table 7.1. Analyses show that the experimental and control group do not significantly differ on any of the background characteristics ( $p \ge .05$ ).

Table 7.1 Participant background characteristics (n=97)

	Experimental group (n=62)	Control group (n=35)
Age, years (mean ± SD)	83.4 ±7.2	84.1 ±7.1
range	62-99	66-96
Sex male, n (%)	10 (16.1)	7 (20)
Marital status		
married, n (%)	11 (17.7)	9 (25.7)
widow/widower, n (%)	46 (74.2)	26 (74.3)
divorced, n (%)	3 (4.8)	0 (0)
unmarried, n (%)	2 (3.2)	0 (0)
Duration of institutionalization		
<3 months, n (%)	1 (1.6)	2 (5.7)
3 months – 1 year, n (%)	14 (22.6)	8 (22.9)
1 – 3 years, n (%)	31 (50.0)	12 (34.3)
> 3 years, n (%)	16 (25.8)	13 (37.1)
Global Deterioration Scale (GDS)		
GDS 2, n (%)	2 (3.2)	1 (2.9)
GDS 3, n (%)	1 (1.6)	3 (8.6)
GDS 4, n (%)	7 (11.3)	1 (2.9)
GDS 5, n (%)	23 (37.1)	8 (22.9)
GDS 6, n (%)	22 (35.5)	18 (51.4)
Missing	7 (11.3)	4 (11.3)
Psychoactive medication use		
antidepressant drugs, n (%)	28 (45.2)	9 (25.7)
antipsychotic drugs, n (%)	27 (43.5)	22 (62.9)
benzodiazepines, n (%)	25 (40.3)	13 (37.1)
ACE-inhibitors/Beta-blockers (%)	6 (9.7)	3 (8.6)

13 residents were lost to post-test due to transfer or death (6 experimental; 7 control) and 8 more residents in the experimental group were lost to follow-up due to death, while 0 in the control group. The collected data of these 21 residents that were lost after pre-test could still be used in the multi-level analyses according to the intention-to-treat principle. Analyses show no differences in background characteristics between residents who were involved until the end of the study and residents who were not ( $p \ge .05$ ).

# Success of the guideline introduction

For 39 of the 65 residents (60%) who participated in the experimental group a Pleasant-Activities-Plan was developed and inserted into the residents care file. For the other 26 participating residents a Pleasant-Activities-Plan was also developed but not entered into the files. This provides an indication of the success of the guideline introduction. Analyses for another paper showed that on three wards the guideline introduction was successful, on four it was moderately successful and on two not successful. On all six moderately and not-successful wards CNAs stated that the actual use of the guideline was inhibited by reorganizations, too few personnel, other training courses at the time of the guideline introduction or no actual support from the team manager and/or higher management. In addition, on all nine wards CNAs stated that involving the non-certified nurse assistants and nursing helpers in the guideline introduction would likely have improved the guideline application.

# Primary outcome: depression severity

Table 7.2 provides the adjusted estimated means and standard errors for the experimental and control group for all outcome measures on pre-test, post-test and follow-up. The table also shows Chi square values that indicate if trends in the experimental and control groups differ significantly ( $p \le 0.05$ ) in a linear or quadratic way.

A significant treatment effect was obtained for depression on the MDS/RAI-Depression Rating Scale (DRS). In the experimental group depression severity reduced from 4.56 ( $\pm 0.35$ ) to 3.91 ( $\pm 0.35$ ) at post-test to 3.79 ( $\pm 0.38$ ) at follow-up. In the control group depression severity at pre-test is 3.84 ( $\pm 0.52$ ), at post-test rises to 4.61 ( $\pm 0.57$ ) and than decreases to follow-up to 4.07 ( $\pm 0.61$ ). The differences are quadratic because of the rise and fall of depression severity in the control group.

Table 7.2 Differences outcome trends between experimental and control group

Outcome measures	Pre-test Mean (se)		Post-test Mean (se)		Follow-up Mean (se)		χ²- linear	χ²-quadratic
	Exp.	Contr.	Exp.	Contr.	Exp.	Contr.		
Primary: Depression								
- MDS/RAI-DRS ( <u>0</u> -14)	4.56 (0.35)	3.84 (0.52)	3.91 (0.35)	4.61 (0.57)	3.79 (0.38)	4.07 (0.61)	2.36	5.69*
- Cornell ( <u>0</u> -38)	11.42 (0.62)	11.48 (0.90)	10.31 (0.57)	11.46 (1.12)	9.96 (0.66)	9.93 (1.18)	0.00	1.19
Secondary: Mood								
1.a FACE-morning care ( <u>1</u> -3)	1.77 (0.09)	1.99 (0.12)	1.73 (0.11)	2.04 (0.15)	1.81 (0.11)	2.04 (0.13)	0.00	0.17
1.b FACE-living room ( <u>1</u> -3)	1.99 (0.07)	1.74 (0.10)	1.94 (0.10)	1.99 (0.06)	2.11 (0.09)	1.95 (0.10)	0.32	3.27

<sup>1</sup> The underlined score behind the measures indicate the most favorable score for the scale

<sup>2</sup> An asterisk (\*) indicates a significantly different trend in the experimental and control groups from pre-test to follow-up in favor of the experimental group (p≤.05; Chi square >3.84, 1 degree of freedom)

<sup>3</sup> Mean=estimated mean score (multilevel analysis); se=standard error;  $\chi^2$ = Chi square (1 degree of freedom); MDS/RAI-DRS= Minimum Data Set/Resident Assessment Instrument-Depression Rating Scale-Dutch version; Cornell=Cornell scale for depression in dementia-Dutch version; RISE=Revised Index for Social Engagement - Dutch version.

The treatment effect was not significant on the Cornell Scale, although the trend in the experimental group shows a reduction of depression from 11.42 ( $\pm 0.62$ ) at baseline to 10.31 ( $\pm 0.57$ ) at post-test, to 9.96 ( $\pm 0.66$ ) at follow-up. The trend in the control group first remains at the same level from pre-test to post-test (11.48  $\pm$  0.90 to 11.46  $\pm$  1.12) and then drops to 9.93 ( $\pm 1.18$ ).

#### Secondary Outcome: observed mood

No significant effect of the guideline introduction was found on observed mood. For both observations during morning care and observations during residence in the living room the mean mood scores remain stable in both the experimental and control groups, from pre-test to follow-up.

#### Discussion

#### **Effects on depression**

This article shows that introducing the nursing guideline on depression for psychogeriatric nursing home residents reduces depression severity as measured with the MDS/RAI-Depression Rating Scale (DRS). The reduction of depression on the DRS is, however, not statistically confirmed by the Cornell Scale for Depression in Dementia, since on the Cornell Scale only a non-significant reduction of depression was established. Kurlowicz et al. (2002) may offer a possible explanation for the finding that we do find significant effects on the DRS, while the decrease in depression on the Cornell is not significant. In their psychometric evaluation of the Cornell scale in a nursing home population Kurlowicz et al. conclude that "...in frail, institutionalized older adults with high rates of dementia, medical illness, and functional disability, depression measurements that are less dependent on items highly sensitive to comorbid conditions and not necessarily associated with depression may be more appropriate". The DRS, having been specifically developed for the frail nursing home population and less dependent on physical conditions, could be a good example of such a more appropriate instrument.

The lack of effects on the variable observed mood may be related to low sensitivity of the FACE-scale in our demented and depressed population. The three-point scale allowed little variation in observed mood as assessed. Analyses showed that observation scores centered around the 'neutral'-

category and were distributed with smaller tails than in a normal distribution.

#### Effect size

The size of the effect of the guideline introduction on depression severity is moderate, with a standardized difference of +1.7 at pre-test and a standardized difference of -0.6 at follow-up (Cohen et al., 2008). The moderate effect may be related to the limited compliance with the guideline for wards on which the guideline introduction had been less successful. In sub-group analyses we found indications of this. We found that the mean reduction in depression severity as measured with the DRS from post-test to follow-up was larger on the successful wards than on the moderately and non-successful wards. Differences were, however, not statistically significant ( $p\ge0.5$ ), probably because of the small sizes of the subgroups.

#### Comparison with BehaviorTherapy-PleasantEvents

The study by Teri et al. (1997) on the effects of BehaviorTherapy-PleasantEvents showed large, significant, clinically relevant reductions in depression severity in people with comorbid depression and dementia. Why were the effects that we found smaller? One important difference seems to be that in Teri's study the people with dementia were still living at home with a close relative who took care for them all the time. The relative learned how to develop and apply the Pleasant-Activities-Plan from a day-care centre geriatrician. In our study the Pleasant-Activities-Plans were developed and applied by CNAs. CNAs had less support with the development of the plans and knew the residents less well than the relatives did. Furthermore, CNAs had to communicate and coordinate application of the plans between themselves and other disciplines. Communication of the method to non-certified nurse assistants and nursing helpers proved to be problematic, because they were not involved in the training, although they delivered a substantial amount of the residents' daily care.

#### Study limitations

The design of the current study has some limitations. Firstly, the randomization of the participating residents was only possible at ward level. In addition, because the CNAs on the control wards had to screen residents for the presence of depression themselves, they may have adapted their care at the moment this diagnosis was established, e.g. by giving more attention

to the residents diagnosed with depression. Changes in attitude of the CNAs could not be controlled for.

Secondly, the participating nursing homes themselves applied for participation. Possibly they already had a more positive attitude towards the method than an average nursing home. This could affect the generalizability of the results. With respect to the international generalizability we know that in most other countries the role and educational level of CNAs on psychogeriatric wards is somewhat different than in the Netherlands. In the United States, for example, CNAs are not trained in developing care plans. In these cases the division of tasks in the guideline could be rearranged according to the specific situation. Licensed Practical Nurses (LPNs) could, for example, take over the development of the Pleasant-Activities-Plans, while CNAs conduct them.

## Conclusion

The current study shows that statistically significant reductions in depression severity can be obtained with the introduction of the nursing guideline on comorbid depression in dementia on psychogeriatric nursing home wards. Effects could probably be enlarged if non-certified nurse assistants and nursing helpers are also trained, and managers pay more attention to the necessary conditions for successful introduction.

# 8

The introduction of a nursing guideline on depression at psychogeriatric nursing home wards

**Effects on Certified Nurse Assistants** 

This article was submitted as:

Verkaik R, Francke AL, Van Meijel B, Spreeuwenberg PMM, Ribbe MW, Bensing JM. The introduction of a nursing guideline on depression at psychogeriatric nursing home wards: effects on Certified Nurse Assistants.

#### **Abstract**

## **Background**

To improve care for residents with depression in dementia, an evidence based nursing guideline was developed. Using the guideline has already shown positive effects on depression in psychogeriatric nursing home residents.

#### Objective

To study the effects of the introduction of the nursing guideline 'Depression in Dementia' on perceived professional autonomy, workload and feelings of powerlessness and confidence in Certified Nurse Assistants.

#### Design

A multi-center controlled intervention study with randomization at ward level, using pre-test, post-test and follow-up measurements.

#### Setting

18 psychogeriatric wards in 9 Dutch nursing homes.

# **Participants**

193 Certified Nurse Assistants working on psychogeriatric nursing home wards for at least 20 hours per week.

#### Methods

An evidence based guideline for nursing teams of psychogeriatric nursing home wards was introduced on nine experimental wards to reduce depression in residents diagnosed with depression in dementia. The guideline introduction consisted of team training and the installation of a promotion group. The nine control wards continued providing usual care. Primary outcomes are: (1) perceived professional autonomy and (2) perceived workload in Certified Nurse Assistants measured with the VBBA subscales 'autonomy' and 'pace and amount of work'. Secondary outcomes are perceived powerlessness and confidence in caring for depressed and demented residents, using two self developed scales.

## **Results**

The guideline introduction had a small, significant, positive effect on generally perceived professional autonomy in the Certified Nurse Assistants of the experimental wards. No short term effects were found on generally experienced workload, or on confidence and powerlessness in caring for depressed residents with dementia.

#### Conclusion

The introduction of the nursing guideline 'depression in dementia' has small, positive effects on perceived professional autonomy among the Certified Nurse Assistants. Long term effects on experienced workload should be studied.

# Introduction

## **Background**

Caring for people with dementia is complex and demanding. On psychogeriatric nursing home wards in the Netherlands, about 85% of the residents are diagnosed with a dementia syndrome (Ribbe et al., 1995; Schols et al., 2004). Much of the care on these psychogeriatric wards is provided by Certified Nurse Assistants (CNAs). About 30% of these CNAs often experience feelings of powerlessness and lack of confidence in caring for their residents (Kerkstra et al., 1999). One of the important sources of this problem appears to lie in the patients' comorbid depressive behaviors (Hallberg and Norberg, 1993; Kerkstra et al.,1999). A study by Edberg et al. (2008) gives a plausible explanation for this with regard to CNAs: they desire to do their best for the people in their care by trying to alleviate their suffering and enhance their quality of life. When they do not have the ability to do so, it causes strain. In the case of depression in dementia, CNAs may lack the necessary ability for several reasons.

In the first place, CNAs are generally not trained to support people with depression in dementia. Breaking through the depression of nursing home residents with dementia is difficult, but becomes even harder without specific training. For instance, one needs to know how to develop individualized care plans that take into account physical and cognitive limitations, abilities and preferences, using a step-by-step approach (Teri L. et al., 1991; Teri, 1994). In the Netherlands CNAs get about three years of basic general nursing training, but without specific attention to the support of people with depression in dementia.

