

**A stepwise process for developing and implementing  
quality indicators to improve psychosocial dementia care  
in European countries**

For reasons of consistency within this thesis, some terms have been standardised throughout the text. As a consequence the text may differ in this respect from the articles that have been published.

The studies presented in this thesis have been performed at the Scientific Institute for Quality of Healthcare (IQ healthcare). This institute is part of the Nijmegen Centre of Evidence Based Practice (NCEBP), one of the approved research institutes of the Radboud University Nijmegen Medical Centre.

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# **A stepwise process for developing and implementing quality indicators to improve psychosocial dementia care in European countries**

## **Proefschrift**

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# Chapter 1

## General introduction



There is no treatment that can cure any type of dementia or even halt its progression, nor is such a treatment expected to become available in the near future.<sup>1,2</sup> Optimising the quality of life of both patients and their informal carers is one of the most important treatment goals in dementia care, and psychosocial care is essential to this process. Nevertheless, the implementation of evidence-based psychosocial dementia care, which is limited in Europe, needs to be encouraged. This thesis is about the development of a set of quality indicators (QIs) to help implement evidence-based psychosocial dementia care in European countries. This general introduction provides information about the dementia syndrome, the scientific evidence for pharmacological and psychosocial interventions in dementia care, and the role of QIs in improving the quality of health care.

### **Dementia syndrome**

Dementia is one of the leading contributors to the burden of disease in Europe.<sup>3</sup> The estimated number of people with dementia in European countries is more than 7 million, of whom 235,000 are living in The Netherlands.<sup>4,5</sup> Numbers of cases in both Europe and The Netherlands are expected to double by 2050.<sup>4,5</sup>

Dementia is a clinical syndrome with a progressive course that is characterised by a continuous decline of cognitive functions and abilities of the patient to independently perform activities of daily living, such as dressing, bathing, toileting, and eating. This decline is often accompanied by various behavioural and psychological symptoms, such as agitation, apathy, aggressiveness, wandering, sleep disturbances, and anxiety.<sup>6,7</sup> These cognitive, functional, behavioural, and psychological symptoms can make living with and caring for a person with dementia burdensome for family and other informal carers.<sup>8</sup>

Although most Europeans with dementia are cared for at home, institutionalisation is often inevitable as the disease progresses.<sup>5,9</sup> Elderly people with dementia are more likely to live in a long-term care facility at some point than elderly people without dementia.<sup>10</sup> A study in five Western European countries has found that most people with dementia die in a long-term care facility.<sup>11</sup>

### **Pharmacological interventions in dementia**

The interventions that are available for dementia focus on postponing cognitive decline as long as possible, alleviating behavioural and psychological symptoms during the course of the disease, and alleviating informal carers' stress. Pharmacological interventions with cholinesterase inhibitors and memantine have shown little efficacy in postponing cognitive and functional decline, but these findings are only for specific types and stages of dementia. Further, these anti-dementia drugs are not tolerated by all people with dementia.<sup>12-15</sup> A Cochrane review has shown that people with dementia treated with cholinesterase inhibitors had more adverse events (29%) than people with dementia receiving placebo (18%). Nausea, vomiting, and diarrhoea were significantly more frequent among people with dementia being treated with cholinesterase

inhibitors.<sup>12</sup> The number of adverse events was low in people with dementia treated with memantine, but its use could be justified only for the moderate to severe stages of one specific type of dementia, namely Alzheimer's disease.<sup>13</sup>

The value of the improvements that these anti-dementia drugs achieve is debatable. Some conclude that the effects are clinically unimportant or marginal at most.<sup>15,16</sup> Others conclude that anti-dementia drugs can benefit people with dementia, that long-term treatment is effective in stabilising cognitive function, and that withholding treatment from people with dementia would be unethical.<sup>12,17,18</sup>

Studies about the efficacy of the drug therapies that are used to treat behavioural and psychological symptoms of dementia show small or inconclusive effects. In addition, the safety of these drugs has been questioned.<sup>7,19-25</sup> A meta-analysis of the effects of atypical antipsychotic drugs shows that the mortality rate was higher among people with dementia treated with these drugs than among those given placebo: OR 1.54 (95% CI 0.004 to 0.02).<sup>21</sup> The use of these drugs for a relatively short time, 8-12 weeks, had already been associated with a small, but increased, risk of mortality.<sup>21</sup> The specific drug risperidone was associated with an almost four times greater risk of serious cerebrovascular adverse events, including stroke: OR 3.64 (95% CI 1.72 to 7.69).<sup>26</sup> Notwithstanding the debate about the clinical value and the safety issues, pharmacological interventions are monitored closely and people with dementia and their carers are seen on a regular basis. This provides the opportunity of hearing them and giving attention to their problems.

### **Psychosocial interventions in dementia**

Psychosocial interventions are non-pharmacological approaches that are behaviour oriented, emotion oriented, cognition oriented, or stimulation oriented, and involve interaction between people.<sup>27,28</sup> Psychosocial interventions aim to improve the quality of life, and psychological and social functioning, and to maximise function in the context of existing deficits.<sup>27,28</sup> A variety of psychosocial interventions are available for both people with dementia and informal carers (Table).

The evidence base for these types of interventions in dementia care has grown quickly during the last decade.<sup>29</sup> Various psychosocial interventions have proven to be safe and effective treatment options.<sup>30-36</sup> The results of a randomised, controlled trial investigating a cognitive stimulation programme for people with dementia were comparable to the results of treatment with cholinesterase inhibitors for improving cognitive functioning. The cognitive stimulation programme produces no adverse events and has no restrictions to the type of dementia.<sup>30,37</sup> Occupational therapy interventions also have positive effects.<sup>33,38-40</sup> A Dutch intervention programme of occupational therapy for people with dementia and their carers who live in the community improved patients' daily functioning and was cost-effective compared to usual home care.<sup>33,40</sup> However, a German study did not find similar effects for the same occupational therapy intervention.<sup>41</sup>

Systematic reviews of the effectiveness of psychosocial interventions have found that exercise has positive effects on the physical, cognitive, functional, and behavioural outcomes. They have also found that the use of sensory-focused strategies have short-term positive effects on behavioural and psychological symptoms of people with dementia.<sup>31,32,34</sup> Psychosocial interventions, in general, are most effective when they are tailored to the patient's background and preferences.<sup>7,35,36</sup>

Informal carers of people with dementia also benefit from psychosocial interventions. In their systematic reviews, both Brodaty *et al.* and Pinquart and Sörensen found that support programmes for informal carers can reduce their psychological morbidity and feelings of burden. Such programmes also improve their subjective well-being and knowledge.<sup>42,43</sup> A recent Cochrane review finds significant benefits of cognitive reframing interventions on the psychological morbidity, depression, and subjective stress of informal carers.<sup>44</sup> Tailored, structured, and multicomponent interventions aimed at both informal carers and people with dementia can delay the institutionalisation of the patients.<sup>29,42,43,45,46</sup>

Besides evidence for the effectiveness of specific psychosocial interventions, there is also evidence available about the principles of psychosocial dementia care in general. This is largely based on best practice and psychosocial theories and models that try to explain the perspective of both the person with dementia and the carers. Specific psychosocial interventions are often based on these theories and models.

One of the central features of psychosocial dementia care is the preservation of personhood, which is reflected in person-centred care for people with dementia.<sup>55-57</sup> Furthermore, psychosocial dementia care should promote the well-being and quality of life of a person with dementia and their carer at any stage of the disease while taking the existing deficits into account. In essence, providing psychosocial dementia care includes meaningful interaction and communication with the person with dementia, awareness of their possible needs, preservation of their dignity and autonomy, and social inclusion of both the person with dementia and their carer.<sup>28,55,58-61</sup> The use of specific psychosocial interventions is essential to psychosocial dementia care.

### **Psychosocial dementia care in Europe**

Psychosocial interventions are recommended as the first treatment option for various symptoms of dementia.<sup>7,24,47</sup> Despite this fact, much uncertainty still exists about the availability of psychosocial interventions and the use of psychosocial dementia care across Europe. Psychosocial dementia care does not seem to be appreciated in the same way and does not seem available on the same scale as medical and pharmacological care. Anti-dementia drugs are available in most European and other Western countries, whereas effective psychosocial care remains under-promoted.<sup>9,62,63</sup> Psychosocial interventions are recommended less often than pharmacological interventions, their limited availability being one of the reasons.<sup>64,65</sup> To improve

the quality and availability of psychosocial dementia care in Europe, its implementation needs encouragement.

**Table. Examples and descriptions of psychosocial interventions for people with dementia and their informal carers**

Target group	Treatment	Description
<i>People with dementia</i>	Cognitive stimulation Reality orientation	Exposure to and engagement with activities and materials involving some degree of cognitive processing, usually within a social context. The intervention is often group-based, with the emphasis on enjoyment of activities. <sup>47</sup>
	Cognitive training	Training exercises geared to specific cognitive functions, and practice and repetition of these exercises; a range of difficulty levels may be available within the standard set of tasks to suit the individual's ability. May be offered in individual or group sessions. <sup>47,48</sup>
	Environmental interventions	The creation of safe and secure, simple, well-structured, and familiar environments that provide cues, support in daily activities, and privacy for people with dementia. <sup>49</sup>
	Physical activity Exercise training	Exercise programme or form of rehabilitative exercises, physical activity, fitness, or recreational physical therapy. <sup>31</sup>
	Reminiscence	Regular individual sessions or meetings of small groups involving the discussion of past activities, events, and experiences, possibly aided by means such as photographs, music, and videos of the past, household and other familiar items from the past. <sup>50</sup>
	Sensory stimulation Snoezelen	Providing sensory stimuli to the primary senses of sight, hearing, touch, taste, and smell through the use of lighting effects, tactile surfaces, meditative music and the odour of relaxing essential oils. <sup>51</sup>
	Validation	The acceptance of the reality and personal truth of another's experience. Providing a high degree of empathy and an attempt to understand a person with dementia's entire frame of reference. The approach can be used as a structured therapeutic activity in a group setting or it can be used on an individual basis. <sup>47,52</sup>
<i>Informal carers</i>	Cognitive reframing	Group or individual programmes to alter maladaptive, self-defeating or distressing cognitions of informal carers relating to their beliefs about their responsibilities to the person with dementia, their own need for support, and why their relatives behave as they do; and to make them more adaptive to the caring situation. <sup>44</sup>
	Psycho-education	Programmes for individuals or groups of informal carers that involve learning how to react to and interact with a person with dementia. <sup>47</sup>
	Respite care	Any service or group of services designed to provide temporary periods of relief and/or rest for informal carers, ranging from a couple of hours to a number of weeks. It can take place in the home of the person with dementia, a daycare centre, or a residential setting and may be provided by trained or untrained staff or volunteers. <sup>53</sup>
	Support groups	Group sessions led by professionals that can provide mutual support, information, and education. <sup>54</sup>
<i>People with dementia and informal carers</i>	Occupational therapy	People with dementia and informal carers learn compensatory strategies to improve the ability to perform activities of daily living, promoting independence, participation in social activities, and increasing the carer's sense of competence. <sup>33</sup>

### **Quality indicators to improve the quality of psychosocial dementia care**

An important step in any effort to implement scientific evidence in practice and hence, improve the quality of health care, is the development of clinical practice guidelines and QIs.<sup>66</sup> Clinical practice guidelines assist health care professionals in making decisions about appropriate health care for diseases or conditions.<sup>67</sup> They state the 'right thing to do' in specific clinical circumstances on the basis of the best available scientific evidence.<sup>66,68</sup> Quality indicators are explicitly defined and measurable elements of practice performance for which there is evidence, or at least consensus, that they can be used to assess improvement and change in the quality of care provided.<sup>66,68-70</sup> Whereas guidelines help professionals to decide during the provision of care, QIs are used to measure adherence to clinical guidelines and to measure, monitor, and improve the quality of care provided by health care professionals and organisations.<sup>68,70,71</sup>

Quality indicators are most often expressed as a numerator and a denominator. The numerator usually describes the number of correct or desired health care actions within the target population. The denominator usually describes the size of the target population.<sup>66</sup> Based on Donabedian's framework for assessing the quality of health care, a quality indicator usually describes and assesses one of the following aspects of care: structures, processes, or outcomes.<sup>66,71-73</sup> Quality indicators that focus on structures of care refer to the organisational aspects of service provision; QIs that focus on processes of care refer to the actual care delivered to and negotiated with patients; QIs that focus on outcomes of care refer to the ultimate goal of the care given.<sup>66,72-74</sup> In general, the use of process indicators is important for achieving quality improvement in health care. Outcome indicators are more often used for purposes of external accountability.<sup>66,68</sup>

Developing a European set of QIs for psychosocial dementia care would enable European dementia care professionals to measure their practice performance and improve the quality of the psychosocial care they provide in daily practice. Such a set of QIs should include measurable key elements for providing psychosocial interventions based on scientific evidence and dementia guidelines, and the set should capture the essence of psychosocial dementia care in general. European sets of QIs have already been developed for measuring the quality of general practice management and cardiovascular care in European countries.<sup>75-77</sup>

### **Developing a set of quality indicators**

A set of QIs can be based on existing sets of QIs, recommendations from evidence-based clinical guidelines, scientific evidence from literature, best practice, consensus among experts, or a combination of these.<sup>66,68,70</sup> The developers of a set of QIs should consider whose perspective the QIs should reflect, which aspects of care should be assessed, and what evidence is available.<sup>68,70</sup> Ideally, QIs are based on high-quality scientific evidence that increases their potential to improve the quality of health care.<sup>66,68,70</sup> However, evidence bases are limited for most health care areas, and consensus among experts in the field needs to be included in the development. Consensus



techniques that are often used for developing QIs are the Delphi technique, the RAND appropriateness method, and the Rand-modified Delphi technique.<sup>66,68,70</sup>

Face and content validity of QIs and their adherence to characteristics such as applicability, measurability, reliability, sensitivity to change, and predictive validity are required to maximise the potential of a set to improve the quality of health care.<sup>66,68,70</sup> Face and content validity is the minimum prerequisite for QIs and concerns the extent to which QIs accurately represent the concept they are supposed to measure. The use of expert panels and clinical guidelines during development leads to QIs with high face validity. Sets of QIs based on rigorous evidence have high content validity. Adherence of the QIs to characteristics relating to their application and feasibility in practice should be established with empirical evidence.<sup>66,68,70</sup>

### **Developing European quality indicators for psychosocial dementia care**

The development of a set of QIs for psychosocial dementia care on a European level was one of the aims of the European Collaboration on Dementia project (EuroCoDe, 2006–2008), which was initiated and led by Alzheimer Europe.<sup>62</sup> This thesis about the development of QIs for psychosocial dementia care was produced as part of this project.

The process of developing the European set of QIs had to fit into the 3-year time frame of the EuroCoDe project. Basing the QIs on existing sets of QIs would have been the most time efficient, but the sets of QIs for dementia care already developed and published focus mainly on diagnostics, screening, and pharmacological treatments.<sup>78-81</sup> Quality indicators for psychosocial dementia care were not yet available and needed to be newly developed.

The principal stakeholders of the set of QIs were European dementia care professionals and their perspectives on quality of psychosocial dementia care had to be represented by the QIs. As our goal was to encourage quality improvement of psychosocial dementia care, processes of care seemed the most appropriate entities to assess with the QIs.<sup>66,68</sup> High-quality scientific evidence is still limited for specific psychosocial interventions and psychosocial dementia care in general, and consensus among European dementia experts was needed for the development of the QIs.<sup>66,68,70</sup> We used a step-wise procedure for developing the QIs to attain face and content validity, measurability, and applicability of the set. The procedure was built on scientific evidence from literature and dementia guidelines, consensus among European dementia care experts, and a small-scale pilot study to test the QIs in practice.

## **Aims and outline of this thesis**

### *Aims and research questions*

The primary aim of this thesis was to describe the development and evaluation of a set of QIs for psychosocial dementia care. More specifically, this set of QIs should be:

- Representative of the standard of psychosocial dementia care based on scientific evidence, best practice, and theories and models of psychosocial care.
- Applicable to people with dementia and their carers in various European countries.
- Measurable in and applicable to the various settings where dementia care is provided in various European countries.

The following research questions were formulated and used to develop and evaluate the European set of QIs for psychosocial dementia care:

1. What gaps exist in the evidence base for psychosocial dementia care, and can these gaps be filled on the basis of the available evidence?
2. To what extent is evidence for psychosocial dementia care included in European dementia guidelines for care professionals?
3. What evidence-based key elements represent psychosocial dementia care of good quality and therefore should be included in the set of QIs?
4. Is such a set of QIs applicable to people with dementia and their carers in various European countries?
5. Is such a set of QIs measurable in and applicable to different settings where dementia care is provided?
6. What are the barriers and facilitators in implementing such a set of QIs in various European countries?

### **Outline of this thesis**

This thesis describes the various steps in the process of developing the set of QIs for psychosocial dementia care. Each of the Chapters 2 to 5 addresses one or more of the above-mentioned research questions.

First, a review of systematic reviews was conducted. This identified a paucity of literature reviews that specifically aim at the effectiveness of psychosocial interventions for people with dementia living in residential and nursing homes.<sup>82</sup> A systematic review was therefore conducted to study the effects of these types of interventions in residential and nursing homes on the communication between residents with dementia and care staff, and the neuropsychiatric symptoms of residents. Chapter 2 presents the results and conclusions of this systematic literature review.

Second, the dementia guidelines that are available in European countries were inventoried. Chapter 3 presents the results of the inventory, a comparison of the methodological quality, and the recommendations for specific psychosocial interventions in these guidelines.

Third, the available evidence from the literature and recommendations from evidence-based dementia guidelines were used to conduct a RAND-modified Delphi procedure that included two dementia expert panels. The purpose of this was to achieve content and face validity of a potential set of QIs. Dementia care professionals from various European countries then discussed these QIs face to face and tested them in practice. In addition, the measurability and applicability of the set of QIs were tested in various dementia care settings in Spain and The Netherlands. Chapter 4 presents the results of this work and the final set of QIs for psychosocial dementia care.

Fourth, focus-group interview sessions were used in a qualitative study to explore the barriers and facilitators in implementing the final set of QIs in various European countries. A purposive sample of 27 dementia care professionals from nine European countries and various disciplines was included. A model of barriers and facilitators for change at six levels of health care was used as a framework for organising the data. Chapter 5 presents the results of this study and the proposed implementation strategy.

Finally, Chapter 6 discusses the stepwise process of developing and evaluating the set of QIs for psychosocial dementia care and its importance for dementia research and practice.

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# **Chapter 2**

## **A systematic review of communication strategies for people with dementia in residential and nursing homes**



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**Abstract**

*Introduction:* The impairment of verbal skills of people with dementia challenges communication. The aim of this review was to study the effects of nonpharmacological interventions in residential and nursing homes on (1) communication between residents with dementia and care staff, and (2) the neuropsychiatric symptoms of residents with dementia.

*Methods:* Pubmed, PsychInfo, Web of Science, the Cochrane Library, and reference lists from relevant publications were systematically searched to find articles about controlled interventions with communication strategies. The data collected were pooled and subjected to a meta-analysis.

*Results:* Nineteen intervention studies were selected for this review. They included structured and communicative “sessions at set times” for residents (e.g. life review) and communication techniques in activities of “daily care” applied by care staff (e.g. sensitivity to nonverbal communication). A meta-analysis of five set-time interventions (communication) and another meta-analysis of four set-time interventions (neuropsychiatric outcomes) found no significant overall effects. Individual set-time intervention studies report positive effects on communication when interventions are single-task sessions, like life review or one-on-one conversation. Interventions around daily care activities had positive effects on communication outcomes. Effects of both types of interventions on neuropsychiatric symptoms were divergent.

*Conclusion:* This review indicates that care staff can improve their communication with residents with dementia when strategies are embedded in daily care activities or interventions are single-task sessions at set times. These results offer the possibility of improving the quality of care, but not of directly reducing neuropsychiatric symptoms. More research is needed to study the effect of communication interventions on neuropsychiatric symptoms.

## Introduction

Currently, about 2 million Europeans are diagnosed with dementia every year.<sup>1</sup> Most of these people continue to live in the community, but various cognitive and neuropsychiatric symptoms become more pronounced as the disease progresses and contribute to placement in institutionalised care.<sup>2,3</sup> Although intensive support programs for people with dementia and their carers can delay institutionalisation<sup>4</sup>, about 70% of these people in the Netherlands are eventually placed in a residential or nursing home.<sup>5</sup>

While caring for one person with dementia can be a difficult task, caring for a group of patients can be a real challenge. Neuropsychiatric symptoms are very common, and more than 80% of the cognitively impaired nursing-home residents in the Netherlands have at least one clinically significant neuropsychiatric symptom.<sup>6</sup> The most frequently observed behaviours (prevalences of 30–35%) are aggression/agitation, apathy, and irritability. In other countries, similar incidences of these behaviours occur among people with dementia whether they are institutionalised or not.<sup>7,8</sup> Care staff find it difficult to cope with the aggressive, hostile, stubborn, resistant, and unpredictable behaviour of residents<sup>9</sup>, so that working with cognitively impaired people is associated with much stress.<sup>10</sup>

Unmet needs can trigger neuropsychiatric symptoms<sup>11</sup>, as can language disorders<sup>12</sup>, discomfort, or pain. The residents' impaired communication skills make it very difficult for care staff to identify and address the source of the disturbed behaviour.

Antipsychotic drugs are frequently used in dementia care to treat neuropsychiatric symptoms<sup>13</sup>, but these medications only relieve the symptoms and do not treat the underlying causes of the behaviour. Furthermore, these drugs are known to cause serious side effects (e.g. stroke or increased mortality rates), and are not suitable for routine use.<sup>14</sup> Nonpharmacological interventions are preferred to drugs in the treatment of neuropsychiatric symptoms.

Interventions therefore need to be investigated to encourage and ease communication between care staff and residents. Communication is achieved by speech, writing, gesture, posture, gaze, affect, and intonation. These are specific to the place and purpose, or the context, of the communication. Care staff need to be aware of how residents signal the need to communicate and how to react to the signals.

Several reviews about the use of nonpharmacological interventions in dementia care have recently been published<sup>15-17</sup>, but these do not focus on people with dementia in institutional care or the effects of communication strategies on neuropsychiatric symptoms.

The aims of this systematic review were to appraise (1) the effectiveness of communication enhancing interventions for the care staff and/or residents with dementia in institutional care settings, and (2) the effects of these interventions on neuropsychiatric symptoms.

## Methods

### *Search strategy*

We searched Pubmed, PsychInfo, and Web of Science (1980–February 2007) for controlled, nonpharmacological, intervention studies that included institutionalised people with dementia and/or care staff. The following search strategy was used:

- (communication OR interaction)
- AND (nursing homes OR nursing home OR residential facilities OR residential facility OR hospitals OR hospital OR institutionalized OR institutionalised OR inpatient OR inpatients OR long-term care OR geriatric nursing OR in-patients OR patients OR residents OR ward OR wards OR “care unit” OR “care units” OR residential OR “assisted living” OR in-patient)
- AND (vascular dementia OR lewy body disease OR alzheimer’s OR alzheimer OR “Alzheimer Disease” [MeSH] OR “Lewy Body Disease” [MeSH] OR “Dementia, Vascular”[MeSH] OR “Dementia” [MeSH: noexp])
- AND (controlled OR trial).

We also identified trials in an additional search of the Cochrane Library in February 2007 using the words Dementia [MESH] AND interact\* OR communicat\*, and we reviewed the references of the studies we included to identify any other relevant studies.

### *Inclusion criteria*

The studies to be included in this review had to meet all of the following criteria:

1. *Type of study*: a randomised or nonrandomised controlled trial with the full text obtainable in English or Dutch. A randomised or nonrandomised controlled trial was defined as a study that compared the results from the intervention group to the results from one or more comparison groups receiving the usual intervention or no intervention at all; or a standardised, comparable intervention without the communication component.
2. *Participants*: people with dementia living in residential care homes or in nursing homes and/or professional carers working in long-term care facilities with people with dementia. The inclusion criteria for the trial required a diagnosis of dementia or screening for cognitive impairment of resident participants. If groups of residents were mixed with nonresidents, at least 80% of the participants had to be residents or else their separate results needed to be available.
3. *Intervention*: an intervention aimed at improving the communication of participants. Multi-component interventions had to include a communicative component. Communication was defined as sharing information by speaking, writing, body movements, or other signalling behaviour.
4. *Outcomes*: at least one outcome measure was required to address the quantity and/or quality of communication performance or else no productive communication (e.g. apathy or noncompliance) of the participants.

Reviews of trials, pharmacological interventions, and studies in which the participants served as their own control group were excluded.

### *Screening the studies*

Two independent reviewers (EV and MVD) assessed the candidate studies for inclusion in three screening rounds. During the first round, they screened articles by title and type of article to determine whether they met the inclusion criteria. In the second round (abstracts) and the third round (full text), they screened the remaining articles if the abstract or full text was available. Studies that failed to meet the inclusion criteria were excluded. In cases of doubt, the articles were included in the next review round.

### *Quality of the studies*

Two researchers (EV and AS) assessed the methodological quality of the studies independently and discussed the results for consensus. They assessed the following criteria, after Higgins and Green<sup>18</sup>, to check for differences in methodological quality between studies: selection bias (method of randomisation, allocation concealment, inclusion/exclusion criteria specified, and similarity of groups at baseline), performance bias (assessors blinded to outcome), attrition bias (characteristics of participants lost to follow-up described, and intention-to-treat analysis), and detection bias (power calculation and valid outcome measures). Blinding of participants was not included as a quality criterion because it is impossible for the types of interventions included in this review.

### *Data collection and analysis*

First, the characteristics of the interventions and outcome measures used for communication and neuropsychiatric symptoms were extracted from the articles. The interventions were then sorted by type so that we could extract their effectiveness on communication and neuropsychiatric symptoms, when data were available.

We performed a meta-analysis using the Cochrane Collaboration Group's Review Manager 5 (The Cochrane Collaboration, Copenhagen, Denmark) when two or more studies were randomised controlled trials and the outcome measures and type of intervention could be compared. Because of the continuous nature of the data and differences in the outcome measures used, we calculated a standardised mean difference (SMD), which is a uniform standardised score, to compare the data from experimental groups with the data from the control groups. We calculated SMDs (for the experimental group and the control group) as the difference between the mean change in communication or neuropsychiatric symptoms, before and after the intervention, divided by the standard deviation of the difference.

If a measurement was repeated, the data from the first measurement after the intervention were used as post-intervention data in the meta-analysis. In case multiple intervention and/or control

groups were included in a study, these groups were combined and included as a single group in the meta-analysis.<sup>18</sup>

Statistical significance was set at  $p < 0.05$ . We set up a fixed-effects model for each meta-analysis. If the statistical heterogeneity, as calculated by the I<sup>2</sup> statistical test, was significant ( $p < 0.05$ ), the analyses were repeated with the random-effects model.<sup>18,19</sup> Significant between-group effects for both communication or neuropsychiatric symptoms of intervention studies that could not be included in the meta-analyses were described separately for each type of intervention study.

## Results

### *Search results*

The search retrieved 721 articles that met the search criteria. After we excluded reviews and pharmacological trials, 488 articles remained. The first screening round resulted in 85 titles of articles that met the inclusion criteria or raised doubt. We screened the abstracts of these 85 articles, and 35 articles remained for full-text assessment in the final screening round. Thirteen of the 35 articles did not meet the inclusion criteria; thus, 22 articles describing 19 different intervention studies were included in this review.

### *Description of the studies*

We identified two overall “types” of interventions within the 19 studies. The first type (10 studies) is a communicative session or intervention for residents carried out by a trained specialist or staff member at a “set-time session”. The aim of the second type (9 studies) was to teach care staff to apply communication techniques in daily care activities, the “daily-care” intervention.

The ten set-time sessions or interventions included a walking program combined with conversation<sup>20-22</sup>, group validation therapy<sup>23,24</sup>, life review programs<sup>25,26</sup>, cognitive stimulation therapy<sup>27,28</sup>, and activity therapy.<sup>29</sup> Table 1 shows the study characteristics of the set-time intervention studies. The number of participating residents in each study ranged from 30 to 201, and the severity of the dementia ranged from moderate (mean study group Mini-mental State Examination (MMSE) score 18.6) to severe (mean study group MMSE score 6). The intervention period varied from 6 to 52 weeks.

The nine daily-care intervention studies consisted of training programs aimed solely at teaching care staff communication techniques<sup>30-35</sup> or multicomponent training or educational programs that also included communication techniques.<sup>36-40</sup> Table 2 shows the study characteristics of the daily-care intervention studies. The numbers of residents varied from 22 to 194, and the numbers of staff members varied from 31 to 124. One study trained specially hired certified nurses to carry out the intervention.<sup>39</sup> The mean study group MMSE score was less than 10 in four studies, indicating that the participants were in a severe stage of dementia.<sup>30,32,38,40</sup> The other five studies included participants with moderate or mild, as well as severe, dementia. All daily-care intervention studies started with a training period for the care staff.

After this period, the intervention was implemented in daily care. Seven studies assessed outcome measures at several times after implementation, varying from 2 weeks to 12 months.<sup>30,32,33,36-40</sup> Each of two studies had only one post intervention assessment of outcomes, which took place at four weeks<sup>31</sup> and 18 months.<sup>34,35</sup>

### *Methodological quality*

There were great differences in the methodological quality of the studies. None of the 19 studies fulfilled all nine quality items. Table 3 shows the results of the quality assessment and the total quality score for each study. The decision whether the criteria were fulfilled or not was based on the information provided in the article, and if this information was inadequate, the decision was labeled “unknown”. Overall, the quality of the daily care intervention studies seemed poorer (mean fulfilled criteria  $3.7 \pm 1.6$ ) than the quality of the set-time studies (mean fulfilled criteria  $4.5 \pm 2.1$ ).

### *Effects of the interventions on communication*

Five set-time studies, which also had the highest scores for total quality, used quantitative outcome measures for communication that could be compared.<sup>20,21,26,27,29</sup> The data from these studies were pooled in a meta-analysis, and a total of 371 residents with dementia (193 in experimental groups and 178 in control groups) were included. The study by Cott *et al.* had two control groups<sup>21</sup>, and we combined data from both groups before we entered them in the meta-analysis.<sup>18</sup> Standardised mean differences (SMDs) were calculated, and we chose the random-effects model because of the heterogeneity-of-treatment effects across studies ( $\chi^2 = 24.59$ ,  $df = 3$ ,  $p = 0.0001$ ,  $I^2 = 84\%$ ). The estimated overall effect was not significant for the treatment groups (SMD = 0.53, 95% CI = -0.07– 1.14,  $p = 0.09$ ; Figure 1).

Among the set-time studies that were not included in the meta-analysis, a group life review intervention found a significant improvement in social interaction for the experimental group<sup>25</sup>, and a walk-and-talk intervention showed significant positive effects for the conversation only group.<sup>22</sup> The other three set-time intervention studies did not show any significant effects on communication outcomes.

It was not possible to pool data for communication outcome data for the daily care intervention studies because the only two studies that fulfilled the quality criterion for randomisation did not use communication outcomes that were suitable for a meta-analysis.<sup>32,40</sup>

Four of the daily-care intervention studies included a multicomponent training and education program for care staff that had a communication component.<sup>36-40</sup> Positive effects on communication were found in all of these studies. Effects on interactive behaviours, nurse–patient cooperation style, and nursing assistants maintaining their communication skills were evident for professional carers. Effects on residents were found for positive affect and interactive behaviour.

**Table 1. Characteristics and findings of set-time studies**

Author/Year	Intervention and comparison	Study design/ Length	N	Outcome measures	Significant between group effects *
Friedman and Tappen, 1991	T: Conversation during planned walking; 30 min 3 times/week C: Conversation only; 30 min 3 times/ week	RCT 10 weeks	R: 30 S: -	Cm: CAS; COS NPS: -	COS ( $p < 0.007$ )
Politis <i>et al.</i> , 2004	T: Individual, standardised, structured activity; 30 min 3 times/week C: One-on-one unstructured interactions; 30 min 3 times/week.	RCT 4 weeks	R: 36 S: -	Cm: NPI apathy NPS: total NPI	None
Spector <i>et al.</i> , 2003	T: CST, 14 group sessions; 45 min/session, twice a week C: Usual activities	RCT 7 weeks	R: 201 S: -	Cm: HCS NPS: CAPE-BRS; RAID	None
Cott <i>et al.</i> , 2002	T: Walk-and-talk intervention in resident pairs; 30 min 5 times/week C <sub>1</sub> : One-on-one conversation with RA; 30 min 5 times/week C <sub>2</sub> : Usual activities	RCT 16 weeks	R: 86 S: -	Cm: FACS NPS: LPRS-SIB	None
Haight <i>et al.</i> , 2006	T: Life review delivered by care assistants; approximately 8 h total C: Usual care	RCT 6 weeks	R: 31 S: 15	Cm: COS NPS: MBP	COS ( $p < 0.005$ )
Toseland <i>et al.</i> , 1997	T: Validation therapy group; 30 min 4 times/week C <sub>1</sub> : Social contact group, one activity each meeting; 30 min 4 times/ week C <sub>2</sub> : Usual care	RCT 52 weeks	R: 88 S: -	Cm: MOSES NPS: CMAI-O; CMAI-N; GIPB	CMAI-O verbal aggression ( $p < 0.01$ ; $C_1$ vs $T+C_2$ ) CMAI-N verbal aggression ( $p < 0.01$ ) physical aggression ( $p < 0.001$ ) physical nonaggression ( $p < 0.01$ ; $C_{1+2}$ vs $T$ )
Orrel <i>et al.</i> , 2005 (also Spector <i>et al.</i> , 2003)	T: Participants in CST groups + maintenance CST sessions C <sub>1</sub> : Participants in CST groups + no maintenance CST sessions C <sub>2</sub> : No intervention	CT 16 weeks	R: 35 S: -	Cm: HCS NPS: CAPE-BRS	None
Tappen <i>et al.</i> , 2002	T: Combined walking and conversation; 30 min 3 times/week C <sub>1</sub> : One-on-one conversation; 30 min 3 times/week C <sub>2</sub> : Walk-only, self-paced, independent or assisted; 30 min 3 times/ week	RCT 16 weeks	R: 55 S: -	Cm: Picture description test	Mean number of information units ( $p < 0.043$ ; $C_1$ vs $T+C_2$ ) Conciseness score ( $p < 0.010$ ; $C_1$ vs $T+C_2$ )
Tabourne, 1995	T: Life review groups; twice a week C: Week 1 and week 12, participation in treatment group Weeks 2-11, recreation activities similar to those used in treatment group but without protocol or cueing for reminiscence	QE-CT 12 weeks	R: 40 S: -	Cm: Observation of behaviour during sessions; Sociograms: communication patterns; Changes in attendance and	Decrease of disorientation ( $p < 0.001$ ) Improvement in social interaction ( $p < 0.001$ )



Author/Year	Intervention and comparison	Study design/ Length	N	Outcome measures	Significant between group effects *
				participation during activities NPS: Checklist of general behaviour	
Tondi <i>et al.</i> , 2007	T: Individual and group validation therapy C: Usual care	CT 4 months	R: 60 S: -	Cm: NPI apathy NPS: total NPI	No statistical tests used

\* Significant effects in favour of treatment group unless otherwise stated.

C= Control group; CAPE- BRS = Clifton Assessment Procedures for the Elderly- Behaviour Rating Scale; CAS = Communication Assessment Scale for the Cognitively Impaired; Cm = Communication ; CMAI-N = Cohen Mansfield Agitation Inventory - Nursing staff-derived; CMAI-O = Cohen Mansfield Agitation Inventory - Observer-derived; COS = Communication Observation Scale for the Cognitively Impaired; CST= Cognitive Stimulation Therapy; CT = Controlled trial; FACS = Functional Assessment of Communication Skills for Adults; social communication and communication of basic needs relative to the independence dimension; GIPB = Geriatric Indices of Positive Behaviour; HCS = Holden Communication Scale; LPRS-SIB = London Psychogeriatric Rating Scale - Socially irritating behaviour; MBP = Revised Memory and Behaviour Problem Checklist; MOSES = Multidimensional Observation Scale for Elderly Subjects; irritability and withdrawal scales; NPI = Neuropsychiatric Inventory; NPS = Neuropsychiatric symptoms; QE-CT = Quasi-experimental controlled trial; R = Residents; RA = research assistant; RAID = Rating Anxiety in Dementia; RCT = randomised controlled trial; S = care staff; T = treatment group

**Table 2. Characteristics and findings of daily care studies**

Author / Year	Intervention	Study Design	N	Outcome measures	Significant between group effects
Magai <i>et al.</i> , 2002	T: Training professional carers in nonverbal sensitivity; 2 weeks, 10 times 1h C <sub>1</sub> : Behavioural placebo, sessions for professional carers about cognitive and behavioural aspects of dementia; no specific attention to patient affect C <sub>2</sub> : No treatment control group	RCT	R: 99 S: 31	Cm: Facial expressions of emotion during interview for positive and negative affect (R) NPS: CMAI (R)	None
van Weert <i>et al.</i> , 2005, 2006	T: NAs were trained in snoezelen by professional trainer; Training: 4 times 4-h in-service sessions and homework C: Usual care	QE-CT	6 NH's 12 wards	Cm: Eye contact (R + S); Smiling (R + S); Affective touch (S); Positive and negative affective and instrumental verbal communication (R + S)	R: NA-directed gaze ( $p < 0.01$ ) Smiling ( $p < 0.05$ ) Negative affective verbal behaviour ( $p < 0.05$ ) S: R-directed gaze, affective touch and smiling ( $p < 0.001$ ) Positive instrumental and affective verbal behaviour ( $p < 0.001$ ) Negative instrumental and affective verbal behaviour ( $p < 0.001$ )
Beck <i>et al.</i> , 2002	T <sub>1</sub> : ADL intervention respecting R cognitive and physical abilities carried out by project NA; 45-60 min/day for 12 weeks T <sub>2</sub> : PSA-intervention involving 25 modules designed to meet psychosocial needs through engagement in meaningful activity; 12 weeks, R eventually participated 30+ min T <sub>3</sub> : Both ADL and PSA interventions; 90+ min/day for 12 weeks C <sub>1</sub> : One-to-one interaction with project NA; 30 min/day for 12 weeks C <sub>2</sub> : Usual care	CT	R: 179 S: -	Cm: DBS; AARS; Observable displays of affect scale; Positive VAS for affect; Negative VAS for affect	Positive affect ( $p < 0.001$ ) (facial expressions, body posture/movements, contentment, interest)
Burgio <i>et al.</i> , 2002	T + C: 4 weeks of behaviour management training with knowledge and performance-based assessments of skill acquisition T: Formal staff management after training phase including additional training and feedback from supervisory care staff C: Usual supervisory system after completing training phase	RCT	R: 88 S: 106	Cm: Occurrences of residents and staff interaction behaviours; BMSC (S) NPS: CMAI (R)	S: maintaining communication skills more effectively 6 months after training ( $p < 0.05$ )
Finnema <i>et al.</i> , 2005	T: Emotion-oriented care applied by trained NAs; 9 months C: Usual care	CT**	14 NH's 16 wards	Cm: Questionnaire social Relationships (R)	None

			R: 194 S: 124	NPS: CMAI (R) BOS-IP (R)	
Wells <i>et al.</i> , 2000	T: Educational program for professional carers; 5 20–30 min sessions C: Usual care	QE-CT	R: 56 S: 44	Cm: MIBM (R) IBM (S) NPS: PAS (R) LPRS (R)	R: MIBM ( $p < 0.046$ ) (more positive and appropriate interactions) PAS ( $p < 0.019$ ) NA: Interactive behaviours ( $p < 0.005$ ) (verbal relevance, personal-attending, relaxed, and social/flexible behaviours)
McCallion <i>et al.</i> , 1999	T: NAs communication skills program; 5 45-min group sessions and 4 individual conferences of 30 min each C: No intervention	CT***	R: 105 S: 88	Cm: MOSES (R) NPS: CMAI (R)	CMAI physical nonaggressive behaviour ( $p < 0.001$ ) CMAI verbal aggressive behaviour ( $p < 0.001$ )
Edberg <i>et al.</i> , 1996; 2001	T: Implementation of supervised individualised planned care C: Usual care	QE-CT	R: 22 S: 39	Cm: Nurse–patient cooperation style from morning care observation NPS: DBAS (R); MDDAS (R)	Nurse–patient cooperation style ( $p < 0.001$ )
Dijkstra <i>et al.</i> , 2002	T: Package of communication enhancing strategies, including memory books and a communication intervention for NAs C: Not mentioned	CT	R: 66 S: 40	Cm: Discourse characteristics from transcripts of conversations between R and NA	Discourse characteristics R: ( $p < 0.05$ ) (information units, indefinite and unique words, repetitions) S: ( $p < 0.02$ ) (more facilitators, encouragement, cues)

\* Significant effects in favour of treatment group unless otherwise stated; \*\* Multi-sited, matched groups; \*\*\* Randomised by nursing home unit

AARS = Apparent affect rating scale; ADL = Activities of daily living; BMSC: Behaviour Management Skills Checklist; BOS-IP = Behaviour Observational Scale for Intramural Psychogeriatrics; C = Control group; Cm = Communication CMAI = Cohen Mansfield Agitation Index; CT = Controlled trial; DBAS = Demanding Behaviour Assessment Scale; DBS = Disruptive behaviour scale; IBM = Interaction Behaviour Measure; LPRS = London Psychogeriatric Rating Scale; MDDAS = Multi-Dimensional Dementia Assessment Scale two subscales used: behaviour and psychiatric symptoms; MIBM = Modified Interaction Behaviour Measure; MOSES = Multidimensional Observation Scale for Elderly Subjects; NA: Nursing assistant; NH = Nursing home; NPS = Neuropsychiatric symptoms; PAS = Pittsburgh Agitation Scale; PSA = Psychosocial activity; QE-CT: Quasi-experimental controlled trial; R = Residents; RCT = Randomised controlled trial; S = Care staff; T = Treatment group; VAS = Visual Analogue Scale

**Table 3. Quality assessment and total score of included studies**

	A	B	C	D	E	F	G	H	I	Total
<b>Set-time studies</b>										
Friedman and Tappen, 1991	+	+	+	+	u	+	+	+	+	<b>8</b>
Politis <i>et al.</i> , 2004	+	+	+	-	+	+	+	u	+	<b>7</b>
Spector <i>et al.</i> , 2003	+	+	+	+	u	-	+	+	u	<b>6</b>
Cott <i>et al.</i> , 2002	+	+	+	-	-	-	-	+	+	<b>5</b>
Haight <i>et al.</i> , 2006	+	u	-	u	u	+	+	+	+	<b>5</b>
Toseland <i>et al.</i> , 1997	+	u	-	u	+	+	u	u	+	<b>4</b>
Orrel <i>et al.</i> , 2005	-	-	+	-	u	+	+	-	u	<b>3</b>
Tappen <i>et al.</i> , 2002	+	u	+	u	u	-	u	-	+	<b>3</b>
Tabourne, 1995	-	-	+	+	u	-	-	u	-	<b>2</b>
Tondi <i>et al.</i> , 2007	-	-	-	+	u	-	u	-	+	<b>2</b>
<b>Daily care studies</b>										
van Weert <i>et al.</i> , 2005;2006	-	-	+	+	+	+	-	+	+	<b>6</b>
Magai <i>et al.</i> , 2002	+	u	-	+	+	+	+	u	+	<b>6</b>
Beck <i>et al.</i> , 2002	-	u	+	-	+	-	-	+	+	<b>4</b>
Burgio <i>et al.</i> , 2002	+	u	+	+	u	+	u	u	u	<b>4</b>
Finnema <i>et al.</i> , 2005	-	-	+	+	-	-	-	+	+	<b>4</b>
Wells <i>et al.</i> , 2000	-	-	+	-	+	-	-	u	+	<b>3</b>
McCallion <i>et al.</i> , 1999	-	-	-	u	+	-	u	u	+	<b>2</b>
Dijkstra <i>et al.</i> , 2002	-	u	-	-	u	+	+	u	u	<b>2</b>
Edberg <i>et al.</i> , 1996; 2001	-	-	-	+	u	-	+	u	u	<b>2</b>

Quality criteria: A = randomisation, B = allocation concealment, C = inclusion/exclusion criteria specified, D = similarity of groups at baseline, E = assessors blinded to outcome, F = characteristics of participants lost to follow-up described, G = intention-to-treat analysis, H = power calculated, I = outcome measures valid.

+ = criterion fulfilled, - = criterion not fulfilled, u = unknown if criterion is fulfilled

Five studies investigated the effects of communication skill training for care staff. One of these studies did not include a communication measurement.<sup>30</sup> The studies that found positive significant effects were an intervention combining a package of communication-enhancing strategies and memory books for nursing assistants<sup>31</sup> and an intervention integrating snoezelen in 24-hour dementia care.<sup>34,35</sup> The first study found effects on discourse characteristics for residents and care staff. Snoezelen aims to communicate at a nonverbal level through the stimulation of the primary senses. Teaching care staff applying these techniques during morning care proved to be effective, even for residents with moderate-to-severe dementia.

The study of Magai *et al.* showed no significant effect on communication outcomes after 12 weeks.<sup>32</sup> However, a sharp increase in positive affect was reported for the intervention group in the first six weeks after the training and the authors suggest that training programs should include refresher sessions in order to remain effective.

*Effects of the interventions on neuropsychiatric symptoms*

Data for effects on neuropsychiatric symptoms in four set-time studies were pooled.<sup>23,26,27,29</sup> Two of these studies had also been included in the meta-analysis for communication outcomes, and the total score for quality was 4 or more for all four studies.