Secondly, related to this lack of specific education, CNAs often have insufficient professional autonomy with regard to cases of depression in dementia. A lack of professional autonomy is reflected in the fact that CNAs, as a rule, do not develop *psychosocial* care plans themselves. This is usually done by psychologists attached to the nursing homes. Although most psychologists involve the CNAs in the development and application of psychosocial care plans, CNAs have stated during interviews, that they would prefer greater professional autonomy in this respect (not published material).

Thirdly, CNAs on psychogeriatric nursing home wards often experience high workload. High experienced workload is influenced by a concrete high task load containing, for example, a large percentage of physical care (Van

den Tooren and De Jonge, 2008) and household activities. ADL (activities of daily living) for nursing home residents with BPSD, like depression, often takes more time than normal because residents may offer resistance to the care they receive (Buhr and White, 2006). CNAs spend as much as 40% of their time managing challenging behaviors (Cassidy and Sheikh, 2002). Besides, many Dutch nursing homes have a high workload, partly caused by difficulties with the recruitment of sufficient staff (Hoek et al., 2000). Experienced workload may also be affected by more subjective factors like perceived professional autonomy (Te Boekhorst et al., 2008) as well as feelings of powerlessness and lack of confidence in caring for demented residents (Kerkstra et al. 1999; Edberg et al., 2008).

#### Nursing guideline

In order to help CNAs in supporting residents with depression in dementia, a nursing guideline was developed. The guideline was approved by the Dutch Nurses' Association (V&VN) (Verkaik et al., 2004). The primary aim of the guideline was to reduce depression in demented nursing home residents. The secondary aim was to support CNAs in their care for depressed residents with dementia. The guideline was based on the socalled BehaviorTherapy-PleasantEvents, which Teri et al. (1997) showed to be effective in reducing depression in home dwelling people with dementia. The main principles of the method are (1) inducing individualized pleasant activities, and (2) reducing unpleasant events. The method is based on the Integrative Theory of Depression and Activity Schedules as developed and studied by Lewinsohn et al. (1985) and is also often applied and has proved effective in a non-demented population with depression (Cuijpers et al., 2007). In the method developed by Teri et al. (Teri et al., 1991; Teri, 1994; Teri et al., 1997) the primary relative of the demented person learned from a geriatrician how to develop and apply a so-called individualized Pleasant-Activities-Plan to their demented and depressed relative.

We adapted Teri's method in such a way that the CNAs of the depressed and demented residents were accorded the central role in developing and coordinating the application of the Pleasant-Activities-Plans. It was hoped to thus increase the CNAs' professional autonomy. Steps in the development of the Pleasant-Activities-Plans include, for instance, observing residents' depressive complaints, and assembling life history and specific information about preferred and disliked activities. In this regard CNAs have to collaborate with non-Certified Nurse Assistants from the nursing team and

with other disciplines (physicians, psychologists, occupational therapists). A person-centered and systematic way of working forms the general framework of the guideline.

#### Effect study

To study the effects of the guideline on depressed and demented residents and on CNAs we conducted a multi-center controlled clinical trial on psychogeriatric nursing home wards. The guideline introduction consisted of training sessions and the installation of a promotion group. Detailed information about the guideline and its introduction is contained in figure 8.1.

Another paper describes how the guideline introduction can indeed reduce depression in residents (Verkaik et al., submitted). Residents who were supported with the guideline were significantly less depressed than residents who received regular care. This current paper describes the effects of the guideline introduction on perceived daily professional autonomy and workload of CNAs, and on feelings of powerlessness and confidence in caring for depressed and demented residents.

# Figure 8.1 Content of the guideline introduction

# Content of the introduction of the nursing guideline on the wards

#### (1) Training and homework

On each participating ward the training was provided by one of three trainers of the Centre for Training and Expertise Osira/Bernardus from Amsterdam. Although the training was focused on CNAs, the nursing team manager and occupational therapist were also invited to attend all three training sessions. This was considered important for adequate support for the CNAs in using the guideline. The course consisted of: three hours of training in week 1 (first training session); homework in week 2 and 3; three hours of training in week 4 (second training session); homework in weeks 5 to 10; a three hour follow-up training session in week 11 (follow-up training);

#### First training session

Core elements of the first training session, in line with the key elements of the guideline, were (1) how to increase individualized pleasant activities, and (2) how to decrease unpleasant events. Additionally, attention was paid to recognition of comorbid depression and dementia and the importance of a person centered and systematic way of working. At the end of the first training session CNAs learned which of their current residents were diagnosed by the nursing home physician or psychologist with depression in dementia. During the training session, groups of three to five CNAs were formed around each diagnosed resident. In the following weeks each group had to develop a Pleasant-Activities-Plan for their resident.

#### Pleasant-Activities-Plans (homework)

As a first step, data about the life history, personality and preferred and disliked activities were collected from the resident and his or her family. Information was also gathered about present depressive symptoms and the contexts in which these occur. Based on the collected information, the Pleasant-Activities-Plans had to contain written information on depression symptoms and the purposes, planning and evaluation of individualized and tailor-made pleasant activities. Activities in the plan could be conducted by CNAs themselves during regular care (e.g. play preferred music or make jokes during morning care) or during additional care (e.g. go outside into the garden). Activities could also be performed by occupational therapists or relatives of the resident (e.g. take the resident to a riding school if he loves horses or to the local pub), but the CNAs are responsible for developing, facilitating and evaluating the activities.

# $2^{nd}$ and follow-up training sessions

In the second training session the formulated Pleasant-Activities-Plans were discussed in the group. After the necessary adaptations were made, the plans were integrated into daily care and evaluated as described in the plan. In the follow-up training the experiences of the CNAs were discussed for each participating resident and plans were made for further introduction of the guideline onto the ward.

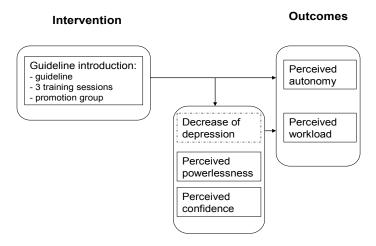
#### (2) Promotion group

A "promotion group" consisting of the nursing team manager, occupational therapist and two CNAs was installed, with a view to encouraging and supporting the team in following the guideline. This group could consult the trainer between weeks 1 and 11.

#### Research model

The research model we used in this part of the study was inspired by the Job-Demand-Control model (Karasek, 1979). In a recent publication, Te Boekhorst et al. (2008), showed that this model very well describes the mechanisms of increased autonomy and decreased workload among CNAs working on nursing home wards. Figure 8.2 describes the research model of this paper.

Figure 8.2 Job-Demand-Control model adapted to current study hypotheses



We expected that the introduction of the guideline would increase perceived professional autonomy in CNAs, because the guideline makes them the central person for developing and coordinating the application of the psychosocial support for residents with depression in dementia. We also expected that workload would decrease in the long term because (a) residents get less depressed (Verkaik et al., submitted) and will therefore cooperate better and/or show less resistance, and (b) because the guideline introduction will decrease perceived powerlessness and increase perceived confidence among CNAs when caring for residents with depression in dementia. In the shorter term, however, workload might increase because of the additional tasks and time the guideline introduction requires. Perceived professional autonomy and workload were in the original Job-Demand-Control model and are final outcomes. Therefore they were taken as primary outcomes of the study. Perceived powerlessness and confidence were added to the original model and were expected to have intermediate effects on

professional autonomy and workload. They were therefore taken as secondary outcomes.

#### The research questions of this paper are:

- 1. What are the effects of introducing the nursing guideline 'Depression in Dementia' on perceived professional autonomy and experienced workload of CNAs working on psychogeriatric nursing home wards?
- 2. What are the effects of the guideline introduction on CNAs' perceived powerlessness and confidence in supporting residents with depression in dementia?

# Methods

#### Design

The study is a multi-center controlled intervention study with randomization at ward level. The study was performed on 18 psychogeriatric wards of nine Dutch nursing homes. Each nursing home provided an experimental and a control ward. On the nine experimental wards the nursing guideline was introduced. On the nine control wards usual care continued. The introduction period lasted 11 weeks per ward.

There were three measurement occasions:

- 1. pre-test (before the guideline introduction);
- 2. post-test (directly after the introduction period of 11 weeks);
- 3. follow-up (10 weeks after the introduction period).

Data collection from pre-test to follow-up started in November 2005 in the first nursing home, and finished in May 2007 in the ninth. The study was approved by the Dutch Central Committee on Research involving Human Subjects (CCMO).

#### **Conditions**

In each nursing home the two participating wards were randomly assigned to one of two conditions (1) 'usual care' (no intervention), or (2) 'introduction of the guideline', in addition to usual care (intervention). An independent employee at the NIVEL institute was assigned to draw lots from a sealed envelope to establish on which ward of each nursing home 'the introduction of the guideline' would take place. Figure 8.1 describes the content of the

guideline introduction. The CNAs on the control wards were kept blind for the content of the guideline. The CNAs on the experimental wards signed an agreement that they would not talk to the caregivers on the control wards about the content of the guideline and the training they received. In the same contract they agreed not to work on each other's wards during the period the experiment took place.

#### Setting

In the Netherlands, psychogeriatric wards are separate wards or units for psychogeriatric residents in nursing homes. These wards are characterized by corridors, colors, and closed-door systems, specially adapted for these residents. They are comparable with specialized Alzheimer units in the United States (Schols et al., 2004). Of the total resident population, 85% are diagnosed with a dementia syndrome (Ribbe et al., 1995; Schols et al., 2004) mostly moderate to severe (GDS stages 5 to 7) (Zuidema et al., 2007). Much of the daily nursing care is delivered by Certified Nurse Assistants (CNAs) who in the Netherlands generally have three years of basic nursing training. In terms of educational level and skills these Dutch CNAs are more comparable with Licensed Practical Nurses in the United States than with US CNAs.

The participating nursing homes had applied in response to an invitation letter that was sent to 109 nursing homes in the central and western part of the Netherlands. The participating homes were the first nine which applied and also met the following eligibility criteria:

- 1. A minimum of two nursing teams working on two separate but comparable psychogeriatric wards;
- 2. The nursing teams did not work on each other's wards;
- 3. The nursing teams were not yet applying any systematic methods that are comparable to the content of the guideline;
- 4. No reorganizations or other interventions had been planned for the wards that might interfere with the introduction of the guideline.

Recruitment of the nine participating nursing homes took place between May and November 2005.

# **Participants**

#### CNAs

Complete nursing teams participated in the current study. Exclusion criteria for individual caregivers were: (1) not certified or not registered; (2) employed for less than 20 hours per week. On the 18 nursing home wards, 223 nurse assistants met these inclusion criteria. The background characteristics of the 193 CNAs who participated are provided in the results section and in table 8.1.

#### Residents

All residents of the 18 participating wards (n=598) were screened for depression in dementia. The details of the diagnostic procedure have been described elsewhere (Verkaik et al., accepted).

Presence of dementia was determined on the basis of the DSM-IV-pc (American Psychiatric Association, 1996) and a diagnosis of depression in dementia was made with the provisional Diagnostic Criteria for Depression of Alzheimer Disease (PDC-dAD: Olin et al., 2002a). In addition, dementia severity (Global Deterioration Scale: Reisberg et al., 1982) was established. Residents with severe dementia (Global Deterioration Scale stage 7) were excluded from the study because the intervention was aimed at residents who were still able to communicate verbally. The mean age of the residents was 83.7 (SD 7.2), 18 % were male (n=17), 32% (n=31) had moderate dementia (GDS 5) and 41% (n=40) moderately severe dementia (GDS 6). There were no significant differences between the experimental and control groups regarding background characteristics.

#### **Outcome measures**

# Primary outcomes

Perceived autonomy of the CNAs in their daily work was measured with the subscale 'autonomy' ( $\alpha$ =.88; 11 items) from the questionnaire 'Experience and Assessment of Work' (VBBA) by Van Veldhoven and Meijman (1994). The VVBA scales are the most reliable, valid and sensitive scales available in Dutch for measuring work related outcomes. Examples of items in the autonomy subscale are: 'Do you have freedom in carrying out your daily activities?', 'Can you influence the planning of your activities?', and 'Do you solve problems yourself?'. Response categories are 'always', 'often', 'sometimes', and 'never'.

Experienced workload was measured with the subscale 'pace and amount of work' ( $\alpha$ =.76; 11 items) from the questionnaire 'Experience and Assessment of Work' (VBBA) by Van Veldhoven and Meijman (1994). Some items from the subscale 'pace and amount of work' are, for example 'Do you have too much work to do?', 'Do you experience problems with the work pace?', and 'Do you have to hurry?'.

#### Secondary outcomes

As secondary outcomes, CNAs' perceived powerlessness and perceived confidence in supporting residents with depression in dementia were assessed. Both variables were measured on a self developed 5-point Likert scale, with the response categories 'completely disagree', 'partly disagree', 'do not disagree/do not agree', 'partly agree', 'completely agree' regarding the following statements:

- 1. 'I feel confident/powerless in caring for <name of specific resident diagnosed with depression in dementia'>.
- 2. 'In general I feel confident/powerless in caring for residents with dementia who are depressed'.
- 3. 'In general I feel confident/powerless in caring for residents with dementia'.