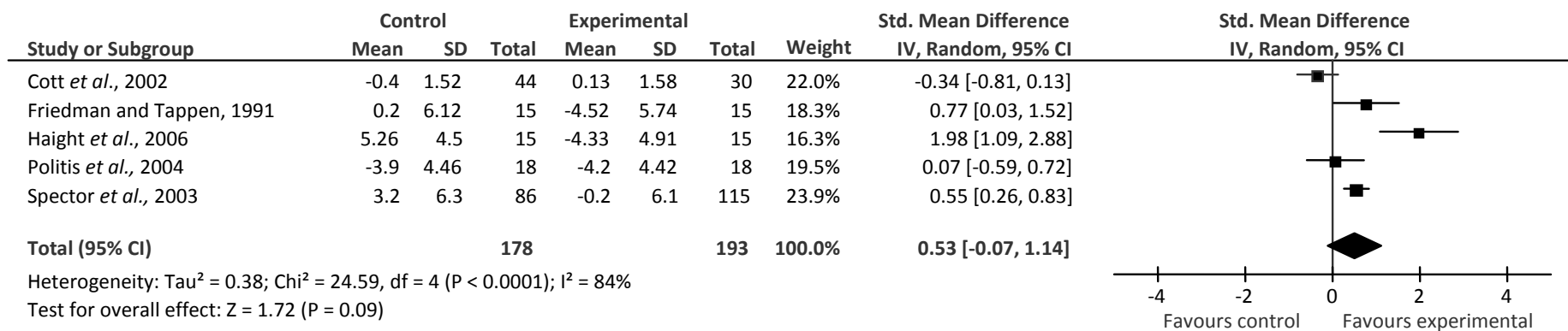
A total of 312 residents with dementia (171 in experimental groups and 141 in control groups) were included in the meta-analysis. We calculated the SMDs for this meta-analysis, and we used a fixed-effects model because the test for statistical heterogeneity was not significant ( $\chi^2 = 4.94$ ,  $df = 3$ ,  $p = 0.18$ ,  $I^2 = 39.2\%$ ). The result was that the estimated overall effect on neuropsychiatric symptoms was zero (SMD = 0.00, 95% CI = -0.23–0.22,  $p = 0.97$ ; Figure 2).

Among the studies unsuitable for meta-analysis, a group life review intervention found a significant decrease of disorientation for the experimental group<sup>25</sup>, and a combined group and-individual validation therapy intervention found a decrease of the mean neuropsychiatric inventory score in the treatment group and a slight increase in the control group, but no statistical test for significance was used.<sup>24</sup> Two studies did not include a measurement for neuropsychiatric symptoms.<sup>20,22</sup>

It was impossible to pool data for neuropsychiatric symptom outcomes within the subset of daily care intervention studies. The two studies that fulfilled the quality criterion for randomisation used the Cohen-Mansfield Agitation Inventory as an outcome measure, but neither reported separate results for this questionnaire.<sup>32,40</sup>

The only two studies that found significant positive effects on neuropsychiatric symptoms were an abilities-focused program<sup>38</sup>, and a program of communication skills for nursing assistants.<sup>30</sup>

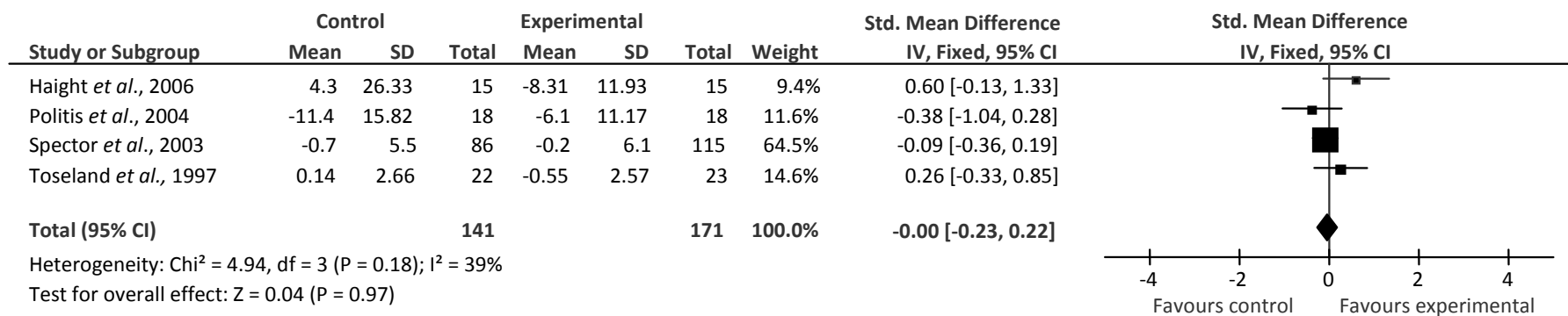
The training of care staff led to positive effects on residents' calm-functional behaviour, agitation behaviour, and physically nonaggressive behaviour assessed after three months, and verbally aggressive behaviour assessed after three and six months. Other daily care intervention studies did not find significant effects<sup>32,36,37,39,40</sup> or did not include a scale for measuring effects on the neuropsychiatric symptoms of the residents.<sup>31,34,35</sup>



**Figure 1. Forest plot, which shows no significant overall effect of set-time studies on communication outcomes.**

Each study is represented by a square (■) and a horizontal line, which correspond to the point estimate and the 95% confidence intervals (CIs) of the standardised mean difference (SMD). The solid vertical line corresponds to no effect of treatment (SMD 0). The area of the squares reflects the weight of the study in the meta-analysis. The diamond (◆) represents the combined SMD, calculated in a random effects model with its 95% CI.

*df* = degrees of freedom; Mean = the mean change in communication outcome and the corresponding standard deviation (SD) for patients in the control and experimental groups, respectively; Total = number of patients included in analysis.



**Figure 2. Forest plot, which shows no significant overall effect of set-time studies on neuropsychiatric outcomes.**

Each study is represented by a square (■) and a horizontal line, which correspond to the point estimate and the 95% confidence intervals (CIs) of the standardised mean difference (SMD). The solid vertical line corresponds to no effect of treatment (SMD 0). The area of the squares reflects the weight of the study in the meta-analysis. The diamond (◆) represents the combined SMD, calculated in a fixed effects model with its 95% CI.

*df* = degrees of freedom; Mean = the mean change in communication outcome and the corresponding standard deviation (SD) for patients in the control and experimental groups, respectively; Total = number of patients included in analysis.

## Discussion

A total of 19 intervention studies fulfilled the inclusion criteria for this review and two overall types of interventions were identified: structured and communicative sessions at set-times, and communication techniques in activities of “daily care”. The latter include training programs for care staff. A meta-analysis of five set-time interventions (communication) and another meta-analysis of four set-time interventions (neuropsychiatric outcomes) found no significant overall effects. Positive effects for communication outcomes are shown in individual studies when set-time interventions are single-task sessions, such as life review or one-on-one conversation, and when care staff apply communication techniques in daily care activities. The effect of both types of communication interventions on the neuropsychiatric symptoms of people with dementia is divergent.

The difference in effectiveness between single and multi-task interventions might be explained by people with dementia having difficulty performing dual tasks.<sup>41</sup> Furthermore, exercise may not benefit the cognitive functioning of people with dementia when cardiovascular risk factors are present.<sup>42</sup> Tappen and colleagues’ study reported that participants were afraid of falling and needed considerable assistance with ambulation, or stopped walking when they were asked a question.<sup>22</sup>

The positive results for the life review interventions are consistent with findings of a review on the effectiveness of reminiscence therapy on dementia patients, which suggested some potential benefits such as improvements in cognition.<sup>43</sup> People with dementia are still able to recall memories from past life events, with the more important life events often being remembered quite clearly, even in the severe stages of the disease.<sup>44</sup> Reminiscence, or life reflection, is therefore a sensible and simple strategy for improving communication between residents and staff.

Training programs for care staff to be used in daily care have positive effects on verbal and nonverbal communication outcomes among care staff as well as residents with dementia. It is known that factors increasing the effectiveness of an educational or training program for healthcare professionals are longer training periods, active participation during the training, and individual attention.<sup>45</sup> We indeed found that effective programs used interactive courses<sup>36-38</sup>, a little self-study<sup>36-38</sup> and individual attention via a supervisory system.<sup>40</sup> The results of the study of Magai *et al.* add to this knowledge in showing that training programs should include refresher sessions to remain effective.<sup>32</sup>

In spite of the effects on communication, the effects of both types of communicative interventions on neuropsychiatric symptoms were marginal. This is remarkable since communication difficulties are associated with neuropsychiatric symptoms.<sup>12</sup> If so, one would expect positive effects on neuropsychiatric symptoms in the studies included in this review. In most studies either no effects on behaviour were found or no outcome measure for neuropsychiatric symptoms were included. Only four out of the 19 studies found positive effects for specific problematic behaviours in residents. Only one study found positive effects on both

communication and neuropsychiatric symptoms. This particular study used a quasi experimental design and only fulfilled three of the nine methodological quality criteria, so it was difficult to draw a conclusion.<sup>38</sup>

The two daily care interventions that had the best methodological quality both studied the effects of nonverbal communication techniques on communication between residents and care staff.<sup>32,34,35</sup> The snoezelen study showed positive effects for communication outcomes.

Methodological weaknesses were common in most of the research projects and the methodological quality of the studies was generally poor. The quality of the set-time studies was better than the quality of the daily care interventions, but the variability was too great to draw overall conclusions. As for the results of the meta-analyses and conclusions of this review, the following should be kept in mind. First, given the kinds of intervention studies we reviewed, it was not possible to blind the residents, care staff, or therapists in the treatment groups. To get reliable and objective data, it is important to at least blind the outcome assessors.<sup>19</sup> Unfortunately, for seven set-time studies, it remains unclear whether this was done properly.<sup>20,22,24-28</sup>

Second, both the quality criteria for random assignment and allocation concealment were fulfilled for only four set-time studies<sup>20,21,27,29</sup> and none of the daily care intervention studies. Using the Cochrane criteria, only two of the daily care intervention studies used a truly random method to assign participants to study groups.<sup>18</sup> Therefore, it was impossible to pool data for daily care intervention studies.

Third, the reliability and validity of the outcome measures that were used for communication were questionable. The validation of outcome measures in some studies included in this review was not justified, or instruments were specially developed and evaluated for the study.<sup>25,27,28,31,36,37,40</sup>

However, these reservations apart, we conclude that there are promising effective psychosocial interventions to be used in residential settings. Moreover, the lack of effect on the neuropsychiatric symptoms of residents with dementia is no reason to preclude improving communication in high level residential care facilities. Instead of measuring effects on neuropsychiatric problems, researchers might think about improvements that retain the positive behaviours of the people in care. Some papers in this review describe improvements in positive behaviours of affect and mood<sup>26,39</sup>, but our results for neuropsychiatric symptoms might not be significant because they included negative behaviours (e.g. agitation) that did not, and perhaps cannot, improve.<sup>32,33,40</sup>

This review indicates that care staff can improve their communication with residents with dementia when strategies are embedded in daily care activities or interventions are single-task sessions at set times. Staff training should include time for personal feedback, interactive learning and refresher sessions. These results offer the possibility of improving the quality of care, but not directly of reducing neuropsychiatric symptoms. More research is needed to study the effect of communication interventions on neuropsychiatric symptoms.



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# **Chapter 3**

## **Guidelines for psychosocial interventions in dementia care: a European survey and comparison**



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**Abstract**

*Introduction:* The effectiveness of psychosocial interventions in treating people with dementia and their carers is increasingly emphasised in the literature. Dementia guidelines should summarise the scientific evidence and best practice that is currently available, therefore, it should include recommendations for psychosocial interventions. The aims of our study were (1) to collate dementia guidelines from countries across Europe and to check whether they included sections about psychosocial interventions, and (2) to compare the methodological quality and the recommendations for specific psychosocial interventions in these guidelines.

*Methods:* The European dementia guidelines were inventoried. The methodological quality of the guideline sections for psychosocial interventions was assessed with the (AGREE) Appraisal of Guidelines Research and Evaluation instrument. The recommendations for specific psychosocial interventions were extracted from each of these guidelines and compared.

*Results:* Guidelines for psychosocial interventions were found in five of 12 countries. Guideline developers, methodological quality and appreciation of available evidence influenced the inclusion of psychosocial interventions in dementia guidelines from Germany, Italy, the Netherlands, Spain and the UK. The UK NICE SCIE guideline had the best methodological quality and included the most recommendations for psychosocial interventions. Physical activity and carer interventions were recommended the most across all guidelines.

*Conclusion:* The inclusion of psychosocial interventions in dementia guidelines is limited across Europe. High-quality guidelines that include psychosocial interventions and are kept up to date with the emerging evidence are needed. Throughout Europe, special attention to the implementation of evidence-based psychosocial care is needed in the next few years.

## Introduction

The value of psychosocial interventions in treating people with dementia and their carers is increasingly emphasised in the literature. The goals of psychosocial interventions are to improve the quality of life and to maximise function in the context of existing deficits.<sup>1</sup> Scientific evidence for the effectiveness of this type of intervention in dementia care is growing because such interventions have shown a positive impact on cognition, quality of life and family carers as well as suppressing neuropsychiatric symptoms and associated distress.<sup>2-5</sup> Psychosocial interventions are not limited to specific types of dementia, and no serious side effects have been reported.

Pharmacological treatments have shown some efficacy, but contrary to psychosocial interventions, antidementia drugs are not effective for all types of dementia and are not tolerated by all patients.<sup>6-8</sup> Furthermore, the efficacy and safety of drug therapies for neuropsychiatric symptoms have been questioned over the last decade.<sup>9-11</sup> Psychosocial interventions are recommended as a safe firstline treatment for neuropsychiatric symptoms and are efficacious at all stages of dementia.<sup>12,13</sup> Psychosocial interventions for carers are effective in postponing and decreasing the odds of institutionalisation, but similar results for pharmacological treatments are lacking.<sup>5,14,15</sup>

The use of scientific evidence in healthcare decision-making is not automatic, and gaps between evidence and decision-making are present at all healthcare levels.<sup>16</sup> Guidelines are an important tool for implementing evidence in daily practice. Ideally, they should summarise the scientific evidence and best practice that is currently available.<sup>17,18</sup> Guidelines for diagnosing and treating dementia have been developed and published in several European countries. Besides scientific evidence, factors such as the healthcare system and professional culture may influence the inclusion of psychosocial interventions in these guidelines.

The organisation and financing of dementia care (particularly social support) is often fragmented and differs between and within European countries.<sup>19,20</sup> Some countries organise dementia care nationally, but others depend on regional and local policies and financing.<sup>19,20</sup> In the latter case, national dementia guidelines, if they exist at all, may include only general and nonspecific recommendations for psychosocial interventions to fit all regions. Or development of dementia guidelines may rely on local initiatives. Furthermore, medical specialists diagnose most cases of dementia, but they tend to focus their treatments on pharmacological interventions.<sup>21</sup> Clinical guidelines developed by medical specialists might not include recommendations for psychosocial interventions.

All Europeans with dementia and their carers should have access to safe care, that optimises their quality of life and increases their chances of staying at home as long as possible. Not including psychosocial interventions in dementia guidelines could have consequences for the quality of dementia care.

Recently published European dementia guidelines should therefore include evidence and recommendations for psychosocial interventions that parallel the emerging evidence base. The aims of our study were (1) to collate dementia guidelines from European countries and check

whether they include sections about psychosocial interventions, and (2) to compare the methodological quality and recommendations for specific psychosocial interventions of these guidelines.

## Methods

We used a pan-European, multiprofessional clinical research network, INTERDEM (Timely Detection and Intervention in Dementia; <http://interdem.alzheimereurope.org/>) to gather information about guidelines and consensus papers for psychosocial interventions in dementia in Europe between May and October 2006. INTERDEM members in the following countries were sent an email with a request to gather relevant national guidelines: UK, Spain, Netherlands, Belgium, France, Germany, Ireland, Italy, Portugal, Switzerland, Greece, Poland, Sweden, Austria, Denmark and Finland.

We extracted the title and the names of the authors and intended users from each guideline and consensus paper that we received. We assessed the methodological quality of the guidelines that included at least one recommendation for a specific psychosocial intervention and that were published from 2000 onwards. We also extracted the recommendations for specific psychosocial interventions from each guideline and compared them. The guideline with the highest Appraisal of Guidelines Research and Evaluation (AGREE) scores was taken as a reference point. We compared recommendations treating carers and neuropsychiatric symptoms in more detail because of emerging evidence of the effectiveness of psychosocial interventions in both matters. To measure the methodological quality of a guideline, we used the AGREE instrument, which was internationally developed and tested for appraising clinical practice guidelines.<sup>22</sup> This instrument assesses the quality of reporting and the guideline development. It provides an appraisal of the predicted validity of a guideline, i.e. the likelihood of a guideline achieving its intended outcome. It comprises 23 items that are unequally divided over six domains:

- (1) Scope and purpose (3 items), which cover the overall aim of the guideline.
- (2) Stakeholder involvement (4 items), which covers the extent to which the guideline represents the views of its intended users.
- (3) Rigour of development (7 items), which covers the process used to gather and synthesise the evidence and the methods for formulating and updating the recommendations.
- (4) Clarity and presentation (4 items), which cover the language and format of the guideline.
- (5) Applicability (3 items), which covers the likely organisational barriers and the behavioural and cost implications of applying the guideline.
- (6) Editorial independence (2 items), which covers the independence of the recommendations and acknowledgement of possible conflicts of interest of the guideline development group.

Each item was rated on a four-point Likert scale ranging from 4 (strongly agree) to 1 (strongly disagree).

Guidelines for psychosocial interventions were rated independently by at least two clinicians, practitioners or researchers in dementia care who were native speakers or who could read the guideline in its original language. We calculated standardised scores for each guideline, and for each domain of AGREE. We added the item scores of all appraisers to calculate the standardised scores as:  $[(\text{obtained score} - \text{minimum possible score}) / (\text{maximum possible score} - \text{minimum possible score})] \times 100\%$ . The maximum and minimum possible scores = the number of items  $\times$  the number of appraisers, either  $\times 4$  (strongly agree) or  $\times 1$  (strongly disagree). The ratings were based solely on the sections about psychosocial interventions. The only other guideline sections considered during the rating were the more general parts about the development of the guideline. Therefore, the scores do not reflect the quality of a guideline as a whole.

## Results

Information about published guidelines and dementia care consensus papers was received from 12 of the 16 countries in the INTERDEM network and supplementary Alzheimer's Society contacts. This information included 31 dementia guidelines and consensus papers from 8 different countries that were published between 1998 and 2006.

There were no recommendations for using psychosocial interventions in four countries (Finland, Belgium, Denmark and Sweden), although two guideline groups in Sweden had work in progress, which they expected to complete in 2009. In France, Switzerland and Ireland, consensus papers that included psychosocial interventions were published, but we found no recommendations for using psychosocial interventions in the dementia guidelines. The range of guidelines and consensus papers for dementia care and their content are described elsewhere.<sup>23</sup>

Seven guidelines from five countries were included for the assessment of methodological quality. They comprised one Italian guideline for clinical specialists<sup>24</sup>, one Spanish guideline for health and social care practitioners<sup>25</sup>, one German guideline for formal carers in institutional care<sup>26</sup>, two UK guidelines for practitioners and service commissioners<sup>27</sup> and healthcare professionals<sup>28</sup>, and two guidelines from the Netherlands for general practitioners<sup>29</sup> and formal carers in institutional care.<sup>30,31</sup>

Table 1 gives the AGREE scores for all seven guidelines. Table 2 shows a comparison of the psychosocial interventions included in the guidelines. Table 2 only shows the interventions that at least one of the seven guidelines recommended. Both tables present the guidelines in order of highest to lowest score for the AGREE domain for rigour of development, which covers the searching for and selecting evidence and formulating and updating the recommendations.

**Table 1. Appraisal of sections about psychosocial interventions in European dementia guidelines. Appraisal of Guidelines Research and Evaluation domain scores**

Domain	Guidelines							Mean domain score
	UK <sup>a</sup>	UK <sup>b</sup>	GE	NL <sup>c</sup>	IT	NL <sup>d</sup>	SP	
Scope and purposes	89	65	<b>89</b>	<b>83</b>	<b>57</b>	39	<b>78</b>	71
Stakeholder involvement	<u>88</u>	<u>32</u>	71	<b>83</b>	36	50	46	58
Rigour of development	90	<b>79</b>	79	52	45	43	38	61
Clarity and presentation	<u>88</u>	56	67	63	42	<b>67</b>	71	65
Applicability	89	46	<u>28</u>	<u>22</u>	<u>6</u>	<u>17</u>	17	32
Editorial independence	<b>100</b>	72	58	50	33	42	<u>8</u>	52

UK = United Kingdom; GE = Germany; NL = Netherlands; IT = Italy; SP = Spain;

All numbers are percentages. For each guideline: the highest domain score is **bolded**; the lowest domain score is underlined

<sup>a</sup>National Institute for Clinical Excellence and Social Care Institute for Excellence

<sup>b</sup>Scottish Intercollegiate Guideline Network

<sup>c</sup>Netherlands Institute for Health Services Research

<sup>d</sup>Wind et al.

**Table 2. Comparison of recommendations for psychosocial interventions in different European guidelines**

Intervention	Guidelines						
	UK <sup>a</sup>	UK <sup>b</sup>	GE	NL <sup>c</sup>	IT	NL <sup>d</sup>	SP
	Recommended (yes/no/NRD)						
Carer interventions	Yes <sup>e</sup>	Yes <sup>e</sup>	-	-	Yes <sup>e</sup>	Yes	Yes
Physical activities	Yes	Yes	Yes	-	Yes	-	Yes
Reminiscence	Yes	NRD	Yes <sup>f</sup>	-	Yes <sup>g</sup>	-	NRD
Multisensory stimulation/snoezelen	Yes	Yes <sup>h</sup>	Yes	Yes <sup>i</sup>	No	-	-
Massage/touch	Yes	-	Yes	-	-	-	-
Behaviour management	Yes <sup>j</sup>	Yes <sup>e,k</sup>	Yes <sup>l</sup>	-	-	-	Yes
Cognitive behavioural therapy	Yes <sup>m</sup>	-	-	Yes <sup>n</sup>	-	-	-
Recreational activities	Yes <sup>e</sup>	Yes <sup>e</sup>	-	-	-	-	Yes
Environmental design	Yes	Yes <sup>e</sup>	-	-	-	-	Yes
Cognitive stimulation	Yes <sup>e,o</sup>	Yes <sup>e</sup>	-	-	-	-	NRD
Music therapy	Yes	NRD	-	-	Yes <sup>g</sup>	-	NRD
Aromatherapy	Yes	No	-	-	Yes	-	-
Animal assisted therapy	Yes	-	-	-	-	-	-
Reality orientation	NRD	Yes <sup>e,p</sup>	-	-	Yes <sup>e,o</sup>	-	NRD
Memory training	NRD	-	-	-	Yes <sup>g</sup>	-	-
Validation	NRD	NRD	Yes <sup>q</sup>	-	No	-	-
Emotion-oriented care	NRD	-	-	Yes	-	Yes	-

UK = United Kingdom; GE = Germany; NL = Netherlands; IT = Italy; SP = Spain;

NRD = Mentioned but no recommendation done

<sup>a</sup>NICE/SCIE

<sup>b</sup>SIGN

<sup>c</sup>Netherlands institute for health services research

<sup>d</sup>Wind et al.

<sup>e</sup>Strongly advised

<sup>f</sup>Recollection of positive memories only

<sup>g</sup>Not beneficial to all patients

<sup>h</sup>Only when tolerated by a patient

<sup>i</sup>In case of apathetic behaviour

<sup>j</sup>Tailored and individualised

<sup>k</sup>In case of depression

<sup>l</sup>Need-Driven Dementia-Compromised Behaviour Model

<sup>m</sup>Patients and carers

<sup>n</sup>Behaviour therapy-Pleasant events/problem solving

<sup>o</sup>Group therapy not individualised

<sup>p</sup>Individualised not group therapy

<sup>q</sup>Validating attitude by nursing staff



### *Quality of guidelines*

Overall, the scope and purposes domain scored highest on average of all the AGREE domains (mean score 71%, range 39–89%, Table 1). Thus, in general, the objectives, the clinical questions covered and the patients to whom the guideline is meant to apply were specifically described in most guidelines. In contrast, the applicability domain scored lowest overall (mean score 32%, range 6–89%). This means that the organisational changes and cost implications of applying the guideline recommendations were ignored or barely described in most guidelines.

The rigour of development domain scored 61% (range 38–90%) on average. The items rated the highest in this domain were about using systematic methods for finding evidence and the criteria for selecting the evidence. The low score items were the two items outlining the guideline updating and the external review process before publication.

The NICE SCIE guideline from the UK scored best in all domains for its coverage of psychosocial interventions; it had the best overall methodological quality in this context. The UK guidelines scored the highest for rigour of development. They used systematic methods to find and select evidence, explicitly linked recommendations to the supporting evidence, mentioned an external review process, and outlined an updating process for the guidelines.

The German guideline scored as high as the SIGN guideline for rigour of development, but did not mention an updating process. It scored under 50% only for the applicability domain.

The two Dutch guidelines scored below the mean domain score for rigour of development. Both explicitly linked recommendations to supporting evidence, but the guideline for general practitioners did not mention an updating process. The Dutch guidelines scores for the applicability domain were lower than their scores for the other AGREE domains.

The Italian guideline clearly described the methods for finding and selecting evidence, and it linked recommendations the supporting evidence. However, it did not provide a procedure for updating the guideline. This guideline had the lowest overall domain score, namely, 6% for applicability.

The Spanish guideline had the lowest score of all guidelines for rigour of development. It did describe how evidence was searched for and methods for formulating recommendations, but did not describe clearly how evidence was selected or set forth a procedure for updating the guideline. Across domains, this guideline had the lowest score for applicability and editorial independence.

### *Comparison of recommended psychosocial interventions*

The psychosocial interventions that were most often mentioned across guidelines were physical activity, carer interventions, multisensory stimulation/snoezelen and reminiscence (Table 2). All guidelines that mentioned the first two interventions also recommended them. While guidelines mentioned light therapy, life review involving negative memories, psychomotor therapy and simulated presence, the guidelines either did not recommend them or advised against them.

Three guidelines advised not using light therapy.<sup>24,27,28</sup> One guideline advised against life review involving negative memories.<sup>26</sup>

The NICE SCIE guideline had the best methodological quality and included the most recommendations for psychosocial interventions. All psychosocial interventions recommended by the SIGN guideline were also recommended by the NICE SCIE guideline. The UK guidelines were the only guidelines that recommended cognitive stimulation. The NICE SCIE guideline, however, included reality orientation and cognitive stimulation as one and the same intervention, whereas the SIGN guideline recommended them as two separate interventions.

Five of the six psychosocial interventions recommended by the Italian and German guidelines were also recommended by the NICE SCIE guideline. In addition, only the Italian guideline recommended memory training. On the basis of the same but one studies, the NICE SCIE guideline did not recommend memory training because of a lack of benefits beyond the particular tasks trained. The German guideline was the only guideline that recommended the use of validation.

The Spanish guideline mentioned several psychosocial interventions, but formulated no recommendations for about half of them. The psychosocial interventions that the Spanish guideline recommended were also recommended by the NICE SCIE guideline.

The two Dutch guidelines combined paid less attention to psychosocial interventions than each of the other five guidelines separately. The Dutch guidelines were the only ones that recommended emotion-oriented care and had the least in common with recommendations of the NICE SCIE guideline.

Five guidelines recommended interventions for family carers of people with dementia (Table 2). The NICE SCIE and the Italian guideline based their recommendations on more than 20 studies, which were generally similar. The SIGN guideline referred to only three studies, while five of the 11 references included in the Dutch guideline were Dutch publications.<sup>29</sup> None of the guidelines were very specific about which carer interventions should be used, except the NICE SCIE guideline. It recommended that carers have a care plan and that interventions be tailored to specific needs. It also suggested different types of interventions (e.g. skills training, social support and psychoeducation).

Six guidelines included recommendations for the use of psychosocial interventions to treat neuropsychiatric symptoms. Both the Dutch and German guidelines for formal carers in institutional care aimed exclusively at managing neuropsychiatric symptoms.

The German, Spanish and NICE SCIE guidelines included general recommendations for the use of psychosocial interventions to treat neuropsychiatric symptoms. They summarised a range of interventions that might be effective because positive, though inconclusive, results were found for their use. In addition, the German and NICE SCIE guidelines included recommendations for assessing neuropsychiatric symptoms.

The Dutch NIVEL guideline and the Italian guideline linked specific interventions to specific neuropsychiatric symptoms. The first one recommended snoezelen for apathy in the later stages

of dementia. The Italian guideline recommended aromatherapy for reducing the agitation and aggression of some patients. The SIGN guideline reviewed the same evidence base, but it concluded that aromatherapy could not be recommended for reducing specific neuropsychiatric symptoms. It also advised against multisensory stimulation for people with moderate to severe dementia.

## Discussion

Our inventory of dementia guidelines showed that recommendations for psychosocial interventions are included in dementia guidelines in five of 12 European countries. We compared the sections on psychosocial interventions in seven guidelines from these countries and found a wide variety between guidelines in the methodological quality and inclusion of recommendations for psychosocial interventions. The NICE SCIE guideline from the UK had the best methodological quality overall, and it included the most recommendations on psychosocial interventions.

Our study revealed important factors that were related to the inclusion of recommendations for psychosocial interventions in guidelines. These factors were the influence of guideline developers, the methodological quality of the guidelines and the appreciation of available evidence. The influence of guideline developers was clearly visible in one Dutch guideline that specifically stated that psychosocial interventions were not included because they involve nonmedical disciplines that were not present in the developing work group.<sup>32</sup> In contrast, another Dutch guideline and a German guideline were developed for formal carers in institutional care and included psychosocial interventions only.<sup>26,30,31</sup> The guidelines that had better methodological quality, and especially, higher scores for the rigour of development domain, included more recommendations for psychosocial interventions in general (Table 2). Evidence was not appreciated in the same way across the guidelines. In the case of specific psychosocial interventions, such as aromatherapy or multisensory stimulation, review of the same evidence base resulted in disagreement between guidelines about whether to recommend it. Scientific evidence shows that psychosocial interventions are effective in dementia care in general, though the evidence for specific psychosocial interventions is still mixed and limited.<sup>13,33,34</sup> Inconclusiveness of the evidence base was also why, in some countries like Denmark and France, recommendations for psychosocial interventions were found in consensus papers only and not in dementia guidelines.<sup>23</sup>

Including recommendations for psychosocial interventions in guidelines is one thing; the practical implementation is another. A dementia survey in six European countries has found that, at the time of diagnosis, physicians recommend this type of intervention far less often than pharmacological treatments.<sup>21</sup> Furthermore, a survey in the UK found that poor access to non-pharmacological interventions was a major limiting factor for their use in the treatment of neuropsychiatric symptoms.<sup>35</sup> Guidelines should encourage the implementation of recommendations by addressing the organisational barriers and the cost implications for

applying them, but in our study, most guidelines had low scores for the AGREE applicability domain.

Most Europeans with dementia are cared for at home, and they want to stay at home as long as possible.<sup>19</sup> In southern European countries, family members taking care of their ill relatives is a cultural tradition.<sup>19</sup> Dementia care services (like home care, respite care and long-term care facilities) are lacking or unevenly distributed in these countries.<sup>19,20</sup> Dementia patients often receive informal care only and the carer's burden in southern countries is the greatest in Europe.<sup>19,36</sup> Considering this, one might expect that guidelines from southern European countries would give extensive attention to carer support. Although the Spanish and Italian guidelines that we studied recommended carer interventions, the recommendations were rather general, and applicability in practice was barely addressed. One reason for this could be that both guidelines were national initiatives, whereas dementia care is organised on a regional and local level with great variability in services found across both these countries.<sup>20,37</sup> In contrast, the NICE SCIE and SIGN guidelines from the UK were national guidelines that did consider local implementation and gave directions for adaptation to the local situation.

There were national guidelines in Germany and the Netherlands as well, but most were aimed at specific professional groups or specific dementia-related issues, such as the use of restraints.<sup>23</sup> Only a few recommendations for psychosocial interventions were included in the Dutch guidelines; this is probably due to poor methodological quality and focus on pharmacological interventions. Furthermore, guidelines for specific professional groups do not promote collaboration, although collaboration between professionals is known to improve the quality of dementia care in both primary care and the institutional setting.<sup>38,39</sup> High-quality, multidisciplinary, dementia guidelines like those from the UK could improve collaboration between professionals and promote the inclusion of psychosocial interventions. They might help remedy the lack of multidisciplinary dementia guidelines that was identified across Europe earlier.<sup>40</sup>

For the support of family carers and the management of neuropsychiatric symptoms, scientific evidence shows that psychosocial interventions are most effective when they are individualised and tailored to the specific needs of the patient and the carer.<sup>14,39,41,42</sup> There are guideline recommendations that simply state that some psychosocial interventions might be effective for carers or the treatment of neuropsychiatric symptoms. Such recommendations do not enable healthcare professionals to provide tailored and individualised care. We did not find clear recommendations for care plans, the assessment of carers, or the assessment of neuropsychiatric symptoms except for those in the NICE SCIE guideline. The knowledge that interventions are more effective when they are tailored and individualised has emerged in recent years. Some of the guidelines had been published before such evidence was available. Guidelines should be updated periodically to keep them up to date with scientific evidence. We note that the description of an updating process was lacking in five of the guidelines reviewed here. However, an update of the Dutch guideline for general practitioners is expected in 2011.

The use of the INTERDEM network enabled us to study the dementia guidelines from many countries. Unfortunately, it was not feasible to gather information about dementia guidelines from all the European countries, and some limitations should be considered in the interpretation of the findings. Our methodology for finding dementia guidelines across countries makes it likely that all the national guidelines were identified, but we may have missed some regional and local guidelines. In addition, our study represents the methodological quality and the recommendations of guidelines that were available at the time of the survey only. Dementia guidelines were being developed in at least one country (Sweden), and more countries may have since published dementia guidelines that include psychosocial interventions. A final limitation is the fact that we used the AGREE instrument, not to assess methodological quality of a guideline as a whole, but only for sections about psychosocial interventions. The instrument is sensitive to quality differences in clinical guidelines, but it is not certain to what degree the instrument allows comparison when only specific guideline sections are assessed.<sup>22</sup>

### *Conclusion*

The inclusion of psychosocial interventions in dementia guidelines across Europe is limited, despite the growing evidence base for their effectiveness in dementia care.

Healthcare professionals and policy makers should ensure that high-quality dementia guidelines that include recommendations for psychosocial interventions become available in all European countries. Guideline developers should ensure that guidelines are kept up to date with the emerging evidence, and they should encourage the implementation of recommendations by addressing the organisational barriers and cost implications for application. Researchers should focus their studies not only on finding significant effects for specific psychosocial interventions, but also on the development and evaluation of strategies for implementing psychosocial interventions effectively in daily practice.

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# **Chapter 4**

## **The development of quality indicators to improve psychosocial care in dementia**



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**Abstract**

*Introduction:* The evidence for the effectiveness of psychosocial interventions in dementia care is growing but the implementation of available evidence is not automatic. Our objective was to develop valid quality indicators (QIs) for psychosocial dementia care that facilitate the implementation process in various countries and settings.

*Methods:* A RAND-modified Delphi technique was used to develop a potential set of QIs. Two multidisciplinary, international expert panels were involved in achieving content and face validity. Consensus on the final set was reached after a conference meeting where a third panel of dementia experts discussed measurability and applicability of the potential set. A retrospective cohort study was conducted to study the feasibility of using the final set in day care centres, hospitals, and nursing homes in Spain and The Netherlands.

*Results:* A total of 104 recommendations were selected from guidelines and systematic reviews and appraised for their contribution to improving the quality of dementia care by 49 dementia experts. Twenty-five experts attended the conference meeting and reached consensus on a set of 12 QIs representing the key elements of effective psychosocial care, such as shared decision-making and interventions tailored to needs and preferences. Data from 153 patient records showed that all but one QI subitem were applicable to all three settings in both countries.

*Conclusion:* Our multidisciplinary and multinational strategy resulted in a set of unique QIs that aims exclusively at assessing the quality of psychosocial dementia care. Following implementation, these QIs will assist dementia care professionals to individualise and tailor psychosocial interventions.

## Introduction

Dementia is one of the leading causes of burden of disease in developed countries, and the number of dementia patients is expected to rise further in the coming decade.<sup>1</sup> Treatments that cure or stop progression of dementia have not yet been found.<sup>2</sup> Consequently, optimizing quality of life of both patient and carer is the most important treatment goal.

Psychosocial interventions aim to improve quality of life and psychological and social functioning, and to maximise function in the context of existing deficits.<sup>3,4</sup> The scientific evidence for the effectiveness of psychosocial interventions in dementia care is growing.<sup>5-7</sup> Dementia guidelines of various countries consider this type of intervention to be the first choice of treatment for various symptoms of the disease.<sup>2,8-10</sup> In other countries, however, the inclusion of evidence on psychosocial interventions in dementia guidelines seems limited.<sup>10</sup> In addition, psychosocial interventions were found to be recommended far less often by physicians than pharmacological treatments at the time of diagnosis.<sup>11</sup>

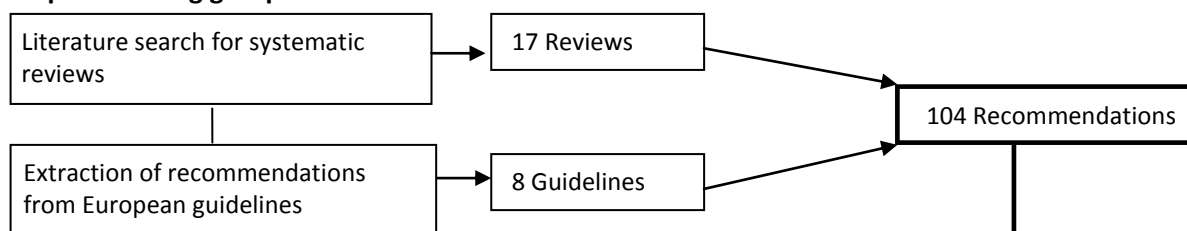
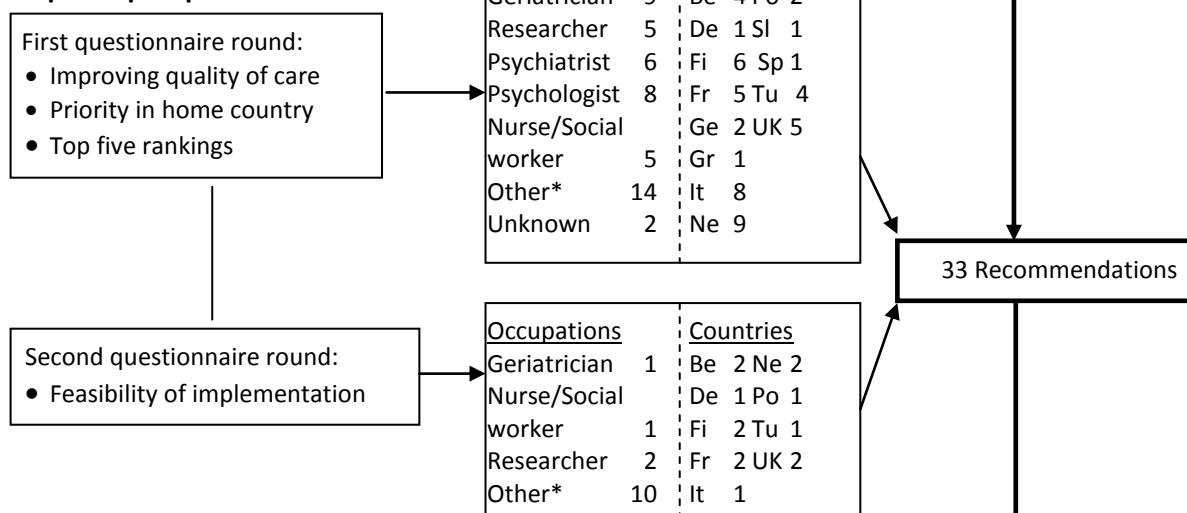
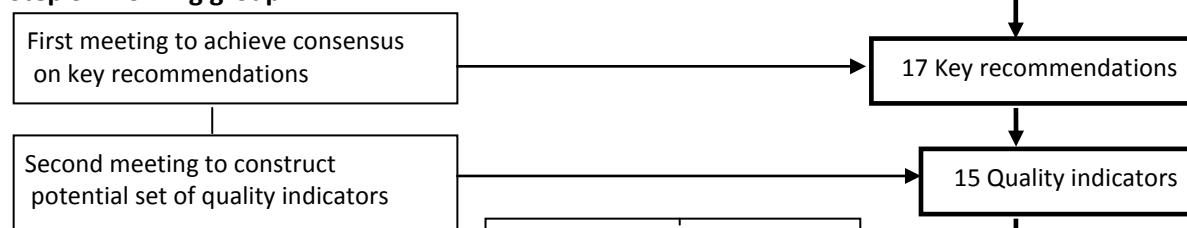
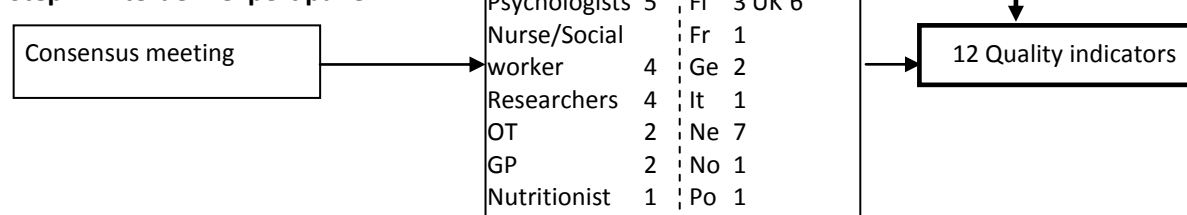
The use of psychosocial interventions in dementia care is not automatic and an additional tool in the form of quality indicators (QIs) is needed to further facilitate the implementation process. Quality indicators are measurable elements of practice performance focusing on the structures, processes, or outcomes of care.<sup>12</sup> Indicator elements are explicitly defined and act as building blocks in the assessment of care.<sup>13,14</sup> A set of QIs for psychosocial interventions in dementia care representing the key elements of effective psychosocial care would enable dementia care professionals to check and improve the quality of the psychosocial care they provide in daily practice.

To our knowledge, sets of QIs that have been developed and published for dementia mainly focus on diagnostics, screening, and pharmacological interventions, but they include very few indicators for psychosocial interventions.<sup>15-18</sup> Our objective was to develop valid QIs for psychosocial interventions in dementia care that apply to various countries and settings. The set should help dementia care services and professionals implement evidence-based psychosocial care for dementia patients and their carers.

## Methods

The QIs were developed as part of the European Collaboration on Dementia project (EuroCoDe, 2006–2008), which was initiated and led by Alzheimer Europe.<sup>19</sup> The working group that developed the QIs consisted of seven members of the Interdem network (Early Detection and Intervention in Dementia Group). The method the working group used to develop the QIs included the following four steps (Figure 1):

1. Selecting recommendations from systematic reviews and guidelines.
2. Expert panel rating of the recommendations.
3. Constructing a set of potential QIs.
4. Consensus meeting on the final set.

**Step 1. Working group****Step 2. Expert panel****Step 3. Working group****Step 4. Interdem expert panel****Figure 1. Step-wise procedure to develop quality indicators for psychosocial care in dementia.**

Be=Belgium; De=Denmark; Fi=Finland; Fr=France; Ge=Germany; GP=General practitioner; Gr=Greece; It=Italy; Ne=Netherlands; No=Norway; OT=Occupational therapist; Po=Poland; SI=Slovakia; Sp=Spain; Tu=Turkey; UK=United Kingdom.

\*General practitioner, neurologist, occupational therapist, working in a memory clinic, a nursing home, or for an Alzheimer society.

Steps 1–3 were part of a RAND-modified Delphi procedure to achieve content and face validity of the QIs.<sup>13,14</sup> This procedure combined expert opinion with evidence from literature and guideline

recommendations and included two expert panels, of which one was the working group itself. The aim of the fourth step was to discuss measurability and applicability of the potential QIs with dementia experts from various countries and to reach consensus on a final set of QIs. After consensus was reached, the feasibility was studied of using the final set of QIs in different countries and settings by extracting data from patient records.

### *Selecting recommendations*

The first step of development consisted of the selection of recommendations for psychosocial interventions by the working group. Evidence-based recommendations were gathered from relevant systematic reviews in the literature and European dementia guidelines.<sup>19</sup> The working group discussed all the recommendations that were obtained in this way in a face-to-face meeting. Recommendations were selected for the second step if they were based on scientific evidence and covered aspects of psychosocial care for people with dementia or their carers.

### *Rating the recommendations*

The aim of the second step was to reach consensus among dementia experts on a key set of recommendations for psychosocial care. The selected recommendations were unequally divided into eight categories and presented to a European expert panel in two postal questionnaire rounds. The experts were professionals involved in dementia care and included researchers and medical and care professionals.

Three strategies were used to include experts from as many countries as possible: (1) approaching experts at the Alzheimer Europe conference in Estoril, Portugal, in 2007, (2) emailing requests to Alzheimer centre coordinators in European countries, and (3) using the personal networks of working group members.

Experts were asked to rate each recommendation twice on a 9-point Likert scale in the first questionnaire round. Recommendations were rated for usefulness in contributing to the improvement of quality of dementia care on a scale of 1 (not useful) to 9 (most useful), and the priority it should be given in the expert's own country on a scale of 1 (lowest priority) to 9 (highest priority). Experts were also asked to list their personal top five recommendations for each category, starting with the recommendation they found most useful for improving the quality of dementia care within the category.

All recommendations included in the first round were also included in the second round. The same experts who took part in the first round were then asked to rate each recommendation for feasibility of implementation in their own countries within five years on a Likert scale of 1 (not feasible) to 9 (most feasible).

### *Constructing a set of potential quality indicators*

The third step consisted of two face-to-face meetings. In the first meeting, the working group discussed the results of the first questionnaire round. A recommendation was selected for the

key set when it scored high on average for contributing to the improvement of quality of dementia care: a median score of 8 or 9. The experts also had to agree, meaning that at least 75% of the experts had to rate the recommendation within the highest tertile (a score of 7–9) to add it to the key set.<sup>20</sup>

If these scores did not differentiate the recommendations well enough, the top five listings of each category were used. The overall ranking of the top five recommendations was calculated for each category. Each recommendation that an expert ranked first in its category was awarded five points, each recommendation ranked second was awarded four points, and so on.

During the second meeting, the working group constructed a potential set of QIs on the basis of the set of key recommendations and the results of the second questionnaire round. Key recommendations that scored a median of 6 or less for feasibility of implementation were rejected as QIs unless the working group agreed that they covered a basic principle of psychosocial care in dementia and were, therefore, essential for improving quality.