A factor analysis was conducted to construct two scales: a confidence scale and a powerlessness scale, each consisting of 3 items. In the confidence scale 70% of the total variance was explained by a one-factor solution. In the powerlessness scale this was 63%. Internal consistency of both scales was good (Cronbach's alpha= .78 for the confidence scale; .70 for the powerlessness scale).

# Control measures

Control variables (covariates) for all primary and secondary outcomes are CNAs' age, gender, educational level, hours of employment per week and working fixed or flexible shifts. The scores on the items of the perceived-confidence / powerlessness scale regarding the care for specific residents were corrected for duration of residence in the nursing home, care dependency (Dijkstra et al., 1996; Dijkstra et al., 1999), cognitive impairment (Morris et al., 1994), and medication use (antidepressants, antipsychotics, benzodiazepines and ACE-inhibitors/beta-blockers) during the study period, as reported by the nursing homes' pharmacists.

#### Data collection

Questionnaires were used for data collection of primary and secondary outcomes and background characteristics of the CNAs. The questionnaires were distributed by the team managers of the wards and posted back to NIVEL by the individual CNAs. To enhance the response rate, CNAs received a gift voucher for each of the three completed and returned questionnaires.

#### Statistical methods

Multilevel Repeated Measures Analysis was used for analyzing the data, using MLwiN-software (Rasbash et al., 2000). Four different levels of analysis were distinguished in the model: (1) measurement; (2) CNA; (3) ward; (4) nursing home. The multilevel model takes into account all available data yielding outcome measures in an adequate way: the paired samples of CNAs that have completed and returned all three or two of the tests as well as the unpaired pre-measurement data of those CNAs that only have completed and returned one of them. The correlated paired measurements are controlled for by modeling the covariance between the measurements at the CNAs' level (Bryk and Raudenbusch,1992; Goldstein, 1995).

The multilevel model cannot be applied to CNAs for whom not all covariate data are complete. These cases (n=13) were excluded from the analyses. Data of the CNAs with complete covariate data (n=180) were analyzed using the intention-to-treat principle: all participants were analyzed according to group assignment. For all outcome measures on pre-test, post-test and follow-up, adjusted estimated means and standard errors were calculated for the experimental and control groups. Adjusted estimated means are the average scores corrected for the scores on the baseline measurement and other covariates.

To compare differences in trends (linear or quadratic) from pre-test to follow-up between the experimental and the control groups, Chi squares (df=1) were calculated. Trends were considered to differ significantly if the Chi-square was  $\geq 3.84$  (p $\leq$ .05). Linear and quadratic differences were both calculated because it is possible that the effects of the guideline introduction are larger immediately after the intervention (post-test) than at follow-up.

## Results

# **Participants**

As described, all 223 Certified Nurse Assistants working 20 hours or more were invited to participate in the study (109 on the experimental wards; 114 on the control wards). In total 193 CNAs were included in the study: 98 on the experimental wards and 95 on the control wards. For the experimental wards, we were able to discern the reasons for non-participation: maternity leave (n=1), illness (n=1), vacation (n=1), only working in night shift (n=3), conflict with the team manager (n=1) and changing jobs (n=4). We do not have information about reasons for non-participation on the control wards. The response of the participating CNAs was rather high across the three measurement times: at pre-test 84% (n=163) of the CNAs responded (83 on the experimental wards; 80 on the control wards), at post-test 82% (n=159) (76 on the experimental wards; 83 on the control wards) and at follow-up 81% (n=156) of the CNAs responded (76 on the experimental wards; 80 on the control wards). Table 8.1 presents the background characteristics of the CNAs at pre-test, post-test and follow-up. The table shows that the experimental and control groups were to large extent comparable on background characteristics. To test the differences in background characteristics, t-tests and Chi-square analyses were used. There were no significant differences between the experimental group at pre-test, post-test and follow-up, or between measures within the experimental group or the control group (p≥.05).

#### Primary outcomes: perceived professional autonomy and workload

Table 8.2 provides the adjusted estimated means and standard errors for the experimental and control groups for all outcome measures on pre-test, posttest and follow-up. The table also shows Chi square values that indicate whether trends in the experimental and control groups differ significantly  $(p \le .05)$  in a linear or quadratic way.

Table 8.1 Background characteristics of participating *CNAs* 

		Experimental gro	oup		Control group	
	Pre-test (n=83)	Post-test (n=76)	Follow-up (n=76)	Pre-test (n=80)	Post-test (n=76)	Follow-up (n=80)
Age, years (mean ± SD)	$37.8 \pm 9.8$	$37.8 \pm 9.6$	$38.8 \pm 9.9$	39.7 ± 10.5	$39.2 \pm 10.2$	$40.4 \pm 9.8$
Range	20-58	20-59	20-59	19-61	20-62	20-58
Sex male, n (%)	6 (7.2)	5 (6.6)	4 (5.3)	3 (3.8)	3 (3.6)	2 (2.5)
Highest educational degree, n (%):						
lower vocational	3 (3.6)	1 (1.3)	1 (1.3)	3 (3.8)	0 (0.0)	1 (1.3)
interm. vocational	65 (78.3)	61 (80.3)	56 (73.7)	60 (75.0)	68 (81.9)	66 (82.5)
higher vocational	7 (8.4)	5 (6.6)	10 (13.2)	6 (7.5)	6 (7.2)	6 (7.5)
other	8 (9.6)	9 (11.8)	8 (10.5)	11 (13.8)	9 (10.8)	8 (8.8)
Hours employed per week (mean hours ± SD)	$27.8 \pm 6.7$	$27.1 \pm 6.8$	$27.5 \pm 7.4$	$27.2 \pm 6.8$	$27.5 \pm 6.5$	$27.0 \pm 6.5$
Working fixed shifts, n (%)	18 (21.7)	18 (23.7)	18 (23.7)	14 (17.5)	18 (21.7)	19 (23.8)

Table 8.2 Differences in outcome trends between experimental and control groups

Outcome measures	Pre-test Mean (se)		Post-test Mean (se)		Follow-up Mean (se)		χ² - linear	χ² - quadratic
	Exp.	Contr.	Exp.	Contr.	Exp.	Contr.		
Primary: Perceived autonomy (Subscale VBBA: <u>0.00</u> -100.00)	43.54 (1.86)	39.37 (1.97)	44.95 (1.52)	41.16(1.93)	42.6 (1.74)	43.72 (1.80)	6.71*	1.61
Primary: Experienced workload (Subscale VBBA: <u>0.00</u> -100.00)	35.82 (1.61)	36.77 (1.75)	33.98 (1.65)	36.79 (1.80)	36.28 (1.67)	38.2 (1.67)	0.39	1.15
Secondary: Perceived confidence (1-5)	3.93 (0.08)	3.79 (0.10)	4.06 (0.09)	3.96 (0.09)	4.02 (0.08)	3.82 (0.09)	0.19	0.40
Secondary: Perceived powerlessness ( <u>1</u> -5)	2.93 (0.07)	3.00 (0.08)	2.96 (0.08)	3.05 (0.09)	2.93 (0.08)	2.87 (0.07)	1.06	0.50

- 1. The underlined scores after the measures indicate the most favorable score for the scale
- 2. An asterisk (\*) indicates a significantly different trend in the experimental and control groups from pre-test to follow-up in favor of the experimental group (p≤.05; Chi square >3.84, 1 degree of freedom)
- 3. Mean=estimated mean score (multilevel analysis); se=standard error;  $\chi^2$ = Chi square (1 degree of freedom)

#### Perceived autonomy

There is a significant, positive effect (linear) of the guideline introduction on the perceived professional autonomy of CNAs (see table 8.2). A decrease on the VBBA-autonomy subscale means an increase in feelings of autonomy. In the experimental group the mean perceived professional autonomy first slightly decreases from pre-test to post-test, and then increases at follow-up to a higher level than at pre-test. In the control group, perceived daily professional autonomy declines from pre-test to follow-up.

## **Experienced workload**

No significant effect of the guideline introduction was found on experienced workload of the CNAs (see table 8.2). In the experimental group experienced workload first decreased from pre-test to post-test and then increased at follow-up. In the control group experienced workload remained stable from pre-test to post-test and then increased at follow-up.

# Secondary outcomes: perceived powerlessness and confidence

No significant differences between the experimental and control groups were found on the variable 'perceived powerlessness' in caring for residents with depression in dementia (see table 8.2). In the experimental group perceived powerlessness remained stable from pre-test to follow-up. In the control group perceived powerlessness decreased slightly from pre-test to follow-up.

Also no significant differences were found on the variable 'perceived confidence' (see table 8.2). In the experimental as well as in the control group perceived confidence first increased from pre-test to post-test and then decreased somewhat at follow-up.

# Discussion

As expected, significant, positive effects of the guideline introduction were found on perceived professional autonomy. However, contrary to expectations, no significant effects on experienced workload, powerlessness or confidence in caring for depressed and demented residents were found.

#### Effects on autonomy

Although the effect of the guideline introduction on professional autonomy was statistically significant, the increase of autonomy in the experimental group from pre-test to follow-up seems rather small: about 1 point on a scale from 0 to 100. A likely explanation for the small size of the effect is that the guideline only concerned about 20% of the residents of a ward (Zuidema et al., 2007; Verkaik et al., accepted), while the scale used measured effects on the general professional autonomy that CNAs experience.

The positive effect, although small, fits however with the finding of Hoogeveen and Smith (1998) that CNAs are stimulated in their job if they themselves can find solutions for behavioral and psychological problems in dementia. As described in the introduction to this paper, before the guideline was introduced psychosocial care plans were mostly developed by psychologists, with generally only a consultation role for CNAs. The guideline introduction redefined these roles. It is important to observe that the CNAs favored this redefinition, but (still) really appreciated and needed consultation with psychologists, especially in cases of multiple behavioral or psychological disturbances (Verkaik et al., submitted).

As we have said, no significant differences were found between the experimental and control groups regarding general, experienced workload. Also in this regard it must be emphasized that the guideline only concerns about 20% of the residents of a psychogeriatric ward, whereas the instrument measured an aspect of the general work experience. Another explanation for the lack of effects on workload is that it probably takes more time to see such effects of the guideline introduction. At post-test and even at follow-up the guideline introduction had just finished and CNAs had yet to integrate the application of the plans into their routines.

However, it may be interpreted as a positive finding that the guideline introduction did not actually *increase* the experienced workload particularly in the short term, as the introduction incurred additional tasks for the CNAs. The fact that we did not establish effects on perceived powerlessness and confidence was contrary to our expectations. This points in the direction of measurement problems. We had to use self developed scales, since no suitable, validated scales were available from earlier studies (Hallberg and Norberg, 1993; Kerkstra et al., 1999). It is possible that our scales did not significantly or adequately measure the complex concepts of powerlessness and confidence. Another possibility is of course that there were no actual

effects on powerlessness or confidence, and that the introduction of the guideline was not successful in this regard. However, in personal interviews with CNAs we did get the impression that they felt more confident and less powerless in caring for this target group.

#### **Study limitations**

The first limitation of this study was that the CNAs on the control wards knew which residents were diagnosed with depression in dementia. These CNAs were also interviewed about the depressive symptoms of the residents at pre-test, post-test and follow-up. It might be possible that this influenced their perceived professional autonomy, workload, confidence and powerlessness.

A second limitation is that the participating nursing homes themselves applied for participation, meaning that they may possibly have had a more positive attitude towards the nursing guideline 'Depression in Dementia' than an average nursing home. It is also possible that the workload on the participating wards was less high than average, or that the CNAs experienced more problems in supporting residents with depression in dementia. These factors could affect the generalizability of the results.

With respect to international generalizability, we are aware that in most other countries the role and educational level of CNAs on psychogeriatric wards is somewhat different to the situation in the Netherlands. In the United States, for example, CNAs are not trained in developing care plans. Accordingly, the division of tasks in the guideline could be rearranged according to the specific situation. Licensed Practical Nurses (LPNs) could, for example, be in charge of developing the Pleasant-Activities-Plans, leaving the CNAs to carry them out. Research should be conducted to establish whether the effects on perceived autonomy and powerlessness in these cases are comparable.

# **Conclusions**

The introduction of the nursing guideline 'Depression in Dementia' on psychogeriatric nursing home wards did have a positive, though small, significant effect on the perceived professional autonomy of CNAs. We did not find any short-term effects on experienced workload, powerlessness and confidence. In all likelihood, in the long term, when the guideline is consolidated, positive effects on workload may also be shown.

# 9

# General summary and discussion

# General summary and discussion

The main aim of this PhD research was to develop, introduce and evaluate a nursing guideline on depression in dementia on psychogeriatric nursing home wards. We also aimed to contribute more fundamentally to the scientific knowledge about depression in dementia. In this chapter the general findings are summarized and put into context. Methodological aspects are discussed, as well as the clinical relevance of the results. Furthermore, recommendations are made for implementation of the guideline and for future research.