#### *Consensus meeting on the final set*

The fourth and final step consisted of a consensus meeting, which was preceded by a pilot study using a convenience sample of dementia patients' records. The aim of this pilot study was to test whether the potential QIs could be applied to dementia patients and their carers in various countries and settings, and whether data were available in patient records.

Members of the Interdem network, including the working group members, were invited to a two-day conference. Before the conference, the members were asked to gather QI data from patient records within the organisations in which they work. A form was constructed in English to enable the extraction of data.

The results of this pilot study and the complexity of formulation of each QI were discussed at the conference. Afterward, the potential set of QIs was adjusted on the basis of the feedback from the conference participants and circulated one more time to reach consensus on the final set of QIs.

#### *Feasibility study*

A retrospective cohort study was conducted to assess the feasibility of using the final set in day care centres, hospitals, and nursing homes in Spain and The Netherlands.

Managers at each setting selected dementia patients. The inclusion criteria were age 65 years or older, diagnosed with any type of dementia at least six months earlier, first visit to the hospital or day care centre at least six months ago, living in the nursing home for at least six months. Informed consent was obtained from each patient or their carer before data were collected.

After the data were collected, they were entered in a database using the Statistical Package for the Social Sciences (SPSS 16.0 for Windows, SPSS Inc., Chicago, IL, USA). A QI was considered adhered to if it was fulfilled. In case of multiple items, all items had to be fulfilled. Quality indicators subitems were considered not applicable if irrelevant to the patient or the carer.

## Results

### *Selecting recommendations*

Seventeen systematic reviews that met the inclusion criteria were analysed.<sup>19</sup> The inventory of dementia guidelines across Europe showed that eight dementia guidelines from five countries included one or more recommendations for psychosocial interventions.<sup>19</sup>

The working group discussed all the recommendations collected from these sources and wrote a questionnaire for the second step. Complex recommendations that included multiple items or more than one statement were split up, so that there were 104 recommendations with a single statement or item to be rated (Figure 1).

### *Rating the recommendations*

About 80 questionnaires were handed out to dementia experts attending the Alzheimer Europe Conference in Estoril, Portugal, in May 2007. The questionnaire was also emailed to the Alzheimer centre coordinators of 34 European countries in October 2007. Nineteen questionnaires were completed and returned. About 60 questionnaires were sent by regular mail to Interdem contacts in European countries. Thirty of the questionnaires were completed and returned. In total, we received 49 completed questionnaires.

The 49 experts who participated in the first round were sent an email in May 2008 requesting them to fill in the second questionnaire, which was attached with the email. Fourteen experts returned the questionnaire.

### *Constructing a set of potential quality indicators*

The working group discussed the results of the first questionnaire round in May 2008. These results showed that for usefulness 84 recommendations and for priority 59 recommendations scored a median of 8 or higher and received 75% or more of the ratings within the highest tertile. Because the statistical results did not differentiate the recommendations well enough, the overall top five rankings were calculated by category. All recommendations in the overall top five rankings also scored a median 8 or 9 and received 75% or more ratings within the highest tertile for usefulness. The working group therefore decided that the set of key recommendations would be based on the results of the top five listings. For the two categories with fewer than ten recommendations, only the top three recommendations were included. One category had only two recommendations, which the experts ranked as equally important and both were included. The working group discussed a total of 33 recommendations to compose the key set. They merged recommendations wherever possible, excluded the ones where the content overlapped with others, and rephrased them if necessary. This resulted in a set of 17 key recommendations. During the second meeting (October 2008), the working group discussed expert ratings for the feasibility of implementation. Six of the initial 33 recommendations scored a median of 6 or less, but none of the 17 key recommendations were excluded or changed because of these ratings. Finally, the working group constructed 15 QIs. They excluded four of the 17 key

recommendations during this phase because of difficulties in turning them into measurable elements, and they split two recommendations into two separate QIs each.

### *Consensus meeting on the final set*

Twenty-five Interdem members from ten European countries attended the two-day conference “Quality indicators for psychosocial care in dementia” in September 2009. The conference participants of eight countries extracted data from patient records and provided feedback for the set of 15 QIs based on this exercise. The other conference participants who were not in a position to extract data provided feedback on the basis of their knowledge of dementia care services in their own countries.

The feedback was used afterward to improve the feasibility of the set of QIs. Of the 15 potential QIs, three were not changed, seven were reformulated, four were merged and reformulated into two QIs, and one was excluded from the set because the conference participants agreed that it covered basic medical care rather than a psychosocial principle of dementia care.

Finally, the conference participants were asked for their consent for these adjustments by email, and consensus was reached on a set of 12 QIs for psychosocial care in dementia. This final set consists of nine process indicators for people with dementia, two process indicators for informal carers, and one structure indicator for professional carers (Table 1).

**Table 1. Quality indicators for psychosocial care in dementia**

<b>Numerator</b>	<b>Denominator</b>
<b>Diagnosis and assessment</b>	
1. Number of people with dementia whose patient file records that diagnosis was discussed with the person with dementia	Total number of people with dementia at service
2. Number of people with dementia who are assessed* periodically <sup>†</sup> for depression and/or anxiety	Total number of people with dementia at service
3. Number of people with dementia with registration in patient file and/or care plan of: <ul style="list-style-type: none"> <li>• Life history</li> <li>• Social and family circumstances</li> <li>• Needs and preferences<sup>‡</sup></li> </ul>	Total number of people with dementia at service
<b>Care plan and treatment</b>	
4. Number of people with dementia whose patient file records that they are currently receiving psychosocial interventions, tailored to the person's: <ul style="list-style-type: none"> <li>• Needs and preferences<sup>‡</sup></li> <li>• Cognitive and physical abilities</li> </ul>	Total number of people with dementia at service



Numerator	Denominator
<b>5.</b> Number of people with dementia with a registered personalised care plan, shared between the person with dementia, informal carer and care professional, that is periodically <sup>†</sup> updated. This means that: <ul style="list-style-type: none"> <li>• At least two types of interventions were discussed with and offered to the person with dementia</li> <li>• The care plan is drawn up in agreement with person with dementia, informal carer and professional at the service</li> <li>• Response to initiated interventions is monitored less than one year ago</li> </ul>	Total number of people with dementia at service
<b>6.</b> Number of people with dementia whose care plan includes: <ul style="list-style-type: none"> <li>• ADL activities</li> <li>• Recreational and social activities</li> <li>• Structured day activities</li> </ul>	Total number of people with dementia at service
<b>7.</b> Number of people with dementia who have an assigned professional who maintains regular contact with the patient and the main carer and ensures coordinated delivery of health and social care services	Total number of people with dementia at service
<b>Behavioural problems</b>	
<b>8.</b> Number of people with dementia who have behavioural problems with registration of a tailored care plan that: <ul style="list-style-type: none"> <li>• Is based on an assessment*<sup>§</sup> to establish factors likely to cause the behaviour</li> <li>• Includes registration of its frequency of review agreed on by the informal carer and staff involved</li> </ul>	Total number of people with dementia who have behavioural problems at service
<b>9.</b> Number of people with dementia who have behavioural problems that are treated with a psychosocial intervention first before pharmacological treatment is started.	Total number of people with dementia who have behavioural problems at service
<b>Informal carers</b>	
<b>10.</b> Number of carers of people with dementia for whom it is registered that: <ul style="list-style-type: none"> <li>• Respite or short-break care is offered to them</li> <li>• Other psychosocial interventions, tailored to their needs and preferences are offered to them</li> </ul>	Total number of carers of people with dementia
<b>11.</b> Number of carers of people with dementia who are periodically <sup>†</sup> assessed* for mood and coping	Total number of carers of people with dementia
<b>Professional carers</b>	
<b>12.</b> Number of staff at care service/facility that receive specific dementia-care training at least once a year	Total number of staff at care service/facility

\*A structured and systematic approach to examine a certain condition. This means using validated scales/questionnaires or at least a standardised method that is used for all similar patients/persons within the organisation/service

†At least once a year

‡Important to person with dementia, related to the quality of life

§ In case of behavioural problems the assessment ideally includes: physical health, depression, undetected pain or discomfort, side effects of medication, individual biography, including beliefs, spiritual and cultural identity, psychosocial factors, physical environmental factors, specific behavioural and functional analysis

### Feasibility study

We extracted data from 153 patient records to assess the feasibility of the 11 QIs for dementia patients and their informal carers. We obtained data for the QI for professional carers from care managers in The Netherlands and care staff in Spain. The subitem about carers being offered respite or short-break care (QI 10) was not applicable in the nursing home setting, so we excluded it when calculating adherence in this setting.

The mean adherence ( $\pm$ standard deviation) to the 11 QIs for patients and informal carers was 26.3% ( $\pm$ 36.6%). Adherence per patient record ranged from 0% to 89%, and per setting from 11% (Spanish hospital) to 50% (Spanish nursing home). Table 2 shows the adherence to each QI by setting and country.

The Spanish settings rated higher for assessing depression/anxiety and mood/coping (QIs 2 and 11) than the Dutch settings, with the exception of mood/coping in the hospital setting. The hospitals in both countries showed 0% adherence for more than half of the QIs for patients.

The indicator for assessing the depression/anxiety of dementia patients received the best adherence across all settings (68%). However, this adherence varied widely from 100% for the Spanish settings to 18%–33% for the Dutch settings. In general, adherence varied widely, although for each QI at least one of the settings rated 75% or more except QIs 5, 8, and 10. This indicates that it is possible to provide psychosocial care in line with these QIs. The low adherence to QIs 5 and 8 was mainly due to the subitems about offering/discussing at least two different interventions (QI 5) and the frequency of review (QI 8), of which no note was found in most patient records.

**Table 2. Percentage adherence to the eleven quality indicators for patients with dementia and informal carers, based on documentation in medical records in Spanish and Dutch hospitals, day care centres, and nursing homes**

QIs Diagnosis and Assessment/ Care Plan and Treatment	Hospital		Day care		NH	
	Ne	Sp	Ne	Sp	Ne	Sp
	(n=27) %	(n=28) %	(n=18) %	(n=29) %	(n=22) %	(n=29) %
1. Diagnosis discussed	85	0	39	3	0	0
2. Depression/anxiety assessed < 12 months	33	100	28	100	18	100
3. Personal information in file	0	0	67	0	32	100
4. Tailored psychosocial interventions	7	4	83	14	50	97
5. Personalised care plan	0	0	0	0	0	0
6. Care plan includes activities	0	4	61	97	100	21
7. Assigned professional who has regular contact	26	0	61	93	91	97
<b>QIs Behavioural Problems</b>	<b>(n = 11)</b>	<b>(n = 14)</b>	<b>(n = 4)</b>	<b>(n = 15)</b>	<b>(n = 16)</b>	<b>(n = 21)</b>
8. Tailored care plan	0	0	0	0	0	5
9. Psychosocial intervention first	0	0	50	0	75	0
<b>QIs Informal Carers</b>	<b>(n = 27)</b>	<b>(n = 28)</b>	<b>(n = 18)</b>	<b>(n = 29)</b>	<b>(n = 22)</b>	<b>(n = 29)</b>
10. Tailored interventions received/offered	26	0	22	0	0	0
11. Mood and coping assessed < 12 months	19	4	50	93	0	100

Ne = Netherlands; NH = nursing home; QI = quality indicator; Sp = Spain

Offering interventions to carers (QI 10) was documented in 28 cases (18%) – all but one from Dutch settings – but information about tailoring was lacking here. One-hundred-eight patients (71%) received psychosocial interventions, but patient records often lacked information about how these were tailored to the person (QI 4). Of the 81 dementia patients (53%) who showed behavioural problems, 14 (17%) had documentation of being treated with a psychosocial intervention first (QI 9). There were records of 58 patients (72%) receiving a pharmacological intervention for behavioural problems.

In both countries, staff needed to have basic psychogeriatric training specific to the setting to work there. Overall, staff members had received training in the preceding year, although ongoing staff training was not obligatory in all settings.

## Discussion

We have developed a set of 12 content- and face-valid QIs that represent the key elements of effective psychosocial care in dementia. To our knowledge, this set is the first that aims exclusively at psychosocial interventions in dementia care. It is applicable to various countries and settings, with the exception of the subitem on respite and shortbreak care being offered to carers. This subitem is meant to be excluded when the set is used in the nursing home setting.

The EuroCoDe project offered a timely and unique opportunity to reach consensus with a large number of dementia experts from different disciplines and countries about the very essence of evidence-based psychosocial care in dementia. The result is a set of generic QIs covering the minimal standard of psychosocial care. The QI content assists healthcare professionals to individualise and tailor psychosocial care, to empower the patient and carer, and to provide social inclusion and continuity of care. Empowerment of the patient and carer means enabling them to control certain situations, providing care options, and creating new meaning in their lives.<sup>21</sup> The QIs reflect this by giving informed choices (QI 5), promoting and enhancing strengths and abilities (QI 4), and taking into account needs and preferences (QIs 3 and 10). Important dimensions of social inclusion are being accepted and recognised as an individual beyond the disease and being able to participate in social activities.<sup>22</sup> Care professionals being aware of the social and family circumstances (QI 3), discussing care options with both patient and carer (QI 5), and offering participation in recreational and social activities (QI 6) contribute to the social inclusion of the dementia patient and carer. As dementia is an ongoing disease process, the provision of care must also be ongoing. Continuity of care ensured by frequent review of the care plan (QI 8), monitoring response to initiated interventions (QI 5), and periodical assessment of depression and coping (QIs 2 and 11) is essential to quality psychosocial dementia care.

All healthcare professionals involved in dementia care, regardless of their nationality or discipline, can use this set of QIs. International collaboration for developing QIs has considerable benefits, but transferring QIs from one country to another is not easy.<sup>23</sup> Differences between developed countries exist in the availability and accessibility of dementia care services.<sup>24,25</sup> Our feasibility study shows that the set applies to Spanish and Dutch dementia patients in hospitals,

nursing homes, and day care centres, and that there is considerable room for improving psychosocial dementia care in these settings. Nonetheless, it is likely feasible to use the QIs in similar settings in other developed countries as well.

Although the EuroCoDe project focused on dementia care in European countries, the method for developing this set of QIs included evidence from the international literature. Furthermore, recommendations for psychosocial interventions in European dementia guidelines do not differ from those in non-European dementia guidelines.<sup>26,8-10</sup> Therefore, using the QIs is not limited by country or continent.

Despite these strengths, there are some limitations that should be taken into account. First, validity should be further tested, and especially the discriminatory capacity should be assessed, both across and within the various countries. Second, we did not measure interrater reliability in our study, but it should be assessed to allow accurate comparison of adherence scores between countries and settings when more than one person collects data. Third, although the set of QIs is, in theory, applicable to people with dementia and their carers living at home, this setting was not included in the feasibility study. For those who receive care from home care services, family physicians, or case managers, it is likely that case records documenting these activities exist. Future studies that access such records in order to check our proposed set of QIs are required. Fourth, the use of written records as a data source has some disadvantages, one of which is that most case records are incomplete. This leads to underestimation of the actual care delivered.<sup>27,28</sup> The use of additional data sources, such as interviews with care managers or carers, should be investigated in further studies. Finally, as was the case with the subitem related to respite and short-break care in the nursing home setting, other QIs may not be applicable to specific settings or disease stages. For instance, discussing the diagnosis is probably not relevant to people and carers in the final stages of dementia. Although discussing palliative care approaches might represent quality psychosocial care in these final stages, we have not included this subject in the current set. The content we outline is the first step toward establishing a broad set of QIs, which are not fixed but should evolve in line with the developing knowledge base. However, we suggest that this be underpinned with an equivalent systematic methodology before future refined QIs are disseminated widely.

In an ideal world, everyone with dementia and his/her carer would have access to the best quality of care. In the real world, many obstacles hamper this access. The use of evidence-based guidelines and QIs in dementia care can lead to substantial improvements in the quality of care.<sup>29,30</sup> The introduction of quality improvement cycles using the QIs for psychosocial care can generate important progress toward ideal dementia care. Professionals and services could use this set of QIs as a starting point to implement and improve evidence-based psychosocial care on a local level.

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# Chapter 5

## Barriers and facilitators in implementing quality indicators for psychosocial dementia care in European countries



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**Abstract**

*Introduction:* Optimising the quality of life is an important goal in dementia care, for which psychosocial care is essential. We developed 12 quality indicators (QIs) to help implement evidence-based psychosocial dementia care in European countries. The purpose of this study was to explore barriers and facilitators in implementing the QIs and to compose an implementation strategy.

*Methods:* Our qualitative study included a purposive sample of 27 dementia professionals from nine European countries and various disciplines including clinical psychology and general practice. These professionals took part in focus group interviews which were audiotaped and transcribed verbatim. We analysed the data inductively with ATLAS.ti. A model of barriers to and facilitators for change at six health-care levels became our framework for organising the data.

*Results:* The QIs being a European initiative was both a barrier and a facilitator. Other implementation barriers were the variety in organisation of dementia care, QI ambiguity, and professionals' lack of skills and motivation. The facilitators included the feasibility of using the QIs in practice, incentives, and QIs fitting in with national and regional policies. The participants proposed some implementation strategies.

*Conclusion:* Our study is unique in exploring barriers and facilitators internationally. A barrier specific to this study context was the variety of dementia care organisation across countries. Implementation of the set must therefore be adapted to the local context and should consider barriers and facilitators in the specific political, economic, and organisational contexts, and the skills of local care professionals. Especially in countries where inclusion of psychosocial care in national dementia strategies or guidelines is limited, introducing the set of QIs could start the improvement of the quality of psychosocial dementia care.



## Introduction

The estimated number of dementia patients in the European Union is more than 6 million and the number of cases is expected to rise in the coming decade.<sup>1,2</sup> No cure exists yet, so patients and their families have to cope with it and adapt their lives repeatedly to the further loss of cognitive function and the neuropsychiatric symptoms that accompany the disease. Optimising the quality of life of both patients and carers is one of the most important treatment goals in dementia care, and psychosocial care is essential to this process.

Psychosocial dementia care aims at improving 'psychological and social functioning, including well-being and cognition, interpersonal relationships and everyday functional abilities such as activities and daily living skills' of both patients and carers.<sup>3</sup> Scientific knowledge about the processes and conditions related to the successful delivery of psychosocial dementia care is accumulating.<sup>4-7</sup> A dementia care innovation in a set of 12 evidence-based quality indicators (QIs) that represents the standard of psychosocial dementia care was developed as part of the European Collaboration on Dementia (EuroCoDe) project.<sup>8,9</sup> The set explicitly defines measurable elements of psychosocial dementia care that act as building blocks in the assessment and improvement of this care.<sup>10</sup>

Dementia strategies and guidelines are available in several European countries. Many of the national dementia strategies emphasise the importance of optimising the quality of life and include statements about the use of psychosocial care.<sup>11-15</sup> Nevertheless, the inclusion of recommendations for psychosocial care in dementia guidelines for care professionals is limited across Europe.<sup>16</sup> European physicians recommended this type of intervention far less often than pharmacological treatments at the time of diagnosis, and poor access is a major limiting factor for their use in the UK.<sup>17,18</sup> The provision of psychosocial care for Europeans with dementia and their carers does not seem automatic and guaranteed. The set of QIs for psychosocial dementia care should facilitate implementation and improvement across countries. The implementation of innovations in health-care, however, is not a simple task, and various factors could facilitate or impede the implementation process.<sup>19-21</sup> To increase the chances of improving the quality of psychosocial dementia care in Europe, the potential barriers and facilitators for implementing the set of QIs should be examined.

Our aim was to explore the potential barriers and facilitators at six health-care levels for implementing the set of QIs across various European countries and to compose an implementation strategy based on these factors. The six health-care levels are the innovation itself, the individual professional, the patient, the social context, the organisational context, and the economic and political context.<sup>20</sup>

## Methods

### *The innovation*

The innovation consists of a set of 12 evidence-based QIs for psychosocial dementia care.<sup>8,9</sup> The set includes nine QIs for patients covering diagnosis and assessment, care planning and treatment, and behavioural problems; two QIs for informal carers covering mood, coping, and offering psychosocial interventions; and one QI for care professionals covering dementia care training (Table 1).

**Table 1. Examples of quality indicators for psychosocial dementia care, i.e. the innovation<sup>8</sup>**

<b>Patients - diagnosis and assessment</b>
Number of patients with registration in patient file and/or care plan of: <ul style="list-style-type: none"> <li>• Life history</li> <li>• Social and family circumstances</li> <li>• Needs and preferences</li> </ul>
<b>Patients - care planning and treatment</b>
Number of patients whose patient file records that they are currently receiving psychosocial interventions, tailored to the person's: <ul style="list-style-type: none"> <li>• Needs and preferences</li> <li>• Cognitive and physical abilities</li> </ul>
<b>Patients - behavioral problems</b>
Number of patients who have behavioural problems that are treated with a psychosocial intervention first before pharmacological treatment is started.
<b>Informal carers – offering psychosocial interventions</b>
Number of carers of dementia patients for whom it is registered that: <ul style="list-style-type: none"> <li>• Respite or short-break care is offered to them</li> <li>• Other psychosocial interventions, tailored to their needs and preferences are offered to them</li> </ul>

### *Study design*

A qualitative design, using focus group interviews, was used to explore potential barriers and facilitators for the implementation of the set of QIs in various European countries. The focus groups met during a 2-day conference on QIs for psychosocial dementia care. The participants were a purposive sample of dementia care professionals and researchers who were also members of the Interdem network. This is a pan-European, multiprofessional network of professionals and researchers in dementia care who focus on psychosocial approaches.<sup>3</sup> Interdem members of 13 European countries, regardless of their disciplines, were invited to join the conference so that a wide variety of nationalities and disciplines were represented. There were no additional inclusion or exclusion criteria.

In preparation for the focus group interviews, the participants received the set of QIs and were asked to use it to collect data from patient records in the organisations where they work. At the conference, each participant was assigned to one of the three focus groups. Each of these groups discussed barriers and facilitators in two sessions of 1.5 hours each.

### *Data collection*

A moderator led each focus group and used an interview guide to structure the discussion. The interview guide included barriers to and facilitators for implementing the QIs for patients and informal carers, professionals and organisations in dementia care, and national healthcare systems. Focus group meetings were audiotaped and transcribed verbatim. The meetings and transcriptions were both in English.

### *Data analysis*

We analysed the focus group transcriptions inductively with ATLAS.ti version 6.2, using a framework approach.<sup>22</sup> This approach consists of five interconnected stages: familiarisation, indexing (coding), charting, mapping, and interpretation. Two researchers (EV and MV) discussed the themes and the tentative framework that emerged during the familiarisation and indexing stages. We used a two-step approach for these stages.

First, we used the interview guide as an initial coding framework and we coded the data as barriers or facilitators. We used open coding to further develop the framework. Second, we used a model for barriers and facilitators for change at six health-care levels (innovation, individual professional, patient, social context, organisational context, economic and political context) to organise the themes that had emerged during open coding.<sup>20</sup> Quotes that related to informal carers of dementia patients were organised at the patient level, which was therefore renamed the patient and carer level. The tentative framework was adapted accordingly and all focus group transcriptions were indexed in line with the tentative framework.

Then, a third researcher (AS) indexed half of the qualitative data using the tentative framework. EV and AS discussed differences and reached consensus about the final framework which was then applied to the whole dataset. If a quotation describing a barrier or facilitator related to more than one of the six health-care levels, it was assigned to the level that contributed the most to the barrier or facilitator.

During the next stages of data analysis, quotes were charted, mapped, and interpreted on the basis of the themes included in the final framework.

## **Results**

A total of 27 dementia experts from nine countries (Denmark, Norway, France, The Netherlands, Germany, Poland, Italy, Spain and the UK) representing the disciplines of clinical psychology, general practice, geriatric medicine, old age psychiatry, medical sociology, nursing and dementia research participated in the focus group interviews.

Analysis of the focus group transcripts identified various barriers and facilitators for the implementation of the set of QIs. We found no barriers or facilitators in the social context, one of the six health-care levels. We found barriers, but no facilitators at the level of the patient and carer. The barriers and facilitators were associated with either the innovation itself or the provision of psychosocial care in dementia (Tables 2 and 3).

Besides barriers and facilitators, some participants proposed practical strategies to implement or disseminate the set of QIs (Table 4). We describe these results separately, after the description of the facilitators.

**Table 2. Barriers, facilitators and quotes associated with the innovation itself per health-care level**

<b>Innovation</b>		
<i>Barrier</i>	Unattractive	<i>The situation in Finland is that we are working on all sorts of indicators for health and social care..... people working in practices are getting a bit tired about receiving these new questionnaires about this and that.(group 1m)</i> <i>I think there's a weakness by doing it across Europe in that sense because it can be dismissed, if it can be fit into a national plan, it's gonna be helpful. (group 1m)</i>
	Feasibility	<i>I think it is a mistake to develop indicators for all situations.....I think the setting where people are is the most important ..... I don't think we can have indicators that just go cross the border. (group 1m)</i> <i>Do we want to have quality indicators we measure at the patient? .... Because this makes us independent from the different structure of health services.... But I also don't know how it's really perfect to manage this kind of assessment or data collection. (group 1m)</i>
	Formulation	<i>We do not discuss preferences, we have mostly one religion, and do not discuss sexuality with older people quickly.(group 3m)</i> <i>I am used to work with medical data which are considered more easily to review and I think it is much more difficult with social and psychological data. It is so easy to misunderstand. (group 2a)</i>
<i>Facilitator</i>	Attractive	<i>I think that most dementia units in Spain not know anything about it [the QIs]..... I think that it is very important to establish a European consensus..... to get a care network, social or health network for dementia care and consider not only pharmacological treatment. (group 1m)</i>
	Feasibility in practice	<i>When I was looking at the form of questionnaire and thinking about the people are busy and they try to find time to fill it in, I think that it is maybe quite helpful if there's a list of explaining what psychosocial interventions are. So people can quickly see, do we have this? (group 1m)</i>
<b>Organisational context</b>		
<i>Barrier</i>	Variety and change	<i>In Spain the other important problem is the different system of care in the country because the social service, health service has been transferred from the national government to the regional government and because of this we can find different models for treatment (group 1a)</i> <i>I know you have it in Holland, don't you. That people can receive cash. And Germany, France is a little bit? So, I think it is increasingly European, which is going to reduce the number of things that you can count[assess with QIs] in that way. (group 2a)</i>
	Use data from patient records	<i>You should not find the GP documentation in the nursing home and you should not find nursing home documentation in GP-files. So if you go with QIs and just say it wasn't in the files, you should not expect it in the different documentation. (group 1o)</i> <i>I did mine in the memory clinic [gather QI data] it's one that actually does offer interventions and I was surprised how vague. I knew people were doing it, but there was no record of it and no clarity. (group 1m)</i>
<i>Facilitator</i>	Include in checklist	<i>I think it is better to have a kind of checklist for did you ask about preferences, did you ask about life history, rather than having checked this afterwards. See the checklist beforehand in the patient file. (group 2m)</i>

<b>Individual professional</b>		
<i>Barrier</i>	Attitude	<i>Perhaps one of the challenges is to say that nothing can be done unless providers and professionals wish it to be done. (group 2m)</i> <i>Everybody is just trying to make sure that they're communicating the right information and they start to lose the carers preferences .... you find people getting involved going in with decisions based on what they've been told by other professionals and still not asking carers and people with dementia what they want and involving them in decisions. (group 2m)</i>
<i>Facilitator</i>	Increased motivation	<i>If you get back a report and it says ok you have these QIs and the other institution has this. It makes people think about what they do different to other people. (group 1m)</i>
<b>Patient and carer</b>		
<i>Barrier</i>	Few QIs for carers	<i>The number of indicators for the carer is rather small.</i> <i>Other participant: I agree with that. (group 2m)</i>
<i>Facilitator</i>	None	
<b>Economic and political context</b>		
<i>Barrier</i>	Confidentiality of patient notes	<i>One of the barriers I had initially to do this was actually to access patients notes without their consent. (group 2m)</i>
<i>Facilitator</i>	Match with policies	<i>Actually in Germany by law the nursing homes are required to look for body mass index (BMI). The BMI is one quality indicator for nursing home care. So every patient will have it. (group 1m)</i>
	Financial support and incentives	<i>They want to get money from the health insurances, or get a proof. We also have QIs for institutions now, every hospital and so are all checked if they meet certain requirements. And if this is something attractive and not something you must do or, which means more work to you. (group 3a)</i>
	Influential organisations or people	<i>There is one organisation that is behind the QIs that are being used now in Holland and you need that organisation to being used and have a big impact. (group 2m)</i>

**Table 3. Barriers, facilitators and quotes associated with the provision of psychosocial care in dementia per health-care level**

<b>Innovation</b>		
<i>Barrier</i>	None	
<i>Facilitator</i>	Growing evidence base	<i>I think that new papers are supporting its promotion because every year we can read papers which are supporting psychosocial intervention.....it is the moment to promote psychosocial interventions as part of the health and social network with dementia patients. (group 1m)</i>
<b>Organisational context</b>		
<i>Barrier</i>	Variety and change	<i>..if I think about the situation in our country [Finland] there is one problem and it is that we don't have enough services ..... Even if people are very skilled in providing psychosocial services and psychosocial support, there are not enough services. (group 1a)</i> <i>I have seen more people in less time and being less thorough and not staying involved with them as long as we used to. How I've practiced 10 years ago would have been a lot easier to have met the QIs or said we are meeting them whereas now people just don't have the time to be that thorough in their assessments and monitoring the people. (group 2a)</i>
<i>Facilitator</i>	Care improvement efforts	<i>Who in the UK coordinates the social health practices, a manager or case-manager?</i> <i>Other participant: Yeh, so often. The item [QI] about coordination would pick up on that and there are efforts to have linked case notes. Probably the care home have a record that includes both the health and social care. (group 1a)</i>

<b>Individual professional</b>		
Barrier	Lack of skills	<i>The care staff [in a specific care home] have no idea what a psychosocial intervention is, I mean they have absolutely no idea (group 2a) Physicians are not educated in all those interventions, they don't know the contents of the interventions, so there is a lot of work to be done. (group 2m)</i>
Facilitator	Feedback	<i>If I think about how to moderate people to fill-in these QIs. I think it is necessary that they get some immediate feedback after doing it. Some ideas about how to develop their care practices. (group 1m)</i>
<b>Patient and carer</b>		
Barrier	Patient's point of view	<i>I had a bit of a problem with the indicators with the word of offering because you're always asking, looking if they understand it and what they want, so it's not really our sight, it's the sight of the patient. (group 2m)</i>
	Refusal of care	<i>We offer a lot but many times it is refused. So, there is a kind of mismatch. We do want to, we have a lot of projects and creativity but the patients do not want that. (group 3a)</i>
Facilitator	None	
<b>Economic and political context</b>		
Barrier	No financial support	<i>I think it is in Finland also the problem that when the project is going everything is fine but when the financing is cut down then the good results also. They give money to those projects, but the implementation is not funded at all.(group 3a)</i>
Facilitator	None	

**Table 4. Implementation strategies and quotes per health-care level**

<b>Individual professional</b>		
Include QIs in guidelines	...	<i>...guidelines differ from country to country, so I think the dissemination of evidence will be more useful more powerful in local, regional guidelines. (group 1m)</i>
Make QIs easy to use		<i>If you want to do quality indicators for benchmarking, you need some objective document, written records and you have to ask: "who is having written records?" and this are hospitals, GP's, nursing homes and eventual ambulatory care systems. I would strongly recommend to structure the quality indicators concerned to these settings. (group 1m)</i>
Include QIs in skills training		<i>In Italy, now in our region they have to give I think 20 hours I hear for training. For those who are working. ....and what I am thinking may be if we needed to introduce something about QIs or psychosocial intervention within this kind of training, to do something. Because they have to do it. (group 1a)</i>
<b>Patient and carer</b>		
Make QIs known to carers		<i>Everybody will have access to the Internet. And this national knowledge center [in Denmark] for dementia has made a homepage where you can go in and make e-learning..... you could put QIs there as well. So, that the population would know or at least the relatives would know what shall I ask the system of. (group 3a)</i>
<b>Economic and political context</b>		
Use existing networks		<i>We have members of Interdem in all countries and I think that it is easy to translate and we could translate quality indicators as a consensus in different languages. (group 1m)</i>

## Barriers

### Factors related to the innovation

**Unattractive.** A set of QIs did not appeal to some of the participants because other sets of QIs had already been implemented in some countries. A new implementation might be perceived as extra work for professionals. The fact that the set was a European initiative rather than a national one made it less attractive to a UK participant.

Feasibility. One of the participants suggested that the ideal way of using the set would be to gather QI data from the perspective of the person with dementia by considering which care providers are involved in the provision of care, instead of taking on the perspective of care providers. However, this type of data collection was also thought to be less feasible to organise. Other participants did not think that the set could be applied to all patients regardless of the disease stage or setting.

Formulation of the quality indicators. The participants thought that some QIs were stated too broadly. They also thought that, in general, QIs covering psychosocial care were more ambiguous and vague than QIs covering medical issues. In addition, one of the QIs stated that the person with dementia's preferences should be registered. This QI included some examples of preferences that could be asked for (religion, sexuality and diet). These examples were thought not to be relevant in all cases and all countries. Some participants foresaw barriers regarding the translation of the set in their countries' languages because of differences in terminology and specific words that were difficult to translate.

### ***Organisational context***

#### Variety and change in organisation of dementia care

The wide variety in the organisation of dementia care between and within countries was seen as a barrier. Whereas QIs were relatively easy to implement in one region, this could be a challenge in another.

In some countries, there was a shift towards governments enabling patients and carers to buy and organise their own care. This was also seen as a barrier because it would be harder to gather QI data about these patients and carers.

A participant from Germany mentioned that, compared to nursing home care, the organisation of home care is a grey area in Germany. Using the QIs to evaluate home care would therefore be difficult to organise nationally. In Finland, the capacity of dementia care services was thought to be insufficient to provide psychosocial care on a national level as the QIs require.

The participants also remarked that the organisation of dementia care practice had changed during the last decade. Nowadays, there is more pressure to perform, and this means less time and fewer opportunities to use the set of QIs properly in practice.

#### Using patient records to assess quality indicators

The use of patient records for assessing the QIs was mentioned as a barrier because the data for all QIs could not be found in one place or setting and patient records were often incomplete.

### ***The individual professional***

Lack of skills. The participants in all three groups saw the skills and competences of professionals working in dementia care as an important barrier. Professionals in dementia care were not

thought to be automatically skilled to provide psychosocial care at the QIs level or to document the psychosocial care process in patient records. The focus group participants discussed the necessity of skills training and increasing awareness with regard to psychosocial care.

Attitude. The attitude of professionals toward psychosocial interventions and the use of QIs were considered important for successful implementation but were also considered potential barriers. However, professionals using the QIs should not become too focused on meeting the quality criteria and documenting QI data no matter the source of the information. Some participants thought that professionals might forget to consult the dementia patient and carer.

### ***Patient and carer***

The dementia patient's point of view. One of the focus groups discussed whether the dementia patient's point of view was reflected well enough in the formulation of some QIs. If not, using the QIs as currently formulated would not guarantee the provision of quality psychosocial care. The participants discussed how to better formulate the QIs, but concluded that certain aspects of psychosocial care were not easy to describe.

Dementia patients and carers might refuse care. One of the groups discussed whether all patients and carers would automatically accept the psychosocial interventions that professionals offered them. In these cases, a professional might not succeed in applying the QIs, despite all efforts.

Too few quality indicators for carers. It was thought that the proportion of QIs for informal carers included in the set was rather small. The participants made suggestions for some additional QIs for informal carers.

### ***Economic and political context***

Specific policies at the national and regional levels and certain economic and financial issues were thought to have a negative influence on the implementation of the set of QIs. One barrier that was mentioned was the laws and policies regarding the confidentiality of patient files and medical notes. This would make it more difficult to access patient notes and to gather QI data in some countries. One group suggested that perhaps patient consent would be needed when QI results became public.

The current negative economic situation was seen as a barrier because it meant less money to improve the quality of care on a large scale. Some participants also had the experience that governments provided financial means for short-term projects only, which meant that once a project was finished, so was the financial support. Subsequently, there was no financial support to implement successful interventions on a larger scale.



A participant from Spain mentioned that the government had set up special dementia units to regulate the expenditures for anti-dementia drugs. The result of this focus on cutting costs for pharmacological treatment was that these units gave little attention to psychosocial care.

### *Facilitators*

#### ***Factors related to the innovation***

Attractive. Some participants saw the fact that the QIs were developed on a European level as a barrier for implementation. However, participants from Spain and Italy thought that this could actually be a facilitator for implementation in their countries.

Feasibility in practice. Participants agreed that professionals should not have too many difficulties applying the QIs or gathering QI data. They thought that the success of implementing the QIs related to their user friendliness.

Growing evidence base. The growing evidence base for psychosocial interventions in dementia care was mentioned as a facilitating factor for implementing the set of QIs.

#### ***Organisational context***

Include quality indicators in checklist. Some participants suggested using the QIs for guidance during the care process would facilitate implementation. They suggested using the QIs as a checklist instead of checking adherence to the QIs retrospectively.

Quality indicators and care improvement efforts. Participants from the UK mentioned that some of the QIs were in line with the current efforts to encourage collaboration between different care services and improve the coordination of care.

#### ***The individual professional***

Professionals who are motivated to work with the QIs could facilitate the implementation process. The participants suggested that the added value of working with the QIs should be made clear to professionals and that they should receive feedback so that they could learn and develop their skills and practice. Incentives, like money or a quality certificate, were also mentioned as a way of motivating professionals to work with the QIs.

#### ***Economic and political context***

Quality indicators match with policies. It was thought that implementation would be facilitated if the QIs matched current national and regional policies or were included in new laws or policies. The participants provided examples of the success of this strategy in their countries.

Financial support and incentives from governments or insurance companies were suggested as facilitating factors. The participants gave examples of such financial support and incentives that had influenced implementation of other care improvement initiatives.

Influential organisations and people. Some of the participants mentioned that, in their countries, specific organisations, insurance companies, and people, some of whom already use QIs, have a lot of influence on the quality of care in general and dementia care in particular. If these influential organisations or people supported the set of QIs for psychosocial dementia care, implementation could be facilitated through them.

### *Implementation strategies*

Participants came up with strategies to disseminate or implement the set of QIs in their countries or across Europe. These strategies were found at the health-care levels of the individual professional, patient and carer, and in economic and political context.

### ***The individual professional***

Include quality indicators in guidelines. Participants from Spain and Italy thought that including the QIs in guidelines aimed at professionals would be an effective strategy. In Spain, publishing the set of QIs in local journals would be the first step toward achieving this.

Make quality indicators easy to use. The participants suggested different strategies for increasing the user friendliness of the QIs. Suggestions were to group the QIs according to the setting where the QI data would be available, to formulate the indicators as clearly as possible, and to include the QIs in a checklist in the patient file to remind professionals what they should do and ask when providing care. Participants from the UK suggested that it would help if the QIs were adapted to the computer systems that are currently used in the UK.

Include quality indicators in skills training. Two participants from different groups suggested that including the QIs in obligatory training and education sessions for professionals could facilitate implementation of the set in their countries.

### ***Patient and carer***

Make quality indicators known. One suggestion for an implementation strategy from the patient and carers' perspective was to make the set available for informal carers so that they could use it as a tool to evaluate their care situation.

### ***Economic and political context***

It was suggested that international networks like Interdem or Alzheimer Europe could be used to disseminate the set of QIs. The Interdem network could be used to translate the QIs to different

languages. It could also be used to gather and compare QI data from various countries. One participant suggested that Alzheimer Europe could help in disseminating the set of QIs by sending it to national and regional Alzheimer Society members.

## Discussion

Barriers and facilitators for implementing a health-care innovation, i.e. a set of 12 QIs for psychosocial dementia care, in various European countries were associated with the innovation itself and the provision of psychosocial care in dementia (Tables 2 and 3). Moreover, these barriers and facilitators were related to five of the six health-care levels included in a model for change at different health-care levels.<sup>20</sup> Among the barriers were the professionals' lack of skills and motivation, the variety in organisation of dementia care between and within countries, and ambiguity of the QIs. Among the facilitators were the user friendliness of the QIs, feedback and incentives to motivate professionals, and QIs fitting in with national and regional policies. No factors related to the social context were mentioned as barriers or facilitators. Focus group participants suggested a few strategies for implementing the set of QIs, most of which were at the level of the individual professional, e.g. including the QIs in skills training and practice guidelines.

Quality indicators are widely used as a tool to assess and improve health-care quality and performance, and factors related to its adoption have been investigated too in other studies.<sup>23-27</sup> Our study is unique in that it explores barriers and facilitators on an international level in various settings, whereas other studies focus on implementing QIs in specific settings within one country. This is probably why the barriers that we found in the organisational context (namely, the variety of dementia care organisation between countries) and political context (namely, laws protecting patient notes) have not been reported in earlier studies.

The European context of the set of QIs was seen as both a barrier and a facilitator. Whereas a participant from the UK thought that a European initiative would be given less priority than national initiatives, participants from Spain and Italy thought it could stimulate change in dementia care in their countries. An explanation for this difference might be that in the UK national dementia guidelines and strategies, including psychosocial care, were published recently and the government is currently encouraging implementation.<sup>11,13,14,28-30</sup> In contrast, national dementia guidelines or strategies are not yet available in other European countries such as Spain and Italy, or they do not include many recommendations for psychosocial dementia care.<sup>15,16,31</sup>

To disseminate the set of QIs in the European countries, the use of existing international networks was suggested as an implementation strategy. In general, networks are useful in the dissemination of innovations, although their exact role in implementation and worth in improving patient care is not entirely clear.<sup>32,33</sup>

Our finding that the perceptions and attitudes of professionals should be taken into account when implementing the QIs in practice is also reported in other studies. A professional's intrinsic motivation and perceptions about ease of usage and the reliability of the data used for the QIs

are related to successful implementation.<sup>23,24,27,33</sup> In addition, feedback based on QI data encourages professionals to improve care practice.<sup>24,26</sup> Incentives could be useful in some contexts, but one study found them less important than professional's intrinsic motivation, while only a proportion of professionals in another study were willing to accept incentives.<sup>23,24,26</sup> If QIs are linked to incentives, these QIs should be formulated unambiguously, and the participants in our study doubted the clarity of the QIs. The ambiguity of psychosocial care QIs in relation to medication measures was a reason not to include psychosocial care QIs in an international set of QIs for benchmarking mental health-care.<sup>25</sup>

Facilitators at the level of the political and economic context, such as endorsement by credible national organisations, and QIs fitting in with local and national policies were identified as factors that could facilitate implementation.<sup>23,27,33</sup> Several participants shared the experience that governments often do not provide the financial means to implement psychosocial care successfully. This finding is not restricted to dementia care only; it is a barrier to disseminating evidence-based psychosocial care in oncology as well.<sup>34</sup>

The social context was not a primary contributor to barriers and facilitators in our study.<sup>20</sup> The reason for this is probably its international focus. The social context, e.g. opinion of colleagues, culture of the network, and leadership, can probably best be investigated on a meso- or micro-level of dementia care. Barriers and facilitators related to the social context should therefore be identified on a local level as part of an implementation process.

A limitation of our study is the inclusion of a purposive sample of dementia care professionals who were members of an international group that focuses on psychosocial dementia care. This means that the attitude of focus group participants was positive and they were relatively much more knowledgeable than other professionals about the provision of psychosocial dementia care and its current evidence base. Conducting focus groups with professionals who have less knowledge or even a negative attitude about psychosocial dementia care could reveal additional barriers and facilitators. Furthermore, our study did not identify many barriers and facilitators at the level of the patient and carer. Including patients and informal carers in focus group interviews could uncover barriers and facilitators at this health-care level.

Another limitation is that focus group discussions took place in the English language even though this was not the first language of most participants. However, we do not think that it undermined the results of the study because most participants had met each other before at Interdem meetings. They were used to, and felt comfortable, expressing their opinions in one another's company, which is an important condition for the success of focus group interviews.<sup>35</sup> The international focus of our study made it essential that participants from different countries discussed barriers and facilitators with one another. Otherwise, important differences between countries, such as the variety in organisation of dementia care and the opinion about the European context of the QIs, would not have been revealed.

## Conclusion

Combining our findings with those of other studies, we conclude that it is not feasible to apply one strategy for successfully implementing the set of QIs in the various European countries. As with clinical guidelines, implementation needs to be adapted to the local context.<sup>36-39</sup>

The organisation of dementia care varies widely between and within countries. National and regional governments, policies, and laws could facilitate, but also hinder, the implementation process. Factors relating to the organisational, political, and economic contexts should be taken into account in all countries, but need to be addressed locally. Local implementation efforts should include strategies to motivate care professionals to use the QIs and to provide opportunities to develop their skills and competences. Successful strategies depend on the local possibilities and structures. They could include making QIs easier to use for local dementia care practice, providing feedback based on QI data, and including the QIs in skills training and dementia guidelines.

Except for pharmacological interventions, the European Union has only a limited role in improving the quality of care across Europe.<sup>40</sup> The collaboration between care professionals from different European countries is therefore necessary to set quality standards and improve quality of health-care in other areas, as in the case of psychosocial dementia care. Networks, like Interdem and Alzheimer Europe, could play a central role in disseminating the set of QIs on a macro-level and raise awareness across countries. Especially in countries where its inclusion in dementia guidelines or strategies is limited, introducing the set of QIs could be the first step in raising awareness and improving the quality of psychosocial dementia care.

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# Chapter 6

## General discussion



In this chapter the development and implementation of the set of QIs and its importance for dementia research and practice are discussed. The set's content, evidence base, implementation, and methodological issues are critically reviewed, and the set's usefulness for research and society is illustrated.

### **The quality indicators represent the standard of psychosocial dementia care**

Psychosocial aspects of care are often under-represented in sets of QIs because medication and other clinical measures are considered easier to assess.<sup>1,2</sup> However, the stepwise procedure described in this thesis resulted in a set of 12 content-valid and face-valid European QIs for psychosocial dementia care (table). Our study shows that valid QIs for psychosocial care that are measurable in and applicable to various countries and settings can be developed and used to evaluate the quality of psychosocial dementia care in clinical practice.