#### Main findings and theoretical reflections

# Depression in dementia on psychogeriatric wards

Our first research questions focused on the characteristics of depression in dementia on Dutch psychogeriatric nursing home wards: what is the prevalence of depression in this population and what are the characteristics? We found that 19% of the residents (only dementia stages 2 to 6 were included) suffered from depression in dementia. Depressed mood, irritability and fatigue were the most prominent symptoms. The mean number of depressive symptoms was 5.6 within a range of 0 to 10 symptoms. We found no differences between the dementia stages in the mean number of symptoms, or in the prevalence of each of the ten symptoms (Chapter 3). Also, on the basis of the literature review of Chapter 2, we conclude that there is no relationship between the severity of Alzheimer Disease and the prevalence of comorbid depression. In other words, depression in dementia occurs as frequently in the latter stages of dementia as in the earlier stages, with a similar pattern of depressive symptoms throughout all stages of dementia.

In 2002 an expert group of the American National Institute of Mental Health concluded that depression in Alzheimer Disease, the most frequent type of dementia, is qualitatively different from depression in non-demented elderly populations (Olin et al., 2002a). The expert group developed specific criteria, the so-called Provisional Diagnostic Criteria for Depression of Alzheimer Disease (PDC-dAD). The syndrome of Depression of Alzheimer Disease has some different symptoms ('irritability' and 'social isolation/withdrawal') than the DSM-IV syndrome of Major Depressive Disorder, and the symptoms are less intense. Without specific criteria for depression in

Alzheimer Disease the chance of under-diagnosis is therefore high. Vilalta-Franch et al. (2006) and Teng et al. (2008) recently showed that the PDC-dAD depression criteria indeed identified higher rates of depression in a demented outpatient population than DSM-IV and ICD-10 criteria for Major Depressive Disorder.

To our knowledge our study was the first to use the PDC-dAD criteria in a demented inpatient population on psychogeriatric nursing home wards. The prevalence rate of 19% that we found is somewhat lower than the 27% of Vilalta-Franch et al.(2006) using the PDC-dAD in an outpatient population. The rate is similar to the 20% found by Zuidema et al. (2007) on Dutch psychogeriatric nursing home wards using the Neuropsychiatric Inventory-Nursing Home version (NPI-NH).

A point prevalence of 19% means that about one out of every five nursing home residents in the dementia stages 2 to 6 suffers from depression in dementia at a certain point in time. This is considerable, especially when keeping in mind the serious consequences of depression in dementia, like decreased quality of life (Shin et al., 2005), greater health care utilization (Kunik et al., 2003) and higher mortality rates (Suh et al., 2005). The extent of the problem becomes even more obvious when we realize that by comparison, 2% of the Dutch elderly population living in the community suffers from depression (Beekman et al., 1999).

An understanding among professionals that the prevalence rate of depression in dementia is high could in itself enhance the recognition of it on psychogeriatric wards. Knowing about the prominent symptoms could also contribute to better recognition. This study showed that irritability, one of the two symptoms specific for depression in Alzheimer Disease, is one of the most prominent symptoms. Because irritability appears significantly more often in depressed than in non-depressed demented patients (Starkstein et al., 2005), irritability could alert caregivers to the possible presence of depression in dementia. Vilalta-Franch et al. (2006) already came to this conclusion for the outpatient population.

#### Guideline development: existing evidence and steps taken

In order to support residents with depression in dementia on psychogeriatric nursing home wards an evidence based nursing guideline was developed. The relevant research questions were (1) 'How much scientific evidence exists to show that often used psychosocial care methods

reduce depression in dementia?', and (2) 'Which steps need to be taken in developing an evidence based nursing guideline?'.

We found scientific evidence, although still limited, that BehaviorTherapy-PleasantEvents can reduce depression in people with dementia. For the other twelve psychosocial methods that we studied no evidence for their effectiveness on depression was found (Chapter 4). For some of the methods the reason was a lack of (high quality) studies (e.g. Gentle care); for other methods there was a lack of positive results (e.g. Skills training) or results were inconclusive (e.g. Reminiscence and Validation).

For our nursing guideline 'Depression in Dementia' we adapted Behavior Therapy-PleasantEvents to be applicable by Certified Nurse Assistants (CNAs) in a nursing home context. In the original BehaviorTherapy-PleasantEvents (Teri et al., 1997) primary caregivers learned from a geriatrician how to reduce depression in their depressed and demented relative who was still living in the community. They did this by increasing pleasant and reducing unpleasant events. Although the effects on depression were convincing and the quality of the study high, the scientific evidence for the method was still considered limited because it was only studied once in a demented and depressed outpatient population. In a nondemented, depressed population the method has been widely introduced and studied. It is based on the Integrative Theory of Depression and the Pleasant Event Schedules developed by Lewinsohn et al. (1985) (see figure 7.1 on page 126). In a recent meta-analysis, Cuijpers et al. (2007) conclude that Pleasant Event Schedules are as effective as cognitive therapies in a cognitively healthy population. They recommend the use of Pleasant Event Schedules in a cognitively disturbed population, for whom cognitive therapies are often no longer applicable.

The nursing guideline 'Depression in Dementia' was developed in seven stages (Chapter 5).

The aforementioned systematic literature review (Chapter 4), which pointed to scientific evidence for BehaviorTherapy-PleasantEvents, was conducted in the *second stage* of the guideline development trajectory. In the *first stage* of the trajectory we assembled existing Dutch guidelines for supporting people with dementia and behavioral or psychological disturbances. Eight guidelines for depression in dementia were found, of which one described a method resembling BehaviorTherapy-PleasantEvents. In the *third stage* of the

guideline development, in which we assessed the applicability of the existing guidelines, we concluded that this existing guideline did not have a practicable format for CNAs. In this stage we also gathered information by reviewing literature about the specific needs of people with dementia and their CNAs, that the guideline should meet. Existing literature showed that Dutch CNAs consider an emotion-oriented attitude to be particularly important in caring for people with dementia. This attitude is also appreciated by dementia sufferers and their relatives. BehaviorTherapy-PleasantEvents is already essentially emotion-oriented and thus met this need. Another important requirement for CNAs was professional autonomy. As Flynn and Aiken (2002) describe it '..... (CNA) ideologies emphasize autonomous practice centered on the needs of individual patients'. The guideline developed also fulfills this requirement.

In stage 4 a draft of the guideline was written based on BehaviorTherapy-PleasantEvents and the identified needs of people with dementia and their CNAs. In stage 5 this draft was discussed with the steering group of the development project and a group of 18 experts, which included practising CNAs, specialized nurses, psychologists, and others. As advised by the steering and expert groups two separate booklets were developed: one with the guideline for CNAs written in CNA jargon, and one with background information for managers and experts. Furthermore, the guideline for CNAs was structured in line with the care cycle (National Centre for Nursing and Care LCVV / Netherlands Institute for Care and Welfare NIZW, 2000) and the importance of an emotion-oriented attitude was emphasized. In stage 6 a practice test with the guideline was conducted in a nursing home and a residential home. The aspects of autonomy and systematic working were explicitly cited by CNAs as positive aspects of the guideline. In the practice test positive effects on depressive complaints were also observed by CNAs and they considered the guideline to be applicable in their care practice. In stage 7 the final adaptations to the guideline 'Depression in Dementia' were made, mainly concerning the lay-out of forms that came with the guideline.

The guideline development largely corresponds with a stepwise approach that was proposed by the Dutch Nurses' Association V&VN and NIVEL for perfecting existing guidelines (Poot et al., 2003). In 2006 the guideline 'Depression in Dementia' was approved by a national committee of the V&VN. The committee used the internationally accepted criteria for guideline evaluation from the AGREE instrument (Appraisal of Guidelines

for Research & Evaluation) (www.agreecollaboration.org). Currently, the guideline is one of five nursing guidelines that have been approved in the Netherlands.

The positive results of the practice test of the guideline development justified a large scale study on the effects of the guideline and the factors influencing successful introduction and application.

#### Guideline introduction and actual use: influencing factors

In Chapter 6 the factors influencing a successful introduction of the guideline 'Depression in Dementia' on psychogeriatric wards were studied. This was conducted on the nine psychogeriatric nursing home wards on which the guideline was introduced as part of the clinical trial. Research questions were: (1) 'Which factors facilitate or inhibit a successful *introduction* of the guideline on psychogeriatric nursing home wards?', and (2) 'Which factors facilitate or inhibit a successful *application* of the guideline on psychogeriatric nursing home wards?'.

The guideline introduction proved to be successful on three of the wards, moderately successful on four of the wards and unsuccessful on two. The level of success was calculated on the basis of: (1) the average score that CNAs gave to the training they underwent as part of the introduction process, (2) the percentage of residents for whom a Pleasant-Activities-Plan, developed with the guideline, was put in their care files, and (3) the number of times the installed promotion group met. Factors influencing the guideline introduction and application were categorized on four levels: nursing home management (level 1), nursing team (level 2), individual CNAs (level 3) and individual residents (level 4). Factors facilitating or inhibiting a successful introduction mainly lay at the level of the nursing home management and the nursing team. Most of these factors are known from previous studies, and have to do with the (in-)stability of the organization (e.g. reorganizations) and the stability of the nursing team (e.g. staff turnover rate) (e.g. Francke et al., 2008; Van Weert et al., 2004; Schrijnemaekers et al., 2002; Holtkamp et al., 2001). Other factors are less well known or are specific for this type of care intervention. For example, a shared emotion-oriented care vision at nursing team level facilitates a successful introduction. The factor most important for a successful guideline introduction seemed to be - as found in our study - the presence of a local opinion leader: a respected person who is related to the ward, who under-

stands the specific content of the intervention and really sees it as his/her job to make the introduction a success.

Factors influencing a successful *application* of the guideline were mainly found on the level of the individual CNAs and residents. A factor that appeared crucial for successful application was the involvement of relatives in facilitating and executing pleasant activities.

Most factors that we found in our study fit with 'theories of integrated care'. These theories also emphasize the importance of a local opinion leader. According to Rogers (2003) theories of integrated care are applicable to changing processes, that focus on improving and managing the care of specific categories of patients. They usually include top-down, management driven approaches in which current practices are reviewed and basically redesigned. Often one person (opinion leader) coordinates the process. Although the content of the guideline 'Depression in Dementia' focuses on the implementation of a new care method (the Pleasant-Events-Method), the bigger picture is that the care processes for depressed and demented residents are reorganized. Prior to the guideline introduction, psychosocial support plans were usually developed by psychologists in collaboration with CNAs. With the guideline introduction these roles were switched.

The importance of involving relatives in caring for psychogeriatric nursing home residents has been underlined in earlier studies. Foley et al. (2003) and Radar and Tornquist (1995) showed that family support and involvement can assist CNAs in reducing residents' behavioral and psychological problems by helping to identify unmet medical, emotional or social needs. Robison et al.(2007) and Port et al. (2001) showed that the involvement of relatives positively influences the quality of care for residents. In addition, Robison and Pillemer (2005) proved that involvement also has a positive effect on the job satisfaction of CNAs.

#### Effects of the guideline on residents

Another main research question was 'What are the effects of introducing the nursing guideline on depression in demented residents of psychogeriatric nursing home wards?'.

We concluded that introduction of the guideline showed significant reductions in depression severity on psychogeriatric nursing home wards (Chapter 7). We found significant results on the Depression Rating Scale of the Minimum Data Set of the Resident Assessment Instrument. On the Cornell Scale for depression in dementia, a decrease in depression was registered also, but this finding was not statistically significant.

The fact that we were able to show that CNAs can significantly reduce depression severity in demented residents, as measured with the Depression Rating Scale, is an important finding. There are many factors, endogenous as well as exogenous, that can influence the presence of a depression. By following the guideline, CNAs were only able to influence some of these, but apparently with significant effects.

The size of the effect on the Depression Rating Scale was moderate. We found indications that the general mean effect was pushed down by the nursing home wards on which the guideline introduction was not or only moderately successful. Methods to achieve a more successful introduction and better compliance can be derived from the research contained in Chapter 6, on factors that facilitate or inhibit a successful guideline introduction.

The fact that we did not find significant reductions of depression with the Cornell Scale, while we did with the Depression Rating Scale, may be explained by findings of a study by Kurlowicz et al. (2002), on the validity of the Cornell Scale in a demented nursing home population. They conclude that the Cornell Scale, being dependent on items highly sensitive to comorbid conditions, does not seem appropriate for use in frail, institutionalized older adults with high rates of dementia, medical illness and functional disability. Our study would appear to confirm this finding. It also again emphasizes the importance of using appropriate instruments in measuring depression severity (Olin et al., 2002b).

#### Effective elements of the guideline

The guideline itself as well as the guideline introduction contain several elements. A relevant question is therefore which elements caused the reduction in depression severity? We asked this in the interviews with CNAs at the follow-up measurements of the clinical trial (see also Chapter 6). The guideline consists of the following main elements: (1) inducing pleasant activities; (2) reducing unpleasant events. In addition, context factors (element 3) may have played a role (e.g. giving attention; using an emotion-oriented approach). In interviews, CNAs were explicitly asked if

they saw a reduction of depression in their residents and, if so, which elements might have induced this. Firstly, from the interviews it became clear that element 2 (reducing unpleasant events) was hardly applied. If depression became less severe CNAs thought that this was caused by an increase in pleasant activities. CNAs induced pleasant activities during regular care (e.g. joking while washing) and in additional situations (e.g. going to shops). In most cases CNAs were of the opinion that these activities reduced the depression because of a combination of distraction by the pleasant activity (element 1) and getting positive attention (element 3). In these cases an emotion-oriented attitude (element 3), when assisting the resident with the activity, was also considered important. In only a few cases did CNAs believe that just the pleasant activity (element 1) reduced the depression.

In the light of Lewinsohn's Integrated Theory of Depression (also see Chapter 7), on which the guideline 'Depression in Dementia' was based to a large extent, this means that CNAs thought that the depression cycle was effectively interrupted at the first part of element C of the model, namely a 'reduced rate of positive reinforcement'. In most of the earlier intervention studies based on Lewinsohn's model, like the Pleasant Events Schedules, only the first part of element C was aimed at. And, as described earlier, this also proved to be effective in reducing depression in the regular adult population (Cuijpers et al., 2007).

We have no indication that part two of element C, an 'elevated rate of aversive experience', was influenced or had any effect on this point, mainly because CNAs hardly applied the second element of the guideline ('reducing unpleasant events'). It is likely that this element of the guideline is more difficult to apply. Paying more attention in the guideline and training to strategies for reducing unpleasant events could probably contribute further towards reducing depression.

From the systematic literature review in Chapter 5 we conclude that psychosocial methods based on a non-cognitive, emotion-oriented theory seem to produce the most promising results in reducing depression or apathy in people with dementia. The Pleasant-Events-Method reduces depression in an outpatient demented and depressed population (Teri et al., 2007) and in depressed and demented psychogeriatric nursing home residents (this thesis). In addition, Multi Sensory Stimulation/Snoezelen, another emotion-oriented approach, reduces apathy in people in the latter

stages of dementia, and more recently has also been shown to reduce depressive complaints in psychogeriatric nursing home residents (Van Weert et al., 2005a). However, other psychosocial methods, such as Validation/Integrated Emotion-Oriented Care or Gentle Care, have not been shown to be effective in reducing depression. In Chapter 5 we cite several methodological reasons why there has been, until now, no or insufficient evidence (Toseland et al., 1997; Bråne et al., 1987) for the effectiveness of these methods: lack of sufficient high quality scientific research (e.g. in the case of Gentle Care), the heterogeneity of the study population, the measurements used or the duration of the implementation period (Finnema, 2000). Another possible explanation is that these interventions are less practicable and concrete than the Pleasant-Events-Method and Multi Sensory Stimulation/Snoezelen, and are therefore more difficult to apply by caregivers, and therefore show limited effects. Besides a non-cognitive, emotion-oriented approach, the Pleasant-Events-Method and Multi Sensory Stimulation/Snoezelen have in common that they consist of concrete steps to come to an individualized care plan, consisting of specified activities. The steps follow the care cycle, promoting a systematic way of working, with which all CNAs are familiar. From interviews with CNAs we learned that, although CNAs were often already familiar with undertaking pleasant events and sensory stimulation, the systematic way of gathering resident information and developing, applying and evaluating individualized psychosocial care plans made the difference.

#### Effects of the guideline on CNAs

An additional research question was 'What are the effects of introducing the nursing guideline on the CNAs of psychogeriatric nursing home wards?'. In Chapter 8 we reported that the introduction of the guideline had a significantly positive effect on the perceived professional autonomy of CNAs. The expected positive effects on general workload, and on powerlessness and confidence could however not be confirmed.

Although the effect of the guideline introduction on perceived professional autonomy was statistically significant, the increase of professional autonomy on the experimental wards seems rather small. A likely explanation for this is that the guideline only affected some 20% of the residents of a ward (as this concerns the percentage of demented residents with co-morbid depression, see Zuidema et al., 2007; Verkaik et al., accepted), while the scale

used measured effects on the general professional autonomy that CNAs experience.

The positive effect, although small, fits with the finding of Hoogeveen and Smith (1998) that CNAs are stimulated in their job if they can find solutions for behavioral and psychological problems of dementia themselves. Before the guideline was introduced, psychosocial care plans were mostly developed by psychologists, with CNAs usually only in a consultative role. The guideline introduction redefined these roles. It is important to observe that CNAs favored this redefinition, but still really appreciated and needed consultation with psychologists, especially in case of multiple behavioral or psychological disturbances (Chapter 6).

As said, no significant effects were found regarding general experienced workload. Also in this regard it must be emphasized that the guideline only concerns about 20% of the residents, whereas the instrument measured general workload. It could however be interpreted as a positive finding that the guideline introduction did not increase the experienced workload particularly in the short term, as the introduction incurred additional tasks for the CNAs.

The fact that we did not establish effects on perceived powerlessness and confidence as measured by some self-developed quantitative scales, was contrary to our expectations. This may be related to measurement problems. We used self developed scales, since no suitable, validated scales were available from earlier studies (Hallberg and Norberg, 1993; Kerkstra et al., 1999). It is possible that our scales did not significantly or adequately measure the complex concepts of powerlessness and confidence. Another possibility is of course that there were no actual effects on powerlessness or confidence, and that the introduction of the guideline has not been successful in this regard. However, in personal interviews with CNAs we did get the impression that they felt more confident and less powerless in caring for this target group. More research is needed.

#### Strengths and limitations of the study

The studies described in this thesis were challenging. In the first place this is due to the complexity of depression in dementia itself. Its etiology and manifestations are still largely unknown. The fact that the Provisional Diagnostic Criteria for Depression of Alzheimer Disease (PDC-dAD), although already published in 2002, are still provisional, is indicative of this. Secondly, introducing a new care method for CNAs on nine different

nursing home wards is complicated. In a field where many reorganizations take place, with a shortage of (qualified) personnel and high staff turnover, few intervention studies are attempted.

A major strength of the studies in this thesis is therefore that we took on the challenge and faced the potential problems, in order to contribute to the care for people with dementia and bring science a step further. For example, we were the first to use the aforementioned Provisional Diagnostic Criteria for Depression of Alzheimer Disease (PDC-dAD) in an inpatient population and found them to be applicable.

Another, related, strength of our clinical trial is that we showed that introducing complex care innovations (i.e. screening of depression by CNAs and making and conducting individualized psychosocial care plans with relevant family involvement) on psychogeriatric nursing home wards is indeed possible. More importantly, our experience is that most nursing teams and individual CNAs are very cooperative and willing to contribute to the improvement of their care, despite the fact that they often have to cope with a shortage of personnel and high staff turnover.

A limitation of our trial is that we were not able to blind the psychologists and physicians, who performed the diagnosis of depression in dementia. At the time of the diagnosis they knew which condition their ward was in, experimental or control. This may have influenced their diagnoses. For example, it is possible that psychologists and physicians on the experimental wards diagnosed more residents as depressed and demented than those on the control wards, because they knew that residents could benefit from the intervention. The fact that the number of residents included on the experimental wards was systematically higher (n=65) than that on the control wards (n=35) could be an indication of this. Analyses however showed that included residents on the experimental and control wards did not differ in background characteristics, number of depressive symptoms or depression severity.

Another weakness is that, due to a limited research budget, we were not able to have a second control condition in our trial and accordingly study the effective elements of the guideline more thoroughly. An interesting control condition would, for example, have been an intervention for residents only consisting of pleasant activities, without CNAs showing an emotion-oriented attitude.

#### Recommendations for future research

This thesis showed that the introduction of the nursing guideline 'Depression in Dementia' on psychogeriatric nursing home wards can decrease depression in depressed and demented residents and is applicable by CNAs. Originally the guideline was also developed for residential care homes (see Chapter 5). In these homes more and more psychogeriatric units are being established that could possibly also benefit from the guideline. Future research should show if the guideline is, with some modifications, also applicable and effective in these units. The guideline could also be applied in nursing homes, residential care homes or comparable institutions outside the Netherlands. Consultations on this with nursing faculties and institutions in the United States, for example, were very promising. Adaptations to the guideline that would be needed for application in the United States, would mainly consist of a division of tasks between CNAs and Licensed Practical Nurses (LPNs), because of the lower educational level of CNAs in the USA. Research should prove if the guideline is indeed internationally applicable and effective.

The studies conducted as part of this thesis have contributed to the knowledge about depression in dementia, more specifically on psychogeriatric nursing home wards. The existing knowledge is however still limited. Our study was, for example, one of the first to use and analyze the Provisional Diagnostic Criteria for Depression of Alzheimer Disease. More research into the criteria and their application needs to be done in order for them to become established in practice. Specifically for psychogeriatric nursing home wards, attention should be paid to residents with dementia in the last stage of the disease (Reisberg's Global Deterioration Scale, stage 7). These residents were excluded from our study, but form 28% of the Dutch psychogeriatric nursing home residents (Zuidema et al., 2007).

In addition to more research into depression in dementia, we recommend that future research be conducted on ways to increase CNAs' professional autonomy. We consider such research important since CNAs' professional autonomy is related to job satisfaction and burn-out (Te Boekhorst et al., 2008), which in turn influence job-turnover (Hinshaw and Atwood 1983) and quality of patient care (Redfern et al., 2002; Cheung and Chow, 2006). A study by Van Weert et al. in 2005 already showed that CNAs on psycho-

geriatric nursing home wards are perfectly able to develop and apply individualized Multi Sensory Stimulation plans ('Snoezelen' plans). The same study also showed multiple positive effects on CNAs' work experiences, among which professional autonomy. Our intervention is largely similar to that of Van Weert et al. (2005b) in the sense that the methods are practicable, systematic, highly patient-centered and place CNAs in a pivotal position. It would be interesting to study which aspects of these (and comparable) interventions are most successful in improving the professional autonomy of CNAs. Such information may also be of value for future implementation strategies.

#### Recommendations for practice

### Developing nursing guidelines

The guideline development process that we followed proved very effective. The seven stages of the process were: 1 assembling existing guidelines; 2 systematic literature review; 3 assessing existing guidelines; 4 developing a draft guideline; 5 evaluation of the draft guideline by a group of experts and the steering committee; 6 testing the guideline in a practice trial; 7 final adaptations to the guideline. As described, the process largely corresponds with an approach proposed for perfecting existing guidelines (Poot et al., 2003). We strongly recommend for future nursing guideline development that the same process be used. In our experience all stages were important and none can be missed. The practice trial is of the utmost importance, because not only can much be learned about the applicability of the guideline, but also about the implementation process needed. The AGREEcriteria only mention that a guideline should be tested among potential caregivers, but no criteria are given for the way this should be done. We strongly recommend a sophisticated practice test, in which caregivers are trained and have sufficient time to experience all aspects of the guideline application.

### Implement the guideline!

As said, this thesis showed that the introduction of the nursing guideline 'Depression in Dementia' on psychogeriatric nursing home wards can decrease depression in depressed and demented residents and is applicable by CNAs. Besides being effective and applicable, the guideline with its Pleasant-Events-Method fits with the current emphasis in Dutch health care regarding quality of life, client-centered care and participation of residents

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in daily activities. An example of this emphasis is the recent implementation of the national Quality Framework for Responsible Care, which states that every nursing home, residential home and home care organization in the Netherlands has to report on ten domains of quality indicators on a yearly basis. Three of the ten domains of quality indicators, to which the guideline 'Depression in Dementia' directly relates are (1) the presence of an individualized care plan for each resident, with much attention for psychosocial care, (2) psychological wellbeing, and (3) participation and social engagement of residents (Actiz et al., 2007). Another recent development in psychogeriatric care is the building of more and more smallscale group-living homes. In these homes a small group of older people with dementia live together in a home-like environment, in which it is tried to keep daily life for the residents as normal as possible. Only one or two CNAs or nurses provide care, and perform domestic tasks, like cooking, as well. The CNAs or nurses involve the residents in such tasks, as far as these fit with the residents' preferences and capabilities (Te Boekhorst et al., 2008). The nursing guideline 'Depression in Dementia' encourages the introduction of aspects of the group-living homes, such as involving residents in preferred daily activities, into more traditional nursing home wards.

We recommend all psychogeriatric nursing homes wards to integrate (the main principles of) the guideline into their usual care. The main principles of the guideline are systematically choosing, realizing and evaluating pleasant activities that correspond with the patient's unique biography, preferences, limitations and capabilities. In comparable settings, like psychogeriatric units in residential care homes or assisted living facilities, these principles may also be used and adapted to the specific care situations.

### Implementation strategy

We studied the factors that influence a successful introduction and application of the guideline on psychogeriatric nursing home wards. The factors that appeared to be most influential are (1) the presence of a local opinion leader, (2) a shared emotion-oriented care vision on the ward, (3) stability of the nursing organization and team, and (4) the involvement of relatives.

Probably the first step for a nursing home or ward aiming to introduce the guideline is to find a *local opinion leader*. In the case of the guideline 'Depression in Dementia' a psychologist or psychiatric nurse who is well known and respected on the participating ward may be appropriate for this

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job. The opinion leader should be someone who is related to the ward(s), who is respected, understands the specific content of the intervention and really sees it as his/her job to make the introduction a success. Together with this opinion leader the nursing home management should develop an implementation strategy that fits the specific circumstances of the nursing home. The implementation strategy should first focus on a shared emotionoriented care vision on the ward(s). If the opinion leader considers that this vision is not sufficiently present, the nursing home should start with implementing this vision, before the actual introduction of the guideline takes place. There are various training programs on emotion-oriented care for nursing teams. Another important aspect of implementation strategy is to plan the introduction in a period in which the nursing team(s) of the psychogeriatric ward(s) experience few organizational changes or other training courses. It is also advisable not to start the introduction in the summer period or around Christmas, when many wards are experiencing personnel shortages due to holidays.

A good way to *involve relatives* and family members is to organize an informative meeting before the nursing team is trained. When CNAs contact the relatives at a later stage to talk about application of the guideline, the chance that they will be enthusiastic about contributing is thus likely to be greater.

An important conclusion from our study was furthermore that the complete team should be trained in using the guideline. This means involving the CNAs working 20 hours per week or more, as we did in our study, but also other team members who are not-certified and/or work less hours. It is not practicable or advisable to train every team member as intensively as we did. However, it is important that all team members are at least centrally informed about the content of the guideline, its purpose and the way they are expected to contribute to its application.

What we studied was the introduction of the nursing guideline, not its actual implementation. We would consider the guideline to be successfully implemented when the guideline has become integrated in usual care and when its use has been consolidated. A local opinion leader ideally stays on the job until this aim has been reached, and application of the guideline has become care as usual.

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# Samenvatting (Summary in Dutch)

### **Inleiding**

In dit proefschrift staat de ontwikkeling, introductie en evaluatie van de richtlijn voor verzorgenden 'Depressie bij Dementie' centraal. Belangrijkste elementen van de richtlijn zijn (1) het vaker ondernemen van geïndividualiseerde plezierige activiteiten, en het (2) voorkomen van nietplezierige gebeurtenissen. Ingegaan wordt op het ontwikkelingstraject, de wetenschappelijke basis, de belemmerende en bevorderende factoren bij de introductie op psychogeriatrische verpleeghuisafdelingen en, ten slotte, de effecten op depressie van bewoners en de effecten op o.a. autonomie en werklast van verzorgenden. Tevens biedt het proefschrift meer inzicht in de prevalentie en de prominente symptomen van depressie bij de dementerende bewoners van psychogeriatrische verpleeghuisafdelingen. In dit hoofdstuk wordt een Nederlandstalige samenvatting van de onderzoeksresultaten gegeven.

Hoofdstuk 1 bevat de algemene inleiding van het proefschrift. De wetenschap dat depressie bij dementie ernstige negatieve gevolgen heeft voor zowel patiënten als voor hun verzorgers vormde een belangrijke aanleiding voor het onderzoek in het proefschrift. Op Nederlandse psychogeriatrische verpleeghuisafdelingen is 85% van de bewoners dementerend en er zijn indicaties dat een groot deel daarnaast aan depressie lijdt. Depressie leidt bij bewoners tot een verminderde kwaliteit van leven, een verhoogd zorggebruik en een hogere mortaliteit. Dit was aanleiding om voor deze populatie een evidence based interventie te ontwikkelen. Gekozen werd voor een richtlijn voor verzorgenden, omdat zij de bewoners dagelijks begeleiden.

Om te weten in welk stadium van dementie de toepassing van een dergelijke richtlijn het meest zinvol is, werd een systematische literatuurstudie uitgevoerd naar de relatie tussen het stadium van de dementie en het vóórkomen van depressie. Deze systematische literatuurstudie wordt in hoofdstuk 2 gerapporteerd. Aanleiding vormde het feit dat eerdere studies vaak tot verschillende conclusies kwamen, mede door het gebruik van uiteenlopende onderzoeksmethoden. Zo werden in bestaande studies verschillende typen methoden om de prevalentie van depressie te bepalen gebruikt: in een deel werd de prevalentie van depressie bepaald door het aantal aanwezige depressieve symptomen, en in een ander deel door het

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aantal gestelde depressiediagnoses. In de systematische literatuurstudie vergeleken we binnen beide typen studies de verschillen en overeenkomsten in de resultaten en beoordeelden we tevens de methodologische kwaliteit. We concludeerden dat er geen relatie bestaat tussen het stadium van de dementie en het vóórkomen van depressie. Depressie komt waarschijnlijk net zo vaak voor in de laatste stadia van dementie als in eerdere.

Hoofdstuk 3 beschrijft een cross-sectionele studie naar de prevalentie en de prominente symptomen van depressie bij dementerende bewoners van psychogeriatrische verpleeghuisafdelingen. De gebruikte gegevens komen uit de eerste, diagnostische fase van de interventiestudie naar de invoering van de richtlijn. Voor de diagnose depressie bij dementie is gebruikt gemaakt van de Provisional Diagnostic Criteria for Depression of Alzheimer Disease (PDC-dAD), die onder andere aanbevolen worden in de NVKGrichtlijn 'Diagnostiek en medicamenteuze behandeling van dementie'. We vinden een prevalentie van depressie bij dementie (stadia 2 t/m 6) op psychogeriatrische verpleeghuisafdelingen van 19%. Het gemiddelde aantal depressieve symptomen op een aantal van 0 tot 10 was 5.6 (SD 1.84). Depressieve stemming, prikkelbaarheid en moeheid zijn de drie meest frequente symptomen. Opvallend is dat prikkelbaarheid, als een van de twee specifieke symptomen voor depressie bij dementie, zo vaak voorkomt. Dit is opvallend omdat prikkelbaarheid eerder niet als symptoom van depressie gezien werd, en nu zelfs gebruikt kan worden bij de herkenning ervan onder dementerende verpleeghuisbewoners.

In hoofdstuk 4 wordt een systematische literatuurstudie beschreven naar de effectiviteit van 13 vaak gebruikte psychosociale interventies om depressie, agressie of apathie bij mensen met dementie te verminderen. Het gaat om de volgende psychosociale begeleidingsmethoden: gedragstherapie, ondersteunende psychotherapie, validation/geïntegreerde belevingsgerichte zorg, zintuigactivering/snoezelen, gesimuleerde aanwezigheidstherapie, reminiscentie, warme zorg, passiviteiten van het dagelijks leven (PDL), realiteitsoriëntatie, vaardigheidstraining, recreationele therapie, kunsttherapie en psychomotore therapie. Bestaande studies worden beoordeeld op hun methodologische kwaliteit en de consistentie van de uitkomsten tussen de studies. Met betrekking tot depressie vinden we dat er wetenschappelijk bewijs bestaat, al is dit nog beperkt, dat een speciale vorm van gedragstherapie 'BehaviorTherapy-PleasantEvents' in staat is om

depressie te verminderen bij mensen met dementie die nog thuis wonen. Belangrijkste elementen van de methode zijn (1) het vaker ondernemen van geïndividualiseerde plezierige activiteiten, en het (2) voorkomen van nietplezierige gebeurtenissen. Zintuigactivering/snoezelen blijkt verder effectief om apathie bij mensen in de laatste stadia van dementie te reduceren. Wij gebruikten de Plezierige-Activiteiten-Methode als basis voor de richtlijn voor verzorgenden 'Depressie bij Dementie'.

Hoofdstuk 5 geeft weer welke zeven fasen doorlopen zijn in de ontwikkeling van de richtlijn voor verzorgenden 'Depressie bij Dementie'. De zeven fasen zijn: (1) inventarisatie van bestaande richtlijnen, (2) systematische literatuurstudie, (3) beoordeling van bestaande richtlijnen in het licht van de uitkomsten van de systematische literatuurstudie, (4) ontwikkelen van nieuwe concept-richtlijn, (5) toetsen van concept-richtlijn in een expertbijeenkomst en door de begeleidingscommissie, (6) praktijktoets gericht op het vaststellen van de bruikbaarheid en haalbaarheid van de richtlijn op een verpleeghuisafdeling en in een verzorgingshuis, en (7) laatste aanpassingen in de richtlijn.

Na het doorlopen van deze zeven fasen lag er een richtlijn voor verzorgenden over 'Depressie bij Dementie' die haalbaar en bruikbaar bleek in de praktijk, maar waarvan de effectiviteit en de bevorderende en belemmerende factoren bij invoering ervan nog nader onderzocht diende te worden. Dit was aanleiding voor de deelstudies die in de volgende hoofdstukken (6 tot en met 8) centraal staan.

In hoofdstuk 6 worden de belemmerende en bevorderende factoren voor een succesvolle invoering en toepassing van de richtlijn 'Depressie bij Dementie' beschreven. De studie is een meervoudige casestudie, waarin kwalitatieve onderzoeksmethoden worden gecombineerd met kwantitatieve. De 'cases' zijn de negen verpleeghuisafdelingen waarop de richtlijn is ingevoerd. De invoering bleek op drie afdelingen succesvol, op vier matig succesvol en op twee afdelingen niet succesvol. Factoren die van invloed zijn op een succesvolle invoering werden voornamelijk gevonden op het niveau van het verpleeghuismanagement en de afdelingen. Belangrijke bevorderende factoren zijn stabiliteit van de organisaties en de afdelingen, een gedeelde belevingsgerichte zorgvisie en de aanwezigheid van een lokale opinieleider. De aanwezigheid van een opinieleider lijkt een belangrijk verschil te maken tussen succesvolle en matig of niet succesvolle afdelingen. Voor een

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succesvolle toepassing van de richtlijn is ook een positieve attitude van familieleden ten aanzien van de richtlijn en het toepassen van de Plezierige-Activiteiten-Methode bij een bewoner van belang.

Hoofdstuk 7 beschrijft de effecten van de invoering van de richtlijn op psychogeriatrische verpleeghuisafdelingen, met betrekking tot depressieve klachten van bewoners. De studie heeft een gecontroleerd pretest-posttest design met randomisatie op afdelingsniveau. Er waren drie meetmomenten: net voor, net na en tien weken na de interventieperiode van elf weken. De interventie op de experimentele afdelingen bestond uit uitreiking van de richtlijn, drie dagdelen training, en de installatie van een zogenaamd stimuleringsgroepje. De zorg op de controle afdelingen bleef onveranderd. Primaire uitkomstmaat was ernst van de depressie, zoals gemeten met (1) de Depression Rating Scale van de Minimum Data Set uit het Resident Assessment Instrument, en (2) de Cornell Scale for Depression in Dementia. Secundaire uitkomstmaat was 'stemming', zoals gemeten met de observatieschaal FACE tijdens de ochtendzorg en tijdens het verblijf van een bewoner in de huiskamer. We vonden een significant positief effect op de ernst van de depressie gemeten met de Depression Rating Scale. Bij de depressie gemeten op de Cornell Scale is ook een afname van de depressie te zien, echter dat effect is niet significant. We vonden geen effecten op de secundaire variabele stemming. Effecten op depressie zouden waarschijnlijk groter zijn geweest wanneer verpleeghuisafdelingen meer rekening hadden gehouden met de factoren die succesvolle invoering van de richtlijn belemmeren of bevorderen (hoofdstuk 6).

Hoofdstuk 8 beschrijft de effecten van de invoering van de richtlijn met betrekking tot verzorgenden. Het design is gelijk aan de studie naar de effecten op bewoners (hoofdstuk 7). Primaire uitkomstmaten bij verzorgenden waren ervaren professionele autonomie en ervaren werklast, zoals gemeten met de VBBA-subschalen 'zelfstandigheid in werk' en 'werktempo en hoeveelheid'. Secundaire uitkomstmaat was ervaren machteloosheid en zekerheid in het begeleiden van depressieve dementerende bewoners, zoals gemeten met zelfontwikkelde schalen. We vonden een klein significant positief effect op professionele autonomie. Dit effect is waarschijnlijk klein, doordat de richtlijn maar een deel van de bewoners van een afdeling aangaat (ongeveer 20% van de dementerende bewoners is depressief), terwijl de ervaren autonomie het werk over de hele

bewonersgroep bestrijkt. We vonden geen effecten op ervaren werklast of op de variabelen ervaren machteloosheid en zekerheid. Het feit dat er geen negatief effect optrad op de ervaren werklast tijdens de invoeringsperiode van de richtlijn is een positieve bevinding; in eerste instantie zullen er immers door de invoering en toepassing van de richtlijn voor verzorgenden taken bij komen.

In *hoofdstuk 9*, tenslotte, bediscussiëren we de resultaten en doen we aanbevelingen voor toekomstig onderzoek en de praktijk. Aanbevelingen voor toekomstig onderzoek zijn:

- nader onderzoek naar toepasbaarheid en effectiviteit van de richtlijn in Nederlandse verzorgingshuizen en in verpleeg-, en verzorgingshuizen buiten Nederland;
- meer onderzoek naar de Provisional Diagnostic Criteria for Depression in Alzheimer Disease, zodat deze kunnen worden geformaliseerd;
- meer onderzoek naar depressie bij mensen in het laatste stadium van dementie; meer onderzoek naar aspecten van interventies die zorgen voor een vergroting van de professionele autonomie van verzorgenden.