All but one quality indicator in the set are process indicators. The information obtained from process indicators provides care professionals direct feedback about the processes that they did or did not follow and need to improve.<sup>3</sup> Indicators describing processes of care are therefore important for achieving quality improvement in health care.<sup>4,5</sup> The processes described in our set of QIs provide dementia care professionals with feedback about the extent to which evidence-based psychosocial dementia care is provided. This includes:

- The importance of tailoring and personalising care to the preferences and needs of the person with dementia and the carer, which is reflected in the QIs by
  - Documenting needs and preferences (QI 3)
  - Taking them into account when offering psychosocial care (QIs 4 and 10).
- Social inclusion, communication with the person with dementia, and preservation of their autonomy, which is reflected by
  - Discussing care options with both the patient and the carer and offering choices (QI 5)
  - Offering participation in recreational and social activities (QI 6)
  - Discussing the diagnosis with the person with dementia (QI 1).
- The use of psychosocial interventions first for behavioural problems, which is reflected in the content of QIs 8 and 9.

To our knowledge, this set of QIs is the first that aims exclusively at psychosocial dementia care. The set provides added value to the available sets of QIs that focus on other aspects of dementia management, such as pharmacological care, medical care, diagnostics, and the management of dementia in general practice and memory clinics.<sup>6-10</sup> If dementia care professionals were to combine and apply these sets, they could improve the quality of dementia care in general. This could be a starting point for integrating medical and social dementia care on the local level. The fact that most of these sets of QIs were developed within the context of one country does not prevent them from being used in other countries as well. Transferring QIs from one country to another is feasible if they are adapted to the local context.<sup>11</sup>

**Table. Quality indicators for psychosocial care in dementia**

<i><b>Numerator</b></i>	<i><b>Denominator</b></i>
<b>Diagnosis and assessment</b>	
1. Number of people with dementia whose patient file records that diagnosis was discussed with the person with dementia	Total number of people with dementia at service
2. Number of people with dementia who are assessed* periodically <sup>†</sup> for depression and/or anxiety	Total number of people with dementia at service
3. Number of people with dementia with registration in patient file and/or care plan of: <ul style="list-style-type: none"> <li>• Life history</li> <li>• Social and family circumstances</li> <li>• Needs and preferences<sup>‡</sup></li> </ul>	Total number of people with dementia at service
<b>Care plan and treatment</b>	
4. Number of people with dementia whose patient file records that they are currently receiving psychosocial interventions, tailored to the person's: <ul style="list-style-type: none"> <li>• Needs and preferences<sup>‡</sup></li> <li>• Cognitive and physical abilities</li> </ul>	Total number of people with dementia at service
5. Number of people with dementia with a registered personalised care plan, shared between the person with dementia, informal carer and care professional, that is periodically <sup>†</sup> updated. This means that: <ul style="list-style-type: none"> <li>• At least two types of interventions were discussed with and offered to the person with dementia</li> <li>• The care plan is drawn up in agreement with person with dementia, informal carer and professional at the service</li> <li>• Response to initiated interventions is monitored less than one year ago</li> </ul>	Total number of people with dementia at service
6. Number of people with dementia whose care plan includes: <ul style="list-style-type: none"> <li>• ADL activities</li> <li>• Recreational and social activities</li> <li>• Structured day activities</li> </ul>	Total number of people with dementia at service
7. Number of people with dementia who have an assigned professional who maintains regular contact with the patient and the main carer and ensures coordinated delivery of health and social care services	Total number of people with dementia at service
<b>Behavioural problems</b>	
8. Number of people with dementia who have behavioural problems with registration of a tailored care plan that: <ul style="list-style-type: none"> <li>• Is based on an assessment*<sup>§</sup> to establish factors likely to cause the behaviour</li> <li>• Includes registration of its frequency of review agreed on by the informal carer and staff involved</li> </ul>	Total number of people with dementia who have behavioural problems at service
9. Number of people with dementia who have behavioural problems that are treated with a psychosocial intervention first before pharmacological treatment is started.	Total number of people with dementia who have behavioural problems at service

<b>Numerator</b>	<b>Denominator</b>
<b>Informal carers</b>	
<b>10.</b> Number of carers of people with dementia for whom it is registered that: <ul style="list-style-type: none"> <li>• Respite or short-break care is offered to them</li> <li>• Other psychosocial interventions, tailored to their needs and preferences are offered to them</li> </ul>	Total number of carers of people with dementia
<b>11.</b> Number of carers of people with dementia who are periodically <sup>†</sup> assessed <sup>*</sup> for mood and coping	Total number of carers of people with dementia
<b>Professional caregivers</b>	
<b>12.</b> Number of staff at care service/facility that receive specific dementia-care training at least once a year	Total number of staff at care service/facility

*\*A structured and systematic approach to examine a certain condition. This means using validated scales/questionnaires or at least a standardised method that is used for all similar patients/persons within the organisation/service*

*†At least once a year*

*‡Important to person with dementia, related to the quality of life*

*§ In case of behavioural problems the assessment ideally includes: physical health, depression, undetected pain or discomfort, side effects of medication, individual biography, including beliefs, spiritual and cultural identity, psychosocial factors, physical environmental factors, specific behavioural and functional analysis*

### **The set of quality indicators is based on the best evidence available**

The European guideline inventory (Chapter 3), the review of systematic reviews<sup>12</sup>, and the systematic review of communication strategies (Chapter 2) contributed to identifying evidence-based key elements for developing the set of QIs for psychosocial dementia care.

Most evidence-based key elements for psychosocial dementia care were extracted from the recommendations in European dementia guidelines. The inventory of European dementia guidelines was therefore an essential step in developing the set of QIs. We used the AGREE instrument to assess the methodological quality of the guidelines. We found that the guidelines that had better methodological quality, and especially the ones with higher scores for the rigour of development domain included more recommendations for psychosocial dementia care. With respect to developing the set of QIs, the AGREE domain 'Rigour of development' is important because it relates to (1) the process used to gather and synthesise the evidence and (2) the methods for formulating the recommendations. The dementia guidelines included in our study had a higher average in this domain (61%, range 38–90%) than clinical practice guidelines in a wide variety of healthcare topics that Alonso-Coello and colleagues<sup>13</sup> reviewed for quality (43%; 95% CI 41.0 to 45.2). More importantly, we extracted most of the recommendations for psychosocial dementia care from the three guidelines that scored the highest for 'rigour of development' in our guideline inventory study.<sup>14–16</sup> This means that the guideline recommendations had a scientifically sound evidence base for obtaining key elements for the set of QIs.

Evidence-based key elements were extracted from systematic literature reviews. The findings of the systematic review of communication strategies extended the evidence base for the use of psychosocial interventions in institutional care. Although the interpretation of results was

complicated by the poor methodological quality of the individual studies, we were able to identify key elements that contributed to improving communication between care staff and people with dementia. These key elements are: (1) an intervention should have simple activities, each consisting of a single task, and these activities should be scheduled at set times or (2) an intervention should teach care staff to apply communication techniques in daily care activities. Other systematic reviews of psychosocial dementia care also distinguished effective from ineffective psychosocial interventions, despite the poor quality of the individual studies. An important key element identified from the best available evidence is: psychosocial interventions and care should be individualised and tailored to the specific situation, background, and needs of the person with dementia and their informal carer.<sup>17-20</sup>

Quality indicators based on high-quality scientific evidence have more potential to improve the quality of health care, but scientific evidence for the effectiveness of psychosocial dementia care from randomised controlled trials (RCTs) only is scarce.<sup>4,5,21</sup> However, the individually focused aims of psychosocial dementia care, such as the preservation of personhood, optimisation of well-being, and the quality of life of a person with dementia and their carer do not match the group-based information provided by RCTs.<sup>22</sup> After all, what improves well-being and quality of life for one person might produce opposite effects for someone else. Providing evidence-based care based solely on the results of RCTs might result in the neglect of psychosocial aspects.<sup>22,23</sup> Therefore, evidence-based psychosocial dementia care should be based on the findings of all the relevant studies. The key elements of effective psychosocial dementia care that we extracted from dementia guidelines and systematic reviews were based on all the relevant studies of varying methodological quality. These key elements represent the best quality of scientific evidence currently available and are therefore essential for developing the set of QIs.

### **Implementing evidence-based psychosocial dementia care**

The ability of clinical guidelines to improve the quality of health care depends not only on its methodological quality, but also on the extent to which health care professionals actually implement and use them.<sup>24</sup> The European dementia guidelines that were included in the guideline inventory study (Chapter 3) gave little attention to the implementation of recommendations. Clinical practice guidelines in general give little attention to their applicability in practice. Alonso-Coello and colleagues'<sup>13</sup> study found that the applicability domain had the lowest overall score of all the AGREE domains (22%; 95% CI 20.4 to 23.9). The dementia guidelines in our study also had the lowest average score in this domain (32%, range 6–89%). A reason for this might be that guideline developers consider guideline implementation as a separate activity, and they might feel that they lack expertise in this specific area.<sup>13</sup> In our case, an additional reason may be that there is a paucity of research about effective strategies for implementing evidence-based dementia care.<sup>25</sup> The set of QIs closes the implementation gap between guidelines and practice by facilitating the provision of evidence-based psychosocial dementia care. As part of the check phase of a quality improvement cycle (Plan-Do-Check-Act

cycle), QIs are an ideal instrument because QI scores show directly what actions need to be taken next.

However, the set's contribution to improving the quality of psychosocial dementia care also depends on the successful implementation of these QIs. The focus group interviews with dementia care professionals from various European countries and disciplines revealed that the European context of the set was perceived as both a positive factor and a negative one for implementing the set. Furthermore, implementation of the set of QIs in European countries must be adapted to the local context and the skills of local care professionals (Chapter 5).

Implementing specific QIs might be relatively easy in one European region, but a challenge in another because of the great variability in dementia care organisation and available services between and within European countries.<sup>26,27</sup> For instance, QI 7 states that each patient and their main carer should have an assigned professional who maintains regular contact. Depending on who is involved in dementia care and how dementia care is organised, this professional could be a case manager in one region, a general practitioner in another region, and another professional in a third region. Furthermore, respite or short-break care (QI 9) can only be offered to carers if these services are available, which is not automatically the case in all European countries.<sup>27,28</sup> Such services need to become available before the QI can be applied. Adapting the set of QIs to the local context as well as adapting the local context to the set of QIs may be necessary for successfully implementing the QIs.

In addition, focus group participants thought that professionals in dementia care lacked skills and competences to provide psychosocial care at the QI level or to document psychosocial care in patient records. One way to overcome this barrier is to combine educating professionals with implementing the QIs. Two strategies that can be used to achieve this are providing feedback based on QI data and incorporating QIs in care processes as a reminder. The first strategy requires adherence to the QIs to be assessed periodically and feedback based on adherence scores to be given to the professionals.<sup>29,30</sup> The second strategy entails reminders for the professionals about the correct processes of giving care according to the QIs. These processes must be incorporated in the routine data collection.<sup>3,31,32</sup> One of these strategies should be included in the local implementation plan for the QIs.

The European context of the set of QIs was perceived as a possible barrier for implementing the set across the UK. A UK focus group participant thought that a European set of QIs would be unattractive to dementia care professionals in the UK. In contrast, participants from Spain and Italy thought that the European context would facilitate implementation of the set in their countries. This difference in opinion was likely because recent UK dementia guidelines include psychosocial dementia care and government encourages implementation, whereas attention of Spanish and Italian guidelines, strategies, and government to psychosocial dementia care is limited, if present at all.<sup>33-39</sup> Dementia care professionals in Spain and Italy might perceive a European set of QIs as imperative, while a European set of QIs probably has less priority than national initiatives for professionals in the UK. Nevertheless, adapting the QIs to the local context

in the UK might take less effort than adapting them to the local context in Italy and Spain. Considering the attention given to improving psychosocial dementia care in the UK, essential prerequisites for implementing the QIs, such as respite care services, are most probably already available.

The EU-funded IMPACT (IMplementation of quality indicators in PAlliative Care sTudy) project, which is currently ongoing, aims to develop effective implementation strategies for using QIs to improve the organisation of palliative dementia care in Europe (<http://www.interdem.org/index.php/projects/current-projects>). This project includes some of the QIs for improving psychosocial dementia care, and it will gather more knowledge about the factors that influence the successful implementation of QIs for dementia care in various European countries.

### **Methodological considerations**

Few European dementia guidelines include recommendations for psychosocial dementia care, and recommendations from three European dementia guidelines, representing the UK and Germany, turned out to be the main sources for the evidence-based key elements for the set of QIs.<sup>14-16</sup> This, however, does not mean that the final set is more applicable to the UK and Germany than to other European countries because the recommendations included in these guidelines are based on scientific evidence from the international literature and are not country-specific. Furthermore, one or more dementia experts represented each of the 13 European countries in the RAND-modified Delphi procedure, and these experts reached a high level of consensus. All 17 key recommendations on which the final set of QIs is based received ratings of 75% or more within the highest tertile for usefulness in contributing to the improvement of quality of dementia care. The set of QIs therefore represents the quality standard for psychosocial dementia care for various European countries. Nevertheless, we cannot be sure to what extent the final set of QIs represents the opinion of dementia care experts from eastern European countries, as only three of the 49 experts were representatives from this part of Europe.

The process of developing the QIs resulted in a set with face and content validity that dementia care professionals can use as a tool to improve the quality of psychosocial dementia care at the local level. However, adherence to characteristics other than measurability and applicability must be assessed before the set can be used as a reliable tool to compare the quality of psychosocial dementia care on a large scale within or across countries. Such assessment is also necessary for governments' or insurance companies' benchmarks for accountability purposes. To allow accurate comparisons of QI adherence scores, the reliability of repeated measurement of the QIs should be established, as should the inter-rater reliability, in case more than one person collects data.<sup>4,40</sup> Furthermore, to set benchmarks for the QIs, it is necessary to establish their discriminatory capacity. We must know how well QIs can (1) discriminate service providers' quality of psychosocial dementia care and (2) detect changes in this quality.<sup>4,21,41</sup> Investigating the set's predictive validity, i.e. its capacity to predict quality-of-care outcomes, might determine

the relation between applying the set of QIs and important outcomes for people with dementia and their carers. These outcomes include quality of life, institutionalisation, and the burden of carers.<sup>4,40</sup> Linking the care processes that the QIs describe directly to better outcomes for people with dementia and their carers would encourage the implementation of the set of QIs.<sup>3</sup>

An additional consideration with regard to the reliability of the set of QIs is the use of patient records as a single source for obtaining QI data, as was done in the pilot studies in Spain and the Netherlands. Written records are often incomplete, which leads to underestimation of the actual care delivered.<sup>42,43</sup> Incompleteness of the patient records in the Dutch and Spanish settings should be considered as a possible explanation for the low adherence scores for some of the QIs in this pilot study. The use of additional data sources, such as observations during care provision and interviews with care managers or carers, should be investigated in further studies to determine whether patient records as a single source suffice for assessing QIs.

Our qualitative study (Chapter 5) reveals important barriers and facilitators for implementing the set of QIs, but its international focus was ineffective in uncovering barriers and facilitators related to the social context, the patient, and the carer. Before any local implementation begins, the local barriers and facilitators related to the social context, the patient, and the carer should be explored. The social context, i.e. the opinions of colleagues, culture of the network, collaboration, and leadership, can best be explored within a region among the organisations and/or professionals who must collaborate in implementing the QIs. In addition, to explore barriers and facilitators at the level of the patient and carer, the patients and carers themselves should be involved in the implementation. Their representatives, such as local Alzheimer's societies, could substitute for patients and carers in this involvement.

### **How can the quality indicators impact the quality of psychosocial dementia care?**

As long as there is no cure for any type of dementia, people with dementia and their carers should at least receive the best quality of care. The set of QIs for psychosocial dementia care can help to improve the quality of dementia care that is provided to Europeans with dementia and their carers. To summarise its strengths, the set of QIs:

- Represents the key elements of effective psychosocial dementia care based on the best available scientific evidence from international literature, European dementia guidelines, and consensus among dementia care professionals and researchers from various European countries.
- Is the first set of QIs that aims exclusively at psychosocial dementia care and enables assessment of the quality of psychosocial dementia care in European countries.
- Is a practical instrument that assists dementia care professionals in implementing evidence-based psychosocial dementia care.

The set of QIs is a timely instrument because dementia has increasingly become a European health care priority and there is growing attention for the provision of effective psychosocial



dementia care. The Eurocode project, as part of which this thesis was produced, was one of the first European research projects to encourage collaboration between European dementia researchers.<sup>44</sup> In continuation of this project, the EU Joint Programme - Neurodegenerative Disease Research (JPND), which focuses on Alzheimer's disease in particular, was launched and a research strategy representing the common vision of 24 European countries was recently presented.<sup>45-47</sup> Among the priorities for research are the further development of psychosocial interventions; promotion of social inclusion and carer involvement; and evaluation of equity of access to, and the effectiveness and cost-effectiveness of, pathways to treatment, care, and support. Furthermore, a growing number of national governments have recognised dementia as a health care priority and launched national programmes and strategies to facilitate improvements in both research and dementia care practice, including psychosocial dementia care.<sup>33,36-38,48</sup> Within the context of this European dementia policy, the set of QIs for psychosocial dementia care offers opportunities for both dementia research and practice to impact the quality of psychosocial dementia care.

#### *Opportunities for research*

One of the research priorities that the JPND has set is the evaluation of equity of access to treatment, care, and support. To date, information about the equity and access to psychosocial dementia care in Europe is scarce, if available at all. In contrast, available European studies compare the presentation of dementia patients in memory clinics, resource use and costs of dementia, prevalence of dementia, place of death of people with dementia, the diagnostic process, and availability of anti-dementia drugs.<sup>26,28,49-54</sup> Using the set of QIs for psychosocial dementia care to assess and compare access to psychosocial dementia care in various European countries would add currently missing knowledge about the equity of dementia care in Europe. The results might encourage governments of countries where the quality of psychosocial dementia care is poor to do something about it.

In addition, the set of QIs facilitates the study of the effectiveness of providing evidence-based psychosocial dementia care on important outcomes for people with dementia and their carers in the real life situation. Better adherence to the processes that the set of QIs describes may be linked to a smaller chance of institutionalisation, less carer burden, or better quality of life. If so, such a link would underline the importance of psychosocial care as part of dementia care and management.

#### *Opportunities for practice*

The set of QIs can be a useful instrument for European dementia care professionals, whether or not their national governments have made dementia a health care priority and/or facilitate improvements in psychosocial care. In countries where governments do encourage improvements in dementia care, the set of QIs provides dementia care professionals with a ready-to-use instrument that makes their improvement efforts transparent to others. The set of

QIs can even be used to evaluate or rate dementia care providers, should a national system of benchmarking and/or reimbursement exist. In countries where governments do not encourage improvements, dementia care professionals can nonetheless introduce the set of QIs to start raising awareness of the importance of psychosocial dementia care. This set of QIs can also start improvements in the quality of psychosocial dementia care in their countries.

The set of QIs can be useful to people with dementia and informal carers, as well as to dementia care professionals. Alzheimer Europe and local Alzheimer Societies can, if they wish, bring the set to the attention of people with dementia and their carers so that they can check the quality of care provided to them. They could then select the best services on the basis of QI performance. Being the care consumers, they could raise awareness among care professionals and demand improvements in the quality of psychosocial dementia care.

The integration of medical and social dementia care services and multidisciplinary collaboration is increasingly being encouraged in European countries.<sup>33,34,48,55-57</sup> As already mentioned, combining the set of QIs for psychosocial dementia care with other sets of QIs for dementia would largely cover the area of medical and social dementia care. If adapted to the local context, such a combination of sets offers an opportunity to introduce quality improvement cycles to guide the integration process on a local level.

## Conclusion

Putting the available evidence into practice is not an automatic process in dementia care, and one of the many challenges is the volume of dementia research.<sup>25</sup> In case of psychosocial dementia care, this is an important obstacle that has been overcome: the set of QIs presented in this thesis represents the key elements of evidence-based psychosocial dementia care, based on the best scientific knowledge currently available. The set offers both dementia researchers and care providers an opportunity to improve the quality of psychosocial dementia care, which would lead to improving the quality of dementia care in European countries.

Although the set is ready for use on a local level, it is necessary to establish the inter-rater reliability, the discriminatory validity, and the predictive validity of the set before it can be used to compare the quality of psychosocial dementia care on a large scale within or across countries or for accountability purposes. These characteristics could be part of a future research project in which the set of QIs can be used to evaluate the quality of psychosocial dementia care in various European countries.

The prevalence and burden of dementia will not only increase in Europe in the coming decades, but will affect countries all over the world.<sup>58,59</sup> Alzheimer's Disease International therefore calls for implementing the best quality of care and investing in research into dementia care worldwide.<sup>59</sup> The set of QIs for psychosocial dementia care may help us face the major challenge of improving and spreading good-quality dementia care throughout Europe. The set is an attractive instrument for improving quality of psychosocial dementia care in countries other than European ones as well.

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# Summary



Optimising the quality of life of both patients and their informal carers is one of the most important treatment goals in dementia care, and psychosocial care is essential to this process. Nevertheless, the implementation of evidence-based psychosocial dementia care in Europe is limited and needs to be encouraged. An important step in any effort to implement scientific evidence in practice and hence, improve the quality of health care, is the development of quality indicators (QIs). Quality indicators are explicitly defined and measurable elements of practice performance for which there is evidence, or at least consensus, that they can be used to assess improvement and change in the quality of care provided. The aim of this thesis was to develop and evaluate a set of quality indicators (QIs) to help implement evidence-based psychosocial dementia care in European countries.

We used a stepwise process for developing and evaluating the set of QIs for psychosocial dementia care. The first step consisted of gathering evidence-based recommendations for specific psychosocial interventions and psychosocial care in general from the relevant systematic reviews in the literature and European dementia guidelines. All evidence-based recommendations that could be extracted from the systematic reviews that were selected for the review of systematic reviews, the systematic review of communication strategies (Chapter 2), and the dementia guidelines gathered in the guideline inventory study (Chapter 3) were used in developing the QIs (Chapter 4). In addition, we explored barriers and facilitators in implementing the set of QIs in various European countries (Chapter 5). The main findings from each of these steps are summarised here.

Seventeen systematic reviews were selected, and evidence-based key elements of psychosocial dementia care were extracted. These key elements refer (1) to psychosocial care being individualised and multicomponent and (2) to care plans for carers including more intensive, long-term interventions. The review of systematic reviews revealed a paucity of reviews focusing specifically on the use of psychosocial interventions in institutional care. A systematic literature review, which **Chapter 2** describes, has filled this gap. This literature review concerns the effects of psychosocial interventions on (1) the communication between residents with dementia and care staff in residential and nursing homes and (2) the neuropsychiatric symptoms of residents with dementia. Two overall 'types' of communicative, psychosocial interventions were identified. The first type (ten studies) is a communicative session or intervention for residents that a trained specialist or staff member carries out at a 'set-time session', such as a life review, one-on-one conversation, walk-and-talk intervention, or cognitive stimulation therapy. The second type of intervention (nine studies) is intended to teach care staff to apply communication techniques in daily-care activities, the 'daily-care' intervention. These interventions are either training programs aimed solely at teaching care staff communication techniques or multicomponent training programs that include communication techniques. The methodological quality of the included studies was generally poor.



A meta-analysis of five set-time intervention studies included two walking programs combined with conversation, a life review program, cognitive stimulation therapy, and activity therapy. Another meta-analysis of four set-time intervention studies included group validation therapy, a life review program, cognitive stimulation therapy, and activity therapy. Neither meta-analysis found any significant overall effect on communication outcomes or neuropsychiatric symptoms. Positive effects in communication outcomes appeared in individual studies when set-time interventions are single-task sessions, such as a life review or a one-on-one conversation, and when care staff use communication techniques in daily-care activities. The effects of the two types of interventions on neuropsychiatric symptoms were divergent. Overall, the review indicates that care staff can improve their communication with residents with dementia when strategies are embedded in daily-care activities or when interventions are single-task sessions at set times.