Aanbevelingen voor de praktijk zijn:

- volg bij de ontwikkeling van richtlijnen voor verzorgenden de zeven fasen beschreven in hoofdstuk 5 van dit proefschrift, en besteed ruim aandacht aan de praktijktoets;
- voer de richtlijn, of tenminste de principes daarvan, in op psychogeriatrische verpleeghuisafdelingen;
- houd daarbij rekening met de vier factoren die het meest van invloed zijn
  op een succesvolle invoering en toepassing, te weten: (a) betrek er een
  opinieleider bij die respect geniet in de organisatie, en zorg voor (b) een
  belevingsgerichte zorgvisie, (c) een stabiele organisatie en stabiel team,
  en (d) betrek familieleden bij het bedenken en uitvoeren van 'plezierige
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# Appendix

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# Supporting people with dementia suffering from depression

# **Guideline for Certified Nurse Assistants**

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4 Appendix

### 1 Introduction

People with dementia and depressive complaints can make nurse assistants feel powerless: These patients are often depressed and hardly willing to do anything at all. This guideline describes a method for supporting people with dementia who are suffering from depression: the Pleasant-Events-Method. This method appears to diminish depressive complaints in people with dementia. The method consists of specific elements that are focused on diminishing depressive complaints. Additionally, the guideline is based on an emotion-oriented attitude and the care cycle. This introduction first gives a short description of the relation between dementia and depression and explains the emotion-oriented attitude and the care cycle. Then, the Pleasant-Events-Method is clarified. In the appendices the reader will find the forms that can be used with this guideline.

#### 1.1 The relation between dementia and depressive complaints

Dementia is caused by changes in the brain. In most cases, it is connected with Alzheimer Disease, vascular dementia or a combination of these two diseases. Changes in the brain disturb memory and cognitive functioning. Formerly learned information is forgotten and people may lose their motoric dexterity, for instance they have problems using cutlery, or getting dressed, even though their motoric functions are undamaged.

Psychological and behavioural problems in people with dementia, such as depression, aggression, agitation, delusions and apathy, are partly caused by changes in the brain; but partly they are due to the way people experience the changes and how they<sup>2</sup> and their environment react. Depression often appears to be caused by the way people experience changes. Someone who is suffering from dementia is aware that his abilities are diminishing as his memory and cognitive function get worse. Every time he undertakes something, he is aware that it is not going as well as before. He may well become depressed by this awareness. He may reduce his activities, become depressed or sulky, lose his lust for life and start worrying more and more. We can reduce the resident's depressive complaints by supporting him appropriately. However, we will not be able to take away all the sadness caused by dementia, or ignore it.

To indicate people "they" is used for male and female, "he" means he or she.

### 1.2 The emotion-oriented attitude and the care cycle

As just noted, we can reduce the depressive complaints of someone who is suffering from dementia with appropriate support. This support process is based on:

- an emotion-oriented attitude;
- the care cycle.

#### Emotion-oriented attitude

A nurse assistant is showing an emotion-oriented attitude when she tries to imagine how it feels to be a resident with dementia.

Two important aspects will facilitate this process:

- a) Get to know the patient better and find out more about his past. The nurse assistant should find out more about his personality and his life: What kind of person is he? What kind of life has he had? What was his job? Appendix III consists of a form that can be used by the Certified Nurse Assistant in this regard.
- b) Try to image what it is like to be a resident with dementia. How would it feel no longer to be able to write or recognize people and things and not to know where you are?

Once the nurse assistant knows more about someone's background and imagines, if possible, what it is like to suffer from dementia, she will understand the person better and adapt her care to this person.

6 Appendix

## The care cycle

The Pleasant-Events-Method for depression is focused on supporting the person who suffers from dementia. We follow the care cycle with this method. This cycle is described below.

#### A. Assess

- A1. Collect information
- A2. Assess needs

#### B. Plan activities

- B1. Define the intended results
- B2. Choose activities

## C. Realize activities

#### D. Evaluate

# 2 Supporting people with dementia who are suffering from depression: the Pleasant-Events-Method

This chapter describes the Pleasant-Events-Method for Certified Nurse Assistants, using the care cycle. The method is based to a large extent on a method, developed by Teri and colleagues in the United States, that has proved to be useful in diminishing depressive complaints of people with dementia.<sup>3</sup> The main assumptions of this method are that client's depression will be reduced if he undertakes pleasant activities and worries less.

#### A. Assess

#### A1. Collect information

Characteristics of depression

Depression is characterised by the following aspects: a depressed mood, no interest or enjoyment in activities, eating much more or far less than before, sleeping less or more than before, restless behaviour or slowed motor behaviour, fatigue or loss of energy, feeling useless or excessive feelings of guilt.

Not necessarily all characteristics occur at the same time in one person who is suffering from depression. Also, some of these characteristics, like slowed motor behaviour and loss of energy, already occur in people with dementia. Recognizing depression in people with dementia is therefore not easy. However, depressed individuals should display the characteristics "depressed mood" or "not interested in activities / not enjoying activities". These characteristics must occur most of the day, nearly every day over a period of at least two weeks.

When you suspect that someone is suffering from depression, first consult the resident and your coworkers involved with him as well as his family. Ask them how they judge the resident's mood and his interest and enjoyment in activities during the past two weeks.

If they confirm your suspicion of depression, ask your team leader or other professional, like a psychologist, geriatrician, psychiatrist or other doctor, or a registered nurse, whether you should start using the Pleasant-Events-

Teri L., Logsdon R.G. et al. 1997. Behavioral treatment of depression in dementia patients: a controlled clinical trial. *J.Gerontol.B Psychol.Sci.Soc.Sci.* 52, no. 4:159-166.

Method. If they agree, and the resident and his family agree to start the method, go on to the next step: collecting information on activities that the resident enjoys. The form in Appendix III also involves a checklist of activities the patient may enjoy. Whenever you need help during this stage of collecting information, ask a psychologist, an occupational therapist, or another consultant in the nursing home.

#### Pleasant activities

As mentioned before, the Pleasant-Events-Method is first of all intended to stimulate the resident to undertake activities that he enjoys. To realize this, you have to find out which activities this resident enjoyed doing in the past and perhaps recently as well. By reading the intake report, by talking with the family and the resident and by talking with coworkers, relevant information can be gathered. When working from an emotion-oriented attitude, it is also important to gather even more information on the resident's personality and his course of life.

#### Worrying situations

The second intention of the Pleasant-Events-Method is to reduce the resident's worries. To achieve this, you have to collect information on situations in which the resident worries. Consult the resident, his family and coworkers involved, and formulate the worrying situations as much as possible in the following way: might be reason to start worrying, what does the resident actually do when he worries, what is his reaction, how do members of his family, coworkers and others react to his worries.

#### A2. Assess needs

#### Pleasant activities

Enjoyable activities from the past now will be translated to his current situation, in other words: the activities will be adapted to the resident's limitations caused by the dementia and to his gloominess and lack of energy caused by the depression.

Start thinking of activities that the resident, with help if needed, can undertake or experience without any risk of failing. Suppose the resident is interested in horses, find activities that are related to horses and that he can enjoy. Examples are: watching horse races on television, looking through books on horses, visiting a horse riding school. For people who used to enjoy cooking you would look for activities that can be undertaken in the kitchen

with help if needed. It is important to invent activities that people really can do without having to face failure.

After you have found an activity in consultation with the resident, you have to find out how to stimulate the resident to undertake this activity step by step. For instance, you can take someone who is interested in cooking first with you to the kitchen to see how food is prepared. A second step could be to ask him to wash the lettuce.

You should involve coworkers, the occupational therapist and the family in translating the resident's interests into activities and in dividing these activities in steps. Use also all you know about the resident's personality and his course of life in the development of the activity and the division in steps.

#### Worrying situations

Now you have to find out how you can prevent the resident from worrying too much. Look at what you have written down about the situations that cause worries, exactly what the resident does when he worries and the effect on himself as well as on others. How can you change the worrying situations or prevent them? If a resident is worrying after a hot meal, try to find out why. Is it caused by what happens during the meal, for instance because he has forgotten how to handle cutlery? Or is it just the time of the day? When the cause appears to be simple, like problems handling cutlery, try to develop a plan to take away the worries. Do this, again, together with coworkers involved, the occupational therapist, the resident and his family.

You also have to find out what kind of guidance is needed when there appears to be no direct reason for worrying, as when the worries are just connected with time of the day. Pay a lot of attention to the resident at this time of the day and do not ignore him. Ask him what is the matter; listen and do not contradict him. Try to show empathy. Additionally, try to distract him. Think of more pleasant subjects and activities to distract him and to make him feel happier. Again, involve your colleagues, the occupational therapist, family and of course the resident.

#### **B. Plan activities**

#### B1. Define the intended results

Before you plan the pleasant activities, you have to consult the coworkers involved, the occupational therapist, the family and, if possible, the resident

about the intended results of the chosen activities. You should formulate your aims in such a way that they can be measured. For example: Mrs. A laughs more often, Mr. B gets up in the morning without complaining, Mrs. C eats her bread. Put your aims down on the Pleasant-Activities-Plan (see appendix 2)

#### B2. Choose activities

Now, make a plan, together with the coworkers involved, the occupational therapist, the resident and his family, for the next week. This plan should consist of the following four parts:

- describe three incidents with different pleasant activities if divided in steps, the first step – distributed over the week. For each activity, indicate who is going to do it with the resident;
- describe a number of pleasant things for the resident that can be introduced at different care moments: for example, take a walk under guidance, help a resident making himself look fresh and nice;
- describe what you do to prevent worrying situations;
- describe what you do if someone still worries.

You can write your plans in the Pleasant-Activities-Plan (see appendix 2). Next, add your plan to the care file.

#### C. Realize activities

Now start using the Pleasant-Activities-Plan. It is important to support the resident in an emotion-oriented manner. Empathize with the resident and try to consider his background and feelings. Emphasize the importance of the emotion-oriented attitude, also to the family, coworkers and other professionals involved with the resident.

#### D. Evaluate

As soon as the Certified Nurse Assistant starts with the chosen activities she has to watch the client's reaction. In this regard she can use the Observation Form (see appendix 4). Write the client's reaction also in the Pleasant-Activities-Plan.

Keep reporting every day the general reaction of the resident to the chosen activities.

After 1 week, the Certified Nurse Assistant should evaluate the Pleasant-Activities-Plan. She should do this in consultation with coworkers involved, other disciplines involved, the family and the resident. The plan is examined on two aspects: 1) the plan's overall effect: this is done by using formulated objectives, 2) the effect of parts of the plan.

Next, the Certified Nurse Assistant should make a new plan for the next week. She once more reviews the care cycle of the Pleasant-Events-Method in order to make this new plan. In short, this means that she has to adapt or replace the parts of the plan that did not have the desired effect on the resident. The parts that resulted in a good response by the resident can be continued. If the resident has reacted well on the first step of an activity, she can consider to go to the next step, or to repeat the first step. Write the plan down in a new form. Once you have a plan that triggers good reactions of the resident, and when the depressive complaints have reduced, keep following this scheme.

#### Case story

#### Mr Wilson (a fictive case)

Mr Wilson has been in the nursing home for 7 years already. He was slowly getting confused and sometimes he was completely lost. First, he tried to hide his confusion, for example by acting as if he was reading the paper. In the end, he could no longer hide it and he has been officially diagnosed with dementia. Ever since, he is getting more and more passive and depressed, and more and more dependent on care. Often, he does not finish his meals, despite repeated urging by the nurse assistants. Previously, he often went downstairs to drink coffee with the other residents, but now he cannot be motivated to do so. The nurse assistants also have problems getting him out of bed in the morning and he is often found sitting at the table with his head on the table. He seems to have given up. Both the nurse assistants and the Mr Wilson's two daughters have problems accepting this situation. The Certified Nurse Assistant (CAN) who is responsible for Mr Wilson reports that he is She proposes, during care planning, to apply the Pleasant-Events-Method. Her team members agree. The responsible CAN makes an appointment with Mr Wilson and his daughters to introduce the Pleasant-Events-Method. She explains the method and describes what the next steps will be: first she wants to know more about Mr Wilson and his daughters - what he liked to do in the past and what activities occurred in his life. She also wants to know more about Mr Wilson's worries – what worries him and how he coped in difficult situations in the past. The responsible CAN explains that she wants to design a scheme next week, in consultation with coworkers, the occupational therapist and of course Mr Wilson and his daughters, to start pleasant activities and to reduce his worries. She also reports that the daughters can play an important role in this and that she will support them. The responsible CNA hears in this meeting that Mr Wilson used to enjoy gardening most, that he was interested in anything about horses and always kept up with the daily news. The responsible CNA uses this information to make a first Pleasant-Activities-Plan. In this plan, she describes three pleasant activities: take a walk in the garden with guidance, look through books with pictures of horses and listen to the news being read from the local paper. She thinks that Mr Wilson will not be hampered by his limitations caused by dementia. She consults her coworkers, the daughters and Mr Wilson himself about this plan. After consultation the decision is made to put the plan into practice next week. Mr Wilson appears to be less depressed, especially during the planned activities. Whenever he is worrying, the nurse assistants or his daughters ask what he is thinking. Then, they try to

distract him by talking about the items of his Pleasant-Activities-Plan. After a week, the responsible CNA evaluates the plan with Mr Wilson and his daughters, a few coworkers and the occupational therapist. They all report positive experiences, in general, and, therefore, the plan seems to be working. After a few adaptations, they agree to continue in the same way and to evaluate again in two weeks time.

#### THE STEPS IN DEVISING A PLESANT-ACTIVITIES-PLAN

**STEP 1:** Whenever you suspect a resident to be depressed, observe him for a week for depressive complaints or symptoms. Ask coworkers, for example during change of shifts or at a residents meeting, and the family whether they have noticed any signs of depression in the resident, and , if so, which signs.

Then, fill question 2 on appendix 1, the "Pleasant-Activities-Plan" (which aspects are an indication that the resident is sometimes depressed?).

**STEP 2:** What are your objectives with the resident? With your support you can, for example, aim for "the resident does not look worried anymore" or "the resident is not crying every day anymore".

Write also your objectives down in the "Pleasant-Activities-Plan".

**STEP 3:** Elaborate on possible pleasant activities: you can do this by filling in appendix 3 "Life, preferences and pleasant activities in past and present times".

**STEP 4:** You now have created objectives (step 2) and collected information on the resident (steps 1 and 3). Therefore, you can start thinking of (a) pleasant activities for the resident, (b) ways to prevent the resident from worrying and (c) what to do when the resident is still worried.

Next, you fill in the remaining questions on the form "Pleasant-Activities-Plan".

**STEP 5:** Discuss the "Pleasant-Activities-Plan" with coworkers involved and with the family and decide who is going to do which activities at what time.

**STEP 6:** Describe the resident's attitude on the "Observation form reactions to pleasant activities" (appendix 4), before, during and after the pleasant activity.

**STEP 7:** If the resident shows signs of not enjoying the activity, verbally or non-verbally, consult your coworkers and the family to decide how the "Pleasant-Activities-Plan" could be adapted.

**STEP 8:** If a resident worries more in a certain situation than at other times, you must support him in the way described before in question 5 of the "Pleasant-Activities-Plan".

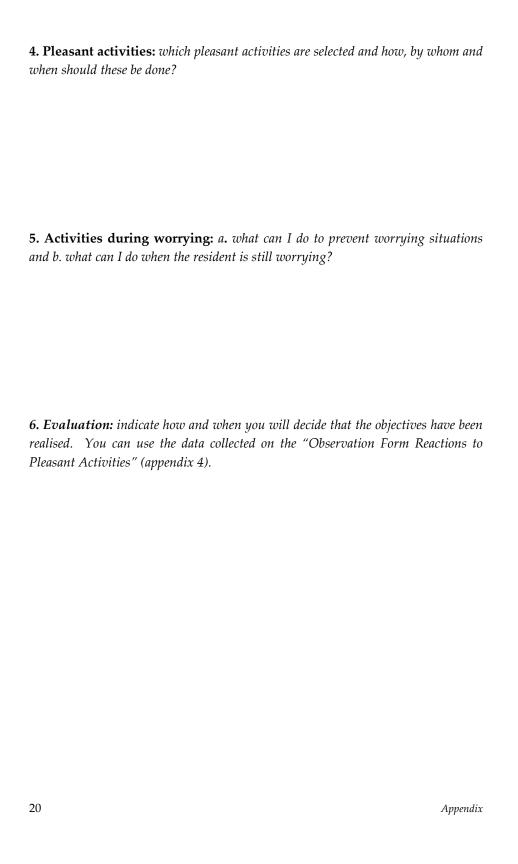
STEP 9: After two weeks of supporting the resident with the "Pleasant-Activities-Plan", look systematically at all reactions of the resident as these have been written down on the "Observation form reactions to pleasant activities" (appendix 4). Additionally, look systematically in other parts of the resident's file what has been written down on the resident's reaction on the different parts of the "Pleasant-Activities-Plan".

Adapt your scheme again where necessary and in consultation with colleagues and the family.

All forms are kept together in the resident's file!

# Appendix 2 PLEASANT-ACTIVITIES-PLAN

Name resident	
Name CNA	
Date of plan development:	
Date of adaption:	
selecting pleasant activities or for	sident. This concerns information relevant for r preventing depressive complaints or symptoms. m "Life, preferences and pleasant activities in the
complaints or behaviour show the	and possible worrying situations: which e resident to be depressed (sometimes)? Are there resident is (extra) depressed or worried?
3. Objective(s): what exactly we and with the pleasant activities be	ould you like to achieve by supporting the resident low?



# LIFE, PREFERENCES AND PLEASANT ACTIVITIES IN PAST AND PRESENT TIMES

Name resident: Name CNA: Date:				
If any data on the resident's life have been gathered before, at the intake or thereafter, please use these data first in this form; do not forget data collected by the occupational therapist or welfare officer				
DATA ON THE PARENTAL I Do you know the family composite the parents, brothers and sis	osition? (if known, also write down the names			
Do you know the father's profe	ession?			
Is the resident still in contact sisters-in-law? (If yes, with whom)	with brothers and sisters/brothers-in-law and			
Were there any dramatic event	s in the past in the parental home?			

# SKILLS AND PROFESSIONAL HISTORY

	courses or studies has the resident taken?
Where	and in which professions has he worked?
	he resident have any special skills or qualities, i.e. in which aspects e excel?
RELA	TIONS AND HOUSING SITUATION
Is the r	resident married or has he been married?
Is the r	resident married or has he been married?  yes, the resident is married to (fill in name)
[] []	yes, the resident is married to (fill in name) no, the resident is not married , but has a long relationship with
[]	yes, the resident is married to (fill in name) no, the resident is not married , but has a long relationship with (fill in name)
[]	yes, the resident is married to (fill in name) no, the resident is not married , but has a long relationship with
[]	yes, the resident is married to
[] []  [] []	yes, the resident is married to
[] []  [] []	yes, the resident is married to
[ ]	yes, the resident is married to
[ ]	yes, the resident is married to
[] [] [] [] relation	yes, the resident is married to

If the resident has children or has had any children, please fill in the names of the daughters and daughters-in-law and the sons or sons-in-law
With whom has the resident the most contact, within or outside the family?
Do these persons visit the resident?
Do they visit the resident at fixed days/times?
Were there any dramatic events in the past within the own marriage or within the family?
DEPRESSION IN THE PAST
Did the resident suffer from any depressive complaints or show any symptoms of depression in the past, i.e. before admission to the nursing home?
How did the resident usually cope during depression or in times of gloominess; did he receive professional help. If so, by whom?

RELIGION OR PHILOSOFY OF LIFE  Does the resident adhere to any philosophy of life or belong to any denomination?
How important is religion/philosophy of life at the moment?
Does the resident feel the need to contact the nursing home's pastora worker?
Does the resident feel the need to contact a pastoral worker of his own church/denomination?
HABITS, LIKES AND DISLIKES
Does the resident have special habits or preferences? Think of eating habits drinking, smoking, the way he looks after himself, does he use make-up toilet visits, is he a morning person or an evening person, how does he communicate with other people, etc.
Does the resident like certain odours?

Does the resident have problems with someone or something or does he dislike someone or something?

## PLEASANT ACTIVITIES IN PAST AND PRESENT TIME

In which activities or subjects was or is the resident interested? Please tick and **clarify** (for example: which music, which card game, which sport or which household tasks).

	past	present	explanation
communication	0	0	
reading books	0	0	
reading the paper	0	0	
reading a magazine	0	0	
writing (letters)	0	0	
watching tv	0	0	
listening to the radio	0	0	
making phone calls	0	0	
watching the news or			
listening to the news	0	0	

	past	present	explanation
flora and fauna	0	0	
plants / flowers	0	0	
forest	0	0	
beach	0	0	
looking at landscapes	0	0	
watching the sky	0	0	
watching the stars/moon	0	0	
listening to sounds in nature	0	0	
garden maintenance	0	0	
pets	0	0	
music listening to music making music singing	past 0 0 0 0 0 0 0	present 0 0 0 0	explanation
	past	present	explanation
sport/moving	0	0	
walking	0	0	
cycling	0	0	
watching sport	0	0	
take part in sport	0	0	
swimming	0	0	
dancing	0	0	

	past	present	explanation
hobbies	0	0	
making clothes	0	0	
needlework	0	0	
creative work	0	0	
drawing/painting	0	0	
photography	0	0	
shopping	0	0	
snooker	0	0	
card game	0	0	
games	0	0	
puzzles	0	0	
collecting	0	0	
good food	0	0	
a tour by car	0	0	
	past	present	explanation
household activities	0	0	
cooking	0	0	
washing the dishes	0	0	
washing	0	0	
dusting	0	0	
laying the table	0	0	
cleaning up	0	0	
	0	0	
	past	present	explanation
going out	0	0	
visiting a pub	0	0	
joining a club	0	0	
theatre	0	0	
cinema	0	0	
travelling/holiday	0	0	
museum/exhibition	0	0	
restaurant	0	0	
going on small trips	0	0	
	0	0	

general	past	present	explanation
politics	0	0	
church and religion	0	0	
meeting new people	0	0	
making friends	0	0	
watching people	0	0	
spend time with family	0	0	
listening to stories told by			
family/friends	0	0	
eating with family/friends	0	0	
visits by friends	0	0	
talking to friends	0	0	
receive/send post	0	0	
going back in time	0	0	
laughing	0	0	
taking a nap	0	0	
getting up early	0	0	
	0	0	
	0	0	
	past	present	explanation
looking after oneself	0	0	
take a shower/bath	0	0	
	•	0	
use make-up	0	0	
use make-up getting one's hair done	0	0	
•			
getting one's hair done	0	0	
getting one's hair done using perfume/aftershave	0	0	
getting one's hair done using perfume/aftershave wearing certain clothes	0 0 0	0	
getting one's hair done using perfume/aftershave	0 0 0	0	
getting one's hair done using perfume/aftershave wearing certain clothes	0 0 0	0	
getting one's hair done using perfume/aftershave wearing certain clothes	0 0 0	0	
getting one's hair done using perfume/aftershave wearing certain clothes	0 0 0	0	
getting one's hair done using perfume/aftershave wearing certain clothes	0 0 0	0	
getting one's hair done using perfume/aftershave wearing certain clothes	0 0 0	0	

#### OBSERVATION FORM REACTIONS TO PLEASANT ACTIVITIES

Name resident: Name CNA:				
<b>NB:</b> In case of mor each activity.	re pleasant activities	s, please fill i	in one observa	tion form for
- C	hort description of ant-Activities-Plan"	-	•	.,

2. Please indicate in the table below the resident's mood, according to your observation, before, during and after the pleasant activity.

Fill in the table in the following way:

- \* First you fill in the date.
- \* Write down **YES** in the box of the date at which you have observed a certain mood to be applicable for most of the time.
- \* When a certain mood is **not** applicable for most of the time, do **NOT** fill in the box; this box remains empty.
- \* When you are unable to judge, fill in ?, i.e. a question mark.
- \* You fill in the table on situations **before**, **during and after** the activity.

MOOD BEFORE THE ACTIVITY	Date	Date	Date	Date	Date
a. Whimpering/sad					
b. Happy/content					
c. Afraid/worried					
d. Confused					

T. I.					
e. Frightened expression					
f. Pondering expression					
g. Worried expression					
h. Apathetic expression					
i. Without emotions/listless					
j. Angry					
k. Defensive					
1. Cheerful expression					
m. Laughing					
MOOD DURING THE ACTIVITY	Date	Date	Date	Date	Date
a. Whimpering/sad					
b. Happy/content					
c. Afraid/worried					
d. Confused					
e. Frightened expression					
f. Pondering expression					
g. Worried expression					
h. Apathetic expression					
i. Without emotions/listless					
j. Angry					
k. Defensive					
l. Cheerful expression					
m. Laughing					
MOOD AFTER THE ACTIVITY	Date	Date	Date	Date	Date
a. Whimpering/sad					
b. Happy/content					
c. Afraid/worried					
d. Confused					
e. Frightened expression					
f. Pondering expression					
g. Worried expression					
h. Apathetic expression					
i. Without emotions/listless					
j. Angry					
k. Defensive					

m. Laughing					
3. Did you observe any reaction <b>verbally</b> , during or after the pleasar the resident liked or disliked the a reactions	nt activit	y that co	uld be a	n indicat	ion that
					_ _ _ _

l. Cheerful expression

# Curriculum Vitae

Renate Verkaik werd geboren op 30 december 1974 te Rotterdam. Zij behaalde in 1993 haar Atheneum-bèta diploma aan de CSG Comenius in Capelle aan den IJssel. In datzelfde jaar startte zij de Psychologie opleiding aan de Universiteit Utrecht en studeerde in 1998 af bij de vakgroep Psychonomie, met als specialisatie Cognitieve Ergonomie. Na haar afstuderen deed ze onderzoek bij de afdeling Mens-Machine Integratie van het Nationaal Lucht- en Ruimtevaart Laboratorium te Amsterdam en bij Research voor Beleid te Leiden. Vanaf 2001 werkt Renate Verkaik bij het NIVEL (Nederlands instituut voor onderzoek van de gezondheidszorg) in Utrecht bij de afdeling Verpleging en Verzorging. In 2002 startte zij met de ontwikkeling van de richtlijn voor verzorgenden 'Het begeleiden van mensen met dementie die depressief zijn', die het hoofdonderwerp van dit proefschrift vormt. In 2003 ontving zij samen met Anneke Francke de ZonMW Stimuleringsprijs voor het ontwikkelen van de handboeken 'Doorbreek depressie bij dementie' in de thuiszorg. In 2005 kreeg Renate Verkaik de mogelijkheid de eerder ontwikkelde richtlijn voor verzorgenden verder te onderzoeken op effectiviteit en randvoorwaarden voor succesvolle invoering.

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246 Dankwoord