**Chapter 3** presents the results of the guideline inventory of evidence-based recommendations for psychosocial care in European dementia guidelines. We used the INTERDEM network, a pan-European, multiprofessional, clinical research network, to collate dementia guidelines published from 2000 onwards in countries across Europe. The methodological quality of the guidelines was measured by means of the Appraisal of Guidelines Research and Evaluation (AGREE) instrument. Our study shows that the inclusion of psychosocial care in dementia guidelines is limited in Europe. Seven dementia guidelines from five of the 12 European countries had sections about psychosocial care that were suitable for inclusion in the study. Dementia guidelines from Germany, Italy, the Netherlands, Spain, and the UK included one or more recommendations for psychosocial care. Physical activity and carer interventions were the most recommended in all guidelines.

The scope and purposes domain, i.e. description of the objectives, the clinical questions covered, and the patients to whom the guideline is meant to apply, had the highest average score of all the AGREE domains. The description of factors related to the implementation of a guideline scored lowest. Five of the seven guidelines lacked a description of an updating process. Important factors related to the inclusion of recommendations for psychosocial interventions in guidelines were the influence of guideline developers, the methodological quality of the guidelines, and the appreciation of the available evidence.

The UK NICE SCIE guideline had the best overall methodological quality and included the most recommendations for specific psychosocial interventions. It recommended the use of carer interventions, cognitive stimulation therapy, recreational activities, physical activities, reminiscence, and other psychosocial interventions.

Our study shows the need of high-quality dementia guidelines that include sections on psychosocial care and that are kept up to date with the emerging evidence. However, dementia guidelines alone cannot improve the quality of psychosocial dementia care. A tool in the form of

a set of QIs is needed to facilitate the implementation of evidence-based psychosocial dementia care in European countries.

**Chapter 4** describes the process of developing such a set of QIs. The evidence-based recommendations gathered from relevant systematic reviews in the literature and European dementia guidelines were included in a RAND-modified Delphi procedure. The procedure combined expert opinion with scientific evidence, and consisted of two postal surveys among 49 European dementia professionals and researchers, face-to-face meetings of a small QI development group, and a final consensus meeting with 25 members of the INTERDEM network. This resulted in a final content-valid and face-valid set of 12 QIs consisting of nine process indicators for people with dementia, two process indicators for carers, and one structure indicator for professional caregivers. The QI content assists health care professionals in individualising and tailoring psychosocial care, empowering the patient and carer, and providing social inclusion and continuity of care.

The measurability and applicability of the set of QIs was studied in practice: data were extracted from 153 patient records from nursing homes, hospitals, and day-care centres in Spain and the Netherlands. Adherence to the QIs ranged from 0% to 89% per patient record and 11% (Spanish hospital) to 50% (Spanish nursing home) per setting. At least one of the settings for each QI rated 75% or more, with the exception of three QIs. This indicates that it is possible to provide psychosocial care in line with most of the QIs included in the final set.

Although the validity of the set of QIs should be further tested on a larger scale, it is ready for European dementia care professionals and services to use it as a starting point to implement and improve evidence-based psychosocial care on a local level.

**Chapter 5** describes a qualitative study that explored the potential barriers and facilitators for implementing this innovative set of QIs in various European countries. An implementation strategy based on the barriers and facilitators was composed. Focus group interview sessions were used as a method to gather the qualitative data. The focus group participants formed a purposive sample of 27 dementia experts from nine countries (Denmark, Norway, France, the Netherlands, Germany, Poland, Italy, Spain, and the UK). These participants represented the disciplines of clinical psychology, general practice, geriatric medicine, old age psychiatry, medical sociology, nursing, and dementia research. All participants were members of the INTERDEM network. The focus group transcriptions were analysed inductively, in a framework approach. A model for barriers and facilitators for change at six levels of health care was used as a framework for organising the qualitative data. These levels were the innovation itself, the individual professional, the patient and the carer, the social context, the organisational context, and the economic and political context.

The results showed that barriers and facilitators related to five of the six health care levels. The social context was not a primary contributor to barriers and facilitators, probably because of the

international focus of our study. The barriers included the professionals' lack of skills and motivation, the variety in organisation of dementia care between and within countries, and the ambiguity of the QIs. The facilitators included the user friendliness of the QIs, the feedback and incentives to motivate professionals, and the QIs fitting in with national and regional policies. The European context of the set of QIs appeared as both a barrier and a facilitator.

On the basis of the results, we conclude that it is not feasible to apply one single strategy for successfully implementing the set of QIs in the various European countries because the organisation of dementia care varies widely between and within countries. Further, national and regional governments, policies, and laws could facilitate, but could also hinder, the implementation. Implementation of the set of QIs therefore must be adapted to the local context. Local implementation efforts should also include strategies to motivate care professionals to use the QIs and to provide professionals with opportunities to develop their skills and competences.

**Chapter 6** discusses the stepwise process of developing and evaluating the set of QIs for psychosocial dementia care and its importance for dementia research and practice. The QIs represent the best quality of scientific evidence currently available for specific psychosocial interventions, and they capture the essence of psychosocial care in general. The set is ready for use on a local level. It is necessary to establish the inter-rater reliability, the discriminatory validity, and the predictive validity of the set before it can be used to compare the quality of psychosocial dementia care on a large scale within or across European countries or for accountability purposes. Within the current context of European dementia policy, the set of QIs offers opportunities for both dementia research and practice to impact the quality of psychosocial dementia care.



# Samenvatting



Het streven naar een zo goed mogelijke kwaliteit van leven voor zowel de persoon met dementie als diens mantelzorger is één van de belangrijkste behandeldoelen bij dementie. Psychosociale zorg is hierbij essentieel. De implementatie van evidence-based psychosociale dementiezorg is echter beperkt in Europa en moet worden gestimuleerd. Een belangrijke stap bij het implementeren van wetenschappelijk bewijs in de praktijk en daardoor het verbeteren van de kwaliteit van de gezondheidszorg is het ontwikkelen van kwaliteitsindicatoren. Kwaliteitsindicatoren zijn meetbare kernelementen van zorgverlening die expliciet zijn geformuleerd en waarvoor (wetenschappelijk) bewijs bestaat, of waarover op zijn minst consensus is, dat ze gebruikt kunnen worden om verbeteringen en veranderingen in de kwaliteit van de geleverde zorg vast te stellen. Het doel van dit proefschrift was het ontwikkelen en evalueren van een set van kwaliteitsindicatoren om de implementatie van evidence-based psychosociale dementiezorg in Europese landen te stimuleren.

Voor het ontwikkelen en evalueren van de set van kwaliteitsindicatoren is een stapsgewijs proces gevolgd. De eerste stap bestond uit het verzamelen van evidence-based aanbevelingen voor specifieke psychosociale interventies en algemene psychosociale zorg uit de wetenschappelijke literatuur en Europese dementierichtlijnen. Alle aanbevelingen, welke werden verzameld via een review van systematische reviews, een systematische review over communicatiestrategieën (Hoofdstuk 2) en een inventarisatie van dementierichtlijnen in Europese landen (Hoofdstuk 3), werden gebruikt als basis voor de meetbare kernelementen voor de set van kwaliteitsindicatoren (Hoofdstuk 4). Aansluitend is onderzocht welke factoren de implementatie van de kwaliteitsindicatoren kunnen belemmeren of bevorderen in verschillende Europese landen (Hoofdstuk 5). De belangrijkste bevindingen uit elk van deze stappen zijn hier samengevat.

Uit de zeventien systematische reviews die werden geselecteerd voor de review van systematische reviews konden de volgende evidence-based aanbevelingen voor specifieke psychosociale interventies en algemene psychosociale zorg worden verzameld: (1) psychosociale zorg moet worden geïndividualiseerd en bestaat uit meerdere, verschillende interventies (2) in zorgplannen voor mantelzorgers zijn psychosociale interventies opgenomen die intensief en langdurig zijn. De review van systematische reviews onthulde verder dat maar weinig reviews ingaan op het gebruik van psychosociale interventies in verpleeg- en verzorgingshuizen. Het systematische review beschreven in **Hoofdstuk 2** gaat hier specifiek op in. In deze review van de wetenschappelijke literatuur worden de effecten onderzocht van psychosociale interventies op (1) de communicatie tussen verpleeg- en verzorghuisbewoners en verzorgenden en (2) de gedragsproblemen en andere neuropsychiatrische symptomen van verpleeg- en verzorgingshuisbewoners. Negentien studies werden geïnccludeerd en twee typen interventies konden worden onderscheiden. Het eerste type, waartoe tien studies behoorden, is een communicatieve activiteit voor bewoners uitgevoerd door een getrainde professional of verzorgende die plaatsvindt op een vast moment, zoals het doornemen van een levensverhaal (life review), een gesprek voeren, tegelijkertijd lopen en praten of cognitieve stimulatie therapie.

Het tweede type, waartoe negen studies behoorden, heeft als doel om verzorgenden te leren communicatietechnieken toe te passen in de dagelijkse zorg aan bewoners. Deze interventies bestaan uit een trainingsprogramma specifiek gericht op het aanleren van communicatietechnieken of een trainingsprogramma bestaande uit meerdere componenten waarvan communicatietechnieken er één is. De methodologie van de meeste van de negentien geïnccludeerde studies was zwak.

Een meta-analyse werd uitgevoerd van vijf studies met een communicatieve activiteit, bestaande uit twee interventies die wandelen combineerden met praten, een life review activiteit, cognitieve stimulatietherapie en een activiteitenprogramma. Een tweede meta-analyse werd uitgevoerd van vier studies met een communicatieve activiteit, bestaande uit een groepsvalidatie studie, een life review activiteit, cognitieve stimulatie therapie en een activiteitenprogramma. Geen van beide meta-analyses vond een significant effect voor uitkomsten op het gebied van communicatie of neuropsychiatrische symptomen. Individuele studies lieten een positief effect zien op de communicatie met bewoners wanneer een communicatieve activiteit bestond uit één taak of activiteit per sessie, zoals bij life review of het voeren van een gesprek met één andere persoon. Wanneer verzorgenden communicatietechnieken toepasten tijdens de dagelijkse zorg had dit ook een positief effect op de communicatie met bewoners. De effecten van beide typen interventies op neuropsychiatrische symptomen waren niet eenduidig. De conclusie van de review is dat verzorgenden de communicatie met verpleeg- en verzorgingshuisbewoners kunnen verbeteren wanneer communicatietechnieken worden toegepast tijdens de dagelijkse zorg of wanneer op vaste momenten communicatieve activiteiten worden aangeboden die bestaan uit één taak of activiteit per keer.

**Hoofdstuk 3** beschrijft de resultaten van de inventarisatie van Europese dementierichtlijnen. In deze studie is gebruikgemaakt van het INTERDEM netwerk, een multiprofessioneel, Europees onderzoeksnetwerk, om dementierichtlijnen te verzamelen die gepubliceerd waren in Europese landen vanaf 2000. De methodologische kwaliteit van de dementierichtlijnen werd beoordeeld met behulp van het AGREE-instrument. De studie liet zien dat de aandacht voor psychosociale zorg in Europese dementierichtlijnen beperkt is. Slechts zeven dementierichtlijnen uit vijf van de twaalf Europese landen waar dementierichtlijnen werden gevonden, bevatten secties over psychosociale zorg. Dementierichtlijnen uit Duitsland, Italië, Nederland, Spanje en het Verenigd Koninkrijk deden één of meerdere aanbevelingen voor psychosociale zorg. Fysieke activiteiten en interventies voor mantelzorgers werden het vaakst aanbevolen.

Het onderwerp en doel van de richtlijn werd in de meeste dementierichtlijnen goed beschreven. Factoren gerelateerd aan de implementatie van de dementierichtlijnen werden niet of nauwelijks beschreven. In vijf van de zeven dementierichtlijnen ontbrak de vermelding van een procedure voor herziening. De inclusie van aanbevelingen voor psychosociale zorg in de dementierichtlijnen werd beïnvloed door richtlijnontwikkelaars, de methodologische kwaliteit van de richtlijn en de waardering voor het wetenschappelijke bewijs dat beschikbaar is.

De dementierichtlijn gepubliceerd door NICE-SCIE uit het Verenigd Koninkrijk scoorde het beste op methodologische kwaliteit en bevatte de meeste aanbevelingen voor specifieke psychosociale interventies. De richtlijn adviseerde onder andere het gebruik van psychosociale interventies voor mantelzorgers, cognitieve stimulatie therapie, recreatieve activiteiten, fysieke activiteiten, en reminiscentie.

De conclusie van deze studie is dat er een behoefte is aan dementierichtlijnen met een sterke methodologie waarin secties over psychosociale zorg zijn opgenomen. Daarbij is het belangrijk dat richtlijnen regelmatig worden herzien, zodat nieuwe wetenschappelijke inzichten kunnen worden toegevoegd. Dementierichtlijnen alleen zijn echter niet voldoende om de kwaliteit van psychosociale dementiezorg te verbeteren. Een set kwaliteitsindicatoren zou de implementatie van evidence-based psychosociale dementiezorg kunnen stimuleren in Europa.

**Hoofdstuk 4** beschrijft het proces voor het ontwikkelen van een set kwaliteitsindicatoren voor psychosociale dementiezorg. De evidence-based aanbevelingen die konden worden verzameld uit relevante systematische reviews en Europese dementierichtlijnen werden geïncorporeerd in een RAND-modified Delphi procedure. In deze procedure werd de mening van experts gecombineerd met het beschikbare wetenschappelijk bewijs voor psychosociale dementiezorg. De procedure bestond uit twee schriftelijke vragenlijststronden onder 49 Europese dementie experts, face-to-face bijeenkomsten van een kleinere werkgroep en een slotbijeenkomst om consensus te bereiken onder 25 Europese professionals uit de dementiezorg en onderzoek. Het resultaat was een inhouds- en indruksvalide set van twaalf kwaliteitsindicatoren voor psychosociale dementiezorg. De inhoud van deze set kwaliteitsindicatoren helpt zorgprofessionals bij het individualiseren en op maat leveren van psychosociale zorg aan mensen met dementie en hun mantelzorgers, het behouden van regie over eigen leven en het waarborgen van sociale inclusie en continuïteit van zorg.

Gegevens uit 153 patiëntendossiers van verpleeghuizen, ziekenhuizen en dagopvangcentra in Spanje en Nederland werden verzameld om de meetbaarheid en toepasbaarheid van de set kwaliteitsindicatoren te onderzoeken in de praktijk. Adherentie aan de kwaliteitsindicatoren varieerde van 0% tot 89% per patiëntendossier en 11% (Spaans ziekenhuis) tot 50% (Spaans verpleeghuis) per setting. Deze praktijkstudie liet verder zien dat het goed mogelijk is om zorg te leveren zoals beschreven door de meeste van de kwaliteitsindicatoren in de set. Hoewel grootschaliger onderzoek nodig is naar de validiteit van de set kwaliteitsindicatoren kan het nu al gebruikt worden door Europese zorgprofessionals en instanties om op lokaal niveau evidence-based psychosociale dementiezorg te implementeren en te verbeteren.

**Hoofdstuk 5** beschrijft een kwalitatieve studie om potentieel belemmerende en bevorderende factoren voor implementatie van de set kwaliteitsindicatoren in verschillende Europese landen te onderzoeken. Op basis van de gevonden belemmerende en bevorderende factoren werd een



voorstel gedaan voor een implementatiestrategie. De kwalitatieve data werden verzameld via focusgroep interviews.

De deelnemers aan de focusgroep interviews waren 27 dementie experts, allen lid van het INTERDEM netwerk, uit negen Europese landen (Denemarken, Noorwegen, Frankrijk, Nederland, Duitsland, Polen, Italië, Spanje en het Verenigd Koninkrijk). Zij vertegenwoordigden de volgende disciplines: klinische psychologie, huisartspraktijk, geriatrie, psychiatrie, medische sociologie, verpleegkundigen en dementieonderzoek. De focusgroep interviews werden inductief geanalyseerd met behulp van een bestaand model met belemmerende en bevorderende factoren voor verandering op zes gezondheidszorgniveaus (de innovatie, de individuele professional, de patiënt en de mantelzorger, de sociale context, de organisatorische context en de economische en politieke context). Voor vijf van de zes niveaus werden belemmerende en bevorderende factoren gevonden. Voor de sociale context werden er geen gevonden, waarschijnlijk door de internationale opzet van de studie.

Belemmerende factoren waren onder andere het gebrek aan vaardigheden en motivatie bij zorgprofessionals, de variatie in organisatie van dementiezorg binnen en tussen landen en dubbelzinnigheid van de kwaliteitsindicatoren. Als bevorderende factoren werden onder andere genoemd het gebruiksgemak van de kwaliteitsindicatoren, feedback en beloningen om professionals te motiveren en kwaliteitsindicatoren die passen in het regionale en nationale beleid. De Europese context van de set kwaliteitsindicatoren werd beschouwd als zowel een belemmerende als bevorderende factor voor de implementatie ervan.

Op basis van de resultaten van deze studie concluderen we dat het niet mogelijk is om één implementatiestrategie te gebruiken om de set kwaliteitsindicatoren succesvol te implementeren in verschillende Europese landen omdat er een grote variatie is in de organisatie van de dementiezorg binnen en tussen landen. Daarbij kunnen nationale en regionale overheden, wetten en regionaal en nationaal beleid de implementatie bevorderen maar ook moeilijker maken. Implementatie moet daarom worden aangepast aan de lokale context. Daarbij zouden strategieën moeten worden gebruiken die professionals motiveren om de kwaliteitsindicatoren te gaan gebruiken en hun de kans geeft om vaardigheden en competenties te ontwikkelen.

**Hoofdstuk 6** bediscussieert het belang van de set kwaliteitsindicatoren voor dementieonderzoek en praktijk. De kwaliteitsindicatoren vertegenwoordigen de beste wetenschappelijke kennis beschikbaar op dit moment voor specifieke psychosociale interventies en ze bevatten de essentie van psychosociale zorg in het algemeen. De set is klaar voor gebruik op lokaal niveau. Voordat de set kan worden gebruikt voor het vergelijken van de kwaliteit van psychosociale dementiezorg op grote schaal binnen en tussen Europese landen of voor verantwoordingsdoeleinden moet eerst de interbeoordelaarsbetrouwbaarheid, het discriminerend vermogen en het voorspellend vermogen van de set worden bepaald. In de context van het huidige Europese dementiebeleid biedt de set kwaliteitsindicatoren kansen voor zowel dementieonderzoek als praktijk om invloed uit te oefenen op de kwaliteit van psychosociale dementiezorg.



# Samenvatting voor leken

Dementie is een ongeneeslijke ziekte die de hersenfunctie aantast. Patiënten zijn steeds minder goed in staat om voor zichzelf te zorgen en dus steeds meer afhankelijk van anderen. Patiënten met dementie krijgen een groot deel van de nodige zorg en aandacht van hun naasten, zogenaamde mantelzorgers. Doktoren en andere zorgverleners streven bij de behandeling van dementie naar een zo goed mogelijke kwaliteit van leven, voor zowel de patiënt als de mantelzorgers. Hierbij is het essentieel dat de patiënt en mantelzorgers zorg krijgen die rekening houdt met de functionele beperkingen door de ziekte. Deze zorg let ook op het psychisch en sociaal welbevinden van patiënt en mantelzorgers en helpt hen om hun dagelijkse activiteiten zo goed mogelijk uit te voeren. Dit is de zogenaamde psychosociale zorg. Tot op heden is het onduidelijk in hoeverre psychosociale zorg deel uitmaakt van de behandeling van dementiepatiënten en hun mantelzorgers in Europese landen. Ook is niet bekend of de psychosociale zorg die ze krijgen overeenkomt met de aanbevelingen uit wetenschappelijk onderzoek.

Mijn proefschrift beschrijft het stapsgewijze proces voor het ontwikkelen en invoeren van een praktisch instrument, een set kwaliteitsindicatoren. Met deze kwaliteitsindicatoren kan men de kwaliteit van psychosociale zorg bij dementie meten in verschillende Europese landen. Het instrument is ontwikkeld in samenwerking met een groep Europese onderzoekers en zorgverleners. Tijdens de eerste stap in het ontwikkelingsproces heb ik uit Europese dementierichtlijnen voor doktoren en andere zorgverleners de aanbevelingen verzameld voor psychosociale zorg (Hoofdstuk 3). Hieraan heb ik toegevoegd de aanbevelingen uit recent gepubliceerd wetenschappelijk onderzoek en de conclusies van het literatuuronderzoek beschreven in hoofdstuk 2. In de volgende stap heb ik Europese zorgverleners en dementieonderzoekers laten beoordelen hoe goed deze aanbevelingen bijdragen aan een goede kwaliteit van zorg bij dementie. De meest waardevolle aanbevelingen zijn op deze wijze geselecteerd en vormden de basis voor de uiteindelijke set van 12 kwaliteitsindicatoren (Hoofdstuk 4). De set meet onder andere of patiënten en mantelzorgers psychosociale zorg krijgen die is aangepast aan hun wensen en behoeften en of regelmatig wordt nagegaan door een vaste zorgverlener of ze nog tevreden zijn met de psychosociale zorg. Als laatste stap heeft een groep van 25 Europese zorgverleners en dementieonderzoekers gediscussieerd over factoren die van invloed zijn op het invoeren van de set kwaliteitsindicatoren in verschillende Europese landen (Hoofdstuk 5). De belangrijkste conclusie hieruit is dat de organisatie van de zorg aan dementiepatiënten en mantelzorgers verschilt tussen en binnen landen. De set kwaliteitsindicatoren kan daarom het beste worden ingevoerd op regionaal niveau, waarbij rekening moet worden gehouden met regionale wet- en regelgeving en het scholingsniveau van zorgverleners. De set kwaliteitsindicatoren voor psychosociale zorg, beschreven in mijn proefschrift, is nuttig voor zowel Europese dementieonderzoekers als zorgverleners. De set geeft onderzoekers de mogelijkheid om de kwaliteit van psychosociale zorg bij dementie binnen en tussen Europese landen te onderzoeken en te vergelijken. Zorgverleners kunnen de set gebruiken om hun eigen kwaliteit van zorg aan dementiepatiënten en mantelzorgers te verbeteren.



# Dankwoord

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## About the author

Emmelyne Vasse was born in Zwolle on November 21, 1978. She grew up in Nieuwleusen where she spent 6 happy years at primary school. Then, she had to bike 17 km back and forth to Zwolle every day to receive pre-university education. After that, she studied Human Nutrition at Wageningen University where she graduated in 2002. She worked as a research assistant until 2006, first at Wageningen University and then at Radboud University Nijmegen Medical Centre. From 2006 onwards she worked as a junior researcher at the department of IQ healthcare where she finished her PhD in 2012. During her PhD she also studied Human Nutrition and Dietetics at HAN University of Applied Science and graduated as a dietician in 2010.

Currently, she works as a research dietician at Ziekenhuis Gelderse Vallei in Ede and as a researcher at Radboud University Nijmegen Medical Centre at the department of IQ healthcare.

